



Report on the social inclusion and social protection of disabled people in European countries

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Background:

The [Academic Network of European Disability experts](#) (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its disability policy Unit. In particular, the activities of the Network will support the future development of the EU Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.

This country report has been prepared as input for the *Thematic report on the implementation of EU Social Inclusion and Social Protection Strategies in European countries with reference to equality for disabled people*.

The purpose of the report ([Terms of Reference](#)) is to review national implementation of the open method of coordination in Social inclusion and social protection, and in particular the National Strategic Reports of member states from a disability equality perspective, and to provide the Commission with useful evidence in supporting disability policy mainstreaming.

The first version of the report was published in 2008. This is the second version of the report updated with information available up to November 2009.



Summary of changes since 2008

Housing and homelessness:

Housing quality for disabled people in Iceland continues to remain relatively high, but with ongoing issues pertaining to accessibility as well as the institutional qualities of the group homes (sambýli).

Homelessness is generally not an issue for disabled people in Iceland, unless one is to extend the definition of disability to include mental illness as well as to consider the impact of long-term substance abuse in producing disability. Municipal service providers, health workers as well as researchers generally agree that mental health problems are usually either the reason for, or the result of, the abuse of alcohol and drugs and it can be argued that the majority of homeless people have mental health problems. Homelessness is generally an issue for the city of Reykjavík and according to an official with the municipal social services, it is generally agreed that there are between 30–40 individuals who are homeless, marginally housed or residing in some form of transitional housing. This number has generally remained unchanged for some time.

The most recent policy development on the issue of homelessness for the City of Reykjavík is entitled [Stefna Reykjavíkurborgar í málefnum utangarðsfólks 2008-2012](#) (*Reykjavík City's Policy Regarding Homelessness 2008-2012*). Among its short-term goals are the creation of shelters to meet immediate needs, establish day programs, as well as to increase access to hygiene facilities. Long-term goals include expanding housing options for homeless women, couples, individuals and men, as well as to facilitate access to social and healthcare workers and services.

New strategies and actions for the inclusion of disabled people:

A recent effort was undertaken by the Ministry of Social Affairs and Social Security (Félagsmála- og Tryggingamálaráðuneytið) in conjunction with the Icelandic Human Rights Centre (Mannréttindaskrifstofa Íslands) to inquire into public attitudes towards discrimination in Iceland. This took the form of an as of yet unpublished Capacent/Gallup survey in April of 2009 of 1200 members of the public who were polled either by telephone or through the internet. All of the questions pertained in some way to disabled people or disability pensioners. When asked how widespread discrimination in Iceland was, disabled people/disability pensioners ranked 3rd as the most discriminated against group of the choices given; the 3rd ranking also applied in terms of the perceived negative implications of being disabled when applying for a job. However, 17% of those polled claimed to have witnessed incidents of harassment or discrimination against disabled people/disability pensioners over the last twelve months; this was only surpassed by incidents of witnessed discrimination against people due to their race or nationality. To what ends these findings will be employed or result in government policies or strategies remains to be seen.

Two organizations in Iceland, comprised of a mix of service-users and advocates and both recently formed, continue to work towards matters concerning independent living. *Samtök um sjálfstætt líf, SSL* (Independent Living Movement) had their third board meeting in August of 2009 and, among other things, established a connection with ENIL (European Network on Independent Living) and are working towards further developments this autumn. Another group provisionally identified with User-Controlled Personal Assistance (Notaendastýrð persónuleg aðstoð) is in the formative stages towards developing an independent living centre operated for and by disabled people and will focus on offering advice and training for those who wish to have user-controlled services/personal assistants. In contrast, the formal service providers at present appear to envision a system that allows for greater control or involvement on the part of service-users, yet continue to retain administrative and fiscal control of the services themselves.

This apparent failure to fully appreciate the ideology of user-led or under-controlled services—as put forth by disability rights organisations in Iceland and abroad—is still evident in governmental discourses on these matters.



The Centre for Disability Studies at the University of Iceland will continue to monitor developments for future ANED reports.

New changes in incomes, benefits and pensions:

The disability pension system in Iceland underwent revisions in 2008–2009. The implementation of these revisions took place in three stages. The first was implemented on April 1, 2008. For the first time in Iceland disability pensions were calculated based upon the individual's income and assets without consideration of spousal income. Individuals were also allowed to earn up to 90,000 ISK a year in dividends and interest (fjármagnstekjur) before it negatively impacted upon pensions. On July 1, 2008, on a trial basis, individuals were allowed to earn up to 100,000 ISK (before taxes) a month in earned income without negatively affecting pensions. This became permanent on January 1, 2009. The beginning of 2009 also saw a 9.6% increase to the base pension amounts, as well as to the amounts of earned income and interest dividends that could be made before impacting upon pensions. A minimum guaranteed income amount for individual pensioners was also set at 180,000 ISK a month and 153,000 ISK a month for those who did not live alone.

New changes in long-term care and support:

To the best knowledge of the authors of this report, there has been no significant developments in 2008–2009 regarding long-term care and support.

Implications of the economic crisis:

The implications of the recent economic crisis are difficult to comment upon due, in part, to a lack of research that has specifically examined these recent developments. Arguably, one could say that the recent economic downturn has contributed to the stalling of large-scale planned changes to the disability support services. The plan to decentralize the regional offices for the affairs of disabled people to the local municipalities according to some sources is proceeding as planned, while others indicate that there is little in terms of practical developments. While, as discussed above, for the moment the disability pension system appears to be unaffected by the crisis, it can be argued that cutbacks to healthcare services and increases in user fees negatively affect those who rely a great deal on healthcare services, such as some disabled people and those with long-term illnesses. Since the economic crisis, the municipalities appear to be taking a greater role in the provision of services that concern disabled people and other marginalized groups, while it could also be argued that the state level government is gradually removing itself from these issues and is somewhat pre-occupied with economic and macro-political matters.



PART ONE: SOCIAL INCLUSION PLANS (GENERAL)

1.1 Please describe how and where disabled people are included in your country's published plans for social inclusion and protection?

The most significant recent policy strategy in Iceland regarding the inclusion of disabled people is entitled *Shaping the future: Services for disabled children and adults. 2007-2016* [Mótum framtíð: Þjónusta við fötluð börn og fullorðna 2007-2016] (Ministry of Social Affairs [Félagsmálaráðuneytið]: 2007 – currently available only in Icelandic at: <http://www.felagsmalaraduneyti.is/vefir/stefnumotun/>).

By 2016, the government of Iceland plans to accomplish, via this policy formulation, a number of key goals. Among these is the goal that all disabled people in Iceland will enjoy commensurate standards of living and quality of life as other members of society; the knowledge and expertise of support staff will be the best that Europe has to offer and similar claims are also made regarding the quality of services for disabled people. The strategy itself is focused explicitly on disabled people, and as such, an argument could be made that disabled people are being treated separately as a distinct group in regard to inclusion and access to resources. However, the overall tone of the document argues for the general inclusion and participation of disabled people in Icelandic society, while recognising the need to ensure access to services required by people with different kinds of impairments in order to make inclusion possible.

The attempt to mainstream disability in this policy strategy is most apparent with regard to employment. A heavy emphasis is placed upon employment in this document as a means to achieve the socio-economic inclusion of disabled people. A key goal is to assist the transition of disabled people, particularly pensioners, into the general labour market.

One way this is to be achieved is through strengthening the experimental supported employment AMS programme (AMS, Atvinna með studningi), discussed in more detail in the ANED document *Report on the employment of disabled people in European countries: Iceland*. The ministry's policy report *Shaping the future* calls for, among other things, increases to the number of people assisted by AMS and their support staff, as well as the integration of the AMS programme with the mainstream employment centres managed by the Directorate of Labour [Vinnumálastofnun] (Félagsmálaráðuneytið [Ministry of Social Affairs]: 2007b:27).

