



## **ANED country report on the implementation of policies supporting independent living for disabled people**

**Country:** Iceland

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## PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

The over-arching issue concerning independent living in Iceland is the very basic fact that 'independent living,' as understood internationally, is not a reality for many disabled people in Iceland who depend upon support services. All indications suggest that the ideology of independent living, predicated upon the core ideas of direct payments, user-controlled services and choice, is not well developed or understood among service providers nor is it part of the regional and municipal service provision. However, the very recent emergence of two independent living organisations is a hopeful sign that things may change for the better in the near future.

Related to the fundamental issue of the lack of independent living is another key theme: the commitments to equality found in formal laws, policy statements, governmental declarations and such rarely coincide with the actual practices and realities experienced by disabled people. While the laws concerning the issues faced by disabled people speak to rights, independence, and equality, they often lack in specificity, the ideals rarely match practice, and the language – either explicitly or implicitly – makes it clear that the municipal and regional authorities are intended to manage the service delivery system; the needs and wishes of the users, while acknowledged, are only one factor among others within the planning and execution of these services rather than serving as the governing principle of service delivery. Parliamentary committees have been created to oversee the policy formulation stage as well to implement changes needed to ratify the UN Convention, and which includes members of disability rights organisations. However, some consultants to this report have raised questions about the effectiveness of these committees, citing a range of issues such as the lack of results to the low numbers of meetings that are held.

Iceland, like many other European nations, has undergone the process of deinstitutionalization and some progress, albeit slowly, has been made towards independent living. But the consultants contacted for this report were also unambiguous in their views that many people in Iceland continue to live in institutional settings. The group home or '*sambýli*', albeit typically small and housing between 4 to 6 individuals, is often cited by critics as merely a small institution in practice. The residents of these homes have very little say over the time and manner in which basic services are conducted, and such arrangements constitute the most common form of living accommodations for those with serious or multiple impairments. Such criticisms also extend to the so-called independent residence (*sjálfstæð búseta*) conditions of private homes. While people in these cases typically live in privately owned or rented housing, it is apparent that home support services are conducted with the needs of the provider taking precedence over the wishes of the users.

Existing research on services and living conditions from independent sources are limited. Furthermore, official statistics, annual reports, operating procedures and service evaluations from the service providers vary considerably amongst the multiple agencies responsible for a number of support services. Some important information is altogether lacking and what does exist in publicly accessible formats is often outdated, partial or misleading. Efforts by the authors of this report to obtain further information from official sources have so far not proven fruitful.

Another theme which has emerged during the research conducted for this report is the complexity of the support services system. Various government bodies, from the national level to the regional and the municipal, are responsible for a number of necessary support services. Compounding this complexity is the fact that these agencies are constantly in a state of flux; eligibility requirements change, responsibilities are shifted, organisations are merged, renamed or reformed.



Overall, there also appears to be a general shift towards moving the responsibility for services for disabled people from the national level, to the municipal and the local level. It is an onerous task even for seasoned researchers to keep up with these changes, let alone for those who have to negotiate the system in their daily lives. The labyrinthine support services also serves as further justification for the simplification of these services through direct payments and user-controlled and managed services.

In recent years some progress and positive developments have occurred in the disability pension system, for example. The services that exist are of course an improvement upon what was on offer only a couple of decades in the past. However, the inescapable fact remains the direct payments and user-controlled services, where they do exist in a small handful of cases, came only as the result of struggle on the part of users, their families, friends and advocates. As such, independent living in Iceland is the rare exception rather than the rule as it currently exists and it is not officially part of any formal service delivery system.



## PART 2: LEGAL AND POLICY CONTEXT

There are a number of laws enacted by the Icelandic parliament which pertain to the issues regarding independent living, one of which is [Lög um félagsþjónustu sveitarfélaga no. 40/1991](#) (Alþingi 1991) (Local Authorities' Social Services Act). This legislation discusses the provision of assistance by the municipal social services – the key providers in Iceland of home assistance – though this legislation is not focused on disabled people exclusively. It could be argued that the language of this law supports the choices of disabled people to live independently in the community and acknowledges their capacity for choice and independence. For example, Chapter 1 Article C of the law states that the goal of the legislation is to provide assistance so that people can live as 'normal' a life as possible. One way this is to be accomplished is through the provision, among other things, of home support services for those who have difficulties maintaining their own households and to assist with the basic issues of daily life (Ch. 7 art. 25). The tone of the legislation is decidedly in favour of providing assistance that allows people to live in their own homes for as long as possible, with references to fostering such ideals as 'self-help' or 'self-sufficiency' [*sjálfsbjörg*].

