

Nordic indicators for cooperation on disability Monitoring the implementation of UNCRPD and Agenda 2030

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Preface

Persons with disabilities have the right to participate in the society on equal grounds with others. Reaching this state of equality, is the aim of modern welfare policy, as well as the intentions of the <u>United Nations Convention on the Rights of Persons with Disabilities</u> (UNCRPD), and it is mentioned explicitly in several of the goals and targets for sustainable development in the <u>UN Agenda 2030 for sustainable development (Agenda 2030)</u>.

The <u>vision of the Nordic cooperation</u> is to become the most sustainable and integrated region in 2030. The vision rests on three equally important strategic priorities:

- A green Nordic Region
 Together, we will promote a green transition of our societies and work towards carbon neutrality and a sustainable circular and biobased economy.
- A competitive Nordic Region
 Together, we will promote green growth in the Nordic Region based on knowledge, innovation, mobility, and digital integration.
- A socially sustainable Nordic Region
 Together, we will promote an inclusive, equal, and interconnected region with shared values and strengthened cultural exchange and welfare.

To reach the ambitious objectives of the vision, a Nordic action plan was adopted by the Council of Ministers of Nordic cooperation in September 2020. Several of the goals and activities in the action plan are relevant for the inclusion of people living with a disability in the Nordic region. There is also a set of indicators to measure the effects of the vision of which several are of importance from a disability inclusive perspective as well as the indicators for monitoring whether we comply with our obligations to follow up both UNCRPD and the Agenda 2030.

In the Nordic countries and our several, but alike, welfare state models, we monitor the developments of living conditions in many areas. Throughout the Nordic region we also face similar challenges concerning inclusion of persons with disabilities. Participation is not equal, not in employment, nor in education, economy, or health.

Through the governmental cooperation and the Nordic Council of Ministers' <u>Action Plan on Cooperation on Disability 2018-22</u>, the

Nordic countries have decided to strengthen and support each other in the political aim of equality and inclusion for all. One of the activities is to follow the implementation of the UNCRPD and define a set of statistical indicators that can measure the following up on the Agenda 2030 targets.

In this report, <u>Nordic Welfare Centre</u> suggests a set of indicators that could be developed further and used to follow the developments towards inclusion. The project builds on knowledge and experience from earlier cooperation and has been conducted in close collaboration with <u>Nordregio</u> and a group of experts.

Even if a set of indicators is not the only way forward, they can help us measure if we are on the right track. Let us join our efforts and take further steps toward a society in which persons with disabilities are included and participate on equal terms with others.

Eva Franzén Director Nordic Welfare Centre

Summary and conclusions

The goal has been to find a common set of indicators that can measure whether the living conditions of people with disabilities are improved. By developing such a set of comparable indicators in the Nordic countries, we can see whether the countries separately and collectively follow up the intentions of the Convention to improve the living conditions of people with disabilities. The indicators are an aid in the work to identify whether we are working correctly to achieve the SDGs.

Suggested indicators

This report describes the statistics behind a recommended set of indicators measuring living conditions in the following areas:

- discrimination
- participation in school and educational background,
- employment,
- standard of living and social protection,
- · and accessibility.

Based on the prioritization of the expert groups at earlier stages in the cooperation on indicators and the availability of data sources, Table 1 includes the suggested indicators for monitoring the implementation of the UNCRPD and Agenda 2030 at the Nordic level and their comparability to the indicators for the Nordic Council of Ministers' Vision 2030 and SDGs.

Table 1.

Indicator	Thematic area	Nordic Vision	CRPD	SDG
Experienced discrimination	Discrimination		Article 5	SDG 10
Number of children	Participation		Article 7	SDG 4
receiving special assistance	in school		and 24	
in mainstream schools	and education			
Number of children	Participation		Article 7	SDG 4
participating in special	in school		and 24	
education school forms	and education			
Activity limitations by	Participation	2.1.1 Level	Article 7	SDG 4
educational attainment	in school and	of education	and 24	
level	education			
Activity limitations by	Employment	2.2.1 Level of	Article 27	SDG 8
labour status		employment		
Activity limitations by	Standard of	3.3.2 Poverty	Article 28	SDG 10
income quintile	living and social	and social		
	protection	exclusion		
Recipients of disability	Standard of		Article 28	SDG 10
pensions	living and social			
	protection			
Access to public transport	Accessibility	2.4.1 Personal	Article 9	SDG 11
		transports		

The suggested set of indicators are what we find most relevant for monitoring our compliance to the UNCRPD and to determine whether we are on the right track towards the Agenda 2030 goals at the Nordic level. Our ambition has been to find available and comparable statistics between the countries.

The results of this project show that there are some challenges. First, there are only very few available indicators describing living conditions of persons with disabilities based on harmonised data sources such as Eurostat, <a href="Nordic Statistics database, and the Nordic Welfare dataBASE, the Nowbase. Second, the available indicators based on national data sources differ in a considerable manner between the Nordic countries and the autonomous regions. There are different factors that make it difficult to compare the indicators between the countries. Third, apart from having indicators that are incomparable, the definition of disability applied for the data collection vary as well.

Instead, these suggested indicators could mainly be used to follow the development within each country and autonomous region, which further would help to understand the current situation in the Nordic Region. Moreover, the fulfilment of this project has led to various recommendations regarding how the work with indicators used to

monitor the implementation of the UNCRPD and Agenda 2030 could be developed further.

Recommendations

During 2021, the entire Nordic cooperation on disability will be evaluated, leading to a proposal for content in the coming action plan. The suggested indicators based on the outcome of this project could be included as input in that evaluation process.

Since most of the suggested indicators are based on national statistical sources, the commitment of these data providers is crucial for developing comparable indicators that can be used to monitor the implementation of the UNCRPD and Agenda 2030 in the Nordic Region.

To further improve the availability of comparable indicators on the living conditions of persons with disability in the Nordic Region, the project group suggests the following:

- When possible, it would be most suitable to use comparable indicators based on Eurostat data. For instance, the European Union Statistics on Income and Living Conditions (EU-SILC) health module that will be collected every third year starting from 2022 could provide new possibilities. It is worth noting, however, that EU-SILC data is based on rather small sample sizes. When necessary, these indicators could be completed with data from national data sources, even if these statistics may not be fully comparable.
- Any Nordic cooperation should be conducted in collaboration with <u>The Academic Network of European Disability Experts</u> (ANED), or at least take into regard what has come out of their work.
- At a Nordic level, it would be recommendable to agree on a set of suitable indicators that would allow for systematic monitoring. If there is an agreement of such indicators, it would be easier to ensure their inclusion in repeated data collections in each Nordic country and autonomous region. In addition, it would be important to agree on what kind of definition of disability is most suitable to use in such data collection. This could be an activity within the official Nordic cooperation.
- While there are nationally relevant data sources, such statistics may not be routinely available and reported for persons with disabilities due to lacking economic resources. To guarantee continuity of updated data material for Nordic comparison, it would be important to allocate funding for such work.

- The Nordic Council of Ministers is currently working to develop its own indicators to measure effects of the goals in the Action Plan 2021 – 2024 for the implementation of the vision to become the most integrated and sustainable region in the world. The work and suggested indicators presented in this report should be taken into consideration when developing common Nordic indicators for sustainability.
- The Nordic countries, the Faroe Islands, Greenland and Åland have different policies concerning segregated, integrated, and inclusive education for pupils and students with disabilities.
 A comparative study on advantages and disadvantages of these approaches could be useful for the Nordic countries.

UNCRPD, Agenda 2030 and Washington Group's questions on disability statistics

This project on common Nordic indicators in the field of disability aims to strengthen the exchange of knowledge and experiences and to suggest indicators for monitoring the compliance with the UNCRPD and our efforts reaching the Agenda 2030 goals at the Nordic level.

In this report, preliminary indicators are suggested for monitoring living conditions, which presents a possible way forward with regards to strengthening the cooperation.

The suggestions are based on discussions with national experts, including organisations representing persons with disabilities, who contributed by participating in project meetings, responding to a survey, and providing comments. The report describes the current situation on what kind of indicators are available in the Nordic region, and it gives an overview of how the Nordic countries aim to measure living conditions of persons with disabilities.

During 2020, Nordic Council of Ministers has compiled 45 indicators that can be connected to the region's Vision 2030 of a green, competitive, and socially sustainable Nordic Region. These proposed indicators, however, do not describe our joint obligations to follow up the human rights for people with disability.

The current Action plan for Nordic cooperation on disability for the period 2018-22 was adopted by the Nordic Council of Ministers for Health and Social Affairs in April 2018, and it is quite in line with the Action Plan to reach Vision 2030 mentioned above. The Action plan on disability is cross-sectoral and aims to contribute to efficient inclusion of people living with disability by strengthening the experience and knowledge exchange in several areas. The plan has three focus areas: Human rights, Sustainable development, and Freedom of movement. Under each area, a variety of activities and projects are carried out. This project is part of the first activity of the plan, aiming to support the Nordic countries' ability to implement the UNCRPD and strengthen the cooperation on statistics and indicators.

