

# **Personalised Support and Services for Persons with Disabilities – mapping of Nordic models**



Nordic Welfare  
Centre

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# Introduction

According to Vision 2030 of the Nordic Council of Ministers the Nordic countries will become the most integrated, green, competitive and socially sustainable region by 2030. The vision reflects the sustainability goals of the UN Agenda 2030 where one of the basic principles is that no one is excluded. For persons with disabilities to have the opportunity to live independently and to be included in the community requires, among other things, that persons with disabilities have different kinds of social services and support available. This is a human right ratified in article 19 of the United Nations Convention on the Rights of Persons with Disabilities.

During 2021, the Nordic Welfare Centre and the Finnish Institute for Health and Welfare (THL) conducted a joint project on the use of personal budgeting as a model for personalised support in the Nordic countries. In several Nordic countries the support and service for persons with disabilities have undergone a reform. The aim has been to increase individual self-determination and influence over the support and service the individual is entitled to. Examples of these are efforts, such as personal assistance and individual plans, as well as different kinds of reforms of freedom of choice where the individual can choose the service provider. One solution is that the individual has a personal budget for their support efforts. This system is applied in some countries and is often called Direct payment.

The Nordic Welfare Centre and THL have examined whether, and in that case how, models for personalised support in form of a personal budget may strengthen the implementation of the UN Convention on the Rights of Persons with Disabilities, especially Article 19 on the right to live independently and to be included in the community. The project has explored available models and the experiences of these. The project is an activity within the framework for Finland's 2021 presidency for the Nordic Council of Ministers 2021. The survey will form the basis for a proposal to reform support and services for people with disabilities in Finland. Main writer of this report is Lars Lindberg, Senior Adviser at the Nordic Welfare Centre, with contributions by Stina Sjöblom, Senior Researcher at THL. The Nordic Welfare Centre and THL wish to thank the researchers and experts that have contributed to the project's workshops and answered questions.

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# Summary

During 2021, the Nordic Welfare Centre and the Finnish Institute for Health and Welfare (THL) conducted a joint project on personal budgeting as a model for personalised support. The project was funded by THL and conducted as part of the Finnish Government's pilot project on personal budgeting for persons with disabilities. The project has studied how models for personalised support, such as personal budgeting, can contribute to the implementation of the United Nations Convention on the Rights of Persons with Disabilities, in particular Article 19 on the right to live independently and be included in the community. Article 19 applies to all persons with disabilities, irrespective of the extent of their disability and need for support. In *General Comment No.5 (2017)* on Article 19, the Committee on the Rights of Persons with Disabilities highlights the importance of the individual having control over the support provided.

The project has surveyed available models in the Nordic countries and experiences of their implementation. This survey was conducted through questionnaires and workshops with researchers and experts, as well as through desk research. The survey will form the basis for a proposal to reform support and services for people with disabilities in Finland.

Personal budgeting is used by healthcare and social services in a number of countries. It is, however, a broad concept with no uniform definition. The ongoing Finnish project has defined personal budgeting as a method for organising assistance, support and interventions so that the individual is at the centre of the planning, choice and implementing of support.

The increasing personalisation of support for people with disabilities has been characteristic of developments over the past 30 years, the primary example being personal assistance. Various forms of free choice have also been tested and incorporated into healthcare and social services in the Nordic region, in the form of systems of choice and increased opportunities for users to choose service providers. This development has been driven by both demands from the disability movement and the influence of new public-sector governance models, primarily through the impact of New Public Management from the 1990s onwards. Inspired by the private sector, these methods are based on quasi-market solutions implemented in the welfare sector.

In the Nordic region, the prime example of support and service based on personal budgeting is personal assistance. Today, all Nordic countries have some form of personal assistance that offers the individual user significant influence over how their assistance is designed. There are, however, national differences in the scope of assistance and who is entitled to support. There are also differences in the leeway to choose private service providers and thus what percentage of the overall assistance is implemented by the private sector.



Another area in which personal budgeting has been implemented is disability aids; One example is that experienced users are offered greater opportunities to choose aids than those with less experience. Another solution is to offer the user a cheque to purchase aids, allowing them to pay the difference should they choose a more expensive aid than would be covered by public funds.

In other areas of social services, such as assisted living, several countries have introduced systems that allow users to choose their service provider. There are also examples from other social areas of projects in which socially disadvantaged individuals have been offered the opportunity to design their own rehabilitation from a personal budget, based on their own goals and wishes.

Adapting the design of support to the individual can be achieved in several ways that do not involve personal budgeting or specific fixed amounts. One common method is to prepare an individual plan to coordinate the support and services the user needs. This is useful if, for example, the individual receives support and services from several units or providers, as it reduces the risk of the support being fragmented.

As the opportunity to make individual choices increases, so too does the need for advice and support. This is particularly important for those whose ability to make decisions is impaired. Advice is available from both the public sector and civil society.

To a large extent, solutions based on personal budgets are inspired by solutions developed in English-speaking countries where public welfare as a rule does not have the same tradition or structure as in the Nordic Countries. It is not uncomplicated to introduce solutions from other systems or traditions. There is also no consensus between organisations representing people with disabilities on whether a system where a person with disabilities becomes a customer or consumer is an advantage for the individual.

The Nordic welfare model faces many and varied challenges in implementing Article 19 of the Convention on the Rights of Persons with Disabilities, one being the fact that a large part of the responsibility for providing support and services to people with disabilities rests with local authorities. In comparison to many other European countries, the organisation of Nordic society is more decentralised and fragmented. When the economy contracts, there is a risk that social and health inequities will increase as municipalities each make their own interpretations of national regulations. Generally speaking, the experts that the project has come into contact with are agreed that most Nordic countries have the necessary legislation in place for support and services to people with disabilities. The challenge lies in implementing the objectives of and rights conferred by that legislation and in living up to undertakings given when ratifying the Convention on the Rights of Persons with Disabilities.

# The aim and implementation of the survey

The Survey of Nordic models and systems for personalised support and service for persons with disabilities started in January 2021. The project is a cooperation between the Nordic Welfare Centre and the Finnish Institute for Health and Welfare THL. The project is an activity within the framework of Finland's 2021 presidency for the Council on Nordic Cooperation on Disability and was conducted during the period 1 January–30 June 2021. The project was led by a steering group with representatives from the Nordic Welfare Centre and THL. The project was funded by THL and carried out as part of the Finnish pilot project with personal budgeting for persons with disabilities. Members of the Council on Nordic Cooperation on Disability contributed actively to the survey.

The aim of the project is to examine whether, and in that case how, models for personalised support in form of a personal budget for support and services may strengthen the implementation of the UN Convention on the Rights of Persons with Disabilities, especially Article 19 on the right to live independently and to be included in the community. The project examines the experience and knowledge of this theme in the Nordic countries.

The Finnish model is planned to be based on the individual's possibility to choose a personal budget for their support efforts. The size of the budget is determined after an assessment of the individual's needs for support efforts, after which the individual can choose the provider for support services. International examples of this are Scotland and Australia, where the personal budget is called Direct payment. The individual receives a sum of money to buy the support they need. Other concepts used in the discussion is cash support, systems of choice, individualisation, and vouchers/cheques. Personal budgeting and other similar systems are covered in a later chapter of the report.

## Implementation of the survey

The project has been implemented in cooperation with THL and lead by a steering group with representatives from the Nordic Welfare Centre and THL. The Nordic countries have been contacted through the Council on Nordic Cooperation on Disability, which is an advisory body to the Nordic Council of Ministers. The council consists of 16 experts, of which half are experts chosen by the Nordic governments and the other half are representatives for the countries' disability organisations.

The survey has been carried out as an extensive collection of examples and models:

A query with questions on existing systems and models for personal budget and individualised support was sent to the experts on the Council on Nordic Cooperation on Disability. The questions related, among other things, to regulation, funding, the extent and criteria for receiving support.

Three workshops have been conducted in order to carry out a deeper analysis of the systems and the experience involving them. The first workshop was held together with the Council on Nordic Cooperation on Disability. The second workshop was carried out together with researchers from each Nordic country where especially support and service included in Article 19 was examined. The third and final workshop involved experts on support and service.

A complementary survey has been performed by the Nordic Welfare Centre by analysing many reports and surveys published in the Nordic countries.

