

The right to a home of my own

Nordic Centre for Welfare and Social Issues

Inspirational brochure

Housing for adults with intellectual disabilities
in the Nordic countries





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Nordic Centre for Welfare and Social Issues

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Author:

Maarit Aalto

Anna Danielsson Öberg

Bengt Rolfer

Jóhann Hauksson

Editorial staff:

Maarit Aalto

Anna Dahlberg

Helena Lagercrantz

Victoria Henriksson

Responsible publisher:

Ewa Persson Göransson

Graphic design: Victoria Henriksson

Cover picture: Eeva Anundi

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**Nordic Centre for Welfare and Social Issues
Sweden**

Box 1073, SE 101 39 Stockholm, Sweden

Visiting address: Drottninggatan 30

Tel: +46 (0)8 545 536 00

info@nordicwelfare.org

**Nordic Centre for Welfare and Social Issues
Finland**

Topeliusgatan 41 a, FI-00250 Helsinki, Finland

Tel: +358 (0)20 7410 880

helsingfors@nordicwelfare.org

The report can be requested in printed format
or be downloaded from www.nordicwelfare.org

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For a better and more inclusive society



Photo: Eeva Anundi

The purpose of this inspirational brochure is to demonstrate how persons with intellectual disabilities in the Nordic countries carry out their lives, and to present their differences and similarities.

This work is founded on the UN Convention on the Rights of Persons with Disabilities. The hope is that this brochure shall contribute to a discussion about future challenges, and to create discussion as to how Nordic society can do more to ensure the rights of persons with intellectual disabilities.

From a historical perspective persons with intellectual disabilities have been excluded from society, something which is still a challenge today. The Nordic countries have, however, over the last decades introduced significant improvements for persons with intellectual disabilities. The attitude towards persons with intellectual disabilities has improved in Nordic societies, and the disability policies nowadays support the same basic rights for persons with intellectual disabilities as for the rest of the population.

The Nordic countries have different processes concerning the development of various types of residences with their applicable services, and also in matters concerning de-institutionalisation, and to oppose the institutionalisation culture's infringement into other types of housing. Many actors in society are working for better living conditions for persons with intellectual disabilities. Municipal councils and housing producers are participating in this development as central actors. The disability organisations have for a long time also had a major influence in housing matters.

Already in the 1960s several Nordic countries were demonstrating, by means of their functional disability policy direction, a positive development of housing for persons with intellectual disabilities. This was proven through moving individuals from institutions to housing out in society. New housing alternatives with their associated support services in the local environment were offered to persons with intellectual disabilities.

All the Nordic countries are signatories to the UN Convention on the Rights of Persons with Disabilities, and the countries are working for the implementation of these rights. The Convention is an important tool for states, local powers and non-profit associations to audit and improve the rights for, inter alia, persons with disabilities. At the present time work is underway to improve living conditions for persons with intellectual disabilities in the countries concerned.

At the same time there is ongoing research, disability political evaluations and investigations conducted by functional disability organisations in the Nordic region that prove shortcomings in the implementation of the rights concerning living conditions.

DEFINITION AND OCCURRENCE

Intellectual disability is a collective term for persons with different cognitive, linguistic, motoric and social skills, whose abilities develop at a slower rate than of their age peers. This means that persons with intellectual disabilities are all different and the functional disabilities in themselves lead to varying degrees of consequences in everyday life.

WHO's definition of Intellectual Disability

The World Health Organisation (WHO) defines Intellectual Disability according to the ICD-10 classification system² as a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.³

The intelligence disability contributes to a collective intelligence level, that according to the definition lies below an IQ of 70.

ICD-10 is an internationally recognised classification system for diseases and related health problems (International Classification of Diseases). In recent years ICF (WHO's International Classification of Functioning, Disability and Health) has supplemented ICD-10. ICF defines persons with functional disabilities based on the following concepts:

1. Functional condition and functional obstacles that encompass

- A. bodily functions and bodily structures
- B. activities and participation

2. Contextual factors that encompass

- A. surrounding factors
- B. personal factors

Persons with intellectual disabilities are also defined from a relationship perspective, which implies that one does not only base this on a person's qualities, but also from the conditions in society, the environment and lifestyle factors. The definition also encompasses the relation between the individual and society.¹

It is difficult to calculate exactly how many persons in the

Nordic countries there are who have intellectual disabilities. This is in part due to persons with intellectual disabilities, for reasons of integrity, for example, not wanting to be registered, and partly due to different interpretations concerning which criteria that have to be met for a person to be diagnosed with an intellectual disability.

The number of persons with intellectual disabilities can be defined based on at least four different definitions:

1. The medical definition – the diagnosis
2. The administrative definition – those persons who are given support from society
3. WHO's definition (refer fact box) and
4. The relationship definition focussing on the relationship between a person with functional and/or intellectual disabilities, and the society around them.

The number can consequently vary depending on which

Taken together, the UN Convention on the Rights of Persons with Functional Disabilities recognises the right:

- to an independent lifestyle,
- to participate in society,
- to live whereabouts they themselves wish to, each individual choosing where and with whom they wish to live,
- to have access to different forms of social services, both in their own homes and within specialised housing,
- to have access to personal support and that society actively works to prevent isolation.
- that society works towards respect for a private lifestyle,
- to not be exposed to gratuitous and illegal interference of one's private life, family life or home,
- a satisfactory standard of living and a suitable place to live as well as continually improving lifestyle conditions,
- to include these matters in public housing programmes.

definition is being used in the context. Another aspect that makes it difficult to state the number of persons with intellectual disabilities is that we know there are persons with intellectual disabilities that have not been diagnosed, and have never undergone investigation, and who have subsequently never had access to services. Within this group we can, for example, also find persons that currently instead are included in groups such as the homeless and those in prison.

The number of persons with intellectual disabilities can therefore vary between 0.5-1.5 % of the population as a whole. However if, despite this, an attempt is made to estimate the number of persons with intellectual disabilities, and that such an estimate is made based on the first definition, that states the lowest number of persons with intellectual disabilities, the result will be as follows: In Sweden the number is estimated at around 40 000, and in Iceland 1 500 persons, equalling 0.5 % of the population in each respective country. In Denmark there are estimated to be around 36 000 persons with intellectual disabilities, and in Norway around 30 000 persons⁴, which in both cases imply that around 0.6 % of the population has an intellectual disability. In Finland there are estimated to be around 40 000 persons⁵, which represents around 0.7 % of the population.

THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The United Nations (UN's) Convention on the Rights of Persons with Functional Disabilities was ratified by the UN General Assembly in 2006, with the purpose of promoting, protecting and ensuring the full and equal enjoyment of all human rights and basic freedoms for all persons with functional disabilities, and the promotion of respect for their inherent value (Article 1).⁶

All the Nordic countries are signatories to the Convention. Sweden, Denmark and Norway as well as the autonomous areas of the Faeroe Islands and Greenland have ratified it. The right to housing is reflected in several of the Convention's articles, inter alia, articles 19, 22 and 28, and emphasizes for example the right to an independent life, respect for private life, a satisfactory standard of living and the right to participate in society.

The implementation of the rights is an important part of the work concerning improvements within the housing sector, and for avoiding worsening standards of living for persons with intellectual disabilities. This is primarily a question of infringement of the right to an equal standard of living, to a private life and to choose *where* and *with whom* one lives with.

How do persons with intellectual disabilities live in the Nordic countries?

Photo: Johannes Jansson/norden.org



A place to live and a home are amongst the most important aspects of our lives. It is a part of our identity, gives us security, and it is in our home that we carry out our private lives. Persons with intellectual disabilities are more often at home than other members of society, who due to their functional disability are not able to take full-time employment. Subsequently the standard of living, including the quality of services, becomes even more important.

A matter of common interest concerning housing for persons with intellectual disabilities in the Nordic countries is that the responsibility is a communal one, that all countries have distanced themselves from institutions and that efforts are being made to strive towards increasing opportunities to offer housing in apartments.

The personnel become a central part of the quality development within housing, and therefore the continual access to personnel training is emphasized.

The Nordic countries have generally the same quality requirements for housing for persons with intellectual disabilities. These requirements are connected to

- a safe and friendly living environment.
- the right to a personal place to live with well-adapted services based on the individual's needs,
- social networking for participating in the local environment,
- an aspiration to being involved.

The municipal councils are responsible for the standard of living for persons with intellectual disabilities meeting the living standards of other persons in society, and the avoidance of the development of segregated and institutional forms of housing.⁷ Persons with intellectual disabilities shall have access to their own accessible apartment with a personal touch⁸ and it ought to be felt to be one's home⁹. In connection to the housing solutions, so-called communal areas are often created. There are surveys that show that the group concerned values the opportunity of sharing common areas and activities together with others as being highly rated.¹⁰

In the Nordic region the implementation of the UN Convention and functional disability policy are described as being guiding principles for persons with intellectual disabilities. Despite this, there is a risk that the institutional culture will encroach upon housing planning and that non individual-centric treatment within the housing solution will remain a frequently occurring problem.

FORMS OF HOUSING AND RULES AND REGULATIONS

The Nordic countries enjoy a high standard of living. Floor space recommendations in apartments for persons with intellectual disabilities are relatively similar across the Nordic countries, and the data shall be comparable with the equivalent figure for other citizens' living standards. In Norway, Sweden and Finland there is a recommended floor space for persons with intellectual disabilities of 35-55m² per person¹¹ and on average the citizens of the Nordic countries enjoy a floor space of 42-59m² per person. There are examples of the floor space offered in housing, communal housing or other types of housing for persons with intellectual disabilities being less than the respective country's recommendations, which can imply greater actual differences in floor space.

In the Nordic countries persons with intellectual disabilities are offered different forms of housing based on their personal needs. Additionally the alternatives that the municipal council is able to offer can affect the housing solution. Different degrees of service are connected to the housing solution. For example, persons may basically live an independent lifestyle and receive support during the week, or they may live in a

communal set-up with round-the-clock access to staff help.

Forms of housing represented throughout the Nordic countries comprise of own apartments, communal living where the person concerned has their own room but with a shared kitchen facility and lounge area as well as the communal housing solution, where several persons in the same house have their own apartment with associated common-use areas. Various forms of institutions still exist in Denmark, Finland and Iceland. Denmark still has certain institutions, but also has newly-built housing solutions which can be likened to institutions. In Finland there is a goal-oriented institutional phasing-out in progress, with around 1 400 persons with intellectual disabilities moving out from the institutions to housing solutions in the local society.

DENMARK

Denmark's disability policy action plan "A society for everybody" (2013) emphasizes support for adult persons with intellectual disabilities with the intention of creating a life of their own in the housing solution. The central point of the action plan is inclusion and equal opportunities and that the UN Convention's rights are respected as public strategies are developed and the work on implementation is ongoing.¹² In Denmark it is the municipal council that is obliged to offer housing on the basis of the Service Act and General Housing Act. Many municipal types of council, however, have long waiting lists, which mean that housing cannot be offered immediately.

In Denmark there are a total of 23 149 residential positions in 1 526 housing units, of which 71 % (2011) of the units for persons with intellectual disabilities are produced by the municipal councils, 13 % by private companies, 10 % by the regions¹³ and 6 % are produced by so-called self-sufficient institutions¹⁴. The housing solutions in Denmark consist of:

- self-sufficient housing (own homes)
- communal housing (communal associations)
- group housing
- institution-like housing solutions (newly-built larger housing units and so-called measures, meaning care homes for persons with special needs (persons with intellectual disabilities combined with psychological disorders)

The **self-sufficient housing solution** (own home) means housing for persons with minor intellectual disabilities, that can basically manage their everyday life on their own, and receive support in the home from social educationalists, home-help or from user-controlled personal assistants.

In **communal housing** there is most often a room of one's own as well as common areas for kitchen, lounge and bathroom, which are shared with the other residents. This housing

Development from the 1960's to the present day

Housing for persons with intellectual disabilities of all ages is being organised at an earlier stage in only two methods in the Nordic countries, with the person concerned either living with relatives or in an institution. Frequently children with intellectual disabilities were moved at an early stage to an institution to enable attendance at school, which often meant they remained in institutional care all their lives. During the 1960's and 1970's the necessity for improving the living standards for the group was observed, and conditions were created for phasing-out the institutions.

In the 1960's the concept of normalisation was minted as a political concept and came to represent a major importance for the political standpoints within the area of housing for persons with intellectual disabilities. The concept of normalisation and its context led to a paradigm shift and to the change of living standards for persons with intellectual disabilities from an institutionalised type of living to integrated housing solutions in the local society. The change was, however, carried out in the Nordic countries in different ways and at different rates of change.

solution is aimed at persons with intellectual disabilities, who need a lot of support.

