See, listen and include

Participation for children and young people with disabilities in the Nordic countries





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Foreword

The Nordic Council of Ministers has a common <u>vision of a sustainable Nordic</u> <u>Region</u>, a Nordic region that is also the best place in the world for children and young people. <u>The action plan for a sustainable Nordic Region</u> 2021-2024 and the cross-sectoral strategy on children's rights, <u>Children and Young People in</u> <u>the Nordic Region</u>, shall help realise this vision.

Equal opportunities for development and participation for all children and young people are a prerequisite for a sustainable Nordic region. This report is one of several initiatives aimed at increasing knowledge about effective methods to promote participation and remove barriers for children and young people with disabilities. The report is part of <u>the Nordic Council of</u> <u>Ministers' action plan on disabilities</u>, 2018-2022, for reinforced knowledge and dialogue on human rights and disabled people in the Nordic region and internationally.

We have prepared this report in collaboration with Nordic experts and have received input from Nordic youth delegates. The experts¹ have been appointed by the Nordic Committee for Children and Young People (NORDBUK), the Council of Nordic Co-operation on Disability and the Nordic Welfare Centre, in dialogue with the Nordic Council of Ministers. The work has its foundations in the Nordic Committee of Senior Officials for Health and Social Affairs.

The expert group has also contributed towards the compilation of a model for integrating a child rights and youth perspective, <u>No child or young person</u> <u>should be left behind</u>. The model has been developed as a guide for the work of the Council of Nordic Co-operation on Disability, and for all those working on promoting participation and involvement in the Nordic region.

The Nordic youth delegates who have contributed recommendations for the report attended a two-day workshop with experts and delegates in Helsinki in January 2020. 30 delegates attended the workshop, representing young people with disabilities from the entire Nordic region, in addition to three from the Baltic States. The delegates' contributions have provided us with valuable insight into and knowledge of the multitude of obstacles faced by young people with

1 The names of the experts involved are provided at the end of the report.

disabilities growing up. We have therefore decided to quote several of their comments as input to the report.

We would like to take this opportunity to thank everyone who has contributed to this project. We would particularly like to thank all our talented Nordic experts and youth delegates for inspiring co-operation and insightful contributions.

The Nordic Welfare Centre is an institution under the Nordic Council of Ministers. Our mandate is to contribute to increased co-operation and knowledge in the Nordic region regarding important welfare issues. One of our most important issues is the conditions in which children grow up. Children are our most valuable resource and our hope for the future.

We hope this report will help produce increased insight into the opportunities and commitments involved in the work on participation for children and young people with disabilities in the Nordic region. The goal is equal opportunities for participation and development, for all.

Eva Franzen	Merethe Løberg
Director	Senior Adviser
Nordic Welfare Centre	Nordic Welfare Centre

Children and young people with disabilities tell of everyday lives where they have less access to participate in social arenas than others in their age group.

Introduction

This report relates to the universal right of all children and young people to participate, to express their views and be heard in all matters concerning them. Our aim is to provide insight into how this right is secured for children and young people with disabilities in the Nordic region. This right refers to article 12 in the UN's Convention of the Rights of the Child and article 7 in the UN's Convention on the Rights of Persons with Disabilities.²

In the report, we highlight some of the most common obstacles to participation that children and young people face in various arenas. Our Nordic expert group has contributed by finding relevant research and good methods to ensure inclusion and participation for more people.

A number of social actors play a key role in ensuring participation for children and young people with disabilities. Our goal in this report is to describe central national and Nordic actors, and the roles they play.

Current status

Good social relationships and opportunities for participation and influence are essential for a positive upbringing. Children who have good social relationships, supportive families and opportunities to participate and to be heard both at home and at school, have better mental health than other children of the same age.³

However, research conducted by the Nordic countries and in comparative Nordic research have shown that there is a distinct gap between the rights children and young people with disabilities have and their daily experiences. Children and young people with disabilities themselves also describes daily situations where they experience having less opportunities to take part in social arenas when compared with children of the same age. They frequently experience being omitted from decision-making, and are seldom invited to have a say in matters that concern them.