Supporting documentation from the preliminary query and the workshops was mainly related to systems for personal assistance, which the majority mention being the primary example on how a personal budget as a model has been implemented in the Nordic countries. Desk research and the final workshop have been aiming at complementing the supporting documentation of existing models.

### **Limitations of the report**

The project has been carried out during a limited period and a deeper analysis of the identified examples on personal budgeting has not been possible. The definition of systems based on personal budgeting and individualisation has been interpreted in a broad manner to collect as many examples as possible. Also, certain models that do not only relate to persons with disabilities have been included if deemed relevant. The examples given in the survey are models and systems that have been identified within the timeframe of the project. Therefore, likely there are further examples on models and systems within the Nordic countries that have not been included in the project.



# Background

## The Nordic vision and Agenda 2030

According to Vision 2030 of the Nordic Council of Ministers the Nordic countries will become the most integrated, green, competitive and socially sustainable region by 2030. The vision reflects the sustainability goals of the UN Agenda 2030 where one of the basic principles is that no one is excluded. The agenda was adopted in 2015 and includes 17 Sustainable Development Goals and 169 objectives for sustainable development that are integrated and indivisible. A number of these goals and objectives directly mention persons with disabilities. Objective 10 regards the reducing of inequality within and among countries and the objective for 2030 is to empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status.

## The UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities was adopted by the General Assembly in 2006. The Convention was opened for signature a year later. The Convention comprises 50 articles. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

The Convention is based on several general principles stated in Article 3.

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons,
- non-discrimination,
- full and effective participation and inclusion in society,
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity,
- equality of opportunity,
- accessibility,
- equality between men and women,
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The principles in Article 3 act as guidance on how the rights and obligations regulated in articles 5–30 are to be read. They enable an understanding of the obstacles for realising the rights and what the rights entail.



**When it comes to CRPD, and the freedom of choice and independent living – we need to make sure that we implement it in a good way so that everyone gets the support they need in an individualized manner.**

***Sif Holst, Vice chair, Disabled Peoples Organisations Denmark***

## How is support and service to be organised in accordance with the UN Convention on the Rights of Persons with Disabilities?

Article 19 is key in the Convention and is seen by many as the core of the Convention. The Article deals with the right to live independently and to be included in the community, which requires, among other things, that persons with disabilities have access to different forms of community services and support. In order to be able to live independently and participate in the community the States Parties must ensure that

- A. persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement,
- B. persons with disabilities have access to a range of in-home, residential, and other community support services, including personal assistance necessary to support living
- C. and inclusion in the community, and to prevent isolation or segregation from the community, and
- D. community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 19 applies to all persons with disabilities, irrespective of the extent of their disability and need for support.

Other Articles that are important for the interpretation of Article 19 and ensuring independent living and a full inclusion in all areas of life for persons with disabilities are, among other things,

- Article 3c: "full and effective participation and inclusion in society"
- Article 4.1 (i) General obligations: "to promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights."
- Article 5.3 Equality and non-discrimination: "In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided."
- Article 8 Awareness-raising: d) "promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities."
- Article 9 Accessibility: 2.b: "to ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities."
- Article 12 Equal recognition before the law: 1. "persons with disabilities have the right to recognition everywhere as persons before the law."
- Article 26 Habilitation and rehabilitation: "support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas."
- Essential in the Convention is the active involvement of persons with disabilities and their organisations in accordance with Article 4.3.

## **General comment NR5[1]**

The Committee on CRPD has drawn up general comments; General comment No. 5 (2017) on living independently and being included in the community, supporting the interpretation of Article 19.[2] Independent life is defined by the Committee as follows:

"Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living."

The Committee distances itself from different forms of institutions and says, among other things, in 16 c.:

"Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. It is not "just" about living in a particular building or setting; it is, first and foremost, about not losing personal choice and autonomy as a result of the imposition of certain life and living arrangements. Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment."

## **Personal assistance**

According to the Committee personal assistance distinguishes it from other types of support efforts. The funding is to be allocated to the individual with the purpose of paying for any assistance required. The funding is to be based on an individual needs assessment. The service must also be controlled by the person with disability, meaning that they can either contract the service from a variety of providers or act as an employer, as well as have the option to custom design their own service, i.e., design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers. The Committee has in addition to these also several other quality requirements on personal assistance.



In the general comment the Committee also takes a stand on support services it sees as not fulfilling the requirements in Article 19. This concerns for example "package solutions" which, among other things, link the availability of one particular service to another, expect two or more persons to live together or can only be provided within special living arrangements. According to the Committee these are not in line with Article 19. Concepts of personal assistance wherein the person with disabilities does not have full self-determination and self-control are also not considered to comply with Article 19. The Committee also takes a strong stand against all forms of collective solutions such as institutional living. Also support services in institutional form are not allowed according to the Convention since they segregate and limit the personal autonomy.

### **Individualised support services**

Regarding other support measures the Committee emphasises in Article 19b that individualised support services must be considered a right. This means that persons with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences. Individualised support should be flexible enough to adapt to the requirements of the "users". This places an obligation on States Parties to ensure that there are a sufficient number of qualified specialists that are able to identify practical solutions to the barriers to living independently within the community, in accordance with the requirements and preferences of the individual.

Individualised services are not to be restricted to services inside the home but must also be able to be extended to a large spectrum of employment and education, as well as travel and recreation. While individualised support services may vary in name in different countries, they must be designed to support living within the community, preventing isolation and segregation from others, and aiming at the realisation of full inclusion within the community.

### **Equal access to community services**

Article 19c states that persons with disabilities must have the right to community services and facilities intended for the general population and that they must be available on equal terms as well as meet their needs. This right covers all community services, and they must also be available and designed to be adaptable in practice. Article 19c is central and individual measures for persons with disabilities do not replace the right to be included in what is offered to the general public.

### **CRPD and the Nordic countries**

All the Nordic countries have ratified CRPD and reported to the Committee.

Denmark ratified the convention on 24 August 2009. Denmark submitted its first report in 2011 with a chapter on the development on Greenland and the Faroe Islands. Denmark received questions from the Committee in 2014. Denmark answered these questions later in the year. After the review in Geneva the Committee sent its closing observations. In 2020 Denmark submitted a combined second and third report, including the report for Greenland and the Faroe Islands.

In Finland the Convention and the additional protocol came into force for ratification on 10 June 2016. The government of Åland reports on the implementation of the Convention in a separate report. Finland submitted its first report, including the development on Åland, to the Committee in 2019.

Iceland ratified the CRPD 2017 and submitted its first report in February 2021.

Norway ratified the CRPD in 2014, submitted its first report in 2015 and received questions from the Committee in 2017. Norway answered the questions in 2019, the same year the review in Geneva took place.

Sweden ratified the CRPD in 2008, submitted its first report in 2011 and received as well as answered the Committee's questions in 2013, the same year the first review in Geneva took place. Sweden submitted its combined second and third report in 2019.<sup>[1]</sup>

## **Conclusions and recommendations from the CRPD Committee for each country**

All countries, except for Iceland, who reported in February 2021, have received conclusions and recommendations from the Committee.

### **Denmark (2014)**

The Committee expresses its concern over the increased number of housing similar to institutions in the municipalities with 39–60 living facilities outside city centres, and the limited possibilities for persons with disabilities to choose where they want to live.

### **Norway (2019)**

The Committee expresses its concern over the lack of an action plan with clear dates and budgets for deinstitutionalising, and that the focus is rather on shared than on independent living, and that not enough measures are taken for adequate resources for user-led personal assistance in the municipalities.

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[1] The quotations are from the Convention on the Rights of Persons with Disabilities.

[2] <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

## **Sweden (2014)**

The Committee expresses its concern over the fact that government-funded personal assistance has been cancelled for a number of persons since 2010, due to a change in the interpretation of "fundamental needs" and "other personal needs", and that the persons still receiving assistance have been hit by heavy reductions without any known or apparent reasons. The Committee is also worried about the reported number of efforts decided upon according to the Swedish law on support and service that have not been executed. The Committee recommends that Sweden ensures that programmes for personal assistance provide adequate and fair economic support in order to ensure that a person may live an independent life in the community.