Of further note in the Ministry's policy strategy is also a focus on education, whereby there are plans to include the teaching of issues pertaining to disability at all levels of education and to make this part of the mainstream teaching curricula. One goal is to combat some of the lack of understanding among the general populace and issues of prejudice. This is to be accomplished through the training of instructors and the provision of educational materials (Félagsmálaráðuneytið [Ministry of Social Affairs] 2007b:45).

It can be argued that a significant component that is missing from this specific policy strategy is an effort to implement legally binding anti-discrimination measures. The report draws attention to the two articles of the Icelandic constitution that are relevant in this context. One is article 76 which states: "The law shall guarantee for everyone the necessary assistance in case of sickness, invalidity, infirmity by reason of old age, unemployment and similar circumstances". Article 65 is often argued to include disabled people, even if not specifically mentioned: "Everyone shall be equal before the law and enjoy human rights irrespective of sex, religion, opinion, national origin, race, colour, property, birth or other status" <http://www.government.is/constitution/>. The *Shaping the future* strategy adopts the argument that disabled people can be located under the 'other status' (Félagsmálaráðuneytið [Ministry of Social Affairs] 2007b:32), though it could also be argued that this omission is not acceptable and can be interpreted as indicative of the marginal status of disabled people. Further, a case can be made that a right to 'assistance' is not necessarily equitable with the right to a commensurate standard of living or quality of life.



The *Shaping the future* report does explicitly state this to be a key objective of policy pertaining to disabled people in Iceland, mentioning specifically ensuring the rights to and the means to achieve adequate employment, rehabilitation, education, and housing, among other issues. This mirrors the language in some ways of existing legislation concerning the rights of disabled people (Lög um málefni fatlaðra [Act on the affairs of people with disabilities] <http://eng.felagsmalaraduneyti.is/legislation/nr/3704>).

However, specific anti-discrimination clauses receive little attention in the *Shaping the future* policy document or in existing legislation. Ensuring equal rights, access to services, and income support focus directly on the circumstances and needs of disabled people, whereas anti-discrimination measures are focused on the larger society where barriers such as negative views about and attitudes towards disabled people are produced and reproduced.

1.2 In reality, what major actions has your country taken and what are the positive or negative effects on disabled people? (Policy or practical examples).

The policy strategy discussed above – *Shaping the future: Services for disabled children and adults 2007-2016* – is indicative that the government of Iceland in recent years has taken an interest in addressing the circumstances of disabled people. There have been a number of ongoing shifts in the provision of social services in Iceland in general. This is reflected in the reorganisation of a number of programmes and ministries. For example, as of January 1st, 2008, the Ministry of Social Affairs was given an increased role when both affairs of elderly people and social security were moved from the Ministry of Health over to the Ministry of Social Affairs, which now is titled Ministry of Social Affairs and Social Security [Félags- og tryggingamálaráðuneytið]. Under the 2006 law Lög um vinnumarkaðsaðgerðir nr. 55/2006 (Act on Labour Market Initiatives), the responsibility for employment matters concerning disabled people that had fallen under the jurisdiction of each Regional Office for the Affairs of Disabled People will now be shifted over to Vinnumálastofnun, the Icelandic Directorate of Labour. The commonly stated reason for this is that employment matters for disabled people will now fall under the common jurisdiction of the Directorate of Labour, as are employment matters for the populace in general. This process is under way and is expected to be complete by the close of 2010. As such, the effects of this policy shift upon labour issues concerning disabled people remains unclear currently. Efforts are also underway to reorganise the services for disabled people that are currently offered at 8 Regional Offices for the Affairs of Disabled People around the country, the responsibility for which will be shifted to the local municipalities. The rationale of such an effort is that it is intended to lessen the segregation and stigmatization of services for disabled people by offering the services at the same locations as the mainstream municipal service centres, as well as to lessen the distance between the service provider and user. The changes are expected to be implemented in 2011 as per an agreement between the Ministry of Social Affairs, the Ministry of Transportation, Communication and Local Government and various other stakeholders. As of yet, it is not apparent what, if any, substantive differences in services this reorganisation will entail.

However, caution must be employed as the reorganisation of programmes and agencies may not always benefit users; it must also be remembered as well that the tone and form of policies pertaining to disabled people in Iceland can also be linked to the input of key politicians and policymakers, ongoing social, political and economic changes in the larger society, and importantly the influence of disability rights organisations and allied advocates. The umbrella disability rights organisation, the Organisation of Disabled People in Iceland (Öryrkjabandalag Íslands – <http://obi.is/english/>), has been actively involved in policymaking as well as efforts to fight discrimination and lobbying for inclusion. For example, this organisation played a key role in the implementation of the age related supplement (*aldurstengd uppbót*) to the disability pension system (Ólafsson 2005:82).

This input from disability rights organisations on policy has also been enshrined in Icelandic law.



Article 4 of the [Act on the affairs of people with disabilities](#) states that a board comprised of members from the Organisation of Disabled People in Iceland, the National Association for Intellectual Disability (Landssamtökin Proskahjálp – <http://throskahjalp.disill.is/>), and the Association of Municipalities in Iceland (Samband íslenskra sveitarfélaga) will offer guidance to the Ministry of Social Affairs as well as proposals for services for disabled people. The *Shaping the future* policy strategy was also drafted with the input from various disability rights organisations and mental health associations.

Very recent amendments to the disability pension system, discussed in greater detail in sections 2.2 and 2.3, suggest that progressive measures are slowly being implemented that will increase income security for many disabled pensioners. In particular, removing structural disincentives to waged labour on the part of disability pensioners, such as significantly raising the ceiling on the amount that pensioners can earn before their pensions are reduced, signals the state's interest in both income security for pensioners as well as encouraging the inclusion of disabled people in the labour market. However, such positive measures must be placed into context of some less progressive policies in the recent past. Changes in governments as well as economic recessions could in the future curtail these positive developments, many of which had only been achieved as the result of hard work and lobbying on the part of disability rights organisations and their allies.

1.3 What is the most recent research about disabled people's equality and social inclusion in your country?

There is a body of qualitative research in Iceland, generally located within disability studies as well as education, that complement the more quantitative sociological work that focuses on the disability pension system and income security programmes. This latter body of work is discussed in greater detail in section 2.1. In regard to the former, this work is comprised of research connected to the [Centre for Disability Studies](#) and the [Centre for Inclusive Education](#) at the University of Iceland, the [Icelandic Network on Disability Research](#), and other academic institutions, as well as work by other researchers in connected fields. It must be kept in mind that disability research of this nature does not have a long history in Iceland, and there are many projects underway whose findings have yet to be published.