Group housing is a housing solution with its own apartments in the same building and with communal areas. This housing solution is most often for persons needing support around the clock.

Institution-like housing solutions¹⁵ consist of larger units with only one's own room as the private sphere. Institution-like housing solutions that are newly built includes many own apartments in one house. This type of housing solution is often characterised by service from a central kitchen, laundry and are localised in rural areas.

The municipal housing units in Denmark are, on average, for around 15 persons with intellectual disabilities and the private alternatives are somewhat smaller (around 10-11 places). The regions offer the largest average housing solutions for around 24 persons.¹⁶ Over and above this housing

units intended for 40-100 persons with intellectual disabilities have been built in recent years.¹⁷

In the investigation conducted by the social educators¹⁸ it has been observed that many persons with intellectual disabilities live in rather cramped conditions, 60 % (around 10 000) have less than 30m² and around 6 400 persons of this figure live in less than 20 m². Another investigation carried out by The National Federation of Social Educators shows that 45 % live in communal groups with 30 or more dwellings, or rooms, in communal housing.¹⁹ How many of these are persons with intellectual disabilities cannot be determined from the investigation.

FINLAND

In Finland a structural change is underway, which means a qualitative improvement effort within housing for persons with intellectual disabilities. It is emphasized in the Government resolution²⁰ that removal may not be effected to places where there are areas of concentrated housing (co-located housing), or to empty institutionalised premises. All joint municipal authorities had filed a removal plan by December 2012.

There is a great need for new and renovated housing both for those moving out from the institutions and adults with intellectual disabilities, who move away from relatives (around 8 000 persons). The charitable, not-for-profit organisation The Housing Finance and Development Centre of Finland, ARA and Finland's Slot Machine Association have reserved funds for housing production in accordance with the housing programme for persons with intellectual disabilities 2010-2015.

The responsibility for planning and accessibility to housing lies with the municipal councils. The production of housing and services can be achieved by the municipal authorities themselves, the joint municipal authorities, private companies, organisations or charitable organisations. Municipal councils can also collaborate with another municipal council.²¹ Due to the major ongoing changes in Finland the lack of housing is consequently significant for persons with intellectual disabilities.

The current housing solutions for persons with intellectual disabilities consist of:

- support housing (separate dwellings)
- controlled housing
- assisted housing
- service housing
- family housing

Support housing (separate housing) is offered to persons who can manage their everyday lives just about on their own. The individual receives help from the personnel as

Goals in the Finnish housing programme for persons with intellectual disabilities 2010-2015²⁶:

- Reduce the number of institutional positions quickly and in a systematic and controlled manner.
- Enable adult individuals with intellectual disabilities to move from childhood homes through offering then housing solutions, individual services and support where needed.
- Increase the offer of housing for persons with intellectual disabilities
- Produce a total of 3 600 housing units during the programme period, intended for persons with intellectual disabilities at an annual rate of 600 units.

necessary, e.g. twice weekly. The housing unit may be a flat that is owned, rented or another form of housing - that is to say an apartment of one's own.

Controlled housing is for persons with intellectual disabilities who receive support on a daily basis, but who manage by themselves during the night hours.

The starting point is that persons can manage with a degree of independence. This alternative, too, can be described as having one's own apartment.

Assisted housing (group home) is organised for persons with intellectual disabilities, which have a significant need for care and need round the clock support from personnel. The individuals have a room of their own and access to communal areas such as kitchen, lounge and hygiene areas.²² Often referred to as a group home.

Service housing is another type of housing intended for persons with intellectual disabilities and who need constant help. This housing solution has become increasingly common and it offers the individual an apartment of their own and services right where they live. This housing solution is also called a residential group, where several apartments for persons with intellectual disabilities are constructed in the same building.

Family housing is a housing solution in which adults with intellectual disabilities live as part of a family. The family is often responsible for several persons with intellectual disabilities. One example of family housing is a home in a rural area or a couple who undertake to offer housing and care for adult persons with intellectual disabilities.

It has been difficult to investigate the number of persons

living in each housing solution, but around 50 % live at home with relatives, 10 % in institutions, around 2 % in family housing and around 40 % in other types of housing solutions.²³ All municipalities in Finland have produced regional plans for phasing-out the institutions and for resource centre activities (2010-2015). The municipalities' plans show that the need for housing and service is increasing as is the pressure on other services, such as healthcare, at the level of the municipalities.

In the recommendations for housing for persons with intellectual disabilities for the years 2010–2017²⁴ it is emphasized that the maximum number of dwellings in small self-contained houses or terraced house is 15 units on the same plot of land. These 15 units are often distributed across several houses on the plot. However, even in Finland municipal councils and private housing boards have been building larger units over the last few decades.

ICELAND

The basic intention in Iceland's policy is to support the social context in the housing environment and the financial stability. All persons regardless of their functional disability shall have the right to a place to live. A principal guarantee for the right to a home, irrespective of social conditions, is created at the responsibility of the state. Since 1999 the Housing Affairs Act No.44/1998 controlled the structure of housing in Iceland. The Housing Financing Fund under the Minister of Social Affairs and Housing is responsible for the administration and control in the area. The Housing Financing Fund creates and lets out apartments to vulnerable groups, among which are persons with intellectual disabilities. This enables a good standard of living despite the low income that many persons with intellectual disabilities have. This also allows a move away from the childhood home, which has increased during the period 2011-2014.

Housing for persons with intellectual disabilities is a prioritised political goal and development area in Iceland. The housing solutions primarily consist of:

- apartments
- residential groups
- communal housing
- institutions

Apartments, residential groups and communal housing equate to housing solutions in the other Nordic countries. Iceland's three quality criteria for housing for persons with intellectual disabilities are as follows:

- **Apartments** shall be situated in housing environments and close to different services and support services

- **Residential groups** ought at a maximum to consist of 4-6 apartments on the same floor and a maximum of ten in the same building.
- **Communal housing** (group homes) can consist of a maximum of 4-6 persons where they share kitchen, hygiene facilities and a common lounge.

The municipal councils can have varying strategies to establish housing for persons with intellectual disabilities. The responsibility primarily entails creating individual housing solutions with services mainly consisting of rental apartments with support functions. This means that varying type of housing is offered in various sizes, such as houses, terraced houses or stairwell apartments. There are two institutions remaining with 45 persons in each.