Since all Nordic countries monitor the developments regarding UNCRPD and Agenda 2030 with statistics and indicators, it is interesting to study national implementation reports from a Nordic regional perspective. Nordic Welfare Centre keeps on its webpage an up-dated list with all documentation of the implementation reports and the dialogue with the UN that can be found at the web page of the Office of the High Commissioner of Human Rights.

The countries that have ratified a UN convention become parties to the convention and are called State Parties. The States Parties report on the implementation of the Convention to a special CRPD committee (hereinafter the UN Committee). Civil society organizations also report in parallel to the UN Committee. The dialogue between the State Parties and the UN Committee begins with the State Party's initial report, continues with a list of questions from the UN Committee, the State Party's answers to the questions, an interrogation and then the UN Committee's final comments to the State Party. After that, the State Party is followed up continuously and the dialogue continues.

In all Nordic countries, existing statistical sources are used for reporting and to assess compliance with the UNCRPD. However, there are exceptions showing that some new indicators are being created in a more systematic way in addition to the use of existing data sources, to be able to report on the implementation of the UNCRPD and Agenda 2030 regarding living conditions for people with disabilities.

Denmark

In Denmark, for instance, Statistics Denmark has started to select a set of indicators that will be used to monitor how the SDGs are met in the country. The Danish Institute of Human Rights has also tried to include disability variables in these indicators.

Finland

Finland uses existing indicators based on population surveys. It is problematic, however, that these indicators are not automatically reported according to the information on disability but require their own analysis and reporting.

Faroe Islands

In the Faroe Islands, data is collected through the central IT system of the Social Authority. Due to the size of the administration, the Faroe Islands have limited resources to produce statistics in comparison to larger countries. Ad hoc statistics are produced according to need. A more systematic survey of statistical data, e.g.,

on the number of people receiving social security benefits and social services due to disability, is underway.

Greenland

In Greenland, the National Institute of Public Health conducts ongoing population surveys in Greenland. It is expected that funds will be set aside in the Finance Act for future surveys. The ambition is to include disability issues in the future. To develop official and ongoing statistics regarding disability, the Government is currently investigating the quality of the data received from the municipalities. If data quality is considered adequate, statistics on participation in, e.g., education and the labour market will be presented.

Iceland

In Iceland, statistics and other reliable information and data concerning people with disabilities is still lacking. The same goes for the dissemination of available data and information. Statistics Iceland seeks ways to incorporate the Washington Questions into its sample surveys to a higher degree.

Norway

In Norway, <u>NTNU Samfunnsforskning's report from 2016</u>, in which a critical analysis was made on the statistics used for Norway's first report to the UN on the implementation of the UNCRPD, will be followed up in the next round of reporting to the UN.

Sweden

In Sweden, existing indicators for following living conditions have been used to monitoring the implementation of UNCRPD and Agenda 2030, but there is also some ongoing development of suitable indicators.

Åland

In Åland, new indicators regarding living conditions for people with disabilities and Agenda 2030 have not been developed yet even if there are specific <u>indicators on sustainable development developed by Statistics and Research Åland</u> (ÅSUB).

During the last decades, <u>The Academic Network of European</u>

<u>Disability Experts</u> (ANED) has worked under the European

Commission to identify indicators and collect data in connection to

UNCRPD, and later the SDGs. There are extensive <u>reports from each</u>

<u>EU country</u>, including Iceland and Norway. Any Nordic cooperation
should be conducted in collaboration with ANED, or at least take
into regard what has come out of their work.

UN Convention of the Rights of Persons with Disabilities

All Nordic countries have ratified the UNCRPD, which includes 34 articles on rights and implementation (United Nations, 2020). In the country reports on the implementation of the UNCRPD, various data sources are used to measure the implementation of the articles.

For this project on indicators, Article 5 on Equality and non-discrimination, Article 9 on Accessibility, Article 24 on Education, Article 27 on Employment and Article 28 on Adequate standard of living and social protection, are the most relevant. Article 31 in UNCRPD specifically treats statistics.

Article 31 UNCRPD

- 1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
- (a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
- (b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.
- 2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
- 3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Denmark, the Faroe Islands and Greenland

Denmark ratified the Convention on the Rights of Persons with Disabilities on 13 December 2006. <u>Denmark submitted its initial report in 2011</u> including chapters on the developments in the Faroe Islands and Greenland. <u>Denmark received the list of issues</u> from the committee in 2014. Later on in the same year, <u>Denmark responded to the list of issues</u>. After the examination in Geneva, the committee

sent its <u>concluding observations</u>. About Article 31 on statistics, the committee expressed the following:

"The Committee recommends that the State party systematize the collection, analysis and dissemination of data, disaggregated by gender, age, disability and region; enhance capacity-building in this regard; and develop gender- and age-sensitive indicators, paying due regard to the need to move from a medical-based to a human rights-based approach to disability."

In 2015, the committee followed up on the situation in Denmark. Denmark submitted a combined second and third report in 2020, also including such for the Faroe Islands and Greenland. In this report, Denmark reports that the Ministry of Social Affairs and the Interior has since 2013 collected statistical data on adults who due to a disability or a particular social problem receive help and support under the Consolidation Act on Social Services. This data contains persons from 18 years and beyond, including older persons over the age of 64.

All national statistical data in Denmark that is collected by using the unique social security number system, allows disaggregation of data by, e.g., sex, age, disability, region, and year. In the latest national statistics collected in this manner, 75 of the 98 local municipalities participated.

The ministry is currently examining different possibilities for collecting national statistical data on children under the age of 18 who due to a disability receive help and support under the Consolidation Act on Social Services. The immediate assessment shows that it should be possible to collect the desired data within a few years and to disaggregate data by, e.g., gender, age, year, and region.

The Ministry of Social Affairs and the Interior has since 2016 published several analyses on recipients of social services due to disability using individual-level data combined with a range of registry data, e.g., demographic, employment, education and health data.

The ministry publishes a yearly <u>Social Policy Report (Socialpolitisk Redegørelse)</u> which gives an overview of the number of persons receiving social services due to a disability, as well as in-depth analyses, e.g., of support for adults with psychosocial disabilities. The 2019 issue was published on 8 January 2020 and includes a separate chapter on children and youth with disabilities.

Finland and Åland

In Finland, the Convention and its Optional Protocol (Treaty Series 26 and 27/2016) entered into force on 10 June 2016. The government of Åland reports on the implementation of the convention in a separate report. Finland submitted its initial report, including the developments in Åland, to the committee in 2019.

Iceland

<u>Iceland ratified the UNCRPD in 2017 and submitted the initial report</u> in February 2021.

Norway

Norway ratified the UNCRPD in 2014 and submitted its initial report in 2015. Norway received the list of issues in 2017. Norway responded to the list of issues in 2019, the same year as the examination in Geneva. The committee had the following concluding observation concerning article 31:

"In view of target 17.18 of the Sustainable Development Goals, the Committee recommends that the State party:

- (a) Rely on the methodology of the Washington Group on Disability Statistics to collect, analyse and disseminate data on its population disaggregated by sex, age, ethnic origin, type of impairment, socioeconomic status, employment, barriers encountered and place of residence, and data on cases of discrimination or violence against persons with disabilities;
- (b) Develop evidence-based policies to respond to the situation of persons with disabilities, in consultation with their representative organizations."

Sweden

Sweden ratified the UNCRPD in 2006 and submitted the initial report in 2011. Sweden received and answered to the list of issues by the committee in 2013. Sweden's response was examined in Geneva during the same year. The committee sent its concluding observations in 2014. Sweden submitted its combined second and third report in 2019.

Denmark, Finland, and Sweden are members of the EU which is the only regional party of the UNCRPD. As the EU has ratified the convention, the union is obliged to report statistical data on the implementation. Norway and Iceland participate in several EU measures and projects to collect data for this aim.

UN Agenda 2030 for sustainable development

All UN member states, including the Nordic countries, have adopted the 2030 Agenda for Sustainable Development (Agenda 2030). The Agenda includes 17 Sustainable Development Goals (SDGs), and the 169 specifying targets are designed to create ideal conditions for a socially, economically, and ecologically sustainable world. People with disabilities are mentioned in 11 targets of the Agenda 2030 (UN Human Rights, 2020). All SDGs, targets and the indicators used to measure the developments are available on the webpage of the UN statistics department.

For this project on indicators SDG 4 on Education, SDG 8 on Decent work, SDG 10 Reduced inequality, and SDG 11 Sustainable cities are the most relevant.

