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# Students' Voices: How Does Education in Iceland Prepare Young Disabled People for Adulthood?

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ABSTRACT *This paper is based on one part of an extensive research project, conducted in 1998–2002, into young disabled adults in Iceland who have grown up with the ideology of integration and inclusion enshrined in law. This is a qualitative study of the experience of being a young disabled adult (16–24 years old) in Icelandic upper-secondary schools, university or equivalent educational settings, in the job market and in society. Attention is focussed on the young people's experiences of schooling in compulsory and upper-secondary schools, general education schools and classes, special schools, and in special classes. The study looks at how the structure and practice of the educational environment, including the organization of teaching, learning and evaluation, and students experiences of participation in school community life, hinder or promote their full active participation in school. This paper also discusses to what extent the young people's experiences of schooling prepare them for adulthood. The main conclusion indicates that schooling is a powerful agent for placing these young people on vastly different tracks, independent of their disability labels, either on a track that leads them to an interdependent adulthood or on a track within a special world for "eternal children".*

This paper is based on one part of an extensive research project, conducted over the period 1998–2002, into the world of young disabled adults in Iceland who have grown up with the ideology of integration and inclusion as the law of the land. This is a qualitative study of the experience of being a young disabled adult (16–24 years old) in Icelandic upper-secondary schools, university or equivalent educational settings, in the job market and in society (Bjarnason 2002a, 2004a). This paper describes and discusses the students' perspectives of how their experiences of participation in general or segregated educational settings, hinder or promote their full active participation as young adult members of their schools and society.

The research is located within the interpretivist paradigm. The theoretical framework applied rests on research and theory that considers disability as a social construction (Ferguson 1987, Bogdan & Taylor 1989, Ferguson & Ferguson 1995). It invoked the interpretivist paradigm, social constructionism and symbolic interactionism (Goffman's stigma, Becker's

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labelling theory) and drew also upon the phenomenological focus (not the whole tradition) on capturing aspects of the lived world of the young disabled study participants. Finally, the British social model of disability has also provided an inspiration (Oliver 1990, Shakespeare 1993, Barton 1999).

*Disability* and *adulthood* are both taken to be socially constructed phenomena that take meaning and content from culture and socio-economic conditions in society in time and space. This author adheres to the school of thought, that defines disability as a phenomenon emerging and resulting from the values and practices embedded within social structure and culture (Oliver 1990, Gabel 2001, Devlieger 1999). From this point of view, the construction of disability is both a complex social construction and a personal identity.

The status of adulthood is endowed with rights, including an array of choices and obligations due to a fully participating, responsible member of society (Ziehe 1993, Giddens 1994). The transition to adulthood is a process embedded in culture (see also Frönes 1995). The term adulthood is used here to refer to a social construction anchored within relationships and endowed with rights and obligations of a culturally fully fledged adult (Bates 1976, in Ferguson & Ferguson 1996:52). Gergen writes: "Identities are constructed largely through the narrative basis of self understanding ... and these narratives are properties of communal interchange" (Gergen 1997). Thus, typical adults are continuously engaged in reinventing themselves via choices, life planning, lifestyle options and consumption of artefacts to sustain their choices symbolically, within a web of relationships, and share who they believe they are via biographical narratives.

It is easier to identify conditions under which a person is denied an adult status, and when we are unable or unsuccessful in wielding the signs that we use when we communicate our adulthood, or are not taken seriously (Ferguson & Ferguson 1996). Such conditions tie in with inappropriate interpretations of a person's claiming adult status within social relationships, and lack of access to the most basic material and existential life quality options. Research shows that disabled young people have problems in embracing their adulthood, due to social barriers, including over-protection, lack of peer group interaction and job opportunities (Högsbro, Kirkebæk, Blom & Danö 1999, Gustavsson 1999, Ferguson 2001, Grue 1998, 1999). Gustavsson found that young people with intellectual disabilities living within mainstream society, experienced themselves as "insiders within an outsiders' world", many contented and socially active, but on the margin of society (Gustavsson 1999). Högsbro, Kirkebæk and their colleagues interviewed young disabled Danish people and found that social isolation, loneliness, the lack of access to age-appropriate friends and activities, and parent and professional overprotection were common complaints. The young people experienced these as disabling, placing hindrances in the way of their fulfilling their potential (Högsbro et al. 1999). Grue's (1998) research into young people with physical impairments, their social participation and quality of life, provides similar perspectives, and his findings resonate with those of Högsbro and colleagues. Grue and Heiberg (2000) carried out an extensive survey of non-disabled students aged between 13 and 20 years from 67

Norwegian schools and two groups of disabled students, one with physical impairment and the other with hearing impairments. They explored how indicators of social integration can explain variations in self-concept among disabled and non-disabled adolescents. They found that "disabled youth as a group do not have lower 'global self-worth' than non-disabled youth, but that social participation on the same social arenas as others and the feeling of being socially integrated" (Grue & Heiberg 2000:54) was of significant importance to the disabled adolescent's self-concept. From this conclusion they move on to ask whether parents, through "overprotection", may serve as gatekeepers for social participation of the disabled people's social participation and with the danger of social isolation and stigmatization, which may explain somewhat lower domain-specific self-concepts ("appearance", "social acceptance" and "romantic appeal") found amongst the disabled adolescents (Grue & Heiberg 2000). These findings and perspectives informed the larger research.