NORWAY

In Norway the starting point is that "persons with intellectual disabilities shall, as far as is possible, live independently and enjoy an active and meaningful life in the company of others"²⁶. Housing for persons with intellectual disabilities shall be a normal housing form in a normal environment, and that everyone shall have their own apartment.²⁷ The thing that sets Norway apart from the other Nordic countries is that the services are tied to the individual (Statutory Ordinance no. 67 1986-1987) and not to the housing solution itself. In 2009 Husbanken recommended small housing groups from 4 to a maximum of 8 apartments in the same building.²⁸

Norway offers five different housing solutions as follows:

- independent housing
- communal housing (housing associations)
- localised community housing
- housing collectives
- owner-occupied apartments for persons with intellectual disabilities²⁹

An independent housing solution is an apartment that can have a private outdoor spot or terrace. Husbanken recommends the apartment is at least 55 m², or larger. Persons who can basically manage by themselves are offered this type of housing solution.

Communal housing (housing associations), is a housing solution for several persons with intellectual disabilities with their own apartments and communal use areas. In this instance the recommendation for the personal floor space is at least 40m² but ought to be 50 m².

Localised community housing is a series of closely-located apartments in the same building or in the vicinity of each other in different buildings and is about the same as for housing association solutions, but without the communal use areas.

Housing collectives offer a group of persons with intellectual disabilities a room of their own of around 28-40 m² with communal kitchen and hygiene areas. Housing collectives are on the way to disappearing completely as an alternative housing solution. In 1994 around 15 % of housing solutions were housing collectives, and the figure has dropped to the present level of 2 %.³⁰

The model of **owner-occupier apartments** is new. The occupants receive a starting loan and then own their own home. In the owner-occupier model there may also be communal use areas.

It turned out recently that there are even housing solutions where certain groups, such as persons with intellectual disabilities, the elderly and persons with mental functional disabilities, are co-located. The housing Committee (Boligutvalget) points out that "The establishment of this type of care-ghetto means the choice ought to be avoided. The state contributions shall be established so as to prevent the development of care-ghettos, and that they support the creation of housing solutions in the municipal councils".³¹

The trade union FO³² in Norway has on its platform described four areas of focus which should stop this negative development in the housing situation for persons with intellectual disabilities:

- Husbankens guidelines for financing ought to be inspected and audited so that they agree with policies.
- Persons with intellectual disabilities have the right to individually adapted services to their homes and not the other way around meaning that he/she has to live where the service exists.
- A home; not an institution. Persons with intellectual disabilities have equal rights to a safe home of their own.
- A part of one's housing solution is the immediate environment and network. An especially important element is that the housing solution is stable and contributes to continuity.

FO's platform for living conditions for persons with intellectual disabilities emphasizes that persons with intellectual disabilities have the same right as everyone else to live wherever they want to, despite their need for support. Within the Social Services Act and Community Health Act, and in the Healthcare ministry's interpretation of the law, the goal is clear that there is an equal right to a home of one's own as for everybody else, and for persons with intellectual disabilities to live wherever they themselves wish to. Norway has continued to emphasize the relationship between the home and one's identity. The meaning of "housing" shall progress to a proper home with the opportunity of developing one's own identity and independence in the home.³³

SWEDEN

LSS – The Act on Support and Service for Persons with certain Functional Impairments³⁴ has strengthened the rights for persons with intellectual disabilities, amongst other matters the right to housing, the right to housing with specially adapted services and other specially adapted housing solutions.³⁵ LSS is a right under law as opposed to other legislation that are framework laws. The Act gives the opportunity to appeal against municipal authorities' rulings regarding services.

In Sweden housing solutions with special services can be designed in various ways, and may be run under both municipal council and private management. Support and service in connection with housing solutions vary, and there are different terms to describe the various forms of housing. The National Board of Housing, Building and Planning (Boverket) has determined that the group collective, also known as group home, can no longer be regarded as a satisfactory housing solution for persons with intellectual disabilities.³⁶ The group collective was the housing solution that was offered in connection with being moved away from the institutions.

The group collective still exists as a form of housing but is in the process of being phased out.

The term "satisfactory housing" is used in Sweden, which places demands on the housing standard and emphasizes that general building regulations applicable to public housing shall also apply to housing with special services.³⁷

The following housing solutions are prevalent in Sweden³⁸:

- housing with special services for adults, i.e. group homes or service homes in accordance with LSS
- satellite apartments or adjoining apartments
- other specially adapted housing in accordance with LSS
- a regular home of one's own

Housing with special services for adults, i.e. group homes or service homes in accordance with LSS. **Group homes** consist of own apartments, either in the same building or within an area in close proximity to communal use areas. This may be a detached house or a "trapphus". Group homes are planned for persons who are in need of extensive support and care. Group homes comprise of personnel who often have their own staff areas. Another form of group home is the shared stairway model ("trapphus"). The apartments are located in the same stairway with one apartment for communal activity use.

In **service homes under LSS** are apartments with access to communal use areas, personnel, recreational activities, etc. More people can live in service homes than in group homes. The National Board of Health and Welfare's general advice, however, emphasizes that the number of people living there

LSS circle of personalities

1 § This Act comprises of regulations for work for specific support and service for persons

1. with intellectual disabilities, autism or autism-like conditions,
2. with significant and permanent intellectual functional disabilities following brain damage as an adult caused by outward violence or bodily complaint, or
3. with other permanent physical or psychological functional disabilities that are obviously not attributable to normal ageing, if they are of a significant nature and cause major difficulties in daily life and consequently an extensive need for support and service.⁴⁴

ought to be such that an "institutional housing environment"³⁹ is avoided.

Satellite apartments or adjoining apartments, are a form of one's own dwelling with support from personnel a few hours per week. This housing solution is directed at persons with minor intellectual disabilities. The apartments have access to communal use areas.

Other specially adapted housing. This housing solution does not consist of communal use areas or care functions. In this solution there are no personnel either, but if necessary, support, service and care as supplementary efforts can be provided.

A **regular home of one's own** is for persons with intellectual disabilities who can manage with only a little support, and where no specific personnel is connected to the home. This may take the form of a rented apartment, an owner-occupied apartment or a privately-owned small house unit. Also in this case support, service and care can be provided as necessary.

