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6 THE SOCIAL CONSTRUCTION OF ADULTHOOD WITH A DIFFERENCE IN ICELAND

INTRODUCTION

Icelandic society is a modern, democratic, Nordic type welfare state, with a high standard of living, and virtually full employment. Both men and women are active in the workforce, and Icelandic families, like families in most western countries, have undergone significant changes in the latter half of the 20th century, with a growth in rates of divorce, remarriage or cohabitations, falling birth rate and a high rate of children born outside wedlock. The population of Iceland is tiny, only 286,000, two thirds of which live in or around the capital city of Reykjavík, and the remainder in fishing villages or on small farms, around the country. Due to the scale of the population, social interactions are typically more 'face to face' than is the norm in most other modern societies. Many families are still close knit, and even when that is not so, people constantly run into each other in all walks of life. Icelanders, therefore, typically have some sense of community.

THE STUDY

The study that began in 1998, seeks to understand the world of young disabled adults in Iceland, the first generation to grow up with the ideology of 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. The study explores the situations and experiences of disabled individuals that lead to exclusion; how they see themselves; and how they are perceived by parents, friends and teachers. The study also considers how different disability labels are attributed and experienced by young people and how the choices made for them by their parents influence their experiences. The study includes a variety of young disabled Icelanders, people from urban and rural sectors, from different socio-economic backgrounds and people with a broad diversity of disability labels (Table 1).

Two broad preliminary questions guide this study. First, what do these young disabled adults, their parents, teachers and friends, believe hinders them most in pursuing their learning, working or participating in society as adults, and what is most helpful? Second, what are the young adults' hopes and expectations for their future as adult members of society?

Table 1: The young disabled adults' home, school and workplace in 1998

<i>School Type</i>		<i>Home</i>		<i>Workplace</i>		<i>Region</i>	
Special school	0	Parental home	23	Regular work	4	Reykavik and gr. Rvík area	16
Special class in high school	12	Own flat/living alone/living with partner	8	Sheltered workshop	7	Towns and villages	16
Regular high school/Tertiary ed/University	11	Group home	5	Unemployed but available to work	1	Farms	4
Adult education for disabled learner	4	Other	1	Farms	1		
TOTAL	27	TOTAL	37	TOTAL	13	TOTAL	36

Three questions, no less broad, have emerged from the data. These are:

1. What does it mean to be a disabled adult in Iceland?
2. How do young people see themselves reaching that milestone when they have significant disabilities, and how do they negotiate adult status?
3. How is the adulthood achieved by young disabled people related to the parenting they receive, including parents' actions, choices, social status and approach to social service bureaucracy? Does the parents' influence vary according to the young person's age, type of impairment and need for support?

Exploring these questions raises new themes related to the interconnected pattern of parenting over time and the young adults' view of their personal situations and future prospects within general and special community settings. Furthermore, the study also looks at how parenting, schooling, work, hobbies, friendships, love and sexuality coincide with the young disabled adult's perception of his or her personal situation and future prospects. Lastly, the links between the individual, his or her family and society (Mills, 1959) are explored. It is underlined elsewhere (Bjarnason, 2002a) that decisions made by parents and their disabled children, often without much support from professionals, can contribute substantially to the inclusion of the children in general society. The main goals of the study are to make visible the important, but not always acknowledged, perspective of young disabled people about their own situation and future possibilities as adults; to explain the impact of choices made by parents and children through childhood and adolescence on their situation as young disabled adults; and to explore how parents, professionals, and the young disabled persons' social relationships play an important role in framing their experiences and their expectations about adulthood.

One metaphor in particular has helped to frame the analysis of the data. It is the metaphor of the young disabled people of the study, as either travelling along two roads (mainstream or special), or wandering about like nomads in the wasteland in between. The highway travellers (Group A), 14 young disabled people, are seen to travel alongside the rest of us. A few travel in the fast lane, and others move more along the middle of the road, but at a slow pace. Another set of travellers (Group C), 15 young disabled people, is seen to travel along a much narrower special lane for labelled people. Finally, the nomads (Group B), seven young disabled people, are seen to wander about in the wilderness between these two roads, sometimes aiming for the one and sometimes the other, but belonging to neither.

Modes of inquiry

This study used qualitative methods largely influenced by grounded theory and hermeneutics (Glaser & Strauss, 1967) and located the work within the interpretivist paradigm (Ferguson & 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). The primary method for collecting data was interviews. 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 severe impairment, inform and focus the research.

The sample, 36 young adults with a variety of disability labels, were interviewed, as well as one or both parents or support persons of 30 young adults (44 individuals), 12 teachers, and 12 friends (Table 2).

Table 2: Key young adults' primary disability labels

<i>Disability Labels</i>	<i>Number</i>
Cognitive	18
Multiple	2
Physical	7
Sensory (3 deaf, 1 visually impaired)	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 many additional disability labels. In most instances the primary label was 'mental retardation' or 'physical disability,' sometimes with an additional condition or a particular syndrome, such as cerebral palsy, seizure disorder, sensory problems, or physical

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