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[1] The cites are taken from a Swedish version, originally translated by The Swedish Agency for Participation, <https://www.mfd.se/vart-uppdrag/publikationer/fns-konvention-och-allmanna-kommentar/>



# Personal budget and personalised support

## Introduction

The last 30 years have been characterised by striving towards a more personal support for persons with disabilities. The primary example of this is personal assistance. All Nordic countries have today some kind of a system for personal assistance where the individual has an extensive influence on the form of support. However, the extent of the system and the definition of who are entitled to the support vary between the countries. Finland implemented personal assistance in 1987 through the Act on Disability Services and Assistance and personal assistance became a subjective right in 2009. Sweden implemented the service as a right in 1994, Denmark in 1999, followed by Norway in 2000 and Iceland in 2018. The requirement of personal assistance has been driven by the disability movement, especially by organisations close to the international Independent Living movement. At the same time the Nordic welfare states have introduced an increasing number of market solutions for social services.[1]

## Personal budget as a model for individualised support

Personal budgeting (PB) is a broad concept with no uniform definition. The concept spans a lot more than money or a payment method the individual has control over themselves. These are often called Direct payments. The concept of personal budgeting may vary in meaning in different countries. The Finnish project is based on the notion that a personal budget is a way of providing assistance, support and efforts, focusing on the person themselves when planning, choosing and implementing these in a comprehensive manner. When the project started in Finland in 2020, it was observed that there is no established definition of a personal budget.



**When we look at the CRPD, it's important to be able to manage the support we have in order to reach our potential in terms of working life and leisure time.**

***Sif Holst, Vice chair,  
Disabled Peoples  
Organisations  
Denmark***

A personal budget is used in health and social services in several countries. England, the Netherlands, Belgium and Germany are some of the examples in Europe. Also, the United States, Canada and Australia are countries with personal budgeting. In England and the Netherlands personal budgeting has been in use since the 1990's as a user's right in the legislation. A personal budget is a sum of money granted to the individual based on an assessment of the individual's service needs and a calculation of a budget for this purpose. The individual can use the budget to buy necessary services. A personal budget may also be called an individual budget, which may include other benefits received by the individual. For example, Scotland uses the term Self Directed Support, meaning an operations model resembling a personal or individual budget. In England the personal budget in healthcare is called a Health budget. Direct payment refers to a personal budget paid to an account to be used by the individual themselves. An Individual Service Fund is also in use in England. In this case the personal budget funds are paid to a service provider. The individual can then agree on the arrangement of the services with the provider in a flexible manner. (Liukko 2016, THL).

In Australia, England, and Scotland more recent legislation for organising efforts and support for persons with disabilities, and the disability policy, have been based on principles on individualisation and self-determination. The new legislation has shifted focus from determining a person's right to pre-established service based on a certain disability to the individual needs based on the situation for the person with disabilities. In other words, the desired results from the efforts are defined by the person themselves (with or without other interested parties) as well as the methods for attaining them. Consequently, the legislation does not include information on who are entitled to services and support. It includes instead underlying principles on personal choice and control, participation, respect and dignity; joint production, referring to professionals and participants required to work together to identify the path to desired results. Furthermore, innovation, referring to that support is not only acquired by buying it but also through natural (non-monetary) support forms and general infrastructure, such as information, development of capacity and competence individually and in families, web services and commitment to the community. The development on the market is also included, taking into account the redesign of resources invested in the elderly, traditional models for service and investments in service providers, especially within individualisation of services. The participants and professionals monitor, report and assess the implementation. The legislation in these countries establishes assessment and planning processes, in which the person with the disability is at the centre of the process, and formal action plans are developed (e.g., trying out self-assessment). The legislation transfers the responsibility for funding to the participant, if competent; to a party nominated by the participant, or with the participant's consent; or to the local authority, which disburses the funding (Pike, O'Nolan & Farragher, 2016 p. 3–4).

Different elements of freedom of choice have been tried out in the Nordic countries and included in healthcare and social services in the form of systems of choice and increased opportunities for users to choose the provider. In the survey at hand we have focused on efforts and support for an independent life for persons with disabilities. Which solutions are there for increased flexibility and freedom of choice when it comes to efforts and support? Which possibilities and risks do these involve?



## Customer choice within the social sector

Different kinds of reforms within the general social services sector have been carried out with the motivation that it increases the freedom of choice for the users. All the Nordic countries, except for Iceland, have adopted the possibility of customer choice within homecare. Other common terms are freedom of choice reform, a money, cheque, or voucher system. The opportunity for customer choice is a part of a broader trend where market-oriented systems are introduced on the public sector - this is called New Public Management (NPM). The development towards New Public Management is described as a reaction against the formerly dominant method of governing with a clear division between public and private, and with the aim of creating an impartial administration. Legal certainty and just procedures were in focus for the governance. The criticism towards the system was that it was not flexible and lead to decreased efficiency and productivity, as well as a lack of respect for the users' wishes. The principles of customer choice models are, among other things, to make the activity more responsive to users and that the providers act as companies and compete over the users' needs. The citizen's active choice becomes the foundation for the organisation of public operations.

In principle, all the Nordic countries have adopted market inspired solutions on the social services sector, but the degree of market orientation varies according to the size and structure of the profit-making sector, as well as the role of the non-profit sector.

New Public Management has been largely debated during the last few years, maybe mostly in Sweden where the adoption of market solutions for welfare services has been more widespread based on New Public Management.

The public procurement of homecare services in the Nordic countries is most commonly used in Sweden and Finland. These countries also chose not to make any exceptions for welfare services in the implementation of the EU public procurement legislation. The use of public procurement has generally been more uncommon in Denmark and Norway where politicians have been more sceptical of this solution. Customer choice models are used the least in Norway. The largest non-profit sector is in Finland. One important reason for this is the funding model from the country's gaming company, Veikkaus (formerly Finland's Slot Machine Association), which has exclusive rights to gambling games in Finland. The surplus, about EUR 1 billion annually, is used, among other things, for supporting the disability movement and other non-profit organisations running several welfare services.

## The Nordic welfare model and individualised support

The Nordic welfare model may be described and defined in different manners. In the report *Viden som virker i praksis* on strengthened Nordic cooperation on the social sector, the former Icelandic Minister of Social Affairs and Social Security, Árni Páll Árnason, describes the Icelandic welfare model as follows:

A solid offering of social efforts, a universal right to tax-funded welfare offers, a strong tripartite cooperation, a key role for municipalities for providing welfare services and an active civil society.

### **Nordic organisation of welfare**

The responsibility and execution of a large part of the Nordic welfare lies within the municipalities. This decentralised organisation of welfare is characteristic for the Nordic countries. However, the number of municipalities varies significantly among the countries. Norway has the largest number of municipalities, 422. Next is Finland (295), Sweden (290), Denmark (98) and Iceland (79). The number and size of the municipalities means that there are differences in the welfare offering between the countries, mainly between large city areas and smaller municipalities. Averaging provisions aim at reducing those differences. Personal assistance in Sweden is a shared responsibility between the government and the municipalities, whereas it in the rest of the Nordic countries is the responsibility of the municipalities. In international comparable studies the social costs in total are higher for the Nordic countries than the average for OECD countries (Organisation for Economic Co-operation and Development). The highest cost for economic support and social services for persons with disabilities as a part of the gross domestic product (GDP) is 6.1 per cent (2014) in Iceland. Next is Denmark with 4.1%, Norway 4.0%, Sweden 3.5%, and Finland 3.4%. The personal assistance effort is more comprehensive in Sweden than in other Nordic countries. The age structure has an impact on the countries' social costs. The population of Iceland is younger than in the other Nordic countries and has more participants on the job market (The Swedish Agency for Health and Care Services Analysis, 2020).

### **Citizens becoming customers**

Systems of choice and individualised support, such as personal budgeting and the consequences of this for the Nordic welfare model, have been largely discussed, both politically and academically. The discussion has, among other things, revolved around if the systems of choice are cost-driving. The Swedish Welfare Commission has highlighted that the large number of private service providers leads to an increasing need for follow-up and control, which again causes increasing costs for the municipalities and the public sector. Systems of choice may make it harder for the municipalities to plan, since it is not known how many individuals may choose a certain alternative, such as a school. They may also be experiencing overcapacity since the municipality according to key legislation regulating the compulsory education for comprehensive school or the obligation to provide healthcare and social services has the utmost responsibility in the matter. Therefore, the Swedish Welfare Commission proposes an assessment of the costs for systems of choice.