The UN member states report on the developments of the implementation on the SDGs on a voluntary basis through Voluntary National Reviews (VNR). The reviews are presented at the High Level Political Forum (HLPF) which is held each year. At the HLPF focus lies on different SDGs or thematic areas of the Agenda.

All Nordic countries have reported at least once since 2016. The reports are published on the UNs knowledge platform.

- Denmark reported a VNR to the HLPF in 2017. Persons with disabilities are not mentioned explicitly in the report.
- Finland presented a report in 2020 on the progress since 2016. It is stated in several parts of the report that challenges remain in relation to inclusion and equality for persons with disabilities.
- Iceland reported in 2019. In the report it is stated that challenges remain regarding welfare and inclusion of persons with disabilities.
- Norway reported in 2016 and will present a VNR in 2021.
- Sweden contributed with a VNR at the HLPF 2017 and reported on the principle of Leaving no one behind in 2020. Persons with disabilities are mentioned in both reports.

Washington Group's questions on Disability Statistics

The Washington Group on Disability Statistics (WG) is a UN city group established under the United Nations Statistical Commission. The WG was constituted to address the urgent need for comparable cross-national population-based measures of disability. Its mandate is the promotion and coordination of international cooperation in health statistics focusing on disability data collection tools suitable for censuses and national surveys. The WG has produced a short list of questions regarding disability and health, a longer list of questions on the same theme and a list of questions aimed towards children of the ages 2-17 years.

The survey conducted within this project shows that the WG questions on disability statistics have not been integrated into national data collection in most cases in the Nordic region. Yet, there are a few exceptions.

Denmark

In Denmark, the WG Short Set on Functioning (WG-SS) of six questions is largely integrated into the Survey of Health, Impairment and Living conditions in Denmark (SHILD) waves collected in 2016 and 2020, but not in the first wave, whereas Statistics Denmark has not integrated WG into national statistics.

Finland

In Finland, the WG questions are included in some data collection but not in an identical form. However, the survey questions otherwise used are very comparable to the WG-SS, i.e. the answer scale is grade 4 or 5 and the same dimensions are used. At least sight, hearing, movement, and cognitive functions are asked about, and the older adults are also asked about their Activities of Daily Living (ADL).

Iceland

In Iceland, Statistics Iceland will seek ways to incorporate the WG questions into its sample surveys into a higher degree. In 2021, this incorporation will be done for a survey of the use of information technology by individuals and homes and a survey of cultural consumption.

Norway

In Norway, most statistics on the living conditions for people with disabilities are taken from surveys conducted by Statistics Norway, such as EU-SILC, the European Union Labour Force Survey (EU LFS),

and the European Health Interview Survey (EHIS). These surveys are largely harmonised with the EU survey standards. Some of the surveys use a more subjective approach than the more functional standard questions in the WG and therefore, they are not fully harmonized with the WG's operationalisation. In addition, the new register-based statistics prepared by the Statistics Norway are based on other definitions and operationalisations.

Sweden

In Sweden, the starting point is largely the same as for Norway since data concerning living conditions for people with disabilities are taken from surveys on living conditions carried out by Statistics Sweden and harmonized with, e.g., the EU-SILC and other EU standards. Harmonisation with the WG has not been carried out so far.

Nordic cooperation on disability and indicators for inclusion

Since 2015, Nordic Welfare Centre has been working on projects about statistics and common Nordic indicators on disability. The Nordic Welfare Centre is an institution under the Nordic Council of Ministers and works within welfare policy. The work on disability indicators started as a project within the Nordic Council of Ministers' Action Plan for Nordic Co-operation on Disability 2015–17. The aim was to strengthen the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) across the Nordic Region, by presenting comparable statistics in the field of disability. The experts participating in the project considered it beneficial to be able to follow and compare statistics on the implementation of the UNCRPD and Agenda 2030, at a Nordic level, related to living conditions and rights for people with disabilities.

The national statistical sources in the Nordic Region provide several different sets of indicators that monitor living conditions for people with disabilities at national level, but they differ substantially. They vary regarding what they measure, and which data collection methods are used. In addition, they differ significantly in how disability is defined. These differences have made the task of identifying suitable comparative indicators challenging. Therefore, the idea has been, that European statistical sources could provide some already harmonised data that is suitable for comparison across the Nordic Region. Relevant sources of date could be, e.g., the European Union Labour Force Survey (EU LFS) and European Union Statistics on Income and Living Conditions (EU-SILC) that collect microdata for all EU member states and Iceland, Norway, Switzerland, and the United Kingdom (Eurostat, 2019). These statistics could also be complemented by other data sources, such as national register data and in-depth studies. Yet, it may be challenging to break out comparable data for the Faroe Islands, Greenland, and Åland.

Statistical material and data sources that could enable selection of common indicators were discussed by the experts participating in the project. The following thematic areas were identified and chosen as prioritized to enable such monitoring across the Nordic Region: 1) discrimination, 2) participation in school and educational background, 3) employment, 4) standard of living and social protection, and 5) accessibility.

Nordic Welfare Centre also organised a side event on the theme of disability statistics together with the Norwegian presidency for the Nordic Council of Ministers 2017. The meeting took place during the annual conference of State Parties to the UNCRPD in 2017. Experts representing disability organisations and national authorities responsible for monitoring of disability policies participated in the event. In the concluding comments of the event, several of the participants underlined the importance of using statistics in a meaningful way from the perspective of people living with disabilities. We should find and use the knowledge we have in ways that support the development toward inclusion and that promote human rights.

For various reasons, e.g., changes of experts in charge of the project, the cooperation in the project that started in 2017, did not proceed as expected. The work continued, however, within the framework of the Council of Ministers' <u>Action plan on Nordic cooperation on disability 2018-22</u>.

Nordic Welfare Centre initiated a collaboration with Nordregio, also an institution under the Nordic Council of Ministers and working with regional development and planning research, to continue finding useful indicators, and the current project started at the end of 2019. The focus of the collaboration has been to find if there are suitable indicators within the prioritized thematic areas mentioned above, which could be used to monitor the compliance of the UNCRPD and our joint efforts fulfilling the Agenda 2030. This report, hence, proposes several indicators and a working model to enable such monitoring. It also describes the identified challenges when it comes to comparison and selection of data that measure living conditions for people with disabilities in the Nordic Region.

The added value of Nordic cooperation

The Nordic countries and the Faroe Islands, Greenland and Åland, have high ambitions for better living conditions for people with disabilities and equal welfare for all. At the national level, different kinds of data are collected, and statistical sources also often exist at local and regional levels. The countries have in several cases established indicators for the living conditions to measure the developments and reporting on the implementation of the UNCRPD and Agenda 2030. At the same time, the data collection methods differ between the Nordic countries. These differences exist despite the many similarities in the welfare systems and ability to measure social impacts across the Nordic region.

The Nordic countries share similar challenges when it comes to measuring inclusion. The added value of cooperation lies in the possibilities of exchanging knowledge and experience around similarities, differences as well as the common challenges within the area of statistics and indicators for measuring progress in inclusion of persons with disabilities.

There are also other ongoing international projects and processes in which Nordic cooperation could be beneficial, like those within the European Union and the Council of Europe.

Project organisation

This project, initiated at the end of 2019, is mainly financed by Nordic Welfare Centre. The participating project members have been Kai Koivumäki and Maria Montefusco from Nordic Welfare Centre, and Johanna Jokinen, Gustaf Norlén and Oskar Penje from Nordregio. Also, the <u>Council of Nordic cooperation on Disability</u> has been included in the work and will follow up the project.

In addition to the project group, a reference group with the following experts was established:

- Katrine Wamsler from the Danish Institute for Human Rights in Denmark
- Anna Amilon from VIVE The Danish Center for Social Science Research in Denmark
- Päivi Nurmi-Koikkalainen and Päivi Sainio from the Finnish Institute for Health and Welfare (THL) in Finland
- Þóra Kristín Þórsdóttir from Statistics Iceland in Iceland
- Þuríður Harpa Sigurðardóttir from ÖBÍ The Icelandic Disability Alliance in Iceland
- Kjersti Høimyr Almenningen and Sverre Helseth from Bufdir The Norwegian Directorate for Children, Youth and Family Affairs in Norway
- Karin Flyckt from the National Board of Health and Welfare in Sweden
- Regin Hammer from the Ministry of Social Affaris in the Faroe Islands
- Lone Sørensen from the Ministry of Social Affairs and Justice in Greenland
- Elin Sagulin from Statistics and Research Åland in Åland
- Gunilla Lindqvist from the Department of social affairs, health and environment in Åland

Method

In order to monitor the follow up on the UNCRPD and Agenda 2030 in Nordic Region, Nordregio has investigated which indicators are the most suitable ones for following the development at the Nordic level until 2030, and to compare between the countries and the autonomous regions within the above-mentioned prioritised thematic areas: 1) discrimination, 2) participation in school and educational background, 3) employment, 4) standard of living and social protection, and 5) accessibility. To be able to compile such a list of suggested indicators, the following data sources have been considered: Eurostat, Nordic Statistics database, the Nordic Welfare dataBASE (Nowbase), and national statistical sources in the Nordic countries, the Faroe Islands, Greenland, and Åland.