The concept *paternalism* is described in the *Oxford Advanced Learner's Dictionary (1989)* as the policy (of governments or employers) of controlling people in a paternal way by providing them with what they need but giving them no responsibility or freedom of choice. Kirkebæk's article, *The bad and the good – on the relationship between paternalism and indifference* (2002), explores the professionals' dilemmas of securing their clients safety, which tends to make (especially vulnerable) clients into dependants, and securing their freedom and personal sovereignty. The juggling of scarce resources, the balancing of support, and of professional, family and parental powers, affect disabled people to the core; how they see themselves, their future prospects, present situations and social networks.

*School inclusion* refers to a process, which implies not only that all students are welcomed to generic schools, but that teaching and learning is organized so as to meet a diversity of talents and learning needs (Bjarnason 2004).

A purpose of schooling is to add to the learning and experiences that students bring with them to school and shape its contents, or in Kirkebæk's terms (Kirkebæk 1999), to provide what the Danes call "*Dannelse*" – students personal and pedagogical development, and "*Tilpasning*" – students' adjustment to social norms. *Dannelse* refers to the pedagogic aspect of education, a personal process of development, and *Tilpasning* refers to student's adaptation to the bureaucratic aspects of education, such as allocation of resources, standards and processes within the context of group teaching (Kirkebæk 1999). These two concepts are used here in discussing how the process of schooling impacts on the disabled learners as they progress through compulsory and upper secondary school levels. It is argued that the way schools manage to balance these two processes affects the extent to which they lend themselves to inclusive and exclusionary practices.

Barton (citing: Booth 1996) points out "that it is useful to think of inclusion involving two processes":

the process of increasing the participation of pupils within the cultures and curricular of mainstream schools and the process of decreasing exclusionary pressures. To attempt the first without the second is self-defeating (Booth 1996:34, cited by Barton 1997:232).

Dyson suggests that Booth's perspective:

...enables us to view inclusion as one educational aim amongst many, providing a means of understanding the complexities and compromises that its pursuit entails. It thus makes it possible for us to understand forms of provisions not as 'inclusive' or 'not inclusive', but rather as *more* or *less* inclusive in *one* or *other* respect (Dyson 1997:17).

That lens focuses the research on the complexities of inclusive and exclusive practices in schools. Dyson, applying Booth's position, opens up the possibility to develop a more sophisticated understanding of the implications of particular forms of educational provision, avoiding the more black and white debate on inclusion *or* exclusion as states of educational practice (Dyson 1997).

### Background: Iceland – Education and Culture

Modern Iceland is a Nordic-type welfare state, but due to the tiny population and liberal social welfare politics, proportionally less money is provided to education and social welfare, than in the other Nordic countries (Ólafsson 1999, Njáls 2003).

The state and local communities provide free compulsory education from the age of 6 to 16 years, and a largely free education at upper-secondary and university levels. The *Education Laws* of 1974, made, for the first time in Iceland, provision for all students, to be educated within the compulsory public school system (*Lög um grunnskóla* 1974, 1995). Special schools and special classes for students with a variety of labels gradually opened in the second half of the 20th century (Bjarnason 1996). Students with a variety of disability labels were not generally invited into upper secondary schools until after the *Education Act* of 1996 (*Lög um framhaldsskóla* 1996).

The 1974 law on compulsory education opened up the school system for disabled students. With the 1979 law on *Support for the Intellectually Disabled* (*Lög um adstod við throskahefta* 1979), and subsequent legislation regarding disabled people, 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 general schools and other institutions in the community. Compulsory education is from the age of 6 to 16 years.

At the upper-secondary school level, students are more or less expected to be or become adults. The organizational structure provides a certain amount of flexibility to individual students, but flexibility according to bureaucratic rules. The students' education is thus formally more aimed at *Tilpasning* to the particular curriculum and to organizational forms than to *Dannelse* (Kirkebæk 1999). In such a system students are expected to keep up with the content taught, or fail.