A similar situation holds for legislation that is directly aimed at disabled people, such as *Lög um málefni fatlaðra* (Alþingi 1991) ([Act on the affairs of people with disabilities, no. 59/1992](#) – in English), whose primary goal is to "ensure to the people with disabilities equality and living conditions comparable with those of other citizens, and to provide them with conditions that enable them to lead a normal life" (Ch. 1 section 1). The focus of the legislation is that of inclusion within the general society and providing assistance for living within one's own home (Ch. 4 art. 8). Chapter 6 Article 10 is very clear on the matter of housing and that residency options are the prerogative of disabled people: "People with disabilities shall have the option of choosing their residence, in conformity with their needs and wishes, insofar as possible." However, it is also very clear based on the input of service users and those familiar with the housing situations of disabled people that in practice these choices are limited and, in certain regards, choice is altogether lacking. A recurrent theme encountered by the authors of this report from contributing consultants is that practices do not necessarily match the ideals found within the legislation; and further, that the concept of 'independent living,' as articulated by disability activists in the United States, the United Kingdom and other European nations such as Sweden and Norway, is not well-developed in Iceland among most service providers and legislators, and, in fact, among many service users.

In order to rectify this situation, a newly formed organisation has emerged in Iceland: Samtök um sjálfstætt líf – SSL (Independent Living Movement). This organisation, comprised of a mix of service users, advocates and professionals working within the field of disability, has a number of objectives which include: promoting and spreading knowledge about the ideology of independent living among service users, the general public and the government; promote ways to implement user-controlled personal assistance; work to improve the legal environment relating to these issues; and to have a measure of control and influence upon the policy process. This organisation's ideology draws inspiration from the ILM movement which emerged in the United States in the 1960s and 1970s. In addition to this new independent living movement in Iceland, a group of service users and people active in the disabled people's movement are preparing to establish an Independent Living Centre, a cooperative run by and for disabled people with the aims such as lobbying for direct payments and user-controlled personal assistance, and offering advice on hiring and managing personal assistants.

The two sets of laws discussed above, while amended in various ways throughout the years, are fast approaching the close of their second decade of existence. The most significant recent policy strategy in Iceland concerning 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). It is important to note that this policy document has an uncertain status as it has not been adopted by the government as an official policy. It is, however, the latest policy document from the Ministry. According to it, by 2016 the government of Iceland plans to accomplish, via this policy formulation, a number of key goals. Among these include the goal that all disabled people in Iceland will enjoy commensurable 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; lastly, similar claims are also made regarding the quality of services for disabled people.

However, while some progress has been made with regard to improving the disability pension system in Iceland (see ANED Report on the social inclusion and social protection of disabled people in European countries – Iceland), a case could be made that little concrete changes with regard to independent living have been implemented in recent years. Examining the language of the *Shaping the future* strategy, it is also apparent that the notion of ‘independent living’ does not quite approximate the understanding of independent living as put forth by organisations such as the independent living movements internationally and the newly established independent living movement in Iceland, SSL. Under the section regarding home services (Þjónusta vegna búsetu 2.6.2:13) it is stated that a number of future goals include the provision that disabled people will have the choice where to live and, in the case of service oriented group homes, with whom and that services are to be individualised to meet the needs of specific individuals. While this is certainly a step forward, it does not quite meet the standards of independent living that are typical among disability rights advocates, such as direct payments and user controlled services. Further, a careful look at the language reveals that the municipalities, while expected to give up a measure of control, still direct and manage services. For example, under this proposal these individualised services ‘take into consideration’ or are designed ‘in terms of’ [*með hliðsjón af*] the wishes of the individual and/or their guardians. But it could be argued that taking one’s wishes into consideration is not commensurate with the practice of user-controlled services.

The current economic situation in Iceland also brings into question what, if any, policy recommendations from this report will be implemented. However, the formation of an Icelandic independent living movement, Samtök um sjálfstætt líf (SSL) and the independent living centre that is being developed, will hopefully result in positive change, both in terms of an ideological shift as well as in practice. Iceland is also a signatory, but has not ratified, the UN Convention of the Rights of Persons with Disabilities and the Optional Protocol. A parliamentary committee [Nefnd um endurskoðun löggjafar vegna Samnings Sameinuðu þjóðanna um réttindi fatlaðs fólks] is also currently at work reviewing the existing disability legislation and considering changes that need to be undertaken in order to ratify the UN Convention. This committee is comprised of two Members of Parliament, two representatives from the disability rights organisations Landssamtökin Proskahjálpi (National Association on Intellectual Disability) and Öryrkjabandalag Íslands, ÖBÍ (The Organisation of Disabled People in Iceland), as well as members from the ministries of Health, Education, Social Affairs and Foreign affairs.



### PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

The first private institution for disabled children in Iceland was established in 1930 and the first private institution for adults opened in 1944, followed in 1952 by the first central state institution. However, these institutions were never large, the biggest housing about 200 inmates, though arguably of a fairly significant size considering the population of Iceland as a whole. The 1980s and 1990s saw the gradual closing of many of these institutions as the result of the gaining influence of the ideas of normalisation and integration (Traustadóttir 2009, see also Margeirsdóttir 2001). However, both private and state run institutions still exist to an extent. An example of the former can be found in the countryside, [Sólheimar](#) (founded 1930), which can perhaps be described as an agricultural commune more so than a traditional institution, similar to a Camphill Community in the UK, and which houses 42 disabled residents out of approximately 100 people in total. Another example is that of [Skálatún](#) (founded 1954), a home for 45 individuals with intellectual disabilities and [Sjálfsbjargarheimilið](#) (1973), a home for 35 individuals with multiple impairments. Those three institutions are private but state subsidised institutions. Following the EU definition of an institution as being a place where more than 30 people live, these are the only three institutions left in Iceland. Other state institutional arrangements housing small numbers of people can be found in the form of dispersed and small scale residences in hospitals, rehabilitation centres, nursing homes and other such facilities, usually for people with significant and/or multiple impairments.

However, the more common housing options that are available could be analysed along a continuum, ranging on the one end from having more institutional qualities to the other approximating independent living. At the more institutional end of the continuum are group homes known as *heimili* or *sambýli*, while at the other end of the spectrum are privately owned or rented homes and apartments, referred to as *sjálfstæð búseta* (independent residence). The former housing option continues to exhibit many of the institutional qualities of the older practices, such as limited control on the part of the individual over the time, manner and place in which the assistance for basic needs is provided. From the perspectives of consultants critical of the existing support services, it appears to be the case that the needs of the service providers usually take precedence over the wishes of the service users in regard to everything from personal grooming to transportation services. This analysis could also be extended to the services offered to those who reside in the so-called 'independent living' options.

While the term 'independent living' (*sjálfstæð búseta*) is often used to describe certain housing arrangements in Iceland, in practice what exists sharply differs from the philosophy of the Independent Living Movement (ILM) that emerged from the United States in the late 1960s. The ILM movement advocates for the empowerment of disabled people through, among other things, user controlled services, personal assistance and choice of delivery through direct cash payments. Such arrangements currently exist in Iceland in limited and rudimentary forms, to the extent that there are no more than a handful of individuals who have made arrangements for direct payments and manage their own services. Further, it also appears to be the case that should an individual manage to achieve direct payments, through a great deal of struggle and effort, that such an arrangement may preclude any further assistance and access to services for an individual from the local Svæðisskrifstofa málefna fatlaðra (Regional Office for the Affairs of People with Disabilities). 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,' and the experiences of individuals vary depending, arguably, upon factors such as the persistence of advocates, the strength of personal support networks, and other such circumstances.



The following overview of the range of available housing for disabled people is adapted from the information provided (in Icelandic only) 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. The group homes are predominantly for people with intellectual disabilities, with some homes intended for people with similar specialised needs, but they can also include people with physical disabilities as well as mental health issues. 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 activities of daily life' (*töluverða færni við athafnir daglegs lífs*).

Publicly accessible information pertaining to the numbers of people who live in such housing arrangements in Iceland is generally lacking. Part of the problem lies in the fact that Iceland is divided into eight regions for the purposes of the administration of the issues pertaining to disabled people, six of which include a local office for the affairs of people with disabilities ([Svæðisskrifstofa málefna fatlaðra í Reykjanesi](#); [á Austurlandi](#); [á Vesturlandi](#); [í Reykjavík](#); [Suðurlandi](#); and [á Vestfjörðum](#)), whereas in the remaining two regions (Norðurland Vestra and Norðurland Eystra) the Ministry of Social Affairs has arranged various contracts for the provision of services. As such, some regional offices provide a significant amount of publicly accessible data, whereas others provide little or outdated information which makes certain quantifiable statements about the situation in each region difficult and of Iceland as a whole impossible with the available information. To further complicate matters, when information is provided, there seems to be little or no standards among the various Regional Offices as to what information is released, the format in which it is presented or the operative categories employed. That being said, through the combined efforts of the authors and consultants, it was determined that there are 101 group homes (*heimili/sambýli*) throughout the country housing a total of 501 individuals. The *sambýli* appears to be the most dominant form of housing for disabled people in Iceland. The self-contained apartment blocks with on-site support staff (*íbúðarkjarnar*) number 12. A total of 342 individuals receive support in their owned or rented homes.