Also individualised systems for disabilities, such as personal assistance, and the relation to the Nordic welfare model have been discussed. Personal assistance as a form of support is heavily connected to the Independent Living movement originating from the United States. One of the basic principles of the Independent Living ideology is that the individuals themselves are the best experts on their needs. Cash support is seen as an important principle in order for the individual to gain power over the support and choose the service provider or product themselves. Representatives for Independent Living have recommended that the principle of cash support be extended to support in the form of assistive equipment and interpreter services. However, in an article (2018) Brennan, Traustadottir, Rice and Anderberg state that "Being Number One is the Biggest Obstacle" the focus of the Independent Living ideology on the individual as a customer in a market can be understood to derive from the US having relatively undeveloped welfare services. They think that the principle of cash support became problematic when it was introduced in other countries with more developed welfare services, such as the Nordic countries, especially the marketization and consumerisation of an individual. The extent of the marketization of personal assistance varies between the countries and over time In the article Personal assistance in a Scandinavian context: similarities, differences and developmental traits. Askheim, Bengtsson and Bjelke (2014) point out that for example Sweden has regulated the system for personal assistance further and gone "from consumerism to re-regulation", motivated, among other things, by the fact that the costs have been higher than anticipated.

The legal situation has also been discussed, especially in context with how social rights are judged by the courts. Andreas Pettersson (2015), who has compared Danish, Norwegian and Swedish legislation in Out and about in the welfare state: the right to transport in everyday life for people with disabilities in Swedish, Danish and Norwegian law, states that the courts are influenced by economic arguments in their judgements. This weakens the individual's social rights. Pettersson also found that legal protection varies in strength in the Nordic countries.

Another topic of discussion is how individualised support efforts are limited and are proportionally related to other efforts within the welfare policy, such as healthcare. A study of the use of personal assistance in Sweden; Do personal assistance activities promote participation in society for persons with disabilities in Sweden? A five-year longitudinal study shows that a decreasing amount of assistance is used for activities aimed at an active life, and that efforts of a more healthcare nature are increasing instead (Von Granitz, Sonnander, Reine and Winblad (2020). According to researchers, personal assistance in Sweden is developing towards an unloading of healthcare rather than being a support form for independent living and inclusion in the community in accordance with Article 19.

A fundamental idea with New Public Management and customer choice systems is that individuals have the capacity to make informed decisions. But they also need time and stamina to understand and assess the information on different alternatives the individual faces when making choices as a customer. For persons with a chronic illness and disabilities leading to reduced decision-making abilities this may pose a challenge. In the overview Valfrihetssystem inom primärvården och personer med intellektuell funktionsnedsättning – en kunskapsöversikt ("Systems of choice within primary healthcare and persons with intellectual disabilities") by Urbas, Mineur, Arvidsson and Tideman (2014) the authors draw the conclusion that the area is unexplored. In order to make choices persons with disabilities need both individualised and available information to support the decision-making process. Formally the development strengthens people's influence and power over their own life but when the individual needs and wishes meet prevailing norms, expectations and structures it will lead to difficulties (p. 30). The authors state, among other things, that research is needed on how persons with intellectual disabilities comprehend, view and act within systems of choice and how this affects how they receive adequate healthcare.

### **The Nordic welfare model and the Convention on the Rights of Persons with Disabilities**

Both the Nordic and the international view is that the Nordic countries have a more comprehensive welfare policy than other countries; and that the Nordic welfare model differs from other methods for the welfare organisation. This is generally established in comparable research. Concerning disability policy, the Nordic countries were in good time closing institutions for persons with disabilities and establishing local support efforts, such as group homes. However, for example Brennan & Traustadóttir (2020) have stated that the self-image of being world leaders in support for persons with disabilities may in itself be an obstacle for implementing the rights of the UN Convention on the Rights of Persons with Disabilities and to conceal the challenges facing the Nordic welfare states. The authors state that research shows a gap between the political objectives and the reality persons with disabilities experience. Individual support has been, and according to the authors, still is characterised by paternalism and an unbalance in the relationship between the individual and personnel, which prevents the possibility for independent living for persons with disabilities. The support needs to be more flexible and based on the individual's needs. The support according to Article 19 is to be based on that everyone, irrespective of disability, have the possibility to live included and participating in the community in full.

## Reform of support and services in Finland

In Finland the legislation concerning service and support for persons with disabilities will be reformed to increase the individual's independence and control over support and service and for meeting the personal needs better. The main acts are the Act on Disability Services and Assistance and the Act on Special Care for People with Intellectual Disabilities. Efforts to combine these two special acts and replacing them with new legislation has been ongoing during several terms of government. In the government programme for the current Prime Minister, Sanna Marin, a goal was set that individual needs for persons with disabilities are to be taken into account better in future. The aim is that a government proposal will be submitted to the parliament during spring 2022. The act is proposed to enter into force on 1 January 2023.

Studies have been launched for examining if a personal budget could be an alternative method for organising support for persons with disabilities. In a pilot project during 2020–2021 the Finnish Ministry of Social Affairs and Health granted funding for nine regional projects within personal budgeting. The objective of the project is to strengthen the self-determination, inclusion and personal choice for persons with disabilities in the planning and implementation process, so that help, and support are available in a flexible manner in different situations and according to personal needs. The purpose is to get information on changes needed in the legislation and to develop principles and methods for personal budgeting as an alternative when organising services and efforts. In addition, the strengths and weaknesses in personal budgeting are to be investigated, tried out and compared to other solutions. During the project period a final report is drawn up based on the national and regional work. The report will, where applicable, be drawn up as a government proposition. The final report is a proposition on how personal budgets should be introduced in Finnish legislation. The final report will be submitted to the Minister of Family Affairs and Social Services at the end of 2021.

The starting point has been that personal budgeting is planned to be introduced in the Finnish service system as an approach, a method for organising services individually and as a concrete method for organising services. A personal budget refers to the funds the person receives for personal use, to manage themselves or to be managed by someone else, in order to arrange individual support and service. It will be voluntary to choose a personal budget in Finland and the system is planned to be used in parallel with the current support and services.

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[1] Askheim, O.P., Bengtsson, H. and Bjelke, B.R., 2014. Personal assistance in a Scandinavian context: similarities, differences and developmental traits. *Scandinavian Journal of Disability Research*, 16(S1), pp.3–18

# Nordic examples on individualised support

## Denmark

The municipalities have the main responsibility for support for persons with disabilities, according to the Act on Social Services, Lov om social service. The law is a framework law, and the municipalities decide the level of service. A service plan is to be drawn up for each matter. The purpose of the support is to enhance the individual's capacity to take care of themselves, make the daily way of life easier and to improve the quality of life.

In § 96 in the legislation on service the support is regulated in the form of personal assistance, Borgerstyret personlig assistance (BPA) ("citizen-led personal assistance"). § 95 regulates the right to support at home in a personalised arrangement. Both forms of support may be given as cash support. Both forms of support concern those who receive support for more than 20 hours per week and are at least 18 years old. BPA is granted as an allowance for covering costs for assistants taking care of, supervising, or guiding a person with broad-spectrum and permanent physical or intellectual disabilities in need of support, which makes it necessary to provide special support. To be granted BPA the recipient must themselves act as an employer for the assistant. The recipient may come to an agreement with a near relative, an association or a company on transferring the benefit and employer's duties to these (§ 96 chapter 16 in the Act on Social Service). The purpose of cash benefits to employ assistants is to create a basis for flexible solutions based on the recipient's self-determination. Citizens who can and want to receive benefits to employ assistants themselves are offered a solution that can be adjusted to their own wishes and needs. The purpose is also to create a possibility for uniform support for persons with extensive disabilities. Also, persons without extensive needs can be offered the possibility if the municipality deems that BPA is the best method for providing a uniform support for them. In order to receive personal assistance, the person must be at least 18 years old. For minors the parents can be granted compensation for loss of income if they leave the job market to take care of a child with extensive and permanent disabilities. The condition is that it is deemed necessary and that it is most practical that a parent takes care of the child. The compensation is based on the parent's income at the time they left the regular job market, and the compensation is capped at DKK 29,918 per month (2017).