The young people in this study have all been entitled to some further education under the law (1996), but their opportunities to go to an upper secondary school in their neighbourhood varied. Most of the young people labelled with intellectual disability, are the first students so labelled, to have had an option of 2–4 years further education in brand new special classes. Others with that label stayed on at their special school or entered adult education classes that provide short courses for adults with intellectual disabilities. Those with other disability labels were entitled to a maximum 4–5 years of upper secondary education, before university. Disabled students, who do not fulfil admittance qualifications of the upper secondary schools, are admitted at the discretion of the school principals (*Lög um framhaldsskóla* 1996).

**Modes of Inquiry and Data Sources**

The study used qualitative methods largely influenced by grounded theory and hermeneutics and located the work within the interpretivist paradigm (Glaser & Strauss 1967, Ferguson & Ferguson 1995) (see also Bjarnason 2003a:77–96, 304–305). The Ferguson and Ferguson characterize the methodology associated with the interpretivist paradigm as "the systematic collection and analysis of the stories people tell about how they interpret reality (Ferguson & Ferguson 1995:105)."

The main sources of data are interviews and their analysis (see also Bjarnason 2002a,b, 2003b, 2004 for a detailed account of the modes of enquiry and data sources). Thirty-six young adults with a variety of severe impairments (Table 1) were interviewed for the larger study, as were 1 or both parents of 30 young adults (44 people in all), 12 teachers and 12 friends. For this paper, students' perspectives are used. The interviews were in-depth, semi-structured and lasted from 45 minutes to over 2 hours. They were typed up, coded and analysed. Documents and interviews with key bureaucratic workers also form part of the data.

**Table 1.** Key young adults' primary disability labels

| Disability labels | *n* |
|---|---|
| Cognitive | 18 |
| Multiple | 2 |
| Physical | 7 |
| Sensory (3 deaf/hard of hearing, 1 visual impairment) | 4 |
| Emotional (autism) | 2 |
| Physical illness/accident | 3 |
| Total | 36 |

Almost all the young adults were identified as significantly 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 additional disability labels. In most instances the primary label was "mental retardation" or "physical disability", sometimes with an additional condition.

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.

"Strategic sampling" was used for selecting informants for the study, i.e. informants are selected for their ability to provide new insights or expand or add to gained insights.

As the interviews developed, we 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 we hoped to include as broad a diversity of young adults with severe disabilities as possible.

At the time of the study, 27 of the young people were still at school, and 4 were working part-time along side their schooling (Table 2). In all, 13 young people had entered the world of work full-time or part-time or were available for work.

The young people in the sample were placed in the educational settings shown in Table 3, for most of their compulsory school years. As this table shows, compulsory school placement varied across the spectrum from segregated to inclusive settings.

The young people in the sample were divided between schools at the upper secondary and university level, as shown in Table 4.

Nine young people attended regular upper secondary schools, and the 2 who had entered university were graduates from such schools, 15 were (or had been) in special classes at this school level, 4 were in adult education for persons with intellectual disabilities, and 6 were either still in compulsory education, individual special education or had left school.

Triangulations and checks were used, but the findings are not generalizable beyond the sample group. These findings do not represent any kind of

**Table 2.** The young disabled adults' home, school and workplace in 1998

| School type | | Home | | Workplace | | Region | |
|---|---|---|---|---|---|---|---|
| Special school | 0 | Parental home | 22 | Regular work | 4 | Reykjavík and greater Reykjavík area | 16 |
| Special class in high school | 12 | Own flat/ living alone/ living with partner | 8 | Sheltered workshop | 7 | Towns and villages | 16 |
| Regular upper-secondary school/ tertiary education/ university | 11 | Group home | 5 | Unemployed but available to work | 1 | Farms | 4 |
| Adult education for disabled learner | 4 | Other | 1 | Farms | 1 | | |
| | 27 Total | | 36 Total | | 13 Total | | 36 Total |

**Table 3.** Compulsory school placement (class 1–10)

| Special school only | Moved from special class to special school | Special class only | Moved from typical class to special class/ special school | Regular school only |
|---|---|---|---|---|
| 5[*] | 1[†] | 5[‡] | 7[§] | 18[¶] Total 36 |

[*]4 labelled intellectually disabled, 1 multi-disabled.
[†]1 labelled multi-disabled.
[‡]3 labelled intellectually disabled, 1 physically disabled, 1 Asperger's syndrome.
[§]4 labelled intellectually disabled, 2 deaf, 1 physically disabled.
[¶]7 labelled intellectually disabled, 5 physically disabled, 5 multi-disabled, 1 autistic.

"truth", but reasonable "trustworthiness" (Lincoln & Guba 1985:300). Inherent in the qualitative method is that lessons learnt are taken to have "transferability" (Lincoln & Guba 1985). To the extent that the study has successfully captured the subject's stories, the more people will read these accounts and find that they resonate with their verisimilitude and "transfer" the ideas in the analysis into their own experience and culture (Eisner 1991:211). Furthermore, in accordance with the political aspect of disability studies, the study hopefully added new voices to the multi-voiced chorus that is taken seriously within Icelandic society.