In regard to work published in recent years, the edited volume *Fötlun: Hugmyndir og aðferðir á nýju fræðasviði (Disability: Ideas and methods in a new field of study)* (Traustadóttir 2006) provides a good overview of the recent work produced in Iceland on disability, particularly in terms of exploring the concepts of disability and research methods. Rice (2009) has also published an analysis and examination of the meaning of the concept of disability in Icelandic legislation and policy documents. Educational issues have been a major area of research in Iceland relating to inclusion and participation. One key focus has been the participation and inclusion of children, youth and young adults in educational settings (Egilson 2003, 2005; Egilson & Hemmingsson, 2009; Egilson and Traustadóttir 2009a, 2009b, 2009c; H. Einarsdóttir, 2009; S. Einarsdóttir 2003; Björnsdóttir 2003; Traustadóttir 2006; Bjarnason 2005a, 2003a; Marinósson 2007; Marinósson and Kristinsdóttir 2004). However, the general experiences of disabled children and youth in Iceland outside of the educational context have not been thoroughly explored. The ongoing multi-year research project *Growing up with disability* is intended to address this shortcoming. Some of the findings from this project are in the process of being analysed and published (Gunnarsdóttir, 2009; Gunnarsson, 2009; Jónsdóttir, 2009; Traustadóttir 2007, 2008). Another key body of research in Iceland relating to social inclusion/exclusion has been that which has focused on the experiences of disabled adults (Bjarnason 2003b, 2004a, 2004b; Björnsdóttir, 2009; G. Stefánsdóttir 2003, 2008; Kristjánsdóttir 2007); the parents of disabled children (Bjarnason 2005b); the adult children of disabled parents (Traustadóttir and Sigurjónsdóttir 2005); parents with intellectual disabilities (Sigurjónsdóttir and Traustadóttir 2002, forthcoming; Sigurjónsdóttir 2005; Traustadóttir and Sigurjónsdóttir 2008, forthcoming); and the intersection of disability and gender (G. Stefánsdóttir and Traustadóttir 2006; Traustadóttir 2004), among others. At the Centre for Disability Studies, University of Iceland, a new research project has been launched to examine the early stages of implementing the philosophy of Independent



Living and direct payments in Iceland and the first publication from this project has been published (Jóhannsdóttir, Haraldsdóttir & Traustadóttir, 2009).

There has also been some research conducted by NGOs on the issues of equality and inclusion in Iceland. One example of this is a report compiled by the Icelandic Red Cross (Rauði kross Íslands 2006), which found that disability pensioners (*öryrkjar*) are one of seven groups in Iceland identified as the worst situated in terms of certain socio-economic factors.

Three key overarching themes pertaining to this body of work could be discussed: First, despite improvements in recent years, many disabled people continue to live in socially and economically marginalized positions in terms of access to resources and services as well as their inclusion as equal members of society (Björnsdóttir, 2009). While the idea of inclusion is generally accepted and is articulated in government policies and strategies, this ideological commitment simply does not match practice in many regards (Björnsdóttir, 2009; Jóhannsdóttir, Haraldsdóttir & Traustadóttir, 2009; Traustadóttir, 2008). Secondly, some negative stereotypes and perceptions of disabled people continue to persist. These negative views are partly the result of the legacy of many years of conceptualizing disability within a medical-deficit model (G. Stefánsdóttir 2008; Rice, 2009), which has influenced policies as well as general socio-cultural attitudes. Thirdly, much of what disabled people in Iceland have either told researchers, authored themselves or as co-produced, counters these negative views. A good example is Björnsdóttir's (2009) PhD dissertation based on collaborative life history research with a number of young adults with intellectual disabilities. This research highlights how the young adults resisted the negative and disabling images in wider society and created a positive identity based on their strengths and abilities (Björnsdóttir, forthcoming). Out of this work a picture emerges of people who continue to struggle against a number of physical, social and economic barriers to inclusion but, despite negative circumstances, view themselves as strong and capable citizens.

Specific research on the inclusion of disabled children in mainstream schools has demonstrated some of the positive impacts of mainstream education on the students as well as their non-disabled classmates, such as the building of friendships; however, the attitudes of educators, administrators and medical professionals have sometimes been the most significant barrier to these efforts. It has been argued that the ideology of inclusion is generally accepted, but that this commitment to inclusion is not matched by existing practices (Bjarnason 2003a). Egilson (2005) has found that the participation of disabled children in mainstream schools in Iceland is highly variable and dependent upon a range of factors, such as individual differences as well as the local contexts of community and schools. Older disabled students in comparison with younger disabled students were found to be less satisfied with their educational experiences, citing a number of unmet needs. Egilson contends that social-structural factors and the environment play key roles in constraining or enabling participation and inclusion, but that a good deal of disability research has underplayed the impact of individual difference. Egilson's work, as well as her work with Traustadóttir (Egilson and Traustadóttir forthcoming a, b, and under review), has also found that despite a positive attitudes towards the inclusion of students with impairments, more knowledge of the child-environment interface is needed within the Icelandic educational system in order to implement the existing legislation and to further the participation of disabled students.

In terms of some NGO research, a key finding of a Red Cross report on groups faced with the most restricted access to resources in Icelandic society noted concerns about the disability pension system. These concerns mirrored those of the research discussed in section 2, citing primarily the low pension levels, reduction clauses, and the disparity between what is considered to be required to live a normal life by the standards of the general society with what is actually earned by disability pensioners or disabled people in the labour market. Mentioned as well by some research participants was the inadequate access to resources, such as limited assistance in the home (Rauði kross Íslands 2006:13-16).



A more recent poll, conducted in May and June of 2009 by Capacent/Gallup, on behalf of Blindrafélagið (The Association for Blind and Visually Impaired People in Iceland), polled 1200 members of the general public in Iceland and 168 of the Association's members on their views on a number of issues relating to the situations of people who are blind or have with visual impairments. When asked as to what they felt were the most important issues currently facing blind and visually impaired people, the clear majority (46.9% and 48.9% respectively) rated increasing job opportunities as the most pressing issue, followed closely by increasing educational opportunities. In contrast, social issues such as reducing prejudice were rated as far less of a pressing concern (17.5% and 12.0% respectively) in comparison to the issues of education and employment, as economic issues clearly occupied the minds of those polled, most likely reflecting the recent and ongoing events in Iceland. When faced with a choice of 7 scenarios, 'finding employment' was rated as the most difficult for blind and visually impaired people; 40.8% rating this as 'very difficult' and 12.2% of those polled as 'difficult in every respect.'

Macro comparative research on the different situations of disabled people pertaining to gender, age, impairment, and other factors needs to be undertaken. However, drawing upon the existing body of research some statements can be made (evidence relating to some of such demographic differences relating to the disability pension system will be explored in greater detail in section 2).

A good deal of the qualitative disability research conducted in Iceland is impairment specific or focuses on specific demographic factors relating to disability, such as disability and childhood or the experiences of family life with one or more disabled parents, among others. While such research is not as easily compared as quantitative data, statements can be made pertaining to some of the situations of specific groups. For example, Snæfríður Egilson's ongoing research with people with spinal cord injuries has identified the physical environment – such as the design of buildings as well as elements of the natural environment – as key barriers, in addition to the deficiencies of programmes and services. Egilson (2005:126–127) has also noted differences between the situations of disabled children in rural areas in comparison to urban settings. While not devoid of prejudice and exclusion, Egilson found in general that rural communities exhibited higher degrees of acceptance and flexibility toward the accommodation of the needs of disabled children and their families. Egilson surmises that this may be due to the intimacy and dense social networks typical of small rural communities.

Valgerður Stefánsdóttir's (2005) thesis explored the situations of Deaf people as a minority linguistic and cultural group in Iceland. She has found that sign language has little respect among the general populace and that its status compared to Icelandic is weak. Stefánsdóttir points to other research which has found that people with hearing impairments in general have for a number of years had less education, lower wages and remained somewhat isolated (V. Stefánsdóttir 2005:21).

Kristjánsdóttir's (2007) research on women with intellectual disabilities, Björnsdóttir's (2009) life history research with young adults with intellectual disabilities and Jóhannsdóttir's et al (2009) research on independent living and user led services, all echo the key point mentioned earlier – in Iceland there is a prevalent ideology of inclusion, but that this is hampered by a lack of opportunities and the service support needed to meet these goals.

The works discussed above are but a few examples of this kind of research that has been done and is currently ongoing, and further comparisons between the circumstances of differently situated disabled people may be made.