There are 22 339 (2013) persons in the target groups⁴⁰ described in LSS, of which the largest group consists of persons with intellectual disabilities, who live in housing solutions with special services in accordance with LSS and 1 015 persons according to the Social Services Act.⁴¹ The National Board of Health and Welfare has previously stated that housing shall comprise of 3–5 persons, but following a ruling in the Swedish Supreme Administrative Court these recommendations have been adjusted to a maximum of 6 persons.⁴² Concerning specific needs housing, for all target groups with functional disabilities, it is estimated by around

45 % of the municipal councils that there is a lack of housing.⁴³ In Sweden the group home is the commonest form of housing solution.

THE DISABILITY ORGANISATIONS' THOUGHTS ABOUT HOUSING

"I live alone in a small apartment. I like it here and get on very well with the personnel. I wish everyone could live the way I do." (Board Chairman Jonne Tallberg, Steg för Steg Finland)⁴⁵

Interest groups and organisations of persons with intellectual disabilities in the Nordic countries work towards improved and more individual-centric housing solutions and increased respect for private life in the home environment. Both types of organisation are functional disability organisations.

The functional disability organisations investigate and carry out projects within the area of housing for persons with intellectual disabilities. One example is the FUB organisation's report "A good life"⁴⁶, FDUV's project "Tailored housing services"⁴⁷ and the report "When I left home"⁴⁸. These interest groups also want to increase the information out to the municipal councils, and, amongst others, Jens Petter Gitlesen of NFU in Norway has created a summary of housing policies and rights for persons with intellectual disabilities in Norway based on "Establishment of larger institution-like housing solutions on the increase".⁴⁹

The organisations in all the Nordic countries express concern for the rights of persons with intellectual disabilities in relation to the UN Convention and the functional disability political goals not being fully met in terms of housing provisions. The organisations state that the current development has elements of re-institutionalisation, co-location of different groups of people, the risk for poverty⁵⁰ and crowded living conditions. Of particular note is the emergence of re-institutionalisation, especially in Denmark where there is concern for the re-establishment of new, large institutions.⁵¹

The national association FUB has recently published a report regarding the persons' own concerns about their homes and support therein; both now and in the future. The report describes the weight of not thinking in terms of "standard solutions", but based on peoples' own concerns for their living standards.⁵²

The functional disability organisations in Finland have several development projects in work⁵³ that support the move from institutions to local housing units.⁵⁴ The functional disability organisations indicate that there is a need for functional disability organisations to contribute at a systematic level in combination with designing functional disability policy goals and housing planning in the municipal councils.

Future challenges

Photo: Jóhann Hauksson



Listed below are five challenges based on the survey that the Nordic Centre for Welfare and Social issues conducted in connection with this publication. The challenges have been discussed at a seminar during the “A right to a home” conference held in Oslo during autumn 2014.

A HOME LIKE OTHER PEOPLES’

A future challenge is to clarify and strengthen the connection between the UN Convention on the Rights of Persons with Functional Disabilities, functional disability political goals and the development of housing for persons with intellectual disabilities. The challenge lies in counteracting the construction of large housing complexes, the institutional culture is recovered within smaller housing solutions, to counteract co-location with other groups in need of support and a reduction in quality of life. There is a need to strengthen the development towards “a home like other people” and to improve the quality of service, inter alia, through reducing crowding and to promote competent personnel staying on and the recruitment of more staff.

NEW GENERATION – NEW CHALLENGES

In the Nordic countries the majority of those belonging to the generation that is now moving into adulthood have lived in the family home with their parents and have lived a life that has included living in society with others. This generation has expectations of moving away from home and to live as others do in the same age group. Despite this, many persons with intellectual disabilities live on at home with their parents for too long a time, due, amongst other factors, to a lack of housing. The challenge calls for offering an equal standard of living to young persons with intellectual disabilities without the need for support.

OLDER PERSONS WITH INTELLECTUAL DISABILITIES

The number of older persons with intellectual disabilities has increased, and shall continue to do so. A challenge is to carry out preparatory studies and plan how older persons with intellectual disabilities are to have the opportunity of carrying on living in their own home and how to maintain the level of welfare in the event that the person has to move. In particular the group of persons with intellectual disabilities and dementia ought to be carefully considered.

SUPPORT TO PERSONS WITH INTELLECTUAL DISABILITIES AND SPECIAL DIFFICULTIES

Persons with intellectual disabilities and other problems such as challenging behaviour, mental illness or several functional disabilities ought, to a greater degree, have access to alternative housing solutions which best match their rights. Many of these people still live in institution-like housing forms.

HOUSING POLICY AND HOUSING FOR PERSONS WITH INTELLECTUAL DISABILITIES

In the Nordic countries the municipal councils have equal responsibility for housing planning and for the supply of housing. The challenge lies in increasing the number of housing solutions out in society for persons with intellectual disabilities, and to involve the functional disability organisations at an early stage of the planning. There is a lack of housing for persons with intellectual disabilities. In order to cover the need of special housing solutions for persons with intellectual disabilities it is important for young persons with intellectual disabilities to move away from their childhood home and for adults with intellectual disabilities who live with ageing parents to be able to move to a home of their own. At the present time the municipal councils cannot offer housing to all persons with intellectual disabilities who need it.

A positive development that split Norway

Photo: Ivar Kvistum, Handikapnytt



Over a 30 year period, between the 1960's and 1990's, housing solutions for persons with intellectual disabilities improved in Norway. However, since the start of the 21st century, things are going in the opposite direction, according to Jan Tøssebro of NTNU, the institute for social work and health sciences in Trondheim.

– But everything is relative. In comparison with many other countries the standard in Norway is still high”, he says.

The approach towards housing for persons with intellectual disabilities has changed over three different points in time, according to Jan Tøssebro. The first occasion in modern times was in the beginning of the 1960's. Criticism was raised against institutional housing, as it implied significantly worsened standards of living, and that the users concerned received a lesser chance to develop. The critics also claimed that the ordinary schooling and healthcare systems ought to manage

to care for persons with intellectual disabilities.

- This was the first step in a normalisation process. The argument was that schools needed extra resources instead of expanding the institutions.

The political signal to the powers-that-be was that improvements were necessary. This led to fewer children being accepted, that the big dormitories were closed, that the personnel received better training and that activities were of a better and higher quality.

- Four-bedded rooms were being discussed instead of dormitories and the signal was that all children ought to grow up in their home environment. If this was not possible, they would have to live in foster homes.

The conditions in institutions continued to improve and fewer and fewer children were placed there. The next change occurred at the end of the 1980's and the beginning of the 1990's.