Finally, this author's 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 significant impairment, informed and focused the research (Bjarnason 2003a).

## Tales from Compulsory Schooling

### Special Schools

Five students in the sample had only attended special compulsory schools. All had labels of intellectual disability or multiple disabilities. Mostly, they had fond memories of the school, and their parents also stressed that they had appreciated the personal support provided by staff. However, most complained that they had not been taught enough. Klara said: "We were always learning the same things, over and over. I wanted to do more maths, I am good at that, but the teacher said I could not take the time." A number of the

**Table 4.** Upper secondary school/university level placement, last year (16–24 years of age)

| General/ comprehensive gymnasium commercial college | University | Special class comprehensive technical college | Adult education for students with disabilities | Other; compulsory education, not in school, etc. |
|---|---|---|---|---|
| 9 | 2 | 15 | 4 | 6 |

parents had similar concerns. Sólrún's mother echoed the views expressed by a number of parents of children from special schools when she said:

> I sometimes thought, hey, what happened to the school year, they are always preparing for something to come or recuperating after something past like the summer or Christmas...what happened to the big work period?....but Sólrún was very happy at that school...while she is happy we cannot complain...

These examples are typical of the narratives from the special schools.

*Special Classes*

Hjalti was a student in a special class in a regular compulsory school before he moved to a special school. He said: "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." He also felt that he had spent too much time waiting for personal help, for someone to push his wheelchair, and for the other children to finish what they were doing. But there were also good memories from the special class. He found his first friend there, and he was sometimes allowed to join regular classes with non-disabled peers. He said:

> I found it just great to get into the ordinary classes. I was happy at being allowed to experience that despite my wheelchair...I got most of the help I needed....The experience...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 disabled student.

He was pleased to move to a special school at the age of 11 years. There he formed a strong bond with one of his teachers who later became a trusted friend.

Hjalti moved across the school spectrum from integrated to segregated settings in compliance with his family's wishes, gained new companions and friends and learnt practical skills. As a young adult he lived in a group home, worked in a sheltered workshop, and became embedded within the special world for "labelled" people, or in Gustavsson's wording, participating "inside the outsiders' group" (Gustavsson 1999).

*Transition to Special Settings*

Seven youths went directly from a regular class, where they had been for varying times from 1 to 6 years , into special class or special school. There main reasons for such moves were: the students had been teased or bullied by fellow non-labelled students, and to get their educational or (in the case of two students with hearing problems) communication needs better met.

The memory of being bullied is shared by too many students in the sample. In all, 15 students said that they had suffered aggressive teasing while in compulsory school. A few were moved into more segregated settings, others to another school. Most reported that they were made to endure their torture,

but the bullying mostly changed with age into their being ignored by peers and even some teachers. One student explained it so: "I wondered if I had become invisible." For these students, the move to segregated settings offered a respite; a safer place where they found more understanding, better support and sometimes a friend.

Four young people were moved from general schools to special schools or classes for educational- or communication reasons. Pála moved from a typical school to the school for deaf students. She said:

> I was in a hearing school until I was ten years old. I did not know sign language. . . Then I went to this school [the Icelandic deaf school], and then I had no language at all, I found that horrendously difficult. I found it difficult to get into the [deaf] group.

Learning sign language opened a new world for her and "gave her a sense of belonging" (Andersson 1997). But she was also critical of her special school:

> . . . it is as if some of the teachers really think that deaf students cannot learn. I mean, the content is idiotic, and some of the teachers...[noise on tape interruption]. . . I have been in a hearing school and there they make demands. I like to be challenged. This is like in a preschool [laughter]. . .

Many of the students who had experienced being moved from regular school to special school or special class shared this complaint; the special school or class was reported to make too few academic demands and teachers were felt to be kind but somewhat patronizing. Almost all said that their social world seemed too narrow in the new segregated settings, but their view on whether that was good or bad varied.

*Mainstream Schooling*

Sigurður was fully included with typical peers in regular classes where teachers emphasized flexibly. He said:

> All my teachers were good . . . [and a little later] Music was great and my teacher was like all the others, praising me and everything . . . I was composing, and . . . people came to listen and they thought it great and fun. . .this also gave me a lot . . .

Pétrún started her education in typical village school. She did not go out on breaks because to do so she would have had to get up and down three flights of stairs each time. She said:

> You get used to it. I was sorry that I could not get connection with the kids, my friends. . . . when I was eight or nine years old I began to notice that I was different. I could not run like them, and that irritated me. . .and then I started looking at myself as a person from outer space. I felt that I was like a Martian in their eyes and they were like Martians in my eyes.

At the age of 13 years, she changed schools. The new school, in a bigger town, received her well.