**Everyone is responsible for their own health, but the welfare state has a responsibility to provide reliable services. The welfare system is about safety and ensuring good living conditions.**

***Hanna Egard, Senior lecturer, University of Malmö***

## Process for receiving personal assistance

The municipalities make an individual assessment of the individual's needs based on the purpose of the BPA, which is to create a flexible and uniform support system focusing on the person's self-determination. After the assessment of needs and the number of hours the individual is entitled to the municipality calculates the amount of the cash benefit. The benefit can at its most cover the actual costs for organising the assistance. The total costs per hour for assistance according to § 95 or BPA can at the most amount to the municipality's average long-term costs for providing assistance according to § 83, accompanying according to § 97 and substitution and unburdening according to § 84. The cash benefit is confirmed annually but can, however, be adjusted in case of significant changes in the preconditions the assessment was based on.

## "The personalised arrangement"

A person with extensive and permanent physical or intellectual disabilities and in need of personal assistance and social services, as well as help or support for necessary practical tasks at home for more than 20 hours a week, may choose a cash benefit for employing the person giving the support. The municipality may in exceptional cases choose to grant the support as social services or to be paid to a close relative who supports the person in full or in part. The personalised arrangement is limited to practical help at home but can be combined with other forms of support in order to cover the need for support outside the home. Examples on support is accompanying to activities outside the home. The municipality may in some cases offer BPA, even if the person is not entitled to it if this is the best way to provide uniform support.

## Other support

According to §83 municipalities shall provide personal help and care and help or support with necessary practical tasks at home, as well as meals-on-wheels service. Personal assistance and care can be provided to persons who due to physical or intellectual disabilities or special social problems are not able to perform these tasks themselves. An individual receiving such support has through a so-called free choice the right to choose the provider between the municipality or at least two private providers, §91, chapter 16, Act on Social Services. The person may also choose to decide themselves a person who will carry out the service if the municipality approves and employs this person as service provider, §94 chapter 16, Act on Social Services).

Denmark introduced in 2003 regulations on the responsibility of municipalities to provide all users of homecare the possibility to choose between different service providers. The system gives the right for the person granted homecare to choose another provider than the municipality. Homecare encompasses meals-on-wheels service, service and personal care.

The local government decides on the level of service, requirements on quality and the price level. The municipality is thereafter obliged to approve or come to an agreement with the providers meeting the requirements, or to enter a procurement procedure with 2–5 service providers. A special database for free choice has been established for municipalities to make the quality and price requirements public



## Personal budget for socially vulnerable persons

During 2017–2020 four Danish municipalities carried out a trial with personal budgeting for socially vulnerable persons with homelessness, drug use and/or mental problems. Individuals had access to a personal budget amounting up to DKK 50,000 and were able to decide on the use based on their own goals. The budget was combined with social support for 12 months in the form of a support person. Based on the individual's dreams and wishes a long-term goal at the start of the effort was decided upon together with the support person. The purpose of the project was to increase the individual's self-determination, rehabilitation and quality of life. The National Board of Health and Welfare has evaluated the projects and, among other things, found that the personal budget has helped individuals to becoming closer to meeting their goals and fulfilling their dreams, but that the decisive factor was not only the personal budget but also the cooperation between the individual and the support person. The individuals and support persons have experienced that the effort has strengthened the alliance and changed the division of roles in the cooperation.

## Personal budget for long-term unemployed

Aarhus municipality carried out a trial in 2015–2018 with a personal budget for long-term unemployed. The individual received a personal budget of up to DKK 50,000 to establish their own efforts on the labour market. The individual was responsible for suggesting the destination of the budgeted means themselves and how they would be used for being employed. The purpose was to open up more possibilities than the traditional labour market efforts, to increase the individual's motivation and that the individual would take ownership and lead themselves to employment. The personal budget was drawn up and approved by a job advisor at the municipality's job centre.

## Free choice of assistive equipment

In Denmark it is the responsibility of the municipality to deliver assistive equipment. The ground rule is that the chosen equipment is the most appropriate and affordable. The municipality may also decide the supplier for the equipment. The individual has, however, the possibility to a free choice of assistive equipment and to choose another supplier than the municipality has chosen. The individual can also choose a more expensive equipment than the municipality but must then pay for the difference. The process is that the municipality evaluates first which assistive equipment the individual needs and is entitled to. If the individual uses the possibility for free choice, they will receive a decision on which requirements and specifications the equipment must fulfil and the municipality's amount for the benefit. It is the individual's responsibility to ensure that the equipment meets the municipality's requirements, which is a condition for the benefit. Although the individual has used own means for the equipment, the equipment is still owned by the municipality. The municipality can negotiate the free choice but not which supplier or assistive equipment the individual should choose. However, the municipality must give instructions on the use of the equipment, if necessary, and if the municipality has knowledge of the equipment. Otherwise, the individual may contact the supplier for support and training.

## Finland

In Finland the municipalities have the responsibility for healthcare and social services.

In the 2010s a few trials with personal budgeting were performed in Finland. One of the trials concerned the provision of a service voucher to individuals, more extensive possibilities of choice in different service situations within healthcare and social services. The project on personal budgeting, *Avain kansalaisuuteen* (The key to the citizenship) and the project *Tiedän mitä tahdon* (in English: I know what I want) is a part of the trial with service vouchers. The focus of the trials was on the evaluation how an operational model for personal budgeting works and to increase freedom of choice. It was voluntary for the individual to participate in the trials. It was not an easy task to recruit service users for the project since many turned it down. Some of the reasons for this was that individuals were satisfied with the service they had, that the budget was too low and that the use of the budget was seen as difficult and unfamiliar. The participants in the projects expressed that a personal budget corresponded to their needs better than before, increased the freedom of choice, participation, self-determination and flexibility.

### Support for persons with disabilities

The support for persons with disabilities is regulated by two laws, Act on Disability Services and Assistance (1987/380) and the Act on Special Care for People with Intellectual Disabilities (1977/519). The Act on Disability Services and Assistance was revised in 2009, partly in order to make the act into a rights law and partly to separate assistance and care.

During 2010–2015 the Disability Policy Programme (VAMPO) was carried by commission of the Finnish government in form of a cooperation between the ministries and other relevant actors. The programme resulted in 122 measures of change identified from 14 content areas. Examples on content areas are independent living, social inclusion and involvement, education and study, work, culture and leisure time, and discrimination encountered by persons with disabilities.

Efforts to reform legislation and the support for persons with disabilities has been ongoing during several terms of government. In 2017 a draft for a new law was presented, the act on special disability services. The law has been circulated for comment and the preparation work is ongoing for new legislation. As a part of the ongoing reform work a work group was appointed which prepared a report with propositions for securing that the new legislation takes into account the inclusion of persons with disabilities in an overall manner.

## Personal assistance

According to the Act on Disability Services and Assistance § 8c personal assistance can be granted to an individual with severe disabilities and to an individual who because of a chronic or progressive disability or illness is repeatedly in need of necessary assistance from another person to be able to perform the functions stated in paragraph 1, and when the need of assistance is not mainly due to illness and disability in connection with normal ageing. Personal assistance refers to the necessary assistance a person with disabilities has:

1. in daily activities,
2. in work and studies,
3. in leisure time,
4. in social activities, and
5. in maintaining social contacts.

The purpose of personal assistance is to help a person with severe disabilities to make their own choices when it comes to the activities mentioned above, why a prerequisite for the support is that the person can define the content of the assistance and the manner it is to be organised. When it comes to leisure activities, social activities and maintaining social contacts personal assistance must amount to at least 30 hours per month, if not a smaller amount is enough to ensure the person receives necessary assistance, § 8c. An evaluation and assessment is performed by the municipality. According to the Act on Disability Services and Assistance a plan for support and service a person with disabilities needs to be able to cope with daily life is to be drawn up. The goal is that when service plan is drawn up the municipality and the person needing support has an understanding that is as uniform as possible of the person's ability to function and of the need for support.

There are three models for personal assistance in Finland:

1. The employer model: a person with disabilities or a guardian of a child with disabilities, or someone else who is the legal representative of the child, is the personal assistant's employer,
2. The service voucher model: the municipality gives the person with disabilities a service voucher referred to in the Act on service vouchers in healthcare and social services (569/2009) in order for them to acquire personal assistance,
3. Service model: the municipality arranges personal assistance services for a person with disabilities from a public or private service provider, or performs the service itself, or makes a service agreement with another municipality or other municipalities.

In 2016 a little under 60 per cent used the employer model, a little under 10 per cent the service voucher model and approximately 30 per cent the service model. In five per cent of the cases the model constituted a combination of efforts.