There is also evidence of disparities to be found in the available statistical data. As will be discussed in further detail in section 2, disabled female pensioners far outnumber males, while pensioners face higher risks of poverty than the populace in general. Iceland also has a high rate of single parent families, most of which are families headed by single mothers.



According to recent figures from Statistics Iceland¹, single parent households stand a much greater chance of falling into poverty than families with two parents. Furthermore, there is also a gender disparity in income levels in Iceland which adversely affects women. All of these factors combined suggest that the situations of disabled women, particularly single disabled mothers, continue to be precarious.

The groundwork of disability research in Iceland is being built, but as of yet little comparative analyses of the existing work has been undertaken. Drawing upon the collective input of scholars working in Iceland on disability issues, the need for further research that foregrounds the experiences and voices of disabled people was highlighted. In addition to the qualitative work, it was suggested that there is value in conducting research that objectively measures and compares the participation of people with different kinds of impairments. Current research focusing on childhood and disability also points to the need to further understand the impact of segregation on disabled children's lives and their possibilities to be included in all aspects of social life.

Participation of disabled people in employment in Iceland continues to be stubbornly low. Research is needed to understand the reasons for this and to provide suggestions for how to achieve equality in terms of inclusion of disabled people in the general labour market. Some research in this area has recently been completed and more is ongoing. María Elísabet Guðsteinsdóttir's (2009) MA thesis *Atvinnumál fólks með þroskahömlun: Velgengni og félagsleg staða á vinnumarkaði* (Employment and People with Intellectual Disabilities: Success and social status in the labour market) investigates the conditions faced by people with intellectual disabilities in the open labour market. Among the factors found to substantially increase the success of finding and retaining employment were: gradual introduction to the working environment, support from co-workers and management, tasks suited to the abilities of the worker and good social interaction with co-workers. Difficulties included too demanding tasks and problems in communication. The conclusion argues that it is crucial for workplaces to offer good training, support and a friendly social environment for people with intellectual disabilities. The forthcoming *Work in the Life of Disability Pensioners in Iceland* (G. Hannesdóttir, S. Thorlacius and S. Ólafsson (in progress)) draws upon publicly available data as well as new survey research. The project's initial findings note that 96% of disability pensioners have worked at some point in their lives, yet only 28% have worked in the last 6 months and only 20% were working during the time of the survey. The primary reason given for absence from the labour market was health status, as well as uncertainty about individual capabilities and an inflexible labour market that does not consider the varying special needs of disabled workers.

The understanding of "disability" is another important area to explore. Despite the emphasis on social understandings of disability in the new policy strategy *Shaping the future* (Ministry of Social Affairs [Félagsmálaráðuneytið] 2007), current research (e.g. Björnsdóttir 2009; G. Stefánsdóttir 2008; Rice 2009) indicates that the bio-medical individual view of disability dominates everyday understanding and practices in disability services. It would therefore be important to examine in-depth the meaning and understanding of disability in Icelandic society.

Finally, it is urgent to explore the intersection of disability and class, gender, ethnicity, age, religion and other social aspects in order to understand the complex barriers that hinder the equality and social inclusion of disabled people in Icelandic society.

¹ <http://www.statice.is/>



PART TWO: INCOMES, PENSIONS AND BENEFITS

2.1 Research publications (key points)

A good deal of the recent research on poverty, income and pension benefits pertaining to disabled people has been produced by the sociologists Stefán Ólafsson and Harpa Njál. In sum they have produced numerous books, journal articles, reports and popular press publications pertaining to poverty in Iceland, with a particular focus on the Icelandic social welfare system.

A key recent work which focused directly on the disability pension benefits in Iceland is by Stefán Ólafsson entitled *Disability and Welfare in Iceland in an International Comparison* (2005). A version in English may be downloaded free of charge². The key findings of this work echo some of the conclusions of Ólafsson's earlier research that found that Iceland lags behind the other Nordic nations in terms of income security and the inclusion of disabled people. For example, Ólafsson has found that fewer disabled people receive rehabilitation and occupational support than in the other Nordic countries. Disabled people are also much less likely to have acquired a skilled trade or receive post-secondary education than the general population, all of which is linked to lower incomes, barriers to employment and many forms of social inclusion. Pertaining to income, the evidence illustrates that in recent years there has been a widening gap between the pensions paid by the disability pension system with the minimum wages in Iceland. Ólafsson has also looked at the issue of taxation. Disability pensions had been tax free in the period from 1998 to 1996, but have since had to bear an increasing tax load which erodes the value of these pensions (Ólafsson retrieved June, 2008).

Another key Icelandic publication in this vein is *Poverty in Iceland at the beginning of the 21st century: The hidden social structure of the community (Fátækt á Íslandi við upphaf nýrrar aldar: Hin dulda félagsgerð borgarsamfélagsins)* by Harpa Njál (2003). In this and subsequent work (e.g. Njál 2006, 2007), Njál has been critical of certain features of the social welfare system. In relation to the disability pension system in specific, Njál noted the structural disincentives to employment. For example, the system penalised pensioners who sought employment by subtracting the wages they earned from their benefits at very low levels. The research also examined the disparity between the income that disability pensioners received from the pension and social assistance system with the amount estimated to be required for sufficient minimum support. It was found in 2000 that disability pensioners received 27–40% less than was needed to maintain minimum support levels. In subsequent research, Njál found in 2005 that this improved only marginally. Pensioners, as well those in the lowest wages in the labour market, earned 19–35% below an amount considered to be sufficient for minimum support in Iceland.

Furthermore, disability pensioners often lost their entitlement or had their pensions sharply reduced if their spouse entered the workforce.

The pension system has also long been predicated upon the notion that the disabled spouse is expected to remain dependent upon a 'breadwinning' spouse, as evident by the fact that spousal income factored prominently in benefit calculation. Njál has also documented the gradual changes to the pension system that may reflect a shift away from this 'breadwinner' ideology. For example, in 1998 a disabled spouse would lose most, if not all, of the important pension income supplement (*tekjutrygging* – discussed in further detail in 2.2) even if the spouse received only low wages in the labour market. By 2000, this reduction was lessened whereby the reductions as the result of the consideration of spousal income meant the pensioner generally retained approximately 70% of the pension. In the spring of 2008, the reduction as the result of spousal wages has been eliminated; however, a number of reductions and income caps remain in place in addition to the erosion of the value of pensions as the result of taxation, high costs of living, and instabilities in regard to other economic factors.

² <http://www.hi.is/~olafsson/>



The findings from this body of research agree that a basis of any good policy in this regard is predicated upon an understanding that disabled people, as anyone else, are entitled to an income that ensures an acceptable standard of living and one that does not deviate from the general population. As will be discussed below in section 2.3, very recent changes to the disability pension system, such as removing the spouse's income when calculating benefits and extending the age for which disabled parents receive the child pension, suggest a shift away from basing the pension system upon the idea of the 'normative' family model of one breadwinner and a dependent spouse to a model which takes current Icelandic realities into consideration. Obviously more work needs to be done, but many of the criticisms raised in research in this area and the arguments made by disability rights advocates and scholars have begun to be addressed in very recent policy amendments.

With regard to poverty and the pension system, there are many areas of research that need to be addressed. Iceland has a very high ratio of single parents, most of whom are women (92%), and the socio-economic situations of single disabled parents and their children need to be further explored. The obvious gender disparities in terms of the disproportionate numbers of disabled women pensioners compared to men warrants further work. The situation of disabled immigrants in Iceland has not received much attention, and the effects upon pensioners during the transition from the bureaucratic designation of 'disability pensioner' to that of 'senior pensioner' at the age of 67 deserves attention as well. This is by no means an exhaustive list but research in these areas are among the most important at this time.