The issue regarding safeguards to ensure that people do not remain in institutions against their will is difficult to address. In the context of Iceland, it could be argued that residency within the group homes is less a matter of personal choice or free will and more to do with the lack of available options, which in turn constrains personal wishes by the lack of direct payments and user controlled services. Further, one of the authors of this report has observed dismay on the part of some residences of apartment complexes over the suggestion of closing these buildings and dispersing the residents within private housing in the community.





The issues of the possible social/psychological effects of long-term institutional living as well as the possibility of imposing the views of disability rights organisation and advocates on disabled people in Iceland in general also has to be considered when analyzing the issue of choice, free will and independent living.

However, there is a legal safeguard in place which is intended to monitor living conditions and to ensure that grievances on the part of disabled people are addressed. A significant development for the rights of disabled people in Iceland found within the 1992 *Lög um málefni fatlaðra nr. 59/1992* was the appointment of a representative or ombudsman (*trúnaðarmaður*) for disabled people in each service region. Ideally, the representative is tasked with ensuring that the rights of disabled people are respected through monitoring how well they are faring through visits, observing service provision and living conditions, following up on complaints, as well as seeking information from service providers and their staff. Such an arrangement could indeed provide an important safeguard to ensure that the rights of disabled people are respected in many regards.

As often appears to be the case in Iceland, the ideals found in laws and policy statements do not appear to coincide with practice. According to information provided by a consultant, one service region has been without an ombudsman since 2007, only two ombudsmen/representatives have received any training within the field of disability, and that all ombudsmen/representatives are chosen by the Ministry rather than by disability movements or disabled people themselves. Furthermore, research that has explicitly focused on these disabled people's ombudsmen/representatives (Baldvinsdóttir Bjargardóttir 2006) found that these representatives either had very few clients in their region (such as in the countryside) and thus held the position as a part-time job, or else (such as in the Reykjavík area) had an excessive workload. Furthermore, it is debatable as to the extent to which disabled people were even aware of the existence of these representatives, as some representatives reported that they had very few people come forward for assistance and even fewer formal cases put forward. Lastly, one disabled people's representative reported that the municipal social services refused to supply the representative with the names and addresses of disabled people in the region who lived in independent homes on the claim that this would violate their privacy. With such perplexing attitudes on the part of service providers, and the organisation of the disability representative system, it is debatable the extent to which the rights of disabled people can be safeguarded under such arrangements.

In terms of studies regarding the costs of the various forms of home assistance in comparison with different forms of housing, very little is known, especially at the national level. A similar problem exists in that different organisations, in different regions of the country and at different levels of government, hold various parts of the data required in order to make such comparisons. The only existing substantive, and publicly accessible, evaluation of the home services provided for disabled people in Iceland was produced in 2004, followed by an MA thesis the subsequent year (Óskarsdóttir and Kristjánsdóttir 2004; Óskarsdóttir 2005). According to the former, in 2003 and drawing upon data provided by the Regional Office for the Affairs of People with Disabilities in Reykjavík, the costs for providing additional support services in the home for disabled people appear to be more expensive within the contexts of group home residences than private dwellings. These costs amount annually to 196.000 ISK (in 2003 terms) per individual residing in private or general housing; 1.200.000 ISK to 3.000.000 ISK per individual residing within an apartment complex (*íbúðarkjarnar*); and 1.800.000 to 10.000.000 ISK per individual within a group home (*sambýli*) (Óskarsdóttir and Kristjánsdóttir 2004:19). It would appear that support in private homes is the less expensive option, although people with more significant impairments living in group homes may indeed have more intensive support needs.

The case can certainly be made that there has been some progress towards independent living in Iceland.





Over the last few decades, formal institutions have been closed and services have been enacted that would otherwise make non-institutional living an unrealistic option, especially for people with significant impairments and their families. However, from the point of view of service providers the group home residence appears to be the favoured housing arrangement for disabled people. Further, patterned criticisms were voiced to the authors of the report from researchers, former and present workers within the service delivery system, as well as the users themselves, that the services on offer are not adequate to meet their needs, service provision favours the needs of the providers rather than users, and that many disabled people in Iceland still lead lonely and isolated lives. It must be emphasised that 'institution' and 'institutional thinking' about the provision of services are not confined within the walls of specific buildings.



## PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY

In regard to support for disabled people who live in their own homes which makes independent living possible, key forms of this support include the disability pension system, the provision of assistive equipment and adaptations (discussed further in section 4.2), home support services and social support, as well as transportation services. It must be kept in mind, however, the personal assistance services that are controlled and managed by disabled people themselves are very rare in Iceland at the moment. As such, user controlled services, personal assistants and direct payments are not official options on the part of the service provision system in Iceland.