One of the reasons why children and young people do not have equal opportunities is the lack of access to arenas and environments that are important for children and young people. Insufficient knowledge and competence among key

² Landsdown, 2011, p. 3

³ Gromada et. al 2020

personnel is another significant factor in terms of children and young people's opportunities for participation and influence.⁴

"We need to do a better job at telling stories about challenges faced by children. Society needs proper knowledge to become more accommodating."

Nordic youth delegates⁵

Lack of participation and influence over important areas of their own lives impairs living conditions for children and young people. We have a duty to act in the best interests of the child. This requires us to involve children, and identify what is important and right for them in different settings.

Children have knowledge about themselves that no one else has. When people around them fail to listen, see or involve children, this has negative consequences. In the worst-case-scenario, this may impair a child's development of social skills and result in marginalisation.

The Nordic region's Vision 2030

This report is one of several initiatives within the Nordic Council of Ministers' action plan on cooperation on disability for the period 2018-2022, aiming to reinforce knowledge and dialogue on human rights. We address the implementation of the UN Convention on the Rights of Persons with Disabilities and the Right to Participation and Inclusion.

The report is also one of several initiatives implemented to realise <u>the UN's</u> <u>Sustainable Development Goals</u>. The Nordic region's <u>Vision 2030</u> is to become the most integrated, green and socially sustainable region in the world. In the <u>Action Plan 2020-2024, for vision 2030</u> there is a special focus on ensuring children and young people's opportunities for development, belonging and participation. Nordic Co-operation shall contribute towards developing more efficient initiatives for improved social inclusion, belonging and well-being for children and young people in vulnerable situations.

We aim to achieve the vision by means of co-operation on relevant analyses, knowledge sharing, debate and development of methods. This work will involve civil society organisations, the private sector, research networks and youth organisations.

⁴ Nordisk ministerråd 2018

⁵ Input from Nordic youth delegates to the Nordic expert group, Helsinki 2020

If children and young people with disabilities are not heard or understood, the consequences can be severe.

See, listen to and include all children

Article 12 of the UN Convention on the Rights of the Child stipulates the right of the child to express their views, be heard and to be involved in all matters concerning them. This is one of the most important rights in the Convention and is recognised as the right to participate, although the word is not mentioned in the actual convention text.⁶

The right to participation and influence is particularly important for children, as children are social individuals who need to participate in order to develop their own identity, find their own voice and learn to express their feelings and needs. The right to participation helps ensure a child's influence over his or her own life, opportunities, and the ability to make competent decisions.

"One challenge is that children don't know they have the right to have influence over their own lives. There is also a tendency not to believe what children say, to think that children lack relevant knowledge and experience to make a contribution."

Nordic youth delegates

The failure of not listening to and understanding children and young people with disabilities could have major consequences for them. They often require facilitation and are reliant on the people surrounding them seeing, understanding and having enough knowledge to protect their rights.

Many children rely on contact and long-term support from family, people close to them and networks, in addition to helpers and support personnel. Genuine opportunities for participation are as such often at the mercy of a number of factors over which the child does not fully control, such as personal qualities, social contacts, time, linguistic skills, knowledge, education, economic resources, accessibility and health. In UNICEF's report <u>Take us seriously – Engaging</u> <u>Children with Disabilities in Decisions Affecting their Lives</u>, children and young people from every corner of the world have been allowed to speak their minds. The report encourages all countries to work more efficiently, listen to children and young people themselves and to reduce inequalities between children and young people with disabilities and other children.⁷

Child rights and youth perspective

The human rights perspective in the work on children's participation and influence highlights the necessity to listen to and promote the experiences of children and young people to a greater extent. This is necessary in order to ensure that all their rights are adequately protected. The aim is to ensure that all children and young people are included, leaving no one behind.

In the work to ensure participation and influence in children's own lives, we need to talk to them and base our work on the child's best interests. We need to incorporate and evaluate the child's perspective. Knowledge of children's circumstances and experiences is essential in ensuring a good basis for decision-making in the work to promote and include children's participation and living conditions. Children's needs are safeguarded when children are involved in the decisions that concern them. The involvement of children and young people with disabilities provides their families, close ones, helpers and society with important knowledge about what is beneficial for the individual.