After compiling the initial list of suggested indicators, detailed information on the indicators and a set of survey questions were sent to disability statistics experts in all Nordic countries and autonomous regions. These national experts were asked to supplement, correct, and comment on the compiled material, regarding lacking content of some thematic areas, possible errors, and ambiguities. They were also invited to evaluate which of the presented indicators would be the most relevant ones, whether the indicators are comparable between different Nordic countries and autonomous regions, and if those indicators could be used to follow the development of the living situation for people with disabilities.

Once the national experts had given possibility to complete the survey, two separate meetings were performed when national experts on disability statistics from Denmark, Finland, Iceland, Norway, and Åland were present. During these digital meetings, a short presentation on the survey results were given and the experts were asked to provide their comments, suggestions, and recommendations verbally. Together with Nordic Welfare Centre, it was eventually decided in which way the indicators were included and presented in the report. All the national experts were also given the possibility to comment a draft version of this report.

To the report, Nordic Welfare Centre has added information from the Nordic countries' dialogues with the UN on the implementation of UNCRPD and the voluntary reports on Agenda 2030.

Defining disability

The criteria for defining who can be said to have or do not have a disability vary between the Nordic countries. Who those definitions include is based to some extent on self-reporting, and it varies

between the countries how such reporting is done. The sample can also be limited to people who receive different forms of help or support from the public sector, such as support for aids. Other committees set criteria for whether the disability is permanent or limited in time.

In the preamble of the UNCRPD, it is stated that the term disability should be recognised as "an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (UN, 2006).

In Article 1 of the UNCRPD, the purpose of the convention is stated with a definition of the group affected: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

The understanding of disability as an evolving concept that appears in interaction between the individual and environment, makes it sometimes difficult to define such a situation within statistical measures. Still, the State Parties are obliged to do so to report on the developments. The modern Nordic welfare states use statistics to make sure that policies and actions taken are efficient. However, this is done differently in different thematic areas and on different levels of data collection. One challenging aspect is that information on a person's health, functional abilities and impairments can be seen as sensitive information.

For example, here below is presented how Norway answered the UNCRPD committee on the implementation of Article 31 in the convention in its <u>initial report 2015</u>:

"Statistics Norway estimates that 12-15 per cent of the Norwegian population has disabilities, depending on how the group is defined. At present, persons with disabilities are not a statistical category, and no official statistics are prepared on this group in particular. A number of surveys have been conducted and several registers are maintained to provide information on persons with disabilities in Norway, both on Norwegian authorities' and organisations' own initiatives and as a result of international cooperation on statistics, for example through Eurostat. The registration of persons with disabilities in statistics and public registers is mainly based on self-reporting and also on peoples' own assessment of their functional

ability. This is due to the <u>The UN Statistics Act</u> sets strict limits for the distribution of personal data, more strict than the Public Administration Act or the Personal Data Act, and it does not distinguish between sensitive and non-sensitive information."

The other Nordic countries that are in the reporting cycle of the UNCRPD have answered similarly to the committee's questions.

Even at national level across Nordic Region, it is a common challenge that disability is defined in distinct ways in different data sources. The following examples were shared by the experts connected to the project, regarding how disability is defined on a general level in some of the Nordic countries.

Denmark

Regarding national statistical sources in Denmark, there are three different ways to define disability. Statistics Denmark, the central authority on Danish statistics, defines people with disabilities in accordance with those receiving benefits related to a disability (based on register data). More specifically, this definition is based on administrative data from Danish municipalities. According to this definition, people who receive disability services under the Danish Social Service Law (*Serviceloven*) are defined as having a disability. This definition is also used by, e.g., Danish Ministry for Social Affairs and the Interior. Yet only a subset of municipalities (75 out of 98) is currently included in the indicator, although the goal is eventually to include data from all the municipalities.

The panel <u>Survey of Health, Impairment and Living conditions in Denmark (SHILD)</u>, which is conducted every four years, applies a definition based on experienced disability. Respondents are asked if they have a long-term physical disability or health problem, or if they have a mental illness. Moreover, the respondent is asked to rate the severity of the physical disability/health problem or mental illness (more or less severe). The last two waves of SHILD, collected in 2016 and 2020, also include two international disability definitions/indicators: the WG-SS and the Global Activity Limitation Indicator (GALI). The SHILD data is therefore comparable with data collected by the UN and the EU, which, in general, use the WG-SS and the GALI to define disability.

Several waves of the Danish version of EU LFS collected in 2008, 2010, 2012, 2014, 2016, and 2019 include a question on disability. The question is based on experienced disability or long-term health problems. Like SHILD, the LFS disability indicator includes a question on severity.

Finland

In Finland, in the present Disability Services Act, the long-term nature of a disability or illness would be assessed individually. According to the established application practice, a disability or illness is considered long-term if it causes a functional limitation for at least one year. Rapidly progressing illnesses, however, meet the requirement for being long-term when, according to the available information, the disabilities resulting from the illness cause needs for essential help and support in normal life. In such situations, the oneyear deadline is not required even under the present Act. Similarly, if a functional limitation caused by a disability or illness can be considered permanent, services must be organised immediately according to need. In the envisaged reform of the legislation on disability services, the person's relationship to and possibilities of being included in the surrounding society are taken as starting points to describe the disability, not the medical, diagnosis-based definition (Storgaard Bonfils, Olsen et al 2013). The reform aims at taking better into account the individual needs of persons with disabilities.

Iceland

In Iceland, the Social Insurance Administration defines people with disabilities in accordance with who receives disability pension. The municipalities define people with disabilities as a person who receive the kinds of support that is only provided due to a disability.

Norway

In Norway, there are also different ways to define disability. The used definitions, for instance, are somewhat different between the EU LFS and EU-SILC. In addition, there are some indicators that are based on register-based statistics. These are new indicators that provide information on people who, for instance, have technical aids and/or receive various public benefits.

Sweden

In Sweden, the existing statistical sources use either diagnoses in combination with activity restrictions, self-assessment, or administrative definitions, including people who receive certain support that is only given to people with disabilities.

Results

Evaluation of the available data sources

Eurostat

Whereas Eurostat provides harmonised data on living conditions in the Nordic countries, only very few of those indicators can be disaggregated by disability. Moreover, Eurostat does not provide statistics for the Faroe Islands, Greenland and Åland. It may also be problematic that EU-SILC, which is Eurostat's database on income and living conditions, only includes data based on relatively small selections when it comes to people with disabilities.

In EU-SILC, the definition of disability is based on the Global Activity Limitation Indicator (GALI) and therefore, no information is provided by type of disability. The GALI concept is operationalised by a question on to what extent, for at least the past six months, a person has been limited because of a health problem in activities people usually do using one of the following answer categories: 1) severely limited, 2) limited but not severely, 3) not limited at all (Eurostat, 2020a). Eurostat has modified the GALI to be a routed question consisting of two questions to reduce its complexity, but it is not in use in EU-SILC yet. Eurostat is also in the process of modernising its social surveys, and its long-term aim is to provide data on additional topics according to the GALI. Every third year from 2022 onwards, data according to a health module will be collected by Eurostat. Since this data collection is expected to include six guestions from the WG-SS, it would allow access to relevant data by type of disability. It is worth noting, however, that the WG-SS does not include information on mental illness.

Regarding the use of EU-SILC data, another limiting factor is that the GALI seems to show suspiciously high occurrences of persons reported to have limitations in some Nordic countries compared to others (Okkonen, 2019; Helsingin Sanomat, 2019; Sihvonen *et al.*, 2017). Some countries do not use the original model question of the GALI but have split it in two or more questions, which have led in lower prevalence of people who have been severely limited because of a health problem. Differences between the Nordic countries in the amount of people who have been limited, but not severely, may be also related to cultural differences (Okkonen, 2019). Although crosscountry comparability is poor with the EU-SILC data, it could be used

to monitor developments in each Nordic country regarding if there have been changes in the amount of people with disabilities.

Nordic databases

The Nordic Statistics database and Nowbase include only very few – if any – indicators on the living conditions of people with disabilities per November 2020. For the available indicators, these databases provide already harmonised statistics, and differing from Eurostat, they often also include data for the Faroe Islands, Greenland and Åland.

National data sources

Whereas EU-SILC can be used as the primary data source when possible, it is necessary to complement those indicators with indicators from national data sources regarding the thematic areas and autonomous regions that are not covered by Eurostat. It is challenging, however, to find suitable indicators on the living conditions of persons with disabilities based on national data sources, which would be fully comparable between the Nordic countries and autonomous regions. Within this field, in general, it is difficult to obtain good and reliable data, for instance due to the existing heterogeneity in the group of people with disabilities. Another limiting factor is that even if most national population survey data include information on disability, the existing statistical portals may not disaggregate the publicly available data accordingly in some countries, for instance in Finland.