**Disability Pensions:** For those not working, a disability pension is a basic requirement for securing an income. 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. A downloadable .pdf of the pension levels for 2009 (in ISK and Icelandic only) is available [here](#). The sums detail the maximum, and thus optimal, amount available to pensioners.

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. The limitations of the pension system are linked to an assessment of individual impairment as determined by a medical doctor employed by Tryggingastofnun for these purposes. 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*), 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. Figures from 2008 (Tryggingastofnun 2009a) indicate that there were 14,103 disability pensioners in Iceland, consisting of 5,473 men and 8,630 women. The disparity in terms of higher instances of disabled female pensioners than males in Iceland is well known among researchers but, as of the time of writing, the reasons for this remain unclear. This is a nationally based pension that is not tied to a particular location within Iceland, unlike the municipally based social assistance schemes.

The most recent and scholarly evaluation of the Icelandic disability pension can be found in the work of the sociologist Stefán Ólafsson (2005), and which has been translated into English (Ólafsson 2005). 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 have entered the disability pension system at a younger age and who would most likely not have accrued the 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 the reductions to disability pensions as the result of spousal income were eliminated. It is important to note as well that due to the economic collapse in Iceland the government will have to make significant cuts in public spending and disability pensions will most likely be cut to some extent.



**In-home support services and social support.** As far as could be determined, people with significant or multiple impairments receive home care services from their local Regional Office for the Affairs of Disabled People. For those who live in their own private homes and/or may need less intensive services, such help is often provided by the local municipal social services (*félagsþjónusta*). The latter will be the focus here. The regulations that govern home support services in the city of Reykjavík ([Reglur um félagslega heimabjónustu í Reykjavík](#)) are one example of such.

To receive these services, one has to meet all the expected eligibility requirements: legal resident of the city, older than 18 years of age, one lives outside of an institution, and one must demonstrate or provide evidence for needing these services. The latter refers to people who have difficulty taking care of basic, daily household needs without assistance, such as personal grooming, housework, shopping, caring for children or teens, and/or lack social support. It must be noted as well that these services are provided to disabled people, but also those who are elderly, pregnant or going through a difficult period in their lives but all of whom reside within their own homes. The costs for these services are borne by the user, with the exception of those who receive a disability pension, or other pension or low wages of similar amounts. In these cases, individuals may be eligible for reduced or waived fees depending upon their financial circumstances.

The specific level and nature of the services that are provided are worked out between the user and service provider. These could include the provision of in-home support for personal hygiene, getting dressed, taking medication, basic housekeeping, assistance with meal times, shopping needs as well as social support (*liðveisla*), such as the worker spending time with the client, offering advice, going out into the community together, and so forth. However, this service is not commensurate with personal assistance. The assistance offered is limited to weekdays and office hours, though some night and weekend assistance is available in certain circumstances. The users are not in control of services. Generally, assistance with shopping and housekeeping is limited to blocks of time twice a month, and the users are expected to assist when and if they can.

**Respite care and support families.** In terms of support to parents or families, temporary care options are available from the Regional Offices of the Affairs of Disabled People or municipality. One form of short-term care placement (*skammtíamavistun*) is available for adults, youth and children. The services offered vary depending upon the particular impairments and circumstances of individuals. However, most of these services are designed for children and youth. These services are offered 7 days a week, excluding holidays. There is also a form of respite care in the form of family support (*stuðningsfjölskyldur*) available to assist families with disabled children under the age of 18 that need a temporary respite period from childcare duties. Families are entitled to this respite care for up to 48 hours a month.

The most recent report on the numbers of users of this service from the City of Reykjavík is from the Social In-Home Support Services in Reykjavík, [Félagsleg heimabjónusta í Reykjavík: Fyrirkomulag, þróun og staða](#) (2007). As of 2006, 3646 people in the city of Reykjavík received some form of home assistance services. It is also clear from the available data that there has been a steady demand for evening and weekend services. In 2001, only 29 people received evening and weekend services and which rose to 349 people in 2006. The most recent service evaluation of the home support services in the City of Reykjavík is [Félagsleg heimabjónusta – viðhorf notenda](#) (2008). In 2004, 1737 individuals received home services from the municipal social services of Reykjavík.

Of those, 433 were randomly selected for a survey in order to evaluate the services on offer and which resulted in a final sample size of 375. Three-quarters of their service users have been clients for between 3 to 10 years, with slightly over 16% using these services for 10 years and more.