> There the teachers received me as if I was just a regular person. There was one teacher who took special notice of me, she knew how to deal with me ... and that one was not allowed to feel sorry for me ...

The disabled students appreciated being in general education schools and classes. They appreciated their opportunities to learn with the typical students and were proud of their achievements. Still, life in the typical class could become very difficult and lonely. Exclusionary pressures began to outweigh inclusive processes as academic subjects became more prominent, particularly in traditional schools. Most of the disabled students in general schools found themselves near the periphery of the curriculum and the school social life as they got older.

## Tales from Upper Secondary Schools

Inclusive education in upper secondary schools is more complex and problematic than in compulsory education, because upper secondary schools are mostly large, bureaucratic institutions set up to prepare young people for work or further studies in the adult world (*Lög um framhaldsskóla* 1996). Most are organized around a module system, where individual students chose certain modules, help construct their individual timetables, and are expected to adapt to relevant rules and achievement standards or fail.

### General Education Settings

Eight of the young people in the sample were placed in general education classes both at compulsory and upper secondary levels. These were all students primarily with physical disabilities. Thór provides a good example of how a student with complex needs was enabled to participate actively in the curriculum and the school culture.

Before Thór joined the school, his father made sure that relevant ramps and electrical equipment were put in place to reduce his problems accessing the school buildings. Thór attended a typical boarding school. The guidance counsellor helped organize the support he needed. He found it easy to get friends to help him, and was not shy to ask for such help. Thór liked his teachers, but because of a high turnover of teachers in country schools at the time, he did not form any special attachment to any of them. He valued that no teacher treated him differently from any other student. Thór's only complaint from those years were related to "getting the wheelchair between buildings through the snow".

Others met with more hindrances. Örn was a typical student for most of his compulsory school years. He entered upper secondary school after an illness left him blind and a wheelchair user. He spent much of his time in general education class, but got some special education support. Örn did not read Braille and had problems getting adequate technical aids and help with note taking. He said:

> My memory is good. Like in some lessons I just sit, the teacher writes on the blackboard,.... and shows pictures. I just sit there.... Very few teachers remember to speak [aloud] the words they put on the blackboard. I mention this sometimes to them but they forget, and do it again almost immediately.

Despite this he was happy with most of his teachers. He got to know many of them personally and he defended their forgetfulness, by saying:

> Well, it is a little difficult for a teacher to help me specially in class, you see, when there are maybe twenty kids in a group... He is alone...

None of the disabled students in general classes at upper secondary school had specific learning problems, but all had significant needs for personal support, and for minor adaptation in the organization of the class work, tests or laboratory work. Because of these needs they had problems with the *Tilpasning* (Kirkebæk 1999), problems that school staff and the student body either did not notice, or approached with indifference.

The general upper secondary schools were not seen to be very able in dealing with the educational or social needs of students who did not quite fit the norm. Attempts were certainly being made, but with varying success. Yet these students were prepared to overlook the schools' inadequacies as long as they did not feel directly and deliberately humiliated or undervalued. Friendship with typical students and an ability to access the curriculum were the keys to overcoming access problems at this school level.

*Transition from Special to General Education Settings*

Three of the young people who participated in general education alongside non-labelled peers in upper secondary school, came from special class or special compulsory school.

María experienced a traumatic change when she moved from the special class into an upper secondary school.

> I needed to learn to do everything on my own, from reading the timetable and finding my way around a school. I knew nothing, did not know a soul, and had to learn to rely on myself.... I had very little belief in myself... felt as if I did not fit into these surroundings. I was always alone... If you are always alone in a corner, it affects your study.

María plucked up courage to ask if she could join a group:

> I just asked...The kids have accepted me as one of the group...so I have done that too...

Personal support was inadequate at the upper secondary school.

> At first I had problems going to the bathroom...The next year some of the teachers helped me. That too involved lots of stress, because it was as if I had to pee to order...

She solved this, like so many other problems, by getting trusted friends to help her.

Educational supports could also be a problem. Some teachers did not put the same educational demands on her as they did on non-disabled students. She gave this example:

> In a recent lesson the teacher 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 . . . He of course let me read and discovered that I could read just like the others, even better if anything [laughter] and he let me read in all the lessons after this, I was the first he would ask.

María was about to give up and leave school in her first year. She said:

> I came home almost every day in that first year thinking that I would quit . . . but then . . . I looked at this as a challenge, gave it time, gave myself time to get to know people and the new surroundings, and then it was not so terrible . . .

Part of María's baggage when she arrived at the upper secondary school could be looked on as learnt helplessness, which made it enormously difficult to overcome the exclusionary hindrances at her school. But she also brought with her strong academic skills, and a determination to overcome the barriers.