Suggested indicators

Based on the prioritization of the expert groups at earlier stages in the cooperation on indicators and the availability of data sources, Table 2 includes the suggested indicators for monitoring the implementation of the UNCRPD and Agenda 2030 at the Nordic level. The indicators in bold are the ones suggested to be prioritized for future cooperation, while the other indicators still need to be developed further in several Nordic countries before they can be included in such cooperation. The table also provides information on which data sources these indicators are based on and the identified gaps. We do not suggest any specific indicators for the additional thematic areas (political participation, freedom and personal integrity, and health), but we provide some examples for them in the report.

Table 2.

Indicator	Thematic area	Data source	Gaps	Nordic Vision	CRPD	SDG
Experienced discrimination	Discrimination	National sources	FO, GL, SE		Article 5	SDG 10
Number of children receiving special assistance in mainstream schools	Participation in school and education	National sources	FO, GL		Article 7 and 24	SDG 4
Number of children participating in special education school forms	Participation in school and education	National sources	FO, GL		Article 7 and 24	SDG 4
Activity limitations by educational attainment level	Participation in school and education	Eurostat	FO, GL, AX	2.1.1 Level of education	Article 7 and 24	SDG 4
Educational back- ground of persons with a disability	Participation in school and education	National sources	FO, GL, IS, AX	employment	Article 7 and 24	SDG 4
Activity limitations by labour status	Employment	Eurostat	FO, GL, AX	2.2.1 Level of employment	Article 27	SDG 8
Labour force status of people with disabilities	Employment	National sources	FO, GL, AX	2.2.1 Level of employment	Article 27	SDG 8
Activity limitations by income quintile	Standard of living and social protection	Eurostat	FO, GL, AX	3.3.2 Poverty and social exclusion	Article 28	SDG 10
Economic situation of people with disabilities	Standard of living	National sources	FI, FO, GL, IS, NO, AX	3.3.2 Poverty and social exclusion	Article 28	SDG 10
Recipients of disability Pensions	and social protection	Nowbase	,	3.3.2 Poverty and social exclusion	Article 28	SDG 10
Economic vulnerability of people with disabilities	Standard of living and social protection	National sources	FO, GL, IS, NO	3.3.2 Poverty and social exclusion	Article 28	SDG 10
Access to public transport	Accessibility	National sources	FO, GL, IS	2.4.1 Personal transports	Article 9	SDG 11
	Political participation	National sources			Article 29	SDG 16
	Freedom and personal integrity	National sources			Article 17 a	SDG 10
	Health	National sources			Article 25	SDG 3

Presentation and reflection of the selected indicators

Even within each Nordic country, there have been difficulties to find indicators that are most suited for measuring efforts towards better living conditions and inclusion in a specific country context. Therefore, it is even more demanding to compare between the countries since they have quite different approaches and systems when it comes to the chosen thematic areas. It may therefore be appropriate to use the most suitable indicators and data sources from each country and autonomous region, and rather make country-level assessments and analyses based on those statistics and figures. Such assessments could be used to evaluate if the situation in the countries and autonomous regions is developing into same direction, instead of comparing the proportions of people between the countries and autonomous regions. A better understanding of the developments at the national level would thus allow more general comparisons across the Nordic Region. Another solution would be trying to identify comparable indicators based on national data sources, which are good enough to allow some comparison between the countries and autonomous regions.

In the following presentation of the selected indicators, we have referred to the relevant articles of the UNCRPD and Agenda 2030. Thereafter, several indicators related to these articles are presented based on EU-SILC, when available, and national data sources. We have only reported for the indicators that the countries have been able to deliver during the project. Thus, the descriptions vary and are incomplete in some cases.

Discrimination

"States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds."

Measuring experienced discrimination versus legal definitions

Based on the UNCRPD Article 5 on Equality and non-discrimination, the proportion of people with disabilities who have experienced discrimination is suggested as a suitable indicator. It is noteworthy that there is no data available on experienced discrimination in the Faroe Islands, Greenland, Iceland, and Sweden. For Sweden, however, data on reported discrimination could be used instead of experienced discrimination. While there are statistics available on different contexts of discrimination for some of the Nordic countries, it is recommended to use the existing data on experienced

discrimination regardless of context to start with the Nordic comparison. Due to quite recent laws on discrimination, several Nordic countries and autonomous regions still lack data on reported discrimination. Therefore, it is not recommended to use data on discrimination in the legal sense as an indicator for Nordic comparison.

Available data on experienced discrimination Denmark

The Danish data on experienced discrimination is based on Survey of Health, Impairment and Living conditions in Denmark (SHILD) which is a panel survey conducted with a representative sample of around 20,000 people in age group of 16- to 64-year-olds in 2012, 2016 and 2020. The survey presents data on the proportion of people who have experienced discrimination because of 1) age, 2) gender, 3) ethnicity, 4) disability, health problems or mental illness, 5) religion, 6) sexual orientation, 7) appearance, height, or weight, and 8) disability of partner, children or parents. The data is shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical disability, and minor physical disability. It is also possible to show the shares who experience discrimination for people with and without a disability according to the WG-SS and the GALI in 2016 and 2020. The survey even includes information on context of the experienced discrimination, such as working life. Moreover, the survey includes a set of questions on experienced violence (Bengtsson, 2017).

Finland

The Finnish data on experienced discrimination was collected through an online survey that was responded by 445 adults with a disability in 2016. The respondents needed to indicate if they have experienced discrimination during the last twelve months due to one of the following reasons: ethnic origin, sexual orientation, gender identity, religion or conviction, disability, age of over 55 years, sex, or age of under 30 years. In addition, the survey includes a separate set of questions on discrimination in working life and access to electronic services. There is also information on the Non-Discrimination Ombudsman's customer statistics, reported discrimination, and court statistics according to the following grounds of discrimination: origin, disability, language, age, nationality, health condition, religion, sexual orientation, family relationships, opinion, conviction, trade union activity, and political activity (Ministry of Justice and the monitoring group for discrimination, 2016). The FinSote survey conducted in 2018 and

2020 includes data on experienced violence during the last twelve months (Finnish Institute for health and welfare, 2020a).

Iceland

Since Iceland has participated in the European Social Survey, there are statistics available for every second year from 2002 to 2018, for the general population (European Social Survey, 2020). Otherwise, there is only data available based on special research projects done by the government, for instance. Usually, such research is only published in Icelandic.

Norway

The Norwegian data on discrimination is based on the survey on living conditions, which is conducted by Statistics Norway every third year. This data has been collected in 2015 and 2020, and the survey corresponds to the EU definitions used in the EHIS. The survey was responded by people aged 20 to 66 years old who have hearing, vision, movement, cognitive, or mental difficulties. In addition to these difficulties, they also state having health problems that affect their everyday life to some or a large extent over a period of six months or longer. The survey includes data on the proportion of people who have experienced discrimination and the proportion of people who have experienced discrimination because of their health or disability. The survey also includes data on experienced theft, damage, violence, or threats and experienced threats, violence, or harassment in the workplace. The survey collected in 2020 on experienced discrimination is a part of the survey on quality of life, and the following reasons of discrimination are shown: age, gender, health problems, illness, and injury, disability, ethnic background, skin colour, religion/life philosophy, political attitudes, sexual identity, uncertain reason, and not discriminated (Bufdir, 2020a). Moreover, there is yearly data on inquires to the Equality and Anti-Discrimination Ombud, divided in the following grounds of discrimination: gender, disability, ethnicity (including language), age, religion, sexual orientation, gender identity and gender expression, and other (Bufdir, 2020b). Statistics Norway has recently published a review concerning quality of life among the population (Statistics Norway, 2020q).

Sweden

While there is no Swedish data on experienced discrimination, the Equality Ombudsman provides yearly data on reported discrimination and written and oral questions about discrimination. The data is presented according to the following grounds of discrimination: ethnicity, disability, gender, gender identity and

gender expression, religion or other belief, sexual orientation, age, and disadvantages in connection with parental leave. The data material also includes information on context of such discrimination (Diskrimineringsombudsmannen, 2020).