Incorporating a child's perspective involves obtaining insight into what the child him/herself sees, hears, experiences and feels; in other words, the reality of a child. The aim is not to take over or adopt the same views as the children, but to take children's opinions into account and consideration. Adopting a children's perspective requires adults and society to see the situation of children and young people based on their reality. A child's views are of equal value to those of an adult.

The way an adult assesses a situation may differ vastly from a child, and the adult's perspective on a child is not the same as the child's perspective. Adults derive their actions from their perspective, based on their knowledge at any given time of what is in the best interest of the child. This may be based on relevant knowledge of children and young people's development, prerequisites and needs. One example is where adults deem a situation to be hazardous and take measures to prevent the hazard. However, the adult's duty to protect the child and prevent hazards must not be allowed to stop us from incorporating the child's perspective.

Adopting the child's perspective does not automatically imply that we are protecting the rights of the child. We must additionally integrate a child rights and youth perspective in our efforts. <u>The Nordic Council of Ministers has developed a policy</u> for integration of sustainable development, equal opportunities and a child rights and youth perspective in all activities.

Child rights and youth perspective:

Integrating a child rights and youth perspective (..) involves becoming acquainted with and considering what different children and young people think of, and how they are affected by, the decisions you take and initiatives you implement. All decisions must be based on the best interests of the child. This also implies that you shall include the knowledge and perspective of children and young people in your work.⁸

Children and young people with disabilities are entitled to the opportunity to express their opinions in all matters concerning them. This covers issues affecting their social, economic, religious, cultural and political lives. The right to participate includes the right to express opinions and be heard, the right to information and freedom of association.⁹ Neither is the right to participate and get involved a duty. Involvement should be facilitated in a way that prevents the child from experiencing it as a burden.¹⁰

The child's right to participate and have a say is not only important for the individual child, but also for the society. Democracy is developed and maintained by addressing the experiences, attitudes and needs of fellow citizens. A democratic society with the optimal prerequisites for sustainability and development is a society that listens to all citizens, including children and young people.

⁸ Nordisk Ministerråd 2020

⁹ Sandberg, K (Red) 2020

¹⁰ Kjellander et al. 2016

"We need to study in more detail how we address structures in society that limits accessibility and participation. It can be incredibly demanding to get your own initiatives up and running, so it is sometimes easier just to stay at home on the sofa and watch TV."

Nordic youth delegates

UN conventions on participation for children

The right to participate and to have a say for children and young people with disabilities is specifically laid down in two of the UN's <u>nine core conventions</u>; The UN Convention on the Rights of the Child, and the UN Convention on the Rights of Persons with Disabilities.

The Convention on the Rights of the Child was adopted in 1989 and the Convention on the Rights of Persons with Disabilities in 2006. All countries, in addition to the Faroe Islands, Greenland and Åland, have ratified the conventions. For information on the status of ratification and implementation of conventions and additional conventions in the different countries, go to OHCHR.org¹¹.

All countries report to and are regularly appraised by the UN in relation to follow-up and compliance with the conventions. The work on the conventions is monitored by the UN's respective committees. The UN Committee on the Rights of the Child, for example, monitors whether countries assign children the rights to which they are entitled. Each country must therefore submit a report every five years to this Committee, describing their efforts to comply with the Convention on the Rights of the Child. This implies that a breach, for example, of the Convention on the Rights of the Child, regardless of the level of administration in the Nordic region, may result in the UN Committee on the Rights of the Child issuing a notice. Such notices gain international attention and may expose the Nordic region, individual countries and the Faroe Islands, Greenland and Åland to international criticism.

Each country's reports can be found in the <u>UN's database</u>, where you can also read recommendations made by the committees for work on rights for each country.

¹¹ Ratification status by country or by treaty, United Nations Office of the High Commissioner of Human Right.