Disabled students in general upper secondary school experienced a number of similar problems. Problems of access, isolation and stigmatization run through these narratives as they did in narratives from general compulsory schooling, but with a difference. Being accepted into the school community, gaining friendship, and becoming a part of a peer group is even more important to students in their teens (Frönes 1995). Despite the fact that most of the disabled students in general upper secondary schools had at least one friend, the isolation is apparently an even greater problem at this school level than in compulsory school. Almost all tried to adapt to the schools' bureaucratic and other organizational requirements and took pride in doing so. But for many *Tilpasning* was as hard, as if they were Cinderella's stepsisters trying to fit the glass slipper.

All these students, and almost all the disabled students in the sample, appreciated their schooling and the opportunity to gain an education, despite having to take on a kind of "steeplechase" to access it. Only one of these students had lost hope in benefiting from school, and admitted that she was afraid of new people. She spent her life on the Internet.

Inclusive and exclusionary processes see-saw on the upper secondary school cliffs; some hang on, and others fall off. Having friends who are active learning members of their school and community, helps students with and without disabilities to hang on.

## Special Education Settings

Fifteen of the young adults in the sample (all labelled "intellectually disabled") were part-time or full-time in special classes at upper secondary schools. Eight came from special compulsory education schools or special classes, and seven from general schools and typical classes. The classes were small and cosy, with 6–8 students, and interaction between students, teachers and paraprofessionals was informal and personal.

The common themes that emerged from their interviews centred around problems in special classes at upper secondary level. These were problems of gaining admittance to school, the small unvaried group of schoolmates, lack of educational challenge, controlling or patronizing staff, good caring teachers, safety and security. It seems that their schooling was marked by teachers' attempts to individualize teaching and learning, to make them feel good, and to break their isolation by organizing extracurricular activities within the special group. These students did not mix much with typical students.

In one of the schools, efforts were made to include the special classes as groups within the school community (Tetler 2000). A few disabled students, particularly students from that school, talked about how great it was to "do things like the others."

Eight students had been in special school or special class throughout (most of) their schooling. Sólrún is one of those. She was not admitted immediately to the special class in the local upper secondary school despite the fact that her parents applied as soon as she had graduated from the special school. Her IQ was deemed too low. Her parents turned to the Minister of Education and to mass media. Two years after her graduation, she was admitted. She said:

> I have fantastic teachers, good teachers. They pay attention to their students. Help them with their tasks, help them if they have problems with learning. I have no bad teachers, all are good. ... I learn lots [of] subjects ... and the kids I am with now are ... fun too ...

At school she met students both with and without a disability. She said she has thought about what it might be like to be in a general education class.

> I wanted to change ... I have been in class with kids that are disabled all my school life. But I ... it is not worth changing now ... Of course it would be really exciting but this is how it is ... Being in class with other disabled kids is like some natural law ...

Almost all the students in special classes praised their special teachers for being "a good teacher", "OK teachers", "good because he cared and helped us" and "good because I learn more in the special class".

Seven young people in the study who had been included in general education for most of their compulsory school years, moved into special class at upper secondary level, varied in their contentment.

Ólafia, has Down's syndrome. She came directly from a general education compulsory school. She was angry at not being able to be with her former classmates. She said:

> I like school. I always have ... I have not changed so why does not the teacher let me be with them [friends and former class mates] now?

Daði, who is labelled autistic, attended a typical class with extra support throughout compulsory school. He explained his experience in the special class at upper secondary school thus:

> I did not do well there. It is a complex system, I had to change classrooms all the time, and sometimes even go from one building to another. I did not get enough help ... I

needed better services. I do strange things sometimes . . . I needed someone to help me make sure I did not do these things. I painted all kinds of artwork [on tables and walls].

His parents confirmed that he was not adequately supported at the school. He dropped out of school, and found a place at a sheltered workshop.

## Discussion

Despite a variety of positive and negative experiences reported by the young people, the overall picture suggests that both compulsory and upper secondary schools are largely unprepared to provide disabled students with a good education and full active participation in the schools' curriculum and the school communities. That is not surprising, and well documented in research elsewhere (See, for example Marinósson 2002, Söder 1997, Dyson 1997).

The storylines about inclusive settings in compulsory school suggest that, at that school level, many of the disabled students felt they were a part of their classrooms for their first few years in general education schools. This suggests, in Booth's terms (Barton 1997), that at that stage the process of stigmatization and exclusion was, to some extent, held at bay by processes of inclusion and participation. By the early teens things began to change for some, but not all, of the young disabled people attending general education schools.

One explanation for students' different experiences in general education classrooms can be found in the way teaching and learning tends to be organized. The national curriculum and school practice provides a lot of flexibility to teachers of younger students in general education schools. Young students frequently work in co-operative groups. Their teachers are encouraged to team-teach and co-operate in curricular development and planning. These methods give teachers greater possibilities to reflect on problems of classroom organization, and address some of the dilemmas and hindrances that may arise in inclusive practices (Tetler 2000). Teachers and schools vary in the extent to which these methods are used, but all work (at least part of the time) lies along these lines. Special teaching is provided inside the general education class, or in the resource room.