But it is also clear that the majority of the services on offer are limited, as over 75% of their users received services only twice a month or less and only 5% received services every work day or every day of the week. It must be remembered that the individuals with more intensive support needs most likely reside with the *sambýli* group homes and thus receive services from the local Regional Office rather than the municipal social services. However, given the lack of direct payments and user controlled services in Iceland, and the fact that the municipal social services offers less intensive home support services, the *sambýli*/group home under the management of the Regional Offices continues to be the de facto residency option for significantly impaired people.

**Transportation Services:** 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' ([Ferðapjónusta 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 and others who have difficulty negotiating the standard bus system. This service is limited and restrictive in a number of ways. The operating hours generally follow the operating hours of the transit system in general. Priority is given to transportation needs for the purposes of work, school, rehabilitation and medical needs. A 'trip' is considered to be a journey from point A to B and are not to exceed 60 trips a month, which is essentially one two-way journey a day for a typical month, though some consideration is given to those who need to travel for regular work or school. The trips must be ordered between the hours of 8am–4pm on weekdays and 9am–12noon on Saturdays 1 day before the planned travel. As of January 2007, trips may be arranged with at least 3 hours notice, at an additional cost, though group trips (4 people or more) still require 2 days notice. Users of the service are required to be in the lobby of the point of departure at the pre-arranged time.

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. A consultant to this report also commented that there is only one private rental car specially equipped for wheelchairs in Iceland. This is also a limiting factor for domestic travel options, particularly during the summer months when most recreational travel occurs. Some impairment specific organisations have made other transport arrangements. For example, the Association of Blind and Visually Impaired People (*Blindrafélagið* <http://www.blind.is/English/>) has made an agreement with a taxi company to provide transport services for their members which is individualised and much more flexible than the general disability transport services described above.

In all of the above examples, monitoring and service evaluations are either limited, internal to the various organisations or, in some cases, practically non-existent. For example, despite the fact that one Regional Office claims that quality management is 'interwoven' in all of its planning stages and service delivery, and that this is accomplished through the use of "clear coordinated, measurable objectives" (The Regional Office for the Affairs of People with Disabilities at Reykjanes 2007), the authors of this report were unable to determine what these measures are.



Furthermore, a consultant for this report with former experience in a Regional Office claims as well that internal quality control measures and mechanisms are generally lacking. As mentioned in section 3, the disabled people's representative (*trúnaðarmaður*) system by which one representative is charged with monitoring and overseeing the quality of services and living standards of disabled people within each service area is questionable in its effectiveness, particularly so when the work of the disabled people's representatives is compromised by the non-cooperation of service providers. An example of such is the failure to disclose the names and address of disabled people living in private residences so they may be contacted (Baldvinsdóttir Bjargardóttir 2006). The small numbers of service evaluations, often conducted by the same agency that delivers these same services, which are released to the public often fail to include the critical analysis and reflection of independent or scholarly studies. Legitimate questions can be raised as to the validity of some of these service evaluations, considering that respondents may be disinclined to openly criticise service providers if the same service providers are conducting the evaluation in question. Furthermore, these evaluations do not appear to be conducted with any regularity and even basic, publicly accessible annual activity reports are few and far between. There are a handful of independent, scholarly evaluations of services (e.g. Óskarsdóttir and Kristjánsdóttir 2004) but these are limited in the sense that they are infrequent, contain no grievance address mechanisms, nor are service providers required to address the findings.



#### **4.1: PERSONAL ASSISTANCE SERVICES**

Personal assistance services for independent living that are controlled and directed by disabled people themselves are, at the time of writing, practically non-existent in Iceland. Such arrangements currently exist in Iceland in limited and rudimentary forms, to the extent that there are no more than a handful of individuals who have made arrangements for direct payments and manage their own services. In these cases, such arrangements were only made possible as the result of intense lobbying and struggling on the part of the service users as well as their families, friends and advocates. Little else can be said regarding personal assistance services at the moment aside from that the concept of 'independent living' is not well-developed in Iceland among most service providers and legislators, and, in fact, among many service users. The kinds of assistance at home provided by the municipality (described earlier) cannot be easily regarded within this concept. However, the recent emergence of independent living organisations in Iceland is a hopeful sign that changes may be on the horizon.