- All institutions were to have been phased out by then. This was realised over the period of a few short years.

Instead, persons with intellectual disabilities were offered a move to two-room apartments which were integrated into the housing areas. Four to five apartments were often built at the same location, but not more than so. During this time relatively major attention was being paid to the conditions for persons with intellectual disabilities and persons with functional disabilities. The state placed demands on the municipal authorities, the politicians often taking up these conditions, personnel and parents associations were active and questions raised were reported in the media. Research showed that many things became significantly better.

- For example parents started visiting their adult children more frequently. This was due to the apartments being physically located closer to home than the institutions had been, and that it felt better to visit them in their own home environment. The personnel also observed that there were fewer conflicts between the residents.

THE 'CARE GHETTO'

However, despite the positive development something happened in the beginning of the first decade of the new millennium. The goal was indeed still for adult persons with intellectual disabilities to have a home of their own. On the other hand it was no longer as important that the housing solution was integrated among other apartments. Instead the municipal councils, with responsibility for healthcare, started to build increasingly larger housing complexes. Twelve and sometimes as many as 40 persons with intellectual disabilities were able to live in the same area.

At the same time apartments were built to suit other

groups, for example older persons who needed support, persons with mental illness or addiction problems.

- These areas became known as 'care ghettos'.

The powers-that-be in the municipal councils claimed that larger housing solutions were better as it had transpired that many felt alone in the smaller units. Another explanation was that better-educated personnel were attracted to more expansive housing complexes. The third was that the municipal councils claimed that it was financially more viable.

- Research proved this not to be the case, however. Persons with intellectual disabilities often feel alone, but this has nothing to do with how they live. Larger units risk making the personnel more passive and take less responsibility.

The financial effects of larger units are unclear, but the municipal councils claim that they become cheaper, he says.

- It is a case of what you believe in, even if there is no solid basis for argument.

The fact the municipal councils sought profits through rationalisation was due, amongst other things, that the demand for housing was greater than anticipated in connection with the closure of the institutions, according to Tøssebro.

- Until the middle of the 1990's half of the adults with intellectual disabilities lived at home. When they got the chance the move to a home of their own a greater need arose.

THE GOVERNMENT'S WHITE BOOK

The larger housing areas, the 'care ghettos', received increasing amounts of criticism. This led to the government in 2010 producing a White Book with a number of declarations of intent concerning care for persons with intellectual disabilities.

- It seemed very ambitious but lacked concrete promises for changes and contained no regulations or directives that could counteract the tendency towards larger housing solutions.

One concrete result, however, was the reduction of the really large housing complexes. The municipal councils are no longer building apartments for 40 persons with intellectual disabilities in the same area. However, they are still larger than before with sometimes 20 apartments. With the benefit of hindsight Jan Tøssebro is surprised that a positive development could be broken so quickly - in a country that is one of the world's richest.

- The only solace is that the standard is high. In many other countries persons with intellectual disabilities still have to share rooms. The problem is only that the starting point for change that took place in the 1960's was that we are a welfare state that could offer good conditions to everybody. This is, however, no longer the case. Many groups have become better off in Norway over the last ten years, but not this one.

Independent siblings Iceland



Photo: Eeva Anundi

Siblings Helga Ósk Ólafsdóttir, 43 and Ólafur Ólafsson, 49 each own their own apartment in an apartment block in Breiðholti, a suburb of Reykjavík. They both have an intellectual disability. Their father Ólafur Ólafsson and mother Kitty Stefánsdóttir look after Ólaf's and Helga's finances, but in future this will be taken over by a users' organisation in collaboration with local authorities.

According to Icelandic law a person with intellectual disabilities may be deemed responsible as regards finances, but exceptions may be made concerning ownership rights and questions of housing.

The parents bought the siblings' homes fifteen years ago. The apartments are just over 63 m² in size and the monthly costs are relatively low.

Both Ólafur and Helga Ósk have worked all their adult lives. Previously Ólafur lived together with several other persons with intellectual disabilities, but he didn't enjoy it as there was such a turnover of tenants.

– The solution was to invest in an apartment of his own, says his father Ólafur. In the beginning we were visited once or twice a week by a consultant, but these visits stopped after a while. We believe it was because the municipal council wanted to save money, but they probably thought that things were going so well for Ólafur and Helga Ósk that they didn't think they needed any extra support.

HELP ONE ANOTHER

Ólafur takes the bus to work at Segelverket, where he has been employed since he was 16. Segelverket makes sails, tents and backpacks.

– I take the bus to Lækjatorg in the centre. There I change bus to another one that takes me to the western part of Reykjavik and the old harbour where the company is located.

Helga Ósk takes the bus to work, too. For the last 5 years she has been working as a cleaner at Laugardalshöll, the big sports arena in Reykjavik. Before that she worked at an old people's home in the western part of Reykjavik.

– It got a bit tough the other day when we had the European Championships in Group Gymnastics in the arena. There was lots of work to do, she says.

Helga likes to take things easy after work and often meets friends over the Internet. Helga has a driving licence, but Ólafur does not.

– I don't have a car of my home. But I am allowed to borrow my parents' car at the weekend, and sometimes I'll look after it when they go on holiday.

Both Ólafur and Helga Ósk like living close to each other. They help each other in their everyday lives and even share the domestic chores.

– I like preparing food, says Ólafur. Most often we'll make food at my place, but I think I make food for Helga more often than she does, says Ólafur with a smile.

SPORTS GIVES CONTACTS

Both Ólafur and Helga Ósk enjoy sports. Their father Ólafur is

a pioneer within sports for persons with intellectual disabilities. In 1980 he started the Ösp sports club and last year was given the "Citizen of the Year" award for Reykjavik for his work for persons with intellectual disabilities. Ösp is now a member of the Icelandic sporting association for persons with intellectual disabilities, and has around two hundred active members.

Previously the family lived in the Västmannanna islands off the south coast of Iceland, where Ólafur and Helga Ósk started their basic schooling. They both describe how they were bullied at school.

Ólafur plays football, bowling, table tennis and boccia. Hanging on the apartment wall is a large number of medals that he has won over the last decades, amongst others gold medals in both football and boccia from the Special Olympics. Helga Ósk has participated in the games as part of the Icelandic bowling team. In 2015 the games are being held in Los Angeles and the entire family intends to be sitting in the crowd.

– We won't be taking part ourselves this time but it will be fun to watch the games, says Ólafur.