As the academic learning takes over more time in the 6th and 7th grades, and preparations start for the national tests in the 10th grade, learning becomes more competitive and teaching methods more traditional. Students who are not able to keep up with their studies are made to feel their shortcoming. In that sense, students are made responsible for their own learning unless they are seen to have something wrong with them, and formally labelled as such. At that point, the schools are expected to decide what is wrong, and provide the student with educational settings that are seen to match his or her special needs (Ferguson 1995, Marinósson 2002). The process of *Tilpasning* gains more weight in the higher grades, even though *Dannelse* remains a focus throughout compulsory school.

Extracurricular activities gain momentum in the everyday lives of older students.

The data demonstrates that as social decentration, and the playing with symbols for roles and styles take on a growing importance amongst the older children (Frönes 1995:184–185), it becomes harder for many disabled students to keep up with peers, unless appropriate support is in place. As a consequence, both formal and informal organizations and processes of the school curriculum and the school culture may result in pushing disabled students further to the periphery. Active membership in a peer group and a supportive interactive classroom climate can counteract the exclusionary processes.

As the school takes on a more bureaucratic organization of teaching and learning, the pedagogical practices shift from emphasizing *Dannelse* towards *Tilpasning* (Kirkebæk 1999). This strengthens further the exclusionary pressures upon students who encounter problems with learning, behaviour, or who need substantial support.

Thus, as disabled students advance within the general education system, the greater the likelihood that the process of exclusionary pressures and stigmatization will hamper inclusive processes (Booth 1995). This becomes more significant as the cohort moves between school levels. Furthermore, the willingness to accommodate disabled students at all also depends on available alternatives. For example, it was more likely that a young person labelled intellectually disabled, was accepted in typical schools if he or she lived outside the greater-Reykjavík area (Menntamálaráðuneytið, home page, OECD 1999).

Students' satisfaction with general education school, and particularly with the teaching, curriculum, access and support varied a great deal. However, these settings provided the disabled students with the opportunity to mirror themselves in activities and behaviours of non-disabled students and general education teachers, and brought some of them good friends. From the point of view of the disabled students it was very valuable to have experienced a typical school.

The transition into general upper secondary school was difficult for most of these students. For most (but not all) young people, a broader social network of friends and girl- or boy-friends and a kaleidoscope of different relationships and impressions await in upper secondary schools. In contrast, the social network was getting smaller for many of the disabled students. *Tilpasning* of students to the school organization, and bureaucratic indifference to students characterizes many upper secondary schools. Thus the transition from compulsory school is difficult for most non-disabled students. Disabled students who need support in their studies or for personal care found it even harder. Students' guidance counsellors, who organize support services at the upper secondary school level, and fellow students who acted as assistants, seldom worked in unison with teachers. Consequently, little was done in these schools to adapt the organization of teaching to include disabled students in the lessons. The indifference experienced by the disabled students in upper secondary schools, and the barriers they ran up against,

escalated the processes of exclusion and stigmatization that pushed many of them further towards the fringes of school life.

Their gains in upper secondary schools were: to study with others in a valued environment, get a certificate of equal value to that of their non-disabled colleagues and thus a ticket to further studies or the job market and the opportunity to compare notes and build relationships with age peers. But, for some, the personal costs were loneliness, isolation and a growing awareness of social barriers and of the social disablement of their bodies.

The main study gave rise to a metaphor of the young disabled people as travellers on two roads or nomading in the wilderness between the roads. It was found that choices made early on in the disabled person's life between generic and special services were of importance for launching them on to the highway, a road often leading to fragile "adulthood with a difference" in mainstream society, or on to the narrower special track to a "special world of disabled people" or as "nomads in the wilderness". The former road holds the promise of greater personal freedom and quality of life, despite significant risks of loneliness and isolation. The latter promises protection and safety at the risk of remaining in the limbo of "eternal youth" within segregated settings subjected to a degree of paternalism and diminished personal freedom. The "nomads" seemed either to have lost hope of belonging to either mainstream society or the special world of disabled people, or had dropped out from these paths for the time being (Bjarnason 2004) According to this metaphor, most of the students who came from general school at compulsory and upper secondary levels were placed as travellers on the highway, because of their orientation to themselves and others as "belonging in and with society".

Disabled students who were moved from regular classes in compulsory school to special classes at upper secondary level had problems fitting in, but a few felt relieved to get the individual attention and reduced academic pressures in the special class. The move out of the general to the special system was a blow to most of these students. When disabled students could not keep up with the lessons in regular classes they were, for the most part, pushed out. Still, the students who managed to hang onto their social network, continued to struggle for their rights, maintained their orientation to themselves and others as belonging in and with society. Such students were also placed on the "highway".