## 4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

**Assistive equipment and adaptations:** The key provider of support for assistive equipment falls under the collective jurisdiction of the Social Insurance Administration of Iceland and the Health Insurance Administration of Iceland ([Sjúkratryggingar Íslands](#)). The organisation which deals with the day to day provision, education, and servicing of assistive equipment is the Assistive Equipment Center ([Hjálpartækjamiðstöð SÍ](#)). The equipment provided covers a range of devices such as wheelchairs, vehicle adaptations, lifts, and specially equipped beds. The legal framework governing the eligibility requirements and the assistance provided is the Ministry of Health's (Heilbrigðisráðuneytið 2008) Statute nr. 1138/2008 on Grants to Cover Assistive Equipment ([Reglugerð heilbrigðisráðuneytis nr. 1138/2008 um styrki vegna hjálpartækja](#)). Sjúkratryggingar Íslands approves the needed equipment based upon an evaluation of each individual as per the assessment of doctor or physical therapist. The eligibility for assistance is first based upon the applicant's legal right to healthcare insurance in Iceland (6 months legal residency) followed by an evaluation of the individual's needs by a doctor or physical therapist. The provision of this equipment is limited to the individual's needs, as determined by the health care professionals noted above, provided that the equipment will be used continually for longer than three months, and that the equipment is needed for the 'necessities' of daily life and not occasionally for the purposes of recreation, sport or leisure activities. While this equipment is provided as a support and service to disabled people, the users are expected to bear some of the costs, depending upon circumstances and the equipment in question. There are a number of other limitations to this assistance which includes, among others, the sharing of devices where possible among those who live in shared residencies; the exclusion of this kind of assistance to those who live in institutions (the institution in question is expected to provide the needed equipment); and the restriction of this equipment for work or school places for adults (in this case, the task falls to the local Regional Office for the Affairs of Disabled People). In an [agreement with the EU and the EEA/EFTA](#), those who are entitled to this assistance within Iceland are entitled to the same assistance in other member nations.

Loans for the purchase of a specially adapted home, or to build such a home or modify an existing home, are provided by [Íbúðalánasjóður](#) (The Housing Financing Fund); the Fund is an independent but government supported agency that finances home purchases and construction. The [aukalan vegna sérbarfa](#) (extra loan due to special needs) offers up to a maximum of 8 million ISK for these purposes. However, the low-interest loans are only available once the work has begun or a purchase has been made, meaning in practice that traditional bank loans are the beginning of this process. The application process begins with a form that requests information on the applicant's special housing needs and nature of illness or disability, and which requires the letter or certificate of a doctor.

The State Social Insurance Administration also offers grants for the purchase or operation of a car in certain cases, which could perhaps also be considered as a form of assistive equipment in terms of mobility and transportation.



## PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE

The question of 'good practice' and the involvement of disabled people and their organisations in the design, management, delivery and evaluation of support services for independent living in Iceland can generally be summarised with the statement that a movement for independent living and a disabled people's cooperative (centre for independent living) are literally emerging as this report is being written. Further and simply put, independent living – as understood elsewhere such as the United States, UK, Sweden and Norway for example – is currently not an official service delivery option for the vast majority of disabled people in Iceland.

Of the very small handful of people who have achieved direct payments and user-controlled services, they are the exception rather than the rule and such arrangements are only possible after lengthy struggles with the existing Regional Offices or municipal services providers on the part of disabled people, their families, friends and advocates. Furthermore, it is apparent that the ideology of the independent living movement is not well understood, if it is understood at all, on the part of the existing formal regional and municipal support services. Consultants to this report have repeatedly stated that the services are organised around the needs and limitations of the service providers and that users are expected to accept institutional arrangements to the patterns of their daily lives, as exemplified by the lack of choice about such matters often taken for granted by non-disabled people such as where to live and with whom, when to wake-up, when to bathe and what to do with one's time, among others, as well as interfering – rather than enabling – the ability to arrive at work or school on time due to inflexible services and the priority of the needs of the service providers.

It is specifically stated in the [Act on the affairs of people with disabilities, no. 59/1992](#) that disability rights organisations, such as Öryrkjabandalag Íslands (the Organisation of Disabled in Iceland) and Landsamtökin Proskahjálpi (National Association of Intellectual Disabilities), among others, are to be consulted for their input regarding policy. As stated elsewhere in this report, representatives from these organisations are often members of committees established regarding various aspects of disability policy. However, again it is a question as to the extent to which the input from disabled people's organisations is translated into practice. Some scholars have suggested that the policy ideals of involving disabled people in policy making fall short in envisioning achievable targets and in their implementation, and that the full inclusion of disabled people in Iceland does not fare well in comparison with other European nations (Flóvenz 2004; Ólafsson 2005). As such, it would be fair to state that the bulk of service planning, delivery and monitoring has been conducted without much input from disability organisations or users.

However, Iceland is also very much a part of a general burgeoning interest in independent living in Europe in general. As well, it may also be fair to say that the recent election of a decidedly left-leaning government after many years of conservative governments in Iceland has generated a measure of optimism among disability rights advocates. Two organisations are in the process of being formed to lobby for the implementation of independent living that is in accordance with the contemporary understanding of the international IL movement and disability rights. One is *Samtök um sjálfstætt líf, SSL* (Independent Living Movement). As discussed in Section 2 of this report, this organisation is primarily concerned with developing the ideology of independent living in Iceland and communicating these ideas to service providers, governments, service users, and the general public.