Åland

In Åland, surveys conducted by Statistics and Research Åland in 2007, 2010, and 2020 include data on experienced discrimination, based on the definition of discrimination according to the Aland Discrimination Act (AFS 2005:66). The surveys were conducted with a random sample of people aged 16 and older living in Åland, including 2,003 people in 2007, 1,523 people in 2010, and 1,619 in 2020. Each year, there was an overrepresentation of people having another mother tongue than a Nordic language. The data material can be separated according to the following reasons of discrimination: gender identity, origin, opinions, language, age, health, family relationships, name, appearance, disability, trade union activity, sexual orientation, political activity, and religion. The surveys also include information on context of experienced discrimination (ASUB, 2007, 2010, forthcoming). The Office of the Åland Ombudsman provides yearly statistics on advisory matters according to the following grounds of discrimination sex, gender expression and gender identity, ethnicity, disability, religion and other conviction, age, sexual orientation, the Children's Ombudsman case, and other (Ålands ombudsmannamyndighet, 2020).

Participation in school and education

Article 24 of the UNCRPD treats education. It is stated that "States Parties shall ensure that:(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;(c) Reasonable accommodation of the individual's requirements is provided;(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion."

SDG 4 on Education

In SDG 4 of Agenda 2030, education is treated in target 4.5 "By 2030, eliminate gender disparities in education and ensure equal access to

all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations."

Indicator 4.5.1 "Parity indices (female/male, rural/urban, bottom/top wealth quintile and others such as disability status, indigenous peoples and conflict-affected, as data become available) for all education indicators on this list that can be disaggregated."

Target 4.a "Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all."

Indicator 4.a.1 "Proportion of schools with access to: (a) electricity; (b) the Internet for pedagogical purposes; (c) computers for pedagogical purposes; (d) adapted infrastructure and materials for students with disabilities; (e) basic drinking water; (f) single-sex basic sanitation facilities; and (g) basic handwashing facilities (as per the WASH indicator definitions)."

Measuring inclusion in education

The ambition of the UNCRPD is to create an inclusive education system that is accessible for everyone, including children with disabilities. However, in the Nordic countries, segregated special education schools or segregated solutions around special education within mainstream school environments are in some cases considered to be individual adaptation. For instance, children with concentration difficulties can learn better in classrooms with fewer children. While there should be as few as possible children receiving compulsory primary and secondary education in segregating school forms, there should still be some flexibility regarding what kinds of educational settings are offered. Therefore, to be able to follow the developments regarding participation in school for children with disabilities in the Nordic Region, we suggest that the indicators on the number of children receiving special assistance and number of children participating in segregating school forms should be included.

However, it is worth noting that there are differences in types of assistance systems between the Nordic countries and autonomous regions and thus, direct comparison between them – by using data from national statistical sources – may not be possible. Because of the differences in policies concerning either segregating or integrating education, it could be interesting to study the advantages and disadvantages more thoroughly. Possibilities for a Nordic project was discussed in one of the expert meetings and

should be discussed further within the Nordic cooperation on education

Available data on the number of children receiving special assistance in school

Denmark

The Ministry of Children and Education (Børne- og Undervisningsministeriet) in Denmark provides yearly data by gender on the number of children who receive special education in mainstream classes in comprehensive school. This data is available since the school year 2008–09 (Børne- og Undervisningsministeriet, 2020a).

Finland

In Finland, Statistics Finland provides yearly data by gender on the number of children who receive intensified or special support in preprimary education, different grades of comprehensive school and additional education (Statistics Finland, 2020a). It is also possible to see to which extent these children receive teaching in a general education group, even if this data is not shown by gender. These data sets are available since 2011 (Statistics Finland, 2020b).

Iceland

In Iceland, Statistics Iceland provides yearly data by gender on children who receive special support in the normal classroom or both in the special education classroom and the normal classroom in different grades of comprehensive school. These statistics are available since the school year 2004–05 (Statistics Iceland, 2020a). In addition, it is shown how many of these students have an official diagnosis – this data being available since the school year 2010-11 (Statistics Iceland, 2020b). There is also data by gender on the number and proportion of children with special needs in pre-primary institutions. These statistics are available since 1998 (Statistics Iceland, 2020c).

Norway

In Norway, the Norwegian Directorate for Education and Training (Utdanningsdirektoratet) provides yearly data by gender on the number of children who receive special education in the ordinary class in different grades of comprehensive school. It is also shown how many pupils receive special education in the ordinary class, in separate groups and alone. These statistics are available since the school year 2006–07. Moreover, there is information on the number of pupils who are allocated a specific number of hours with an assistant or for special education with teachers

(Utdanningsdirektoratet, 2020). Statistics Norway provides data on the percentage of children in municipal kindergartens with special education assistance. These statistics are available since 2015 (Statistics Norway, 2020a).

Sweden

In Sweden, the Swedish National Agency for Education (Skolverket) provides yearly data by gender on the share of children who receive special support, including the information on how many of them receive individual tuition or participate in a special education group. These statistics are shown for different grades of comprehensive school, and they are available since the school year 2012–13 (Skolverket, 2020a, 2020d).

Åland

In Åland, Statistics and Research Åland provides yearly statistics on Teaching with special educational or multi-professional support on the number of children receiving teaching with special educational or multi-professional support, and if over or under half of this teaching takes place within general education. The data is available since 2015 (ÅSUB, 2020a). Åland is also included in the aforementioned statistics provided by Statistics Finland (2020a, 2020b). Moreover, there are statistics available on the number of schools with access to adapted infrastructure and materials for students with disabilities since 2000 (ÅSUB, 2020c).

Available data on the number of children participating in special education

Denmark

The Ministry of Children and Education in Denmark provides yearly data by gender on the number and proportion of children who receive special education in comprehensive school. These statistics are available since the school year 2008-09 (Børne- og Undervisningsministeriet, 2020a). Information on the degree of inclusion is also provided, i.e., the proportion of pupils who participate in general education in public schools (Børne- og Undervisningsministeriet, 2020a, 2020b).

Finland

In Finland, Statistics Finland provides yearly data on the number of children who receive all or a certain percentage of teaching in a special education group or a special education school. The data is provided for both pre-primary education, comprehensive school grades 1–6 and 7–9, and additional education. These statistics are available since 2011 (Statistics Finland, 2020b).

Iceland

In Iceland, Statistics Iceland provides yearly data by gender on the number of children in special education class in different grades of comprehensive school. These statistics are available since the school year 2010–11 (Statistics Iceland, 2020b).

Norway

In Norway, the Norwegian Directorate for Education and Training provides yearly data by gender on the number of children who receive all teaching in a permanent special education group or a special education school. These statistics are shown for grades 1–7 and 8–10 of comprehensive school, and they are available since the school year 2012–13 (Utdanningsdirektoratet, 2020).

Sweden

In Sweden, the Swedish National Agency for Education provides yearly data on the number of children who participate in primary special school, special school, and high school special school, including both public and private schools. These statistics are available since the school year 2006–07 (Skolverket, 2020, 2020c 2020e, 2020f).

Åland

In Åland, Statistics and Research Åland provides yearly data by gender on the number of children who participate in adapted special education. These statistics are available during the period 2000–14 (ÅSUB, 2020b). Åland is also included in the aforementioned statistics provided by Statistics Finland (2020b).

Available data on educational background

Regarding educational background of persons with a disability, it is recommended to use data provided by Eurostat, which could be complemented with data based on national sources.

Eurostat provides yearly data by gender on self-perceived longstanding limitations in usual activities due to health problem by educational attainment level since 2008 (Eurostat, 2020a). The education attainment levels of individuals are classified according to the International Standard Classification of Education (ISCED) version of 1997 and are grouped into the following main categories: 1) pre-primary, primary and lower secondary education, 2) upper secondary and post-secondary non-tertiary education, and 3) first and second stage of tertiary education. It may be problematic, however, that the indicator provides information on educational background in reverse order. In other words, it would be more suitable to use statistics on educational attainment level by the level of self-perceived long-standing limitations in usual activities due to health problem. This indicator is part of the EU-SILC, in which disability is defined in accordance with the GALI (Eurostat, 2020b).

Denmark

In Denmark, SHILD provides data by gender and age on the proportion of people with disability who state that they have a tertiary education, i.e., medium-long, or long higher education. The information on gender and age is included in SHILD via the personal identification number, and the SHILD data can be merged with register data, which includes information on ethnicity, for instance. The data is shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical disability, and minor physical disability. It is also possible to run the analysis for individuals with and without a disability according to the GALI and the WGSS. These statistics can be found for the age group of 16- to 64-year-olds in 2012, 2016 and 2020. (Bengtsson, 2017). There are also several other indicators available on education background of people with disabilities in 2016 (Rode Larsen and Larsen, 2017) and 2017 (Dalskov Pihl and Salmon, 2019). While SHILD includes a question on the individual's highest level of education, it is also possible to get more reliable educational information via the registers (see Amilon et al. 2017, p. 36).

Finland

In Finland there is data by gender on educational background based on the population surveys of FinSote for the age group of 20 years old and over (Finnish Institute for Health and Welfare, 2020a) and FinHealth for the age group of 18 years old and over (Finnish Institute for Health and Welfare, 2020b). These statistics can be extracted separately for people with different types of disability, such as a vision, hearing, mobility, and cognition impairment, based on customised Washington Group questions. The data can also be found for the different GALI categories. The statistics can be seen by the type or level of disability only if they are separately analysed from the wider data material, i.e., they are not easily available through national statistical portals.