Students who started their schooling in special classes or special schools or who were moved into such settings while still at compulsory school were used to their exclusion from general schooling. They were placed in the special stream. Their educational settings were either exclusive or grafted onto a general school. They were used to being with small groups of other disabled children and youth, used to adults focusing on their impairment and their needs for support. They were also used to adults making decisions on their behalf, organizing, for example, their social lives. This, hampered their opportunities for social decentration (Frönes 1995), and narrowed their possibilities for culturally appropriate socialization processes in anticipation of young adulthood. Exclusionary processes created by barriers at school and

in society, surpassed attempts at including them in most general settings, and they had learnt to live with their stigma. The special world of disabled children and youth, endowed with symbols indicating disability and child-ishness, offered the disabled students membership and participation in the special community, acceptance and protection. Despite feelings of being under-challenged at times, most of these students lived more or less within a warm protective arena of extended childhood.

Transition from a special compulsory school to a special class in general upper secondary school was a big leap closer to ordinary community life. For some, that leap held both dangers and the promise of moving individually, or with the group of disabled classmates, closer to a generic school community. Where their special class organization erred towards paternalism, that promise did not hold, and despite situational integration (Söder 1993) the students were embedded within the special world. For these students, their teachers' ability to balance their work between paternalism and indifference (Kirkebæk 2002), and between *Dannelse* and *Tilpasning* (Kirkebæk 1999) was the key to the special school students accessing inclusive processes and acceptance. When parents and teachers were in agreement on proceeding with the segregated special education, the disabled student's ability to step out of the special track was minimal.

Most of the disabled young people who had mainly attended segregated settings were placed in the special stream because of their compliance with their situation and acceptance of their predicament. The gains of placement in the special stream were security, access to special supports and facilities, and companionship. The trade-offs were a small, constant and uniform social network, a lack of opportunities to experiment and learn from their own mistakes in a variety of settings, narrower opportunities to engage in a culturally appropriate socialization processes, and lost opportunities to build a broad base of age appropriate relationships. Finally, the norms and values of the special stream threatened to keep the young adults in a prolonged state of young adolescence.

The nomads in the "wasteland" have in common that at the time of the interview they were excluded from both the segregated and the general settings, sometimes both educationally and socially. They were neither included nor segregated. School, both special and general, had failed them, leaving them in a limbo of indifference and isolation for the time being. Some were breaking away from one type of setting but not fully accepted as part of the alternative.

**Conclusion**

The conclusions point towards inclusive and exclusionary processes affecting students' learning and membership of inclusive educational settings, and also pinpoint strengths and weaknesses of educational experiences in segregated special education settings. The gains of attending and remaining in general schools appear to have the strongest impact, if the school in question is prepared to support a team of a variety of teachers, in adapting the

organization of teaching and in a flexible and reflective program which aims at meeting both individual and group needs (see Ferguson 1995, Tetler 2000). With diminished flexibility, exclusionary processes stigmatize disabled learners, pushing them closer to the edge of the road of general community living. The inclusive processes at school get consequently weakened, but the impact of peers, families and basic support and an individual student's ability to stay on track with his studies, counteract these pressures (Booth 1995, 1998). Their gains from inclusive schooling are many: the opportunity to obtain an education that is expected to enable them to access ordinary life and work in the community, the potential for building varied relationships with peers, and the possibility of gathering broad experiences and processing along culturally appropriate socialization patterns (Dyson 1997). The trade-off for many disabled students in general schools, could be to live with bullying, and later with stigmatization, negative awareness of one's impaired body, loneliness, isolation and indifference. The gains from segregated schooling are a tailor-made education and training, security, understanding of students' impairment, and access to appropriate support and a group of companions, friends and potential girl- or boy-friends. The trade-off many disabled students in special schools and special classes may have to make varies in form and intensity depending upon where on the spectrum (from inclusion to exclusion), of their particular educational location, and how far its organization and professional involvement strikes a reasonable balance between paternalism and indifference, and *Dannelse* and *Tilpasning*. The trade-off for the students can vary from prospects of some kind of group inclusion into the community and the world of work, to that of remaining indefinitely as a protected childlike person in an adult form, living in the special world of services for disabled persons.

The main conclusion indicates that schooling is a powerful agent for placing these young people on vastly different tracks, independent of their disability labels; either on a track that leads them to an interdependent adulthood or a track within a special world for "eternal children". No-one is predetermined to spend his or her life on the same track, but experiences at school, with its processes of inclusion and exclusion, can stifle or further each and every disabled student's ability to remain on the current road, move across to the alternative, or wander into the wilderness.

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