The Convention on the Rights of the Child

One of the main principles of the Convention is the child's right to co-determination, which is expressed in Article 12. The UN Committee on the Rights of the Child – the body that monitors the individual country's follow-up of and compliance with the Convention – has designated Article 12 as one of the four general principles of the Convention. The four¹² general articles are:

- Non-discrimination, Article 2
- The best interests of the child, Article 3
- The inherent right to life, survival and development, Article 6
- Respect for the views of the child, Article 12

This means that these four articles shall guide our interpretation and use of the other articles. They are instructive for all aspects involving implementation and use of the Convention. 13

Article 12. The child's right to express his or her views

- States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
- 2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

The four articles are not just principles to be used for the interpretation of the majority of other articles. They are also positive rights for all children and young people.¹⁴

This means that any violation of the rights of children and young people with disabilities shall be understood as a violation of their human rights. Such violation shall not be perceived as a consequence of the child's immaturity or attributed to limitations resulting from the child's disability.¹⁵

Respect for the child's views, including the right to be involved and participate, is often considered one of the less integrated and observed rights. Article 12 imposes a duty on all authorities to ensure that children's views are sought and assessed in all matters concerning children and young people's lives. In

¹² Sandberg, K (Red) 2020

¹³ Council of Europe, 2009 p. 18

¹⁴ Sandberg, K (Red) 2020

¹⁵ Traustadóttir et al, 2015 p. 23

other words, Article 12 goes beyond the Universal Declaration of Human Rights' article regarding freedom of speech. The difference here lies in that the UD-HR's freedom of speech applies to all and any matters. The right to be heard in Article 12 relates to matters concerning a child. Each country is, in other words, assigned a positive duty to guarantee this right for children.¹⁶

The reference to giving due weight to the child views in accordance with the child's age and maturity is important. This formulation makes it clear that the child's ability to form opinions should be assessed in relation to the child's age and ability.¹⁷ The gradual and individual development of a child is an underlying principle in the convention. As the child grows older, he or she shall have increasing influence over his or her life. All people have views and can express them from birth, to a greater or lesser extent. Even infants and toddlers are experts on their own feelings. Infants express what they like and dislike and can make their views known in many ways.

In practice, the maturity criterion can become a trap, where the child may be considered immature if he or she has a different opinion or challenges the adults through actions or words.¹⁸ The challenges implied in the work to ensure participation for all children therefore particularly relate to the need to ensure that all persons who meet children and young people have good communication with the child. On this basis, such communication will, in many scenarios, require special knowledge and competencies, such as when teaching children with mental disabilities.

Article 12 is closely related to Article 3. When taking the child's views into account, the best interests of the child must also be assessed. The child's best interests shall be a fundamental factor when determining all types of actions and decisions affecting children.

Each country and their authorities are assigned responsibility for ensuring the right to participation for children and young people with disabilities. This requires all parents and guardians, persons close to the child, teachers, health and support personnel, and all other adults to be able to listen to, understand and transmit the child's views. Most people seek out family, friends or other persons close to them for backup and support if needed. One of the most important factors in promoting participation and self-determination for children with intellectual disabilities is that the people close to them or personnel provide support in decision-making.¹⁹

In the Convention on the Rights of the Child, the rights of children with disabilities are specifically mentioned in two separate articles, Articles 2 and 23. In Article 2, non-discrimination, disability is explicitly mentioned among the overarching principles for general protection against discrimination. In Article 23, children with disabilities are assigned special rights in order to meet their special needs for services and facilitation.²⁰

¹⁶ Sandberg, K (Red) 2020

¹⁷ UNICEF, 2018

¹⁸ Sandberg, K (Red) 2020

¹⁹ Ellingsen, K. E. (Ed.) 2007

²⁰ Sandberg, K (Red) 2020

"You have to ask about disability if you want answers. It is important that we are taken seriously so that we can openly discuss what can be done. Children need to be included in the work to find good solutions. One example is the work to stop bullying."

Nordic youth delegates

The UN's Committee on the Rights of the Child has urged its member states in particular to include children with disabilities on councils and involve them in decision-making to give them more influence over their life circumstances.²¹ The right to be heard is also an instrument that can be utilised to stimulate full development of the child's personality in accordance with Article 6, the child's inherent right to life and development.