2.2 Type and level of benefits (key points and examples)

The disability pension system is administered by the Social Insurance Administration of Iceland (Tryggingastofnun ríkisins), which is also responsible for senior pensions, health insurance, and occupational injury insurance. Tryggingastofnun ríkisins is now supervised (as of January 1, 2008) by the Ministry of Social Affairs and Social Security (Félags- og tryggingamálaráðuneytið), after previously falling under the jurisdiction of the Ministry of Health. The two principle acts which had long governed the disability pension system are the Social Security Act (*Lög um almannatryggingar No. 117/1993*: English³) and the Social Assistance Act (*Lög um félagslega aðstoð 118/1993*⁴). These acts were recently reissued and, combined with a number of amendments made over the years, are now known as the Social Security Act No.100/2007 (In Icelandic, [Lög um almannatryggingar nr. 100/2007](#)) and the Social Assistance Act No.99/2007 (In Icelandic, [Lög um félagslega aðstoð nr. 99/2007](#)). A series of amendments were subsequently issued (e.g. Lög nr. 17/2008; Lög nr. 57/2008; Lög nr. 155/2008, among others) which primarily concerned the cut-off points at which earned income will negatively affect pension levels. Of particular concern to disability rights organisations was the recent revision to the 2007 law on social security that came into effect on July 1, 2009. The changes included, among others, a negative effect upon benefits for pensioners who also receive payments from contributory pension schemes (*lífeyrissjóður*), an increase to the reduction ratio used to calculate the effect of income upon the pension supplement (*tekjutrygging*), and numerous other changes that may at first glance not appear to be very significant but which have the cumulative effect of eroding the value of disability pensions.

The disability pension system in Iceland underwent important revisions in 2008–2009. The implementation of these revisions took place in three stages. The first was implemented on April 1, 2008. For the first time in Iceland disability pensions were calculated based upon the individual's income and assets without consideration of spousal income. Individuals were also allowed to earn up to 90,000 ISK a year in dividends and interest (*fjármagnstekjur*) before it negatively impacted upon pensions. On July 1, 2008, on a trial basis individuals were allowed to earn up to 100,000 ISK (before taxes) a month in earned income without negatively affecting pensions. The beginning of 2009 also saw a 9.6% increase to the base pension amounts, as well as to the amounts of earned income and interest dividends that could be made before impacting upon pensions.

³ English version at <http://eng.heilbrigdisraduneyti.is/laws-and-regulations/nr/35>

⁴ English version at <http://eng.heilbrigdisraduneyti.is/laws-and-regulations/nr/36>



A minimum guaranteed income amount for individual pensioners was also set at 180,000 ISK a month and 153,000 ISK a month for those who did not live alone. However, it would also appear to be the case that the changes that were implemented in July of 2009 work to counter some of these gains and the speed at which these changes moved from discussion into law, as well the arguable lack of consultation with stakeholders and disability rights organisations on these issues, are not a positive sign for the future.

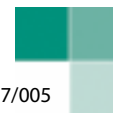
The general disability pension is referred to as *örorkulífeyrir*, but the pension itself is comprised of numerous supplements that are subject to further eligibility requirements. The benefits that rehabilitation pension recipients (*endurhæfingarlífeyrir*) receive are also governed by the Social Insurance Administration and the amounts parallel those of the disability pension system, but these benefits will not be discussed further here. There is not adequate space here to delve into the complexities of the system, but a few general points can be made. The basic flat pension (*grunnlífeyrir*) is awarded to those who have a medically recognised disability or disease, are between the ages of 16–67, and have resided in Iceland for 3 years. Each applicant is medically assessed and evaluated as per the criteria of the Social Insurance Administration. The highest disability evaluation for which one is considered to be ‘fully disabled’ for the purposes of the pension system is an evaluation known as ‘75%’ disabled. The origins of this specific ‘75%’ figure are complex and relate to the historical development of the Icelandic pension system and will not be dealt with here.

As per the disability pension system, there are essentially two classifications of recipients: those who receive a full pension (a rating of 75%, who are referred to as ‘disability pensioners’ – *örorkulífeyrisþegar*), and those whose impairments are not considered as severe and receive a rating of 50–74%. The latter receive a much less generous ‘disability allowance’ (*örorkustyrkur*). The maximum amount of this allowance as per the guidelines released in July, 2009, is ISK 21.657 a month, therefore alternative sources of income from waged labour or social assistance from municipal social services are required for those who are only eligible for this allowance. Those who receive a disability rating below 50% (often referred to as a rating of 10–49%), typically the result of an injury, are usually paid in a one-time lump settlement either from the State Social Insurance Administration or from insurance companies.

On top of the basic pension is included the pension supplement (*tekjutrygging*). This is paid to full disability pension recipients (75%) or those receiving rehabilitation (as well as old-age pensioners). This, however, is no mere ‘supplement’ as the basic flat pension is a fairly low amount and a significant amount of the pension received by a typical recipient is comprised of this supplement. Another important supplement is the household supplement (*heimilissuppbót*) paid to those who live alone, however this supplement is not exclusively limited to disability pensioners. Further, there is also a fairly recent age-related pension supplement (*aldurstengd örorkuuppbót*) based upon the age at which one applies to the pension system. The parent or parents who receive a disability pension are also entitled to receive a supplement for each dependent child (*barnalífeyrir*) they support up to the age of 18. Between the ages of 18–20, the children can apply for payments from this pension for themselves as long as they are in school. There are also a number of smaller benefits available to disability pensioners, such as discount cards for pharmaceuticals, as well as additional support for specific individuals who meet certain medical and economic criteria, such as assistance to buy and maintain a vehicle.

The amount that an individual receives largely depends upon the variables outlined above, among others. It is also important to note as well that the published details on the amounts paid by these pensions on government websites, such as the Social Insurance Administration of Iceland (in Icelandic, but often with English translations⁵), often highlight the optimal amounts or the unreduced benefit levels.

⁵ <http://www.tr.is/stadtolor/toflur>



The following chart is a simplified example adapted from information provided by the Social Insurance Administration

(http://www.tr.is/media/skjolpdf/greidsutegundir_2009jul_%282%29.pdf)

as to the maximum amounts paid for specific pensions and supplements as per July 2009.

Benefit	Per Month, unreduced, individuals living alone
Disability/Rehabilitation* basic pension (<i>Grunnlífeyrir</i>)	ISK29.294
Age-related supplement (full) (<i>Aldurstengd örorkuuppbót 100%</i>)	ISK 29.294
Pension supplement (<i>Tekjutrygging</i>)	ISK 93.809
Household supplement (<i>Heimilisuppbót</i>)	ISK 27.242
Maximum amount	ISK 179.639

* The rehabilitation pension is limited to no longer than 18 months due to illness or accident.

The basic set of criteria for eligibility for a disability pension is based upon age (16–67 years of age); residency (resident of Iceland for 3 years prior to the submission of an application); and a medically assessed permanent impairment. It is important to note as well that there are a number of restrictions and reductions built into the system. First, there is a structured divide between those who are evaluated as ‘fully disabled’ (75%) and those who are not (50–74%). The financial implications for the latter category are quite significant, as they are ineligible for a full pension. These pensions and supplements are also means tested, as income from waged labour or contributory pension schemes (*lífeyrissjóður*) are considered in the calculations. There are also income caps placed upon the pensions.

Those whose incomes exceed a certain amount (*frítekjumark*) begin to see a reduction in their pensions. As of July 2009, reductions on the basic pension amount are implemented should an individual’s income exceed 214.602 ISK a month. An individual is completely ineligible for a basic pension should one’s income exceed a cut-off point (*núllmark*) of ISK331.778 ISK a month.