Iceland

Iceland participates in the EU-SILC and LFS but otherwise there are no available statistics on educational background of people with disabilities.

Norway

In Norway, Statistics Norway provides data by gender on education level of people with disabilities. The data is part of the survey on living conditions, and it is available for 2002, 2005, 2008, 2012 and 2015. The statistics can be also shown by several different types of disabilities. The following education levels are included: basic school level, upper secondary education, higher education and unknown or no completed education (Statistics Norway, 2020b). There is also Labour force survey data on the number of employed people with disabilities by the level of education, including the following categories: primary and lower secondary education; upper secondary education; tertial education, four years or less; tertial education, more than four years and unknown or no completed education. These statistics are available since 2006 (Statistics Norway, 2020c). Furthermore, there is additional data based on the recently published register-based statistics (Statistics Norway, 2020h).

Sweden

In Sweden, Statistics Sweden provides data by gender on the proportion of people with disabilities by the highest completed education. The data collection was part of the survey on living conditions, and it is shown by the type of disability for people aged 30 years old and over in 2016–2017. The following categories are included: pre-secondary education, secondary education, postsecondary education, unknown level of education, suspended but not completed upper secondary education and suspended but not completed post-secondary education (Statistics Sweden, 2020). In addition, the Public Health Agency of Sweden provides data by gender on the number and proposition of people with disabilities with different education levels. These statistics are shown by several different types of disabilities, and the following education level categories are included: pre-secondary education, secondary education and post-secondary education. The data is available since 2004 (Folkhälsomyndigheten, 2020a).

Employment

Article 27 UNCRPD treats the right to employment. It is stated that the State Parties shall take appropriate steps to "(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions; (b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe

and healthy working conditions, including protection from harassment, and the redress of grievances."

SDG 8 of Agenda 2030 treats working conditions and inclusion on labour market. Target 8.5 states that: "By 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value."

Indicator 8.5.1 "Average hourly earnings of female and male employees, by occupation, age and persons with disabilities."

Indicator 8.5.2 "Unemployment rate, by sex, age and persons with disabilities."

Measuring progress on work inclusion

Regarding labour force status of people with disability, it is recommended to use data provided by Eurostat, which could be complemented with data based on national sources. The Nordic statistics indicator shows data for inactive people because of "own illness or disability" and therefore, it may not be relevant. According to the Nordic Statistics Database, the concept of inactive people refers to people who are neither employed nor unemployed.

Available data on the number of people with disability by labour force status

Eurostat provides yearly data by gender on self-perceived long-standing limitations in usual activities due to health problem by labour status since 2008 (Eurostat, 2020c). The following activity and employment status categories are included: employed persons, employees, employed persons except employees, not employed persons, unemployed persons, retired persons and other inactive persons. It may be problematic, however, that the indicator provides information on labour status in reverse order. In other words, it would be more suitable to use statistics on labour status by the level of self-perceived long-standing limitations in usual activities due to health problems. This indicator is part of the EU-SILC, in which disability is defined in accordance with the GALI (Eurostat, 2020 b).

Denmark

In Denmark, SHILD provides data by gender and age on the proportion of people with disability who state that they are employed. The data is shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical disability, and minor physical disability. Regarding data from 2016 and 2020, it is also possible to run the

analysis for people with and without a disability according to the WGSS and the GALI. These statistics can be found for the age group of 16- and 64-year-olds in 2012, 2016 and 2020 (Bengtsson, 2017). Further, it is possible to analyse employment among people with disability by merging SHILD with register data (see, e.g., Amilon et al., 2017, p. 45-47). There are also several other indicators available on employment and labour market status of people with disabilities in 2016 (Rode Larsen and Larsen, 2017). Information on the labour market status by disability is also available in 2008, 2010, 2012, 2014, 2016, and 2019.

Finland

In Finland, FinTerveys (FinHealth) provides data by gender on the proportion of people who estimate being able to work (Finnish Institute for Health and Welfare, 2020c) and estimate being able to work until retirement age, in the age groups of 18-64 years old and 65 years old and over (Finnish Institute for Health and Welfare, 2020d). The Welfare Compass portal, based on the National FinSote Survey organised by the Finnish Institute for Health and Welfare, provides information by gender on the proportion of people who assume that their ability to work has deteriorated (Finnish Institute for Health and Welfare, 2020e) and who think that they probably will not be able to continue working until retirement age. The FinSote data is available for the age group of 20-64 years old since 2013 (Finnish Institute for Health and Welfare, 2020f). Even if the indicators that are available on employment through the aforementioned data portals are not broken down by disability, the data itself has been collected by involving information on disability according to the Washington group and GALI. For the time being, obtaining disaggregated data by the type and level of disability requires own analysis of the data.

Iceland

In Iceland, Statistics Iceland provides data by gender on the labour force status of people with disabilities, in the age group of 16 to 66 years old. The following categories of labour force status are presented: inactive – available but not seeking, inactive – seeking but not available, unemployed, employed – underemployed (parttime), employed – other in part-time, employed – full-time temporary, and employed – full-time (Statistics Iceland, 2020d). There is also data on the number and percentage of inactive people whose self-perceived status is "disabled". These data sets are available since 2003 (Statistics Iceland, 2020e).

Norway

In Norway, Statistics Norway provides data by gender on the labour force status of people with disabilities since 2006, in the age group of 15 to 66 years old. The data material only includes the labour force status categories of employed and unemployed (Statistics Norway, 2020d). There is also a data set that includes information by gender on people with disabilities who are part-time employed (Statistics Norway, 2020e). Moreover, there is available data on the number and proportion of non-employed people with disabilities by desire for employment (Statistics Norway, 2020f). Furthermore, there is additional data based on the recently published register-based statistics (Statistics Norway, 2020h).

Sweden

In Sweden, Statistics Sweden together with the Swedish Public Employment Service publish a yearly report based on a survey data on the labour market situation for people with disabilities. The survey data is available since 1996, and it covers people aged 16-64 years old who are registered in Sweden. The latest report includes the following statistics, for instance: the number and proportion of people with disabilities in the employed population, the proportion of people with disabilities with reduced working capacity, the proportion of employed and unemployed among the people with disabilities – with and without reduced working capacity, and the proportion of employed people with disabilities by the scope of work (full-time versus part-time). Some of these statistics are available by gender and/or type of disability (Statistiska centralbyrån, 2020). Statistics Sweden also provides data by gender on the proportion of people with disabilities by main labour market status, form of employment, scope of employment, and the NEET rate (not in education, employment, and training). These data sets are part of the survey on living conditions, and they are shown by the type of disability for the age group of 16–64 years old in 2016–2017 (Statistics Sweden, 2020).

The Public Health Agency of Sweden provides data by gender on the number and proposition of people with disabilities with different labour market statuses and socioeconomic statuses. These statistics are shown by several different types of disabilities, and the following labour market status categories are included: employed, unemployed, with sickness benefit compensation, and student/trainee. Data for the following socioeconomic statuses is included: blue-collar worker, lower-paid white-collar employees, medium and highest-paying white-collar employees, and other. These data sets are available since 2004 (Folkhälsomyndigheten,

2020b, 2020c). The Swedish Public Employment Service publishes an annual report on labour market policy measures, which presents statistics on subsidised employments – primarily wage subsidy employment (Norberg, 2020).

Standard of living and social protection

Article 28 UNCRPD treats adequate standard of living and social protection. It is stated: "(b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes; (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care; (d) To ensure access by persons with disabilities to public housing programmes; (e) To ensure equal access by persons with disabilities to retirement benefits and programmes."

SDG 10 of Agenda 2030 treats reduced inequality. Target 10.2 states that "By 2030, 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."

Indicator 10.2.1 "Proportion of people living below 50 per cent of median income, by age, sex and persons with disabilities."

Available data on standard of living

Regarding standard of living of people with disability, it is recommended to use data provided by Eurostat, which could be complemented with data based on national sources.

Eurostat provides yearly data by gender on self-perceived longstanding limitations in usual activities due to health problem by sex, age and income quintile since 2008 (Eurostat, 2020d). It may be problematic that the indicator provides information on income quintile in reverse order. In other words, it would be more suitable to use statistics on income level by the level of self-perceived longstanding limitations in usual activities due to health problem. This indicator is part of the EU-SILC, in which disability is defined in accordance with the GALI (Eurostat, 2020 b).