The Convention on the Rights of Persons with Disabilities

The purpose of the UN Convention on the Rights of Persons with Disabilities is to promote, protect and ensure full and equal access to all human rights. The



Ensuring that children and young people with disabilities can participate largely has to do with creating accessibility and opportunities, despite obstacles.

²¹ Sandberg, K (Red) 2020

Convention is a central source of knowledge that provides key insight into the process of ensuring equal participation.

The Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities both include definitions and terminology that provide insight into what the right to participation constitutes, and the prerequisites to consider. The two conventions supplement and complement each other.

Participation for children and young people with disabilities mainly entails ensuring accessibility and opportunities for participation. Accessibility is pre-requisite in order to obtain inclusion as obstacles otherwise can impose limits to children and young people with for example physical disabilities such as movement, vision and/or hearing.

The multitude of obstacles to participation is vast and is associated with individual, structural and site-specific challenges. This is precisely why the need for interaction and participation is so crucial for children and young people with disabilities.²²

Article 7. Children with disabilities

- 1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
- 2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
- 3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 3. General principles

- a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- b) Non-discrimination
- c) Full and effective participation and inclusion in society
- d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e) Equality of opportunity
- f) Accessibility
- g) Equality between men and women
- h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities



Input from the youth delegates, obstacles that need to be solved

Nordic youth delegates and Nordic experts held a workshop in Helsinki in the winter of 2020. During the workshop, they discussed what was required to ensure participation and inclusion for children and young people with disabilities. Below is a list of quotations referring to what they feel are some of the most important challenges to be solved.

"It's important that young people are heard and taken seriously when they talk. That we are people with special knowledge and experience."

"We need everyone to be more accepting of children and young people with disabilities. We are human beings, just like everyone else, and have the same feelings and dreams."

"There should be more discussion about who needs to contribute more to the work on participation. People with disabilities need to be allowed to take part and talk about their experiences."

"We need more politicians who care about human values. Society needs to become more humane. Far too often, cases involve acute help for children and young people with disabilities." "Everything related to support comes with a price. We kind of have a price tag on us and have to constantly fight for our rights. How do you find the energy to participate in the outside world, when we have to struggle so much with the system?"

"There will always be challenges, but people with disabilities shouldn't feel like they're a problem."

"More universal design is important. You must have the freedom to move around. Political decisions often fail to support creating/increasing participation for people with disabilities."

"Send the parents out of the room so that children and young people can find their own voice. We have to have the chance to learn from our peers and to make mistakes and do stupid things as a young person."

"The transition from being a child to being an adult is a huge challenge for the individual and for society."

Some key definitions

Disability

Our definitions of the term's disability, disabled and persons with disabilities either refer to the capacities of a child or the relationship between the individual, his/her environment and society. The term "child with disability" is a description of the capacities of the child. This includes, in line with the UN Convention on the Rights of Persons with Disabilities, all persons 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 terms disability and disabled refer to limitations inherent in the right to and opportunity for participation. Disability describes the capacities of the individual, which do not necessarily obstruct participation or inclusion if the environment and surroundings are accessible. The concept of inclusion presupposes equality and the right to be different, and not just a right to be part of a community, as is the case with the concept of integration.²³ Within medical terminology, disability is used when the focus is on treatment and medical rehabilitation. It is also used in social sciences and the humanities to shed light on anti-discrimination laws and human rights.

The use of the term disability describes the gap that exists between the child's prerequisites and universal design or requirements on function. The disability is not a characteristic of the child, the child's circumstances or situation, in relation to society. There will always be an interaction, a synergy between people and their surroundings. Understanding this forms the basis for the gap model, which shifts attention from problems to opportunities for participation.²⁴ The environmental model²⁵ describes much the same distinction between having a disability versus disability as a societal phenomenon.

Article 2 of the UN Convention on the Rights of Persons with Disabilities defines concepts that are important to note in the work to safeguard children's rights. The need to define a number of the concepts inherently puts the spotlight on the multitude of barriers to participation that children and young people with disabilities can face.

²³ NOU:2019:18

²⁴ Lie, 1989

²⁵ Storgaard Bonfils et al. 2013

Communication comprises language, texts, braille, tactile communication, large fonts, accessible multimedia, as well as fonts, audio, easy-to-read language, reading aloud etc. Furthermore, language comprises all forms of speech and sign language, as well as all forms of non-verbal communication such as body language and facial expressions.