Photo: Eeva Anundi

Everyone has the right to a life of their own Finland



Photo: Juha Rahkonen

The Finnish government's goal to reduce the number of institutional places as soon as possible is good. It will, however, take longer than anticipated, argues Jyrki Pinomaa, CEO for the Aspa foundation, one of Finland's housing bodies for persons with functional disabilities. He has personal experience of how it is to try and find housing for adult children with intellectual disabilities. Two years ago both his two adult sons moved to a home of their own.

– There’s so much to consider when you have a child with special needs who is going to move away from home. Many thorough preparations were necessary to undertake, he says.

The housing solution for his sons has turned out very well. They each have their own apartment, and they both have access to a communal utility area. Each apartment has its own front door like any other apartment, as well as a door to the communal area. This is important, emphasizes Jyrki Pinomaa.

– We call it the “two-door” model. It means that the users can choose if they want to be private or be part of the community.

But it took a long time to find somewhere to live. Jyrki Pinomaa and his wife Marianne, who looked after their sons on a full-time basis, started the process ten years ago. The alternatives offered were institution-like housing solutions, and that was not an option. The Pinomaas got together with twelve other families and finally a housing solution was built for their 13 adult children via the Aspa foundation, but this was before he himself became the foundation’s CEO. The process of preparing the adult children for the move and preparing the personnel for their individual needs took a lot of time and energy. Additionally the parents had to get used to the idea that their sons, who needed round-the-clock support, were no longer going to be at home.

– That was tough. At the same time it is incredibly important that parents of disabled adult children actually take the important steps. If the parents wait too long there is a risk that they die before anything is arranged for the children and by then it is too late. In that case it is others who get to decide the children’s’ future, he surmises.

Now Jyrki Pinomaa gets to see his sons when they come home once a week, and he and his wife visit them at regular intervals.

- Everyone has the right to a life of their own.

In his role as CEO for the Aspa foundation he can draw a lot of benefit from his own experiences. Behind the foundation are 13 of Finland’s largest disability organisations. The purpose of the foundation is to build or buy various forms of support housing for persons with functional disabilities. The foundation’s activities are financed through state grants and contributions from Finland’s Slot Machine Association or through bank loans. The residents rent their homes, which are adapted to their needs. All homes shall be integrated in the residential areas, and preferably not be more than twelve adapted units - or housing groups, as they are called - in the same area.

Finland's Slot Machine Association

In the 1920's Finland saw an increasing amount of gaming machines, or 'one-arm bandits' as they are known more colloquially. A discussion started about how wrong it was for private enterprise to make money from people's desire to gamble. In 1938 the Slot Machine Association was founded to counteract the criticism. The purpose was, and still is, to use the profits from the machines to promote health and social welfare. Every year the government decides on how the profits are to be shared. In 2014 300 million Euros was shared between 800 different associations and foundations.

DEVELOPMENT IN THE RIGHT DIRECTION

The Finnish government's goal of producing 3 600 homes for persons with intellectual disabilities is very good, thinks Jyrki Pinomaa. Since the decision was made in the middle of the 1990's to reduce institutional housing, finding suitable housing has been very slow in coming. However, an investigation a number of years ago indicated the weaknesses and additionally taught state, municipal and private actors how to cooperate. This led to the government raising its ambition bar, he says. But it still takes time before all persons with intellectual disabilities get a home of their home. The construction need was calculated based on the number of persons who lived in institutions without taking into consideration those who lived in their parental home.

– And there are quite a number of them. In addition, there are persons who have lived in institutions all their lives and who do not want to move.

Despite this, development is going in the right direction, says Jyrki. Another important point is that the state authority that approves housing maintains its quality. According to this, a large number of housing solutions for persons with special needs cannot be concentrated in the same location.

– This is important to avoid creating these "care ghettos".

BETTER SERVICE NEEDED

Something that doesn't work so well in Finland is the service the residents receive. There is a great deal of competition and many private companies that compete for contracts by submitting unrealistically low tenders. Consequently this frequently leads to a significant lack of personnel. However,

Jyrki Pinomaa's sons receive a good level of service.

– I believe this is due to the fact that where they live there are residents who come from different municipalities. Companies can therefore not submit tenders for only one municipal authority, but have to adapt the service level to each individual resident. Individually-adapted service is offered.

There are a number of other improvements that could be introduced, he explains. One is to create some form of service coordinator for persons with intellectual disabilities. Apart from all the time that Marianne Pinomaa invested in caring for her sons, it took at least as much time to keep track of which financial aid and service they had the right to receive. That time could have been better used for her sons - or to rest, she believes. Another underestimated difficulty with having adult children with functional disabilities living at home is concern about money. In Finland care support is paid to those who stay at home, but the sum is low and subsequently other grants connected to persons with functional disabilities are an important addition. If the adult children leave home it can lead to very negative financial effects for the parents.

– Not least for those who live alone. In the worst case it may lead to the person not being able to move to a home of their own.

Building new homes Denmark

Photo: Københavns Kommune



Around a tenth of Denmark's 36 000 persons with intellectual disabilities live in Copenhagen. There is an ongoing process for rebuilding and building new homes to integrate these persons in society and be able to receive more in the growing capital city.

– The trend is that we are building larger and smaller-sized "housing associations", says Copenhagen's social mayor Jesper Christensen. He is a social democrat, but emphasizes there are no direct political differences of opinion concerning disability policy.

– There is major agreement about how we are to compensate for functional disabilities that a number of our citizens have, and to ensure they are able to manage their everyday lives as far as possible, says Jesper Christensen.

For many decades Denmark has been working to abandon the institutions and work towards a normalised housing situation. There is currently a minority of the group in question in Copenhagen that lives in institutions. This comprises a group of around a hundred children and youngsters under the age of 18. The rest live in some form of group or service housing, or in their own homes with access to various levels and scope of support.

Jesper Christensen says the ambition is to move from larger to smaller solutions. By way of example, a large service centre at Amager with more than 200 places has been divided into a number of smaller units with 30 to 70 places.

– Additionally, we are integrating these housing solutions into ordinary residential areas so that the people living there can become more included in society. We are striving for as many people as possible to get their own apartment, but at the same time be able to become part of a group if they so wish. Some of them think that a communal housing solution can become too social and do not want to share so much with others, he says.

There is also a tendency to abandon the really small units for somewhat larger ones. However, the political ambition is the same in that respect, too, according to Christensen.