As mentioned above, it is indeed a rare situation for disability pensioners to receive the maximum amount. For example, a close examination of one table entitled *Number of recipients with unreduced pensions and allowances 2008* ([Tafla 1.16 Fjöldi lífeyrisþega með óskertan lífeyri og tengdar greiðslur 2008](#)), reveals that in 2008 only 15.6% of all pensioners received unreduced pension supplements (*tekjutrygging*) (as a percentage of total elderly, disability and rehabilitation pensioners). Further, the household supplement (*heimilisuppbót*) is solely intended for those who live alone and is never received by those who cohabit. Only 5.5% of the total number of senior, rehabilitation and disability pension recipients received this full benefit. Lastly, the age-related supplement (*aldurstengd örorkuuppbót*) penalizes older applicants. For example, (as of January 1, 2009) an individual would receive the full age-related supplement if one first applied for a disability pension between the ages of 16–24. By the age of 25 there is a 5% reduction. By the age of 32 one would receive only 55% of this supplement and only 10% by the age of 50. As such, the hypothetical maximum amount would only be received by a single, childless person who lived alone, between the ages of 16–24 who was evaluated as fully disabled (75%), whose earned income did not exceed *frítekjumark* cut-off level and who had no significant savings or investments.

According to the most recent figures from the Social Insurance Administration of Iceland from 2008⁶, there were 14,103 recipients of the disability pension (*örorkulífeyrir*), comprised of 5,473 men and 8,603 women.

⁶ http://www.tr.is/media/frettir/stadtolur//arsskyrsla_stadtolur_2008.pdf

As of December, 2008, the population of Iceland between the ages of 16–66 was 215,588. As such, 7.4% of the population of Iceland in this age range received a disability or rehabilitation pension. The following table illustrates the growth in numbers in recent years of those who receive this pension; below that is the breakdown by gender and age group. Additionally, it should also be mentioned that 651 people received the disability allowance (*örorkustyrkur*) in 2008, meaning that these people were not evaluated as ‘fully disabled’ and as such were not entitled to a full disability pension.

Year	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Disability Pension recipients	7.982	8.673	9.329	9.780	10.443	11.199	12.011	12.755	13.230	13.616	14.103

	Disability pensioners (Örorkulífeyrisþegar) 2008	
Age	Men	Women
16-19	144	104
20-24	272	228
25-29	319	423
30-34	324	541
35-39	391	662
40-44	522	942
45-49	650	1077
50-54	764	1215
55-59	756	1261
60-64	919	1467
65-66	412	710
Total	5473	8630

More detailed information can be found on the website of the Social Insurance Administration of Iceland (Tryggingastofnun ríkisins⁷). Some of the website is translated into English (accessed by clicking on the icon of the flag of the United Kingdom), however this is generally very basic information. A wealth of statistical information on the disability pension system can be found in the form of online statistical yearbooks covering recent years⁸. While the titles of the tables are in Icelandic, most headings and categories within each table include English translations. The following translations of key terms should ease the negotiation of the titles of these tables:

- Bætur almannatrygginga* (general social security benefits)
- Félagslega aðstoð* (social assistance)
- Lífeyrisþegar* (general social assistance pension recipients)
- Grunnlífeyrir* (basic pension)
- Örorkulífeyrisþegar* (disability pensioners)
- Ellilífeyrir* (senior/old-age pension)
- Örorkulífeyrir* (disability pension, often translated as ‘invalidity pension’)
- Aldurstengd örorkuuppbót* (age-related disability pension supplement)
- Tekjutrygging* (pension supplement)
- Örorkustyrkur* (disability allowance)
- Barnalífeyrir* (child pension)
- Heimilisuppbót* (household support)
- Óskertur/óskertar* (unreduced)
- Útgjöld* (expenditures)

⁷ www.tr.is

⁸ <http://www.tr.is/stadtolor/toflur>



Fjöldi (number of)
Greiðsla/greiðslur (payments/remittances)

2.3 Policy and practice (summary)

The financial income of disabled people has been an important political question in Iceland in recent years. From the perspective of disability rights organisations, allied advocates and critical scholars it has been a struggle to ensure an adequate income, modernise legislation, remove policy barriers that penalised disabled people from working, or for their spouses from working, as well as to counter some misinformation and stigmas about disabled people. There have been some successes in these regards, but more work needs to be done.

Policy development in Iceland relating to social welfare assistance in general has sometimes been regressive. For example, the sociologist Harpa Njáls (2003) has examined a policy shift in 1993 wherein the existing law pertaining to social assistance was split into two separate bodies of laws regarding social security. One effect of this split was to strengthen the link between social assistance and income as well as to implement a number of reduction clauses to the existing assistance. It has been argued that this has created disincentives to seeking waged labour as well as producing a 'welfare trap' for some of those who receive disability pensions as well as general social welfare benefits (Njáls 2003, 2006).

But in recent years it is also important to note some positive changes to the disability pension system, which often arose as the result of the efforts of disability rights organisations and allied advocates. The work of critical scholars has also had significant impact as the result of the influence of their research on policy formulation. One of the most significant changes in recent years was the implementation of the age-related disability pension supplement (*aldurstengd örorkuuppbót*). This agreement between the state and the Organisation of Disabled People in Iceland (*Öryrkjabandalag Íslands*) was made in 2003 and implemented in 2004. This supplement is intended to assist those who entered the disability pension system at a younger age and who would most likely not have accrued the same yearly contributions to pension funds as people who began to receive their disability pensions at an older age. Of equal importance, in April of 2008 reductions to disability pensions as a result of spousal income were eliminated. In a recent letter posted on the website of the Social Insurance Administration of Iceland⁹, the chair of the Organisation of Disabled People in Iceland at the time, Halldór Sævar Guðbergsson, comments that these changes signal that disabled people are no longer dependent; their benefits are no longer seen as linked to the income of a spouse and are as such independent individuals. Further, as of July 2008, disability pensioners may earn up to 100,000 ISK a month without reductions being applied to their benefits. Guðbergsson argues that this will enable some pensioners to dig their way out of poverty, earn income in the labour market and develop skills without the fear of their benefits being greatly reduced.

There is no question that both the benefit system and some specific tactics to address poverty focus on disabled pensioners as a distinct group, though many of the issues relating to poverty in Iceland (e.g. high taxation, high costs of living, low incomes) affect all low-income people in general. Some policies and social security measures generally benefit the populace at large, but the social assistance schemes in Iceland target specific 'groups' and are administered by different agencies and at different levels of government. The disability pension system, as well as senior/old-age pensions, health insurance, and occupational injury insurance, are all administered by the Social Insurance Administration of Iceland (*Tryggingastofnun ríkisins*) under the supervision of the Ministry of Social Affairs.

As such, it may be more accurate to say that disabled people, seniors, and those undergoing rehabilitation are treated as a specific 'group' from the point of income protection schemes.

⁹ <http://www.tr.is/tryggingastofnun/umraeda-um-almannatryggingar/i-sigtinu/nr/813>



PART THREE: CARE AND SUPPORT

3.1 Recent research publications (key points)

It must be understood that what is meant by ‘independent living’, either in terms of ideology or practice, is rather underdeveloped in Iceland in comparison with other countries in northern Europe and North America. Little extensive research in this area has been undertaken and more work needs to be done. The key research that has been done which has looked specifically at the issue of services is best exemplified by a MA thesis on disability, youth and independent living from 2005 (Óskarsdóttir 2005) and a service evaluation conducted in 2004 (Óskarsdóttir and Kristjánsdóttir 2004).