## Norway

In Norway the responsibility for individualised support for persons with disabilities lies within municipalities. Regulating legislation is mainly Lov om kommunale helse- og omsorgstjeneste (The Act Relating to Municipal Health and Care Services) and Lov om pasient- og brukerrettigheter (Act on Patient and User Rights). The overall goal for the act on patient and user rights is to ensure that patients and users receive equal access to healthcare services of good quality. The regulations in the law shall contribute to the promotion of the relationship between the patient and the care recipient respectively and healthcare services, promote social security and protect the individual's life, integrity, and human dignity. A user has the right to necessary support and valued services from the municipality. Drawing up an individual plan is an obligation for the municipality, as well as to cooperate with other service providers in order to contribute to the overall support for the individual. Those in need of long-term and coordinated services are provided a coordinator by the municipality. The support itself should as much as possible be designed in cooperation with the person being the object of the effort.

### Personal assistance

The support municipalities are obliged to provide for persons with disabilities according to the act on patient and user rights may be offered in the form of personal assistance, Brukerstyrt personlig assistanse (user-led personal assistance) (BPA). Originally it was required that the person granted the support could themselves supervise the assistant's work, but this was abolished in 2005. Thus, BPA also began to include children and persons with cognitive disabilities. In 2015 the law became a rights law. The aim of the BPA is that persons with disabilities with support needs will have as an active and independent life as possible. In order to receive BPA, the person must be under the age of 67, have a long-term need for at least two years and a need for assistance at least 32 hours a week. Persons needing support for 25–32 hours are entitled to the service if the municipality can prove that arranging the support in some other manner will be more costly (§ 2–1). The municipality decides on the organisation of BPA.

## User passport

The Norwegian Labour and Welfare Administration (NAV) is responsible for fitting and delivering assistive equipment in Norway. A new system for the delivery of assistive equipment, Brukarpass ("user passport") was introduced in 2006 with the purpose of simplifying the delivery and fulfilling the user's needs and wishes better. The passport is an agreement between the user of the equipment and the NAV Assistive Technology Centers and constitutes a power of attorney. With the user passport the individual can choose a cooperation partner for fitting, change of equipment or technical services and repairs. The division of tasks and responsibilities between NAV Assistive Technology Center and the individual is regulated in the agreement and can be changed if necessary. The target group for the passport is experienced users with a good insight of their needs and who want to play an active role in the process. The assistive equipment is included in NAV's framework agreement and are found in the assistive equipment database. The system was evaluated in 2009 and it was shown that the majority of the users thought that the assistive technology center works better with the user passport, the waiting time is shorter and that they have an increased influence over the choice of equipment. The obstacles are, among other things, that many users do not know the system and that the assistive technology centers do not communicate actively, and that the responsibility for receiving the user passport to a high degree relies on the user themselves.

# Iceland

## Personal assistance

Iceland reformed its support for persons with disabilities in 2018 with the introduction of the personal assistance effort in the social welfare law. Assistance was funded earlier in development projects. The reform was prepared for example through surveys and evaluations by the Institute for Social Research and The Centre for Disability Studies at the university of Iceland.

According to the law the individual has the right to user-led personal assistance if they have an extensive and permanent need for assistance and services, for example within daily activities, housekeeping, participation in social activities, education, and employment. This is regulated in the act on services for persons with disabilities with long-term support needs. Article 11 includes user-led personal assistance (BPA).

An agreement is made with a municipality which means that the user manages the assistance they receive so that they can organise it, decide when and where it is given and chooses assistants. User agreements can be in the form of a direct payment agreement where the user is fully responsible for the managing themselves, so-called user-led personal assistance. An external partner, for example a cooperative, can be given the responsibility to employ and be in charge of the administration of the assistance. The most common method of organising personal assistance is through the co-operative NPA-Miðstöðin (BPA Centre). There are also other co-operatives and non-profit organisations administrating the assistance.

The municipalities are responsible for making and implementing BPA-agreements irrespective of how the assistance is organised and who the responsible administrator is. After a concluded relevant assessment of the need for assistance according to the rules determined by the municipality in question, the user and the municipality conclude an agreement in writing on the value of the agreement and the number of available work hours. The scope of the granted assistance hours is based on an assessment of the level of assistance the user needs to live a full, meaningful, and independent life, irrespective of their disabilities.

In Iceland 96 persons have a BPA agreement (2021). However, according to the Icelandic Disability Alliance, the umbrella organisation for disability organisations, there are a long line of applicants. A survey of NPA against the background of experiences will be conducted in 2021. The survey comprises current legislation, rules and the service guide. The work is expected to be completed at the end of 2021.

## Personal budget

In the municipal service law (Lög um félagsþjónustu sveitarfélaga 1991) paragraph 28 was introduced in 2018 stating that municipalities can provide support to users and control support and services for individuals and families with children in the form of user agreements for a personal budget with free choice of services for the individual or families.

# Sweden

## Personal assistance

Personal assistance is in Sweden one of the ten support and service efforts available in the Act concerning Support and Service to Persons with Certain Functional Disabilities (LSS), introduced on 1 January 1994. The goal with the effort is that the person can "live like others" in the community and have "good living conditions".

The responsibility for personal assistance is divided between the municipalities and the state-owned Försäkringskassan (Swedish Social Insurance Agency). If someone needs help with the needs listed in the law for more than 20 hours a week the Försäkringskassan has the responsibility to assess and pay out assistance compensation. If the need is less than 20 hours per week the municipality is responsible for personal assistance.

The compensation for assistance is an economic support effort for covering the costs for personal assistance to a person with severe disabilities. This is regulated in the Socialförsäkringsbalken (Social Insurance Code) (2010:110). In order to receive governmental assistance compensation from Försäkringskassan the person needs to be included in one of the personal circles in LSS. The person must also have a need for assistance for more than 20 hours per week with six needs established in the legislation: breathing, personal hygiene, eating meals, dressing and undressing, communication with others or other kind of help requiring in-depth knowledge of the person. Those needing personal assistance for their fundamental needs have also the right to personal assistance for other personal needs if the needs are not met in another manner.

Persons using assistance can choose to employ their assistants themselves or let the municipality, a company or a cooperative arrange the assistance. If the individual is not satisfied with their assistance, they can change assistants or the organiser of their assistance.

In order to apply for personal assistance from Försäkringskassan the person needs to be included in one of the personal circles in LSS. The three personal circles are:

- Personal circle 1: Persons with intellectual disability, autism, or autism-like conditions.
- Personal circle 2: Persons having a significant and permanent intellectual disability because of a brain injury in one's adult life due to external violence or a bodily illness.
- Personal circle 3: Persons with other permanent physical or intellectual disabilities that are not due to normal ageing. This is applicable if the physical or intellectual disabilities are significant and cause considerable difficulties in the person's daily life and the person therefore has a considerable need for support or service. Significant difficulties in the person's daily life can include needing assistance with dressing, cooking, transport, or communication with the community.



## Systems of choice in the social sector

The Act on Systems of Choice (LOV) entered into force on 1 January 2009. According to the proposition the law is a part of the efforts towards putting the user in focus, the transfer of power from politicians and officials to citizens, increased freedom of choice and influence, as well as an increase in the number of providers and a broader diversity. Through the increased user influence also increased the quality of services. (Prop. 2008/09:29 s. 54).

LOV is a procedure law with regulations on what to do when introducing a system of choice. The law does not determine which requirements are to be set for the service providers and how the system of choice should be developed. The law is applied to municipalities and regions when introducing systems of choice for healthcare and social services. It is voluntary for the municipalities to introduce systems of choice but compulsory for primary healthcare regions. Services included in the systems are, among others, social care for persons with disabilities such as group homes, personal assistance, and daily activities. The law regulates the rules for municipalities and county councils wanting to organise a tender competition for municipal and regional operations by transferring the choice of provider for support, care and social services to the user or patient.

A system of choice includes three parties

- The municipality that grants the service, approves providers, and monitors and evaluates that the provider meets the requirements for quality
- The individual who chooses the provider or a new provider if they are not satisfied with the current one.
- The provider competing through quality or profiling. The provider can be a municipal body or a company.