This organisation is in the process of being established. Another organisation – provisionally identified with User-Controlled Personal Assistance (*Notaendastýrð persónuleg aðstoð* – NPA) – will focus on offering advice and training for those who wish to have user-controlled services as well as work towards establishing an independent living centre operated for and by disabled people.



The Centre for Disability Studies at the University of Iceland has close and direct contact with both of these organisations and will be able to report in the future on the progress and impact of the work of these two groups.



## PART 6: REFERENCES

Alþingi (Icelandic Parliament) 1992. [Lög um málefni fatlaðra no. 59/1992](#) (Act on the affairs of people with disabilities).

Alþingi (Icelandic Parliament) 1991. [Lög um félagsþjónustu sveitarfélaga no. 40/1991](#) (Local Authorities' Social Services Act).

Baldvinsdóttir Bjargardóttir, H. 2006. *Réttindagæsla fatlaðra: fyrirkomulag réttindagæslu á Íslandi með hliðsjón af réttaröryggi fatlaðra*. BA thesis. Reykjavík: Kennaraháskóla Íslands.

Félagsmálaráðuneytið (Ministry of Social Affairs). (2007). [Mótum framtíð: Þjónusta fötluð born og fullorðna 2007-2016](#) (Shaping the future: Services for disabled children and adults. 2007-2016).

Flóvenz, B.G. (2004). *Réttarstada fatlaðra* (Rights of the disabled in Iceland). Reykjavík: Mannréttindaskrifstofa Íslands og Minningarsjóður Jóhanns Guðmundssonar.

Heilbrigðisráðuneytið (Ministry of Health). 2008. [Reglugerð heilbrigðisráðuneytis nr. 1138/2008 um styrki vegna hjálpartækja](#). (Grants to Cover Assistive Equipment 1138/2008).

Margeirsdóttir, Margrét (2001). *Fötluð og samfélag: um þróun í málefnum fatlaðra* (Disability and society: on the development of the affairs of the disabled). Reykjavík: Háskólaútgáfan

Ólafsson, S. (2005). [Disability and welfare in Iceland in an international comparison](#). Reykjavík: Social Science Research Institute, University of Iceland.

Óskarsdóttir, H.K. (2005). *Ungt fatlað folk: Sjálfstætt líf, sjálfstæð búseta* (Young disabled people: Independent lives, independent living). MA thesis. Reykjavík: University of Iceland, Faculty of Social Sciences.

Óskarsdóttir, H.K., and Kristjánsdóttir, H. (2004). *Þjónustumat: Sjálfstæð búseta fatlaðs fólks í Reykjavík*. (Program evaluation: Independent living for disabled people in Reykjavík). Reykjavík: Social Science Research Institute, University of Iceland.

Reykjavíkurborg Velferðarsvið (City of Reykjavík Welfare Division). (2008). [Félagsleg heimaþjónusta – viðhorf notenda](#)

(2007). [Félagsleg heimaþjónusta í Reykjavík: Fyrirkomulag, þróun og staða](#)

(2006). [Reglur um félagslega heimaþjónustu í Reykjavík](#).

Svæðisskrifstofa málefna fatlaðra á Reykjanesi (Regional Office for the Affairs of Disabled People in Reykjanes). 2009. [Þjónusta fyrir 18 ára og eldri: Búseta](#) (Services for those aged 18 and older: Residences).



2007. *The Regional Office for the Affairs of People with Disabilities at Reykjanes (ROAPDR)*. Unpublished Power Point Presentation. Svæðisskrifstofa málefna fatlaðra á Reykjanesi

2006. [Ársskýrsla SMFR 2004 – 2006](#) (Annual Report 2004–2006).

Svæðisskrifstofa Reykjavíkur um málefni fatlaðra (Regional Office for the Affairs of Disabled People in Reykjavík). 2004. Ársskýrsla 2003 ([Annual Report 2003](#)).

Traustadóttir, R. 2009. *Trapped in the Institution: Deinstitutionalization in Iceland*. Paper presented at the Nordic Network on Disability Research (NNDR). 2–4 April 2009, Nyborg, Denmark.

Tryggingastofnun ríkisins (Social Insurance Administration of Iceland). 2009a. [Tafla 1.22 Fjöldi örorku-, endurhæfingarlífeyrisþega og örorkustyrkþega 1986-2008](#) (Invalidity and rehabilitation pensioners and recipients of invalidity allowances 1986-2008).

2009b. [Upphæðir bóta almannatrygginga árið 2009](#) (Social Insurance Rates for the year 2009).