There are a number of key findings and recommendations that arose from this work. Firstly, the approach to service provision in Iceland has generally been framed in a medical discourse. Impairments, and thus disabled people, have been constructed as ‘problems’ that need to be addressed by professionals, in the process overlooking the social aspects of disability. The expectation has generally been that it is primarily disabled people who need to adjust to the societal context. According to these reports there is a need for service providers to consider that society and services have to adjust to the needs of disabled people as well.

Secondly, according to this research, there is a lack among service providers of an appreciation of what ‘independent living’ entails, particularly in terms of practice, for example in the provision of user controlled services. Choice is sorely lacking for many disabled people in terms of where they can live, with whom, under what conditions, the arrangement of services, and in many cases even the basic freedoms of daily existence that are often taken for granted by non-disabled people.

Third, the goal of empowerment needs to be placed front and centre as a guiding principle with regard to the provision of services. This is currently not the case.

Lastly, a recommendation is made from this body of work that there needs to be a greater emphasis on preparing disabled youth for making the transition to adult life on their own. As will be discussed in greater detail below, while there are no formal institutions for disabled people in Iceland in the traditional sense, there are a number of people who continue to reside in group homes that exhibit institutional qualities, such as common eating facilities and a lack of choice in a number of areas of daily life. The struggle to achieve independent living, as understood and practiced elsewhere, is currently underway.

First and foremost, simply more research on long term care and services needs to be undertaken. The struggle for independent living, specifically that of direct payments for personal assistance, choice of living accommodation, improvements to transportation options and many other important issues, is currently underway in Iceland. This information is an important tool with which to understand the issues, formulate policy, as well as to bring public attention to these concerns.

3.2 Types of care and support (key points and examples)

There are no formal institutions for the care and housing support for disabled people in Iceland in the traditional sense of the term. However what is available could be analysed along a continuum, ranging on the one end from having more institutional qualities to the other of independent living. But it must be noted that while the term ‘independent living’ (*sjálfstæð búseta*) is often used to describe certain housing arrangements in Iceland, in practice what exists markedly differs from the philosophy of the Independent Living Movement (ILM) that emerged from the United States in the late 1960s.

The IL movement advocates the empowerment of disabled people though, among other things, user controlled services and choice of delivery through direct cash payments. Such arrangements do not currently exist in Iceland.



Thus while some disabled people may indeed live to an extent independently in their own homes, the quality of the available care services and the lack of control on the part of the user are generally not in accordance with the ILM understandings of 'independent living.' The following overview of the range of available housing for disabled people is adapted from the information provided (in Icelandic only¹⁰) from the Regional Office for the Affairs of Disabled People in Reykjanes (*Svæðisskrifstofa málefna fatlaðra á Reykjanesi*), but which can be seen as representative of other regions of Iceland.

- Group home (*Heimili/sambýli*): These homes are intended for people with significant impairments. They typically house 4 to 6 residents. Each resident has their own personal room, but all other facilities are shared.
- Shared apartment residence (*Íbúðarheimili*): This arrangement typically houses 5 to 6 residents. Each individual has their own small studio apartment with sleeping quarters, small living room, cooking quarters and toilet. Communal areas contain laundry facilities, kitchen and living room.
- Apartment complex (*Íbúðarkjarnar*). The residents usually live alone in a self-contained apartment within a larger complex which has support staff on site. Each apartment contains a bedroom, living room, laundry facilities and bathroom, with no common areas.
- Independent residence (*Sjálfstæð búseta*): These would be apartments rented from organisations or the municipality, or privately rented or owned housing. Such housing is typically envisioned for those who have 'considerable capabilities for daily life' (*töluverða færni við athafnir daglegs lífs*).

Loans for adapting existing homes to meet the needs of disabled people, or to assist with the construction of new housing, are available from the Housing Financing Fund – an independent state institution which operates under the auspices of the Ministry of Social Affairs (*Íbúðalánasjóður*¹¹). The interest rates and terms for these 'augmented loans for special needs' (*aukálána vegna sérparfa*) are generally more favourable than the loans available from private financial institutions.

Personal assistance schemes are currently very limited in Iceland. Much of what exists could be considered as experimental programmes at the moment. This issue is in the process of becoming a key focal point for disability rights organisations which are looking to the arrangements of personal assistance schemes in the other Nordic nations as well as Western European countries as potential models.

The care that is available to assist disabled people with various aspects of daily life is usually provided in the home. This would include assistance with waking, dressing, food preparation, personal hygiene and other basic matters. While this assistance is often framed in the discourse of 'independent living,' these services are not user controlled. Furthermore, complaints from users to disability researchers have ranged from a number of issues such as a lack of control as to deciding who these assistants are, the services they provide and how often and when, to the quality of the care received, among others. The assistance that is offered focuses on the basic matters of existence and rarely on matters of a social or recreational nature.

Temporary care options are available from the Regional Offices of the Affairs of Disabled People. One form of short-term care placement (*skammtímavistun*) is available for adults, youth and children. The services offered vary depending upon the particular disabilities and circumstances of individuals. These services are offered 7 days a week, excluding holidays.

¹⁰ <http://www.smfr.is/default.asp?fl=1&pg=2>

¹¹ English <http://www.ils.is/index.aspx?GroupId=281>



There is also a form of temporary care available to support families with disabled children under the age of 18 (*stuðningsfjölskyldur*). This support is offered to families that need a temporary respite period from childcare duties. Families are entitled to this respite care for up to 48 hours a month.

A key transportation service available for disabled people in the capital area of Reykjavík is operated by Strætó, the municipal transportation service. This service is referred to as the 'Transportation service for the disabled' (*Ferðabjónusta fatlaðra*) and consists of small, specially equipped buses that are also visually distinct from the buses used in general service. Similar arrangements exist in the greater Reykjavík area as well as larger towns throughout the country. An application for the use of this system must be approved beforehand and priority is given to people with mobility issues, such as wheelchair users as well as people with visual impairments. This service is limited and restrictive in a number of ways. For example, reservations for this service must be made over the telephone one day in advance and during business hours on weekdays from 8am to 4pm, as well as Saturdays from 9am to noon; this means as well that trips on Mondays must be arranged on the preceding Saturday. 'Group trips,' meaning a group of 4 or more individuals, must be made 48 hours in advance. As per January 1, 2007, an allowance was made, due to special circumstances, which allows individuals to order same-day service, but such a request must be made 3 hours in advance. Depending upon the day of the week, service commences from 7:30am to 10am and concludes at 12pm. Trips designated as 'private purposes' are limited to 18-one way trips a month and the total number of trips within a month may not exceed 60. Regular pre-arranged trips are "confined to travel for job and education purposes." Lastly, a 'journey' is defined as 'from point A to point B.' In other words, the service does not officially assist with entry to the point of destination or exit from the point of departure. If the need arises to cancel the service, the users are required to do so the day before if possible or at the very least 3 hours prior. The failure to do so requires that payment for the trip be made and which will count towards the monthly limit of total trip allowances.

A number of critical observations about this service can be made. It is apparent that the users of this service have limited choices and must arrange their schedules to fit the needs of the transport service. It is also apparent that social needs are given a low priority. The conclusion of the hours of operation at midnight are further suggestive of this, considering in the case of Reykjavík that many cultural events – particularly on the weekends – tend to run rather late and that the nightlife of the city is well known to commence when this service is concluding its operations. In such events, private (and fairly expensive) taxicabs are often the only viable option.

Some impairment specific organisations have made other transport arrangements. For example, the Association of the Blind and Sight Impaired (*Blandrafélagið*¹²) has made an agreement with a taxi company to provide transport services for their members.