In a system of choice, the individual can choose only between the providers the municipality has procured and has concluded an agreement with. For individuals who cannot choose, or do not have next of kin who can help them with the choice, there should be an alternative of no choice, which is to be selected in a competition neutral manner. If only one provider is selected to be the alternative of no choice, this should be carried out through a method according to the Act on Public Procurement in order to secure competition and competition neutrality.

## Evaluations

The Act on Systems of Choice has been evaluated by The National Board of Health and Welfare in 2012. The focus has above all been on the choice of health centres and homecare providers. Here are some of the conclusions:

In order for the individual to be able to change provider there must be several providers to choose from. The individual must also be coping and have the ability to act as a customer on the healthcare and social services market or receive help doing so.

The majority value and want to have the option to choose homecare providers and the health centre, especially within elderly care and healthcare. In some municipalities, or rather parts of municipalities, there are a very large number of service providers. The individual can then experience difficulties in choosing the provider, although having a positive attitude towards the freedom of choice per se.

Well-informed choices require the citizens receiving easily available information on the quality and efficiency of different care units. In this respect the information supply is very limited. It seems that the service providers have also not found any adequate forms for marketing themselves.

A surveyor was appointed in 2012 for carrying out analyses and evaluations of the effects of the introduction of systems of choice within social services. According to The survey on correct information within healthcare and social services (SOU 2014:2) 181 of the country's 290 municipalities (2013) had introduced or decided to introduce systems of choice within one or more operations. The most common area is homecare. The number of service providers has increased significantly and a little more than 70 per cent provide profiled services where language is the most common profiling. Of the 846 private providers included in the survey 83 were providers connected to daily activities. Daily activities according to LSS are aimed at persons of working age but who do not have a gainful employment and are not studying. Daily activities were the activity having the largest profiling variation. Examples on offerings are carpentry, gardening, different kinds of animal husbandry, culture, dancing, different forms of therapy, practical training, music, therapy forms and companies with special competence in different forms of disabilities. Only a small part of the municipalities that published query results as a base for systems of choice was related to activities aimed at persons with disabilities. In other efforts, such as group homes according to LSS, the number of municipalities was 1–8. The most common part of social services where systems of choice have been introduced is homecare. According to the survey one of the reasons for this is that the investment costs compared to other areas are relatively low. Most of the costs are variable costs and comprise of personnel costs which makes it relatively easy to become established on the homecare market.

The survey also investigated in which areas LOV should be extended to, for example housing for persons with disabilities. This was deemed to be more complex than for other areas and would pose more requirements for the municipalities. This would also require large investments from the provider and limited possibilities for the user to rechoose.

## Free choice of assistive equipment

A stronger right to choose assistive equipment was introduced in 2014 in the Health Care Act (1982:763) and in the Patient Act (2014:821). The motivation was to give the individual larger opportunities for influence (Prop. 2013/14:67). A part of the increased opportunity to introduce assistive equipment was the introduction of the so-called Free choice, a model in addition to the traditional prescription of assistive equipment (Prop. 2013/14:67). Some county councils had since 2007 pursued a trial with the support of governmental stimulus funding. Free choice means that the user of the assistive equipment can buy equipment outside the operator's procured offering of assistive equipment based on a given order figure. The user of the assistive equipment can use their own means to pay the difference in excess of the amount of the order to get more expensive equipment. This makes the user of the assistive equipment the owner of the equipment and in charge of its service. However, a service account is often used with a certain sum of money for equipment needing more extensive service.

The motivated purpose of the model is that it would increase influence, participation, and freedom of choice within the area of assistive equipment. An evaluation of the model carried out by the National Board of Health and Welfare (2016) concluded, however, that the model has not led to increased participation. The surveyor of the National Board of Health and Welfare states in the evaluation report and the life cycle impact analysis of free choice of assistive equipment that:

The free choice of assistive equipment requires that there is a diversity of suppliers of assistive equipment on the consumer market which is not the case. The model requires also that the user of the equipment has access to independent consumer guidance which to a large degree is lacking at the moment. This makes it more difficult for the user to make an informed choice. (National Board of Health and Welfare (2016), p. 7)

It is noted that the number of users receiving assistive equipment through freedom of choice is small, with the exception of hearing aids. The reason for the low use of freedom of choice in other areas of assistive equipment is thought to be that those prescribing assistive equipment do not to a large degree inform of the possibility and that the demand is low among the users. The hearing area being dominating is explained by economic incentives for audiometric offices to promote their own products. The audiometric technicians have a double role, partly as caregivers and partly as hearing aid sellers.

The model has received criticism, among other things, from The Swedish National Council on Medical Ethics in the report Co-payment and out-of-pocket payment in public health care – ethical aspects, where the council states that co-payment contradicts the intentions of the Health Care Act – that good care is to be given on equal terms. Also organisations within the disability movement have expressed criticism, and for example the National Association for Hearing Impaired People has stated that hearing care has become a ruthless business, more expensive and of poorer quality for individual hearing impaired people.

The Equality Commission states that the model has equality problems, that private caregivers have economic interests to choose a certain alternative. The Commission proposes instead a solution where only an employee of the region may give out the assistive equipment and give neutral information. If private caregivers are used, they must not have a connection to a certain producer of equipment (SOU 2020:46).

## **Personal representative**

A personal representative is a form of support for persons with intellectual disabilities who need help with influencing their situation in life and to be able to participate more in the community.

Personal representatives were introduced in 1995 when ten municipalities in the country received the possibility to carry out trials with personal representatives for three years. Personal representatives were one of the propositions in the psychiatry reform (Prop 1993/94:218), which was supposed to lead to an improvement of the living conditions for persons with intellectual disabilities.

The representatives act as support in contacts with the authorities, caregivers and other actors the individual needs to be in contact with. Using personal representatives is aimed at persons with intellectual disabilities and considerable and essential difficulties in performing activities in different areas of life. To be entitled to a personal representative a person must be 18 years old or older, and have extensive care, support and services, rehabilitation and employment needs. In addition, the person must have a need for long-term contacts with social services, primary health care and specialised psychiatry and other authorities. Such persons are for example those who in addition to an intellectual disability have an addiction problem.

Personal representatives are managed by the municipalities and are partly funded by the government, the National Board of Health and Welfare and the provincial government. A decree on government grants to municipalities managing personal representatives entered into force on 1 August 2013. The decree regulates the operations, purpose and tasks. The decree also regulates the conditions for receiving government grants.

## **Coordinated support for parents to children with disabilities**

Parents to children with disabilities are often obliged to take on a big responsibility in coordinating and administering the support the child needs. The number of contacts and the related work can be extensive and strenuous. To ease the situation for the parents initiatives have been taken to improve the cooperation for the child's support. The Swedish NAO proposed in 2011 trial operations with certain cooperators to help families and ease the cooperation with the actors involved. The National Board of Health and Welfare presented in 2017 a cooperation model in the form of knowledge support. The model is expected to increase children's access to functioning support and reduce the parents' workload. The knowledge support presents organisational and practical success factors in the efforts to develop the coordination.

## Faroe Islands

In the social legislation of the Faroe Islands there is a "system of choice" but no legal grounds for "personal budgeting". The system of choice includes the authority to grant support efforts for purposes that do not require professional competence – healthcare and practical help, as well as night shifts. The recipient has the decision-making competence in relation to who is the employee and how and when assistance is given if the recipient has the cognitive competence to make the decision and manage the system. The person in question is, however, employed and paid by the Almannaverkið (social administration). The legislation is new and is to be based on Article 19 in CRPD.

## Other issues

### Institutions

Despite the Nordic countries closing institutions early on in accordance with the CRPD requirements, there are still many institutions and institution-like forms of housing in the Nordic countries. This is also something that has been criticised by the CRPD committee.

For example, in Norway a problem is that the support for persons with disabilities is to a high degree still connected to housing and therefore becomes a package solution. Also, the support in private alternatives is to a high degree standardised with little possibility to individualisation (NOU 2016:17). In Sweden children have lost their right to assistance, which has for example led to that children to a larger extent have been granted housing.