Criticism has, on the other hand, been levelled at the fact that larger institution-like housing is being built in other parts of Denmark. For example, Thomas Gruber from the interest group LEV expressed concern over these new “care factories”.

Jesper Christensen is of the opinion that there is no reason for worry, at least not as far as Copenhagen is concerned. The case there is to abandon really small housing solutions in favour of larger ones in order to be able to maintain better service, competence and staffing. Consequently there is no deviation from the general ambition that everyone who wants to shall be able to live in a home of their own in an integrated area and have access to both community living and to maintain respect for their privacy, according to the social mayor.

– When Denmark received new social legislation in 1998, the institutional concept was abolished. Nowadays concepts such as normalisation and equal treatment are held as guiding lights. This is also the goal that I want to live up to, he says.

NEW CHALLENGES

At the same time Christensen admits that Copenhagen is

facing major challenges in the area. The capital is growing and increasingly more young people with functional disabilities are in the process of moving away from home. What is needed is that the building rate keeps up with demand so that long waiting times are avoided.

– An unanimous social committee has decided that the capacity shall increase over the next four years. We have set aside funds for new housing so that more users can have their own home and feel that they live in an open and accessible city. The municipal council also has ongoing contact with the central disabilities council to determine what is needed to be done, he says.

Does this seem conflict-free?

– No, it's not. Copenhagen has been a poor city and many buildings are inaccessible. We are lagging behind in terms of housing solutions that live up to the accessibility requirements. However, we do have a plan for the future. The goal is for everyone in the groups to feel that they live in an integrated city.

Jesper Christensen hopes that this approach can inspire other municipal councils not just in Denmark but in the entire Nordic region.

As to the matter of what he is inspired by in the other Nordic countries, he replies:

– Sweden and Denmark, for example, are quite similar in the way we approach including people with disabilities. However, as far as educational methods are concerned, we have a lot to learn from both Sweden and Norway.

The right to a good quality home Sweden



Photo: Victoria Henriksson

Phasing-out of institutions for persons with intellectual disabilities in Sweden started in the 1960's. All institutions were to have been closed down before the year 2000. Today we can clearly see the positive effects of this. So says Riitta-Leena Karlsson, disability ombudsman in the City of Stockholm.

– We get a lot of educational visits, especially from Finland, where they want to follow-up on what happened after we had phased-out the institutions. It is really cool to be able to say that everyone concerned had their quality of life improved. This is the best reform we have ever had, she says.

On the other hand there are other problems in this area, but it is more a question of availability of apartments for this particular target group than the actual quality of the housing solutions.

Stockholm is the only municipal authority in Sweden that has a specific functional disability ombudsman. Riitta-Leena Karlsson was appointed in 2002 following a decision in the local council, and her task is to monitor the functional disabili-



lity issues within all of the council's areas of activity. This means, inter alia, to spread the word, collaborate with other actors and to offer advice to persons with functional disabilities. Every year she publishes a report to the city executive board to follow-up on how the city has managed to meet its stated goals.

Riitta-Leena Karlsson thinks that the ombudsman function has led to functional disability issues becoming more visible.

– Great advances have been made in the field of accessibility. Conversely, in regard to support to individuals under LSS (The Act on Support and Service for Persons with certain Functional Impairments) the climate is harsher today than it was ten years ago, she explains.

Concerning housing for persons with intellectual disabilities Riitta-Leena Karlsson gives a two-edged picture of the situation. She states that LSS places tough quality demands on how housing is to be shaped.

– It is incredibly positive to know we have managed to keep to our intentions of not building larger housing solutions than the law allows for. But now we have to be on our guard and not relinquish those requirements. We hear increasingly louder voices for building larger housing solutions. But there are reasons for the law being as it is. My role is to stubbornly state how important it is for persons with intellectual disabilities, just as everyone else, to have the right to a decent standard of living.

– Most of the housing solutions we see are fine in themselves. The problem is that there are far too few of them. We need to build at a faster rate, concludes Riitta-Leena Karlsson.

She's backed-up by Eva Palmér Andersson - the unit manager in the borough of Farsta at the support unit for persons with functional disabilities - who emphasizes how important it is to have support in law for the design of the housing solutions:

– There's a procurement process to be adhered to, and anyone not sticking to the letter of the law won't be awarded any contracts.

KNOWLEDGE OF THE LAW

Eva Palmér Andersson emphasizes the importance that those working on these issues really know the ins and outs of LSS. She thinks that social worker training and education does not focus adequately on the applicable law, and that many who work on support evaluation have too little experience in how it should be applied.

The clearest trend today is that increasing numbers wish to live in ordinary housing with a number of hours of support each week. This applies not least where young people are

concerned. There is also a growing number of persons with primarily neuro-psychiatric disabilities who want to live in a home of their own.

– Our officials talk a lot with parents of children and youngsters with functional disabilities and say that they should place their children in a housing queue, says Eva Palmér Andersson.

Both she and Riitta-Leena Karlsson say that it is a good thing for all parties if persons with intellectual disabilities can get the support needed to be able to live in a place of their own. However, for many this is just not possible. It is important that the city also can supply group housing solutions and service housing.

– There are many people waiting for housing and there is a severe lack of new housing production. This is nothing that a specific borough can be held responsible for. The creation of group housing and service housing is something the state has to take responsibility for, says Eva Palmér Andersson.

WISHING LIST

When the two women are asked the question about what their respective wishing lists look like, it is not surprising that the question of new production of more groups and service housing lands at the top, followed by access to competent personnel. They stress that the city has an important role in solving the supply of personnel and the competence requirements.

If the question is extrapolated from the level of city and borough to a national and even global level, even more points appear on the wishing list. Riitta-Leena Karlsson wants, for example, that the question of responsibility for functional disability issues to be made clearer at both national and municipal council level.

– For the last eight years we have had a “children and elderly minister” responsible for these matters. There’s a world of difference between the needs of a 20 year-old and a 90 year-old. Additionally it’s easy for functional disability issues to disappear if there is a strong focus on issue concerning children and the elderly, she says.

The undisputed quantity of the long queues for own housing in Stockholm do not meet the requirements expressed in the UN Convention for persons with Intellectual Disabilities.

The Convention discusses, inter alia, the right to live independently and with respect for the private life of the individual.

– Not everyone even has a home of their own. How can there then be any private life? That’s where we’re letting people down, says Riitta-Leena Karlsson.

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