The current system of care and support in Iceland is arguably weighted in favour of the care providers rather than the users. The lack of direct payments for personal assistance schemes has a significant impact upon the daily realities of many disabled people and the extent to which they can live up to the typical standards of the general society. The lack of the ability to make choices in the delivery of needed services demonstrates a key area in which disabled people in Iceland do not participate in wider society on equal terms. The question as to the extent to which quality and care depend upon the financial (and social) resources of individual disabled people and their families is an interesting one. In recent years Iceland has been experiencing rapid change, which includes the development of wealth in private hands to the extent that was practically unheard of a few decades in the past. It remains to be seen if wealthy families will, or perhaps currently are, purchasing private care and support services that are unavailable to the general society.

While very little has substantively changed in terms of the care and support system during 2008-2009, it is important to note the recent rise of activist organisations dedicated to promoting the ideology of independent living and user-led services.

¹² <http://www.blind.is/English/>



Three organizations in Iceland, comprised of a mix of service-users and advocates, continue to work towards matters concerning independent living. Samtök um sjálfstætt líf, SSL (Independent Living Movement) had their third board meeting in August of 2009 and, among other things, established a connection with ENIL (European Network on Independent Living) and are working towards further developments this autumn. Another group provisionally identified with User-Controlled Personal Assistance (Notaendastýrð persónuleg aðstoð) is in the formative stages towards developing an independent living centre operated for and by disabled people and will focus on offering advice and training for those who wish to have user-controlled services/personal assistants. In contrast, the formal service providers at present appear to envision a system that allows for greater control or involvement on the part of service-users, yet continue to retain administrative and fiscal control of the services themselves. This apparent failure to fully appreciate the ideology of user-led or user-controlled services—as put forward by disability rights organisations in Iceland and abroad—is still evident in governmental discourses on these matters. The third and most recent group is ViVe (virkari velferð¹³). This group is also pursuing ways in which to place the control of services in the hands of users, as well as discussing ways in which to improve services in the context of the recent economic crisis and governmental cutbacks. The Centre for Disability Studies at the University of Iceland will continue to monitor developments for future ANED reports.

¹³ description in English can be found at http://vive.is/?page_id=38



PART FOUR: SUMMARY INFORMATION

4.1 Conclusions and recommendations (summary)

In summary, it could be argued that overall current policies serve to maintain the existence of disabled people in Iceland, but much more work needs to be done to ensure equality, social inclusion and income security. As discussed in section 1.3, the ideology of inclusion and participation has been generally adopted by the state and service providers, but the current state of services are not adequate in a number of regards to put these ideas into practice. As discussed in section 1.1, the lack of legally binding anti-discrimination measures is a significant omission, and sections 2 and 3 respectively outlined some of the deficiencies of the income security measures as well as the care and long-term support system.

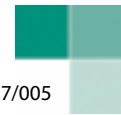
That being said, the recent drafting of the initiative *Shaping the future: Services for disabled children and adults 2007-2016* is a positive sign that the government of Iceland is taking these issues seriously. However, it remains to be seen if the initiatives arising from this new policy framework will continue to be plagued by the issues currently afflicting the delivery of services, primarily the ongoing disparities between policy goals and ideals with that of practice. The recent rise of organisations dedicated to promoting and implementing user-controlled services in Iceland is a very positive development. But of course, the recent economic crisis that hit Iceland in the autumn of 2008 looms large over all of these issues. Recent changes to the disability pension system in 2008 and 2009, which removed some serious reductions of pensions among others, are also a step in the right direction. The involvement of disability rights organisations deserves mention as well, as they have been the driving force behind many improvements of the pension system, but more efforts needs to be done in regard to other issues, such as direct payments.

Lastly, a number of issues relating to differently situated disabled people in terms of gender, age, and impairment, among others, have been mentioned in various points in the report. However, the current lack of comparative research makes it difficult to make broad comparative statements.

It could be argued that the delivery of services for disabled people is due for some significant changes. The lack of user controlled services and direct payments continues to leave many disabled people, particularly those with serious or multiple impairments, disempowered and with little say in regard to the services they depend on. These are core issues which affect many disabled people and which impairment specific as well as umbrella disability rights organisations are currently mobilising for. Further research on these issues is always needed in order to aid in the struggle for the improvement of the current state of services and to lobby for a number of social, economic and political changes.

4.2 One example of best practice (brief details)

From a practical or logistical point of view, the recent changes to the disability pension system are a good example of a step towards the social inclusion of disabled people in Iceland in two key ways. Firstly, the significant raising of the earned income ceiling at which disabled pensioners can earn an income before pensions are reduced is important. The earlier ceilings were much too low and they removed any incentive for pensioners to seek waged labour, as a good deal of the income they earned was taken back with pension reductions. As of July 2008, disability pensioners may now earn up to 100,000 ISK a month without reductions being applied to their benefits. The ability to earn a reasonable income before the pensions are reduced will not only enhance income security for disabled workers, but also potentially boost their work experience and skills. This is in accordance with one of the goals of the EU Disability Action Plan (DAP) which advocates, among other things, the implementation of policies to foster accessibility to the labour market. Secondly, in 2008 as well, the earned income of the spouse of a disabled pensioner no longer reduces the pensioner's income. This is significant not only for income security, but because it enables pensioners to be independent individuals, as their pension amounts are no longer linked with the income of her or his spouse.



The social welfare infrastructure of Iceland has long lagged behind the developments of the other Nordic nations, and much more needs to be done regarding this as well as the delivery of services and the inclusion of disabled people in other contexts.

As such, it is unlikely that Iceland currently has policies and ideas in these regards that can serve as models elsewhere. That being said, the recent policy initiative *Shaping the future: Services for disabled children and adults. 2007-2016* (Ministry of Social Affairs [Félagsmálaráðuneytið]: 2007¹⁴) looks promising and has potential for positive change. The framework of this document bears many similarities to goals outline by the DAP. Of particular significance is how the idea of the empowerment (*valdefling*) of disabled people is given prominence in this document (Félagsmálaráðuneytið 2007c). Work produced by the Centre for Disability Studies at the University of Iceland, and one thesis in particular (Sigurjónsdóttir 2005), was cited as the inspiration underlying this emphasis upon empowerment. It is evident that the state and service providers are listening, to varying degrees, to disability rights organisations, disability scholars and disabled people themselves, but the concrete benefits arising from this policy strategy remains to be seen.

Lastly, the effects of the recent economic crisis must serve as the background for any recent discussions of social protection in Iceland. Arguably, one could say that the recent economic downturn has contributed to the stalling of large-scale planned changes to the disability support services. The plan to decentralize the regional offices for the affairs of disabled people to the local municipalities—a longstanding vision of service delivery—according to some sources is proceeding as planned, while others indicate that there is little in terms of practical developments. The disability pension system has undergone some cuts, the most notable of which were implemented in early July, 2009. While these cuts generally affect to a greater degree pensioners in the higher income brackets, the way in which they were implemented, in terms of rapidity and the lack of consultation, is not a positive sign. And it is clear that the pension system is a possible target of future cuts and streamlining. Cutbacks to healthcare services and increases in user fees can negatively affect those who rely a great deal on the healthcare services, such as some disabled people and those with long-term illnesses. Since the economic crisis, the municipalities appear to be taking a greater role in the provision of services that concern disabled people and other marginalized groups, while it could also be argued that the state level government is gradually removing itself from these issues and is somewhat pre-occupied with economic and macro-political matters.

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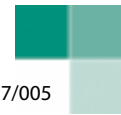
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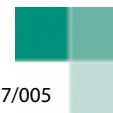
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