## Competence

A question that has been raised in the discussion about quality is competence and the education level of the personnel groups working with support and service. In Norway 60 per cent of those working with social services or housing for the elderly and persons with disabilities have an education level corresponding to comprehensive school or upper secondary school (videregående skole) as their highest education (NOU 2020:13). In other groups a university degree was more common. The National Board of Health and Welfare in Sweden presented in 2021 a national survey of the competence of personnel working in housing with special service according to the Act concerning Support and Service to Persons with Certain Functional Disabilities, LSS. The report shows that only 38 per cent of the personnel with permanent employment in LSS housing for children and young people have a basic education in healthcare and social services from a upper secondary school or the municipal adult education. In housing for adults, the share is 64 per cent. Even less, about 8 per cent, of permanently employed at housing for both children and adults have graduated from the Child recreation programme. The access to competence development is also limited. This can, among other things, be a result of lack of resources or available education and to the fact that planned education has been cancelled due to the pandemic. FUB, The Swedish National Association for People with Intellectual Disability, has for a long time required increased competence among the personnel and stated that there are big risks involved with uneducated personnel, causing for example an increased risk for violence. In an interview for Radio Sweden, Eva Borgström, who works for FUB, says that:

"It is a question of not having enough knowledge of intellectual disability and autism. There is a lack of knowledge of how to communicate in the manner the residents do. All this, when the competence is lacking, the risk is that it leads to that a person living in the group home and feels that they are not understood by the personnel may react by getting angry or maybe hurt themselves. And in the worst case it may lead to the personnel resorting to violence or threats. This is of course forbidden but the risk increases if the personnel does not know how to do their work correctly." (Radio Sweden, 2019)

The authorities are also planning to develop knowledge support about communication, directed to LSS activities. In addition, the authorities are also of the opinion that there is a need for perseverance and sustainability in the access to education and competence development for personnel in LSS housing.

## Welfare technology

Extensive investments on welfare technology have been carried out in the Nordic countries during the last few years. The concept has not a uniform definition in the Nordic countries, but the Swedish National Board of Health and Welfare states that welfare technology refers, among other things, to "digital technology aiming at maintaining or increasing safety, activity, participation or independence for a person who has a disability or is at high risk of becoming disabled". In Denmark and Norway, the concept is broader and includes also assistive equipment. Examples on solutions are safety alarms and robots. An important reason for the development is the challenges faced by the welfare sector involving increased needs, especially due to the demographic development and the possibilities for recruiting personnel. New technology can increase efficiency and productivity. Arguments put forward also include an increase in the individual's self-determination and participation. The Norwegian survey *Velferdstjenestevalget* states in the report NOU 2020:13 that new technology means that the individual themselves becomes their own service provider, faster and better. The individual can then make their own choices and the service provider becomes an adviser and partner.

## Coordination

Coordination is generally one of the big challenges in the welfare system with extensive simplified thinking. Persons in need of several different efforts from different actors are in risk of receiving fragmented efforts, and the individual or next of kin often takes on a large responsibility for the cooperation of efforts. There are a number of methods for creating an entity and coordinate welfare services, such as an individual plan, cooperation agreements and coordinator. But there are still shortages. Norwegian municipalities have for example an obligation to draw up an individual plan for users in need of long-term and coordinated efforts. Despite this, a small number of persons with disabilities have an individual plan (NOU 2016:17).

## Guidance

As the possibility to choose service or other efforts websites with information for example on service providers have been developed. Examples of such websites for personal assistance are BPA-portalen and Assistanskoll. For choosing assistive equipment there are examples such as organisations developing their own guidance service, such as Hörsellinjen or where more experienced persons with disabilities of their own provide support to persons with less experience, such as HLF Likeperson. In social media and discussion groups many individuals are sharing their experiences to others in the same situation.

## User surveys

One method for clarifying the individual's and next of kin's view of the activities and services they use is through user surveys. The Swedish Agency for Health and Care Services Analysis presented in 2020 a study on the in the Nordic countries, which shows that there is limited knowledge of the social service from the user's perspective. The knowledge gaps are therefore extensive. The area studied the most is the elderly care and especially the users' experience and satisfaction with the care. The authority's view is therefore that there is a need for a more extensive Nordic cooperation in user surveys and states several suggestions in the report.

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# Possibilities and challenges for Nordic countries

Within the project surveys have been sent out and three workshops have been carried out with three target groups.

- The Council on Nordic Cooperation on Disability
- Researchers on disabilities
- Experts from authorities and organisations.

An overview of the emerged views is below.

## Implementation of rights and legislation

Experts repeatedly brought forward that the Nordic countries in general have the legislation needed and that it is comprehensive. The existing problems the individuals face in their daily life are found especially in the implementation of the legislation. The prevailing self-image that the Nordic countries are best at providing support to persons with disabilities may be a contributing factor in that decision-makers are not seeing the shortages.

## Decentralised service

In the Nordic countries the responsibility for support and service lies mainly within the municipalities. Know-how and resources vary significantly between the municipalities, leading to inequality. In a tightened national economy, the risk for even broader inequality increases. Municipalities often interpret national legislation according to their own guidance and regulations, which differ between municipalities. The possibility of moving is also limited when the decisions supporting you in one municipality are not automatically transferred to another municipality. Instead, a new assessment of needs is performed, which may lead to a decrease in the quality of support.

## Marketization

Private actors are increasingly becoming service providers, which leads to changes in the requirements. This also means more possibilities for the individual, but in some cases also the responsibilities change. This is the case for example within assistive equipment where the individual buys their own equipment making the individual handling repairs and service together with the supplier and making consumer legislation applicable. The development towards the individual becoming the customer has caused different views among the disability movement. Some are positive, some negative. The combination of a decentralised community organisation and the increasing number of systems of choice may in itself cause challenges for the individual and groups with extensive needs.



**It's obvious that we have a long, long way to go to fill the requirements of Article 19**

***Rannveig Traustadottir, Professor Emerita, University of Iceland***

### **Increased focus on legislation**

In several Nordic countries the individual has the possibility to appeal the decisions on efforts. This increases the possibilities for the individual but leads to an increased need for lawyers and legal advice. This may lead to inequality depending on the availability of such advice, and also that an increasing number of negative decisions are made by the municipalities or the government, knowing that everybody does not have the possibility to further their case.

### **Guidance and support**

Successful examples on personal budgeting are generally based on an existing teamwork between the party assisting with the personal budgeting and in the choice on how to use the means. An important requirement is, however, that this party is unbiased in relation to the alternatives on offer. If the adviser or fitter has economic incentives, for example to a certain supplier, or has a public task but is prevented from giving detailed information or advice due to legislation (public procurement), the individual must receive the information/advice in some other manner in order to be able to make an informed choice.

### **Old traditions and norms**

In many activities for support and services for persons with disabilities, many within the professions have worked for a long time and in many activities, there are still old conceptions and norms present. A key part of the implementation of the CRPD is that there should be change in paradigm, from seeing persons with disabilities as objects for charity to bearers of rights with the same rights as everybody else. Personal budgeting and individualised working methods, together with efforts such as competence development and awareness, may speed up the change in paradigm.

### **Simplified thinking and the need for cooperation**

In countries with developed welfare systems, such as the Nordic countries, there are often organisational simplified thinking in the form of several responsible parties for support and service, regulations as well as for costs. For those with many and extensive needs this often leads to a large cooperation need and many regular contacts. Cooperation within the systems, such as coordinators, are important in order to solve these problems.

# Personal budgeting

Personal budgeting makes it possible for the individual to shape the support in the desired manner. But it also requires that the individual has the knowledge and/or a network of knowledge in order to be able to make a choice. Education and knowledge are also necessary.

## Possibilities

- the individual can prioritise based on their own situation, needs and wishes.
- the individual can become more motivated to make changes and carry out life projects.
- to make choices based on their own life situation.
- to choose another provider if not satisfied.
- less bureaucracy concerning rules and requirements on following procured alternatives or decided on beforehand.

## Challenges

- The individual must become more involved with their solution and not all have the knowledge or network to make an informed choice.
- To choose from different providers may vary significantly between municipalities and parts of the country.
- The responsibility is transferred to the individual, regarding for example assistive equipment, and other legislation, such as consumer legislation, becomes applicable in repairs.
- In order to monitor that the system is used as planned, leads often to the development of an administrative control device which can be both costly and challenging for the personal integrity.
- In systems for personal budgeting costs are more transparent compared to regular activities since they are embedded in a larger operation, which may lead to a backlash and a distorted focus.
- If there are only a small number of alternatives to choose from, the risk is that the freedom of choice becomes an illusion.
- The sum received by the individual do not correspond to the needs and becomes more a basic level.
- A risk for increased inequality.

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## Nordic Welfare Centre

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