Denmark

In Denmark, SHILD provides data by gender and age on individual income per month before tax. Based on this information, it is possible to calculate the proportion of people with disability who state that they have a personal income of less than 60 percent of the

median income. The SHILD data can be merged with register data to allow for a more detailed analysis of income. The data is shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical disability, and minor physical disability. It is possible to run the analysis by disability status based on the GALI and the WGSS. These statistics can be found for the age group of 16–64-year-olds in 2012, 2016 and 2020 (Bengtsson, 2017).

Sweden

In Sweden, Statistics Sweden provides data by gender on the proportion of people with disabilities who state that they have fallen behind with at least one payment of the following: rent/fee for the dwelling, interest and repayments for the dwelling, or bills for electricity, gas, telephone, water, waste collection or similar. There is also data available on the proportion of with disability who state that their household would not be able to pay an unexpected expense of 12,000 SEK within a month, without borrowing the money or asking for help. These data collections were part of the survey on living conditions, and they are shown by the type of disability for people aged 16 and over in 2016–2017 (Statistics Sweden, 2020). Information on the financial situation of people with disabilities is also available in the annual survey on Health on equal terms published by the Public Health Agency of Sweden, which includes screening questions about disability (Folkhälsomyndigheten, 2020d).

Available data on social protection

Regarding social protection of people with disability, it is recommended to use data provided by Nowbase, which could be complemented with data based on national sources. In additional, national data sources could be used to show the number of people receiving activity grants.

Nowbase provides data by gender on the number of recipients of disability pensions since 2000. The data is available for all the Nordic countries and the Faroe Islands (Nowbase, 2020).

Denmark

In Denmark, SHILD provides data by gender and age on the proportion of people with disability who state that they experience deprivation. In this case deprivation means that there have been periods during the last three years when the respondent has been prevented form living a normal life for financial reasons. The data is shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical

disability, and minor physical disability. The data can also be analysed for people with and without a GALI defined and a WGSS defined disability. These statistics can be found for the age group of 16–64-year-olds in 2012, 2016 and 2020 (Bengtsson, 2017).

Finland

In Finland, FinSote includes data on an unsatisfied need for social benefits. In the survey, the respondents were asked to answer if they think that they have received enough of specified social benefits or social support during the last twelve months, such as basic income support received from the Social Insurance Institution of Finland or supplementary income support received from municipalities. The following answer options were included: has not needed, would have needed but has not received, has used but was not sufficient, and has used and was sufficient. These statistics can be extracted by the level and type of disability.

Sweden

In Sweden, Statistics Sweden provides data by gender on the proportion of people with disabilities by main labour market status, form of employment, scope of employment, and the NEET rate. These data sets are part of the survey on living conditions, and they are shown by the type of disability for the age group of 16–64 years old in 2016–2017 (Statistics Sweden, 2020). The Nowbase data can be supplemented with information on the number of recipients of additional cost allowance. The National Board of Health and Welfare also occasionally produces information on financial aid (social assistance) among people with certain disabilities. One could consider making this indicator recurring, as a measure of social vulnerability (and a complement to social security).

Åland

In Åland, Statistics and Research Åland provides data on economic vulnerability and social protection (ÅSUB, 2016).

Accessibility

Article 9 UNCRPD treats accessibility. The State Parties shall identify and eliminate obstacles and barriers to accessibility applying to "(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;(b) Information, communications and other services, including electronic services and emergency services."

SDG 11 of Agenda 2030 treats Sustainable cities. Target 11.2 states "By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably

by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons."

Indicator 11.2.1 Proportion of population that has convenient access to public transport, by sex, age, and persons with disabilities

Target 11.3 "By2030, enhance inclusive and sustainable urbanization and capacity for participatory, integrated and sustainable human settlement planning and management in all countries."

Indicator 11.3.2 "Proportion of cities with a direct participation structure of civil society in urban planning and management that operate regularly and democratically."

Experienced obstacles in public transport Denmark

In Denmark, SHILD provides data by gender and age on the proportion of people with disability who state that they can use the bus and train, even when there are many passengers. In addition, there are also statistics by gender on the proportion of people who state that they have problems with accessibility in buildings. These data sets are shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical disability, and minor physical disability. It is also possible to analyse the data by disability status according to the GALI and the WGSS in 2016 and 2020. These statistics can be found for the age group of 16–64-year-olds in 2012, 2016 and 2020 (Bengtsson, 2017). In addition, SHILD includes information on the frequency by which people go to public places, such as cinema, concert, theatre, sports event, restaurant, café, bar, and disco, and whether they visit parks, green areas, etc. (see Amilon et al., 2017, p. 93).

Finland

In Finland, FinSote provides data on how satisfied people are with their access to public transport and/or other means of transport and with conditions in their residence in 2018 and 2020. FinTerveys includes questions on the experienced barriers in the housing and living environment in the age group of 70 years old and over in 2017. These statistics have not been reported by the level or type of disability, but such breakdown would be possible. There is also available data on barriers to accessing health services (Sainio et al., 2019).

Norway

In Norway, the Norwegian Directorate for Children, Youth and Family Affairs (Bufdir) provides survey data on challenges people with disability experience travelling by public transport. The data is show by type of disability, but it cannot be sorted based on gender. There is also more detailed information on the mode of public transport and the type of obstacles that have been experienced in each of them. The data collection was based on a representative sample of the Norwegian population, besides more targeted surveys for people with various types of disabilities (Bufdir, 2017). There is also additional data on accessibility in transport (Bufdir, 2020c), housing (Bufdir, 2020d) and public buildings (Bufdir, 2020e).

Sweden

In Sweden, Transport Analysisprovides results of a panel survey regarding the proportion of people with disability who travel by public transport and who experience obstacles to travel by public transport. The data is shown by type of disability, but it cannot be disaggregated by gender. There is also more detailed information on the type of obstacles that have been experienced (Trafikanalys, 2019). The Swedish Agency for Participation provides additional data on accessibility (Myndigheten för delaktighet, 2020).

Åland

In Åland, Statistics and Research Åland provides data by gender on poorly adapted means of transport and public buildings in 2007, 2010 and 2020 (ÅSUB, 2007, 2010).

For some countries, there are also other statistics available on accessibility regarding public buildings, parking facilities, type of dwelling (the proportion of dwellings that are accessible according to standardised rules), transportation service (taxi service for the disabled), car adaptation, etc. According to the expert comments, however, it may be good to first focus on the statistics on obstacles in public transport.

Additional thematic areas

In addition to the prioritised thematic areas, the following thematic areas were mentioned by the expert groups at earlier stages in the cooperation on indicators and the availability of data sources: political participation, freedom and personal integrity, and health. Below some indicators related to these themes are mentioned as examples.

Political participation

Denmark

In Denmark, SHILD provides separate data set by gender and age on the proportion of people with disability who state that they voted in the last parliamentary election and who is a member of a political party. These statistics can be found for the age group of 18–64-year-olds in 2016 and 2020. There is also data by gender on the proportion of people with disability who is a member of an organisation. This data is available for the age group of 16–64-year-olds in 2012, 2016 and 2020. All these statistics are shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical disability, and minor physical disability. This analysis can be also done by disability status according to the GALI and the WG-SS (Bengtsson, 2017).

Freedom and personal integrity

Denmark

In Denmark, SHILD provides data by gender and age on the proportion of people with disability who experience having a high degree of influence on their own life and who experience having less influence or no influence at all on their own life. The data is shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical disability, and minor physical disability. Analysis is also possible by WGSS defined and GALI defined disability in 2012 and 2016. These statistics can be found for the age group of 16–64-year-olds in 2012, 2016 and 2020 (Bengtsson, 2017).

Sweden

In Sweden, Kolada reports results from user surveys conducted in the Swedish municipalities. In these surveys, people with disabilities who live in group housing, have daily activities, etc. estimate the degree of their self-determination, integrity, etc (Kolada, 2020).

Health

Eurostat provides several health-related indicators based on the EHIS. However, most of these indicators are only available for year 2014 per November 2020.

Denmark

In Denmark, SHILD provides data by gender and age on the proportion of people with disability who state that they have good or very good health and who indicate a weight and a height which gives them a BMI over 25 or over 30 (i.e., overweight versus obesity). The data is shown separately for people with different types of disability, including major mental illness, minor mental illness, major physical disability, and minor physical disability. This analysis can be done by disability status according to the GALI and the WGSS. These statistics can be found for the age group of 16–64-year-olds in 2012, 2016 and 2020 (Bengtsson, 2017).

Finland

In Finland, FinSote and FinHealth surveys provide data on self-perceived health, long-standing illness, and various self-reported chronic conditions. The same sources also include data on many health behaviours, such as smoking, alcohol intake, physical activity, etc. These data sets can be disaggregated by disability (Finnish Institute for health and welfare, 2020a, 2020b).

Sweden

In Sweden, the annual survey on Health on equal terms, published by the Public Health Agency of Sweden, includes screening questions about disability and questions on the theme of health (Folkhälsomyndigheten, 2020d).

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