Lack of participation is often attributable to discrimination. Discrimination, for whatever reason, must not be allowed to prevent children from fully exercising their rights; to physical, social, economic and cultural environments, to health and education and to information and communication.

Accessibility and universal design are necessary so that all children and young people can have an independent life and be able to participate freely in all areas of life. In accordance with Article 9 of the UN Convention on the Rights of Persons with Disabilities, States Parties shall take appropriate measures to ensure that all children and young people with disabilities have access, on an equal basis with others, to the physical environment, to transportation, to information and communications, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures shall also include the identification and elimination of obstacles and barriers to accessibility.²⁶

Nordic region's Vision 2030 and Agenda 2030

In 2015, all UN Member States in the world adopted <u>17 goals and 169 targets for</u> <u>sustainable development up to 2030 referred to as Agenda 2030</u>. According to the plan, the 17 UN's Sustainable Development Goals, shall be reached by 2030.

The Nordic region is committed to implementing the agenda. The long-term strategic measures for Nordic co-operation are discussed in <u>A Good Life in</u> <u>a Sustainable Nordic Region: Nordic Strategy for Sustainable Development</u> <u>2013-2025</u>. The ministers for specific policy areas within the Nordic Council of Ministers monitor the strategy with specific measures, and developments in the Nordic region are monitored by means of indicators.

The <u>Action Plan 2020–2024</u> sets out the Nordic Council of Ministers' objectives relating to the sustainable development goals up to 2024.

A key message and goal for Agenda 2030 is not to leave anyone behind in the work on the development goals – "leave no one behind". This message provides a guideline for the work to achieve the sustainable development goals in the Nordic region, and the Nordic Council of Ministers has developed its own <u>policy</u> for the integration of sustainable development, equal opportunities and a child rights and youth perspective in every aspect of the Council's work.

The goals are based on the acknowledgement that sustainable development is not possible unless we ensure that all children have opportunities to participate and develop in all areas of life, in education, work, health and care, culture

²⁶ United Nations: Committee on the Rights of Persons with Disabilities, u.d., ss. Article 9 - Accessibility

and leisure. In order to achieve the goals, the UN has stressed the importance of ensuring the participation and inclusion of people with disabilities. The most vulnerable groups must have priority so that no one is left behind.

How do we define participation

Social participation and inclusion for all children and young people are often referred to in connection with the terms participation, autonomy, integration, normalisation and accessibility for all.²⁷ There is no one unambiguous opinion among researchers and professionals about how the concept of participation should be understood.²⁸ Our definition of the term will vary and change in terms of content and meaning depending on the context. The WHO describes participation as how and to what extent a child is involved in various life circumstances in terms of personal care, mobility, communication, social relations, family life and community and citizenship.

The International Classification of Functioning, Disability and Health (ICF)²⁹, adopted by the WHO, is often used to determine functional ability in relation to the individual's potential for participation in social life. Participation may require adaptation of aids and surroundings. The ICF is used to describe functions such as body structures, body functions, activities and participation and environmental factors. The emphasis is not on illness and diagnosis, but on the individual's functioning in interaction with the environment.

It is also common to distinguish between two forms of participation³⁰: Individual participation, when the circumstances involve one individual, and general participation, which involves different degrees of participation. The most widely used models describing degrees of and forms of participation are the models developed by Harry Shier³¹ and Roger A. Hart.

Shier's model outlines participation in five levels:

- 1. Children are listened to
- 2. Children are supported in expressing their views
- 3. Children's views are taken into account
- 4. Children are involved in decision-making processes
- 5. Children share power and responsibility for decision-making

Participation occurs at all five levels, and the model shows that participation is so much more than participating in a decision. The model consists of 15 questions, which when asked in order, serve as a useful tool for planning and facilitating genuine participation.

- 30 Stenhammar et al., 2011
- 31 Shier, 2001

²⁷ Traustadottir et al. 2015

²⁸ Kissow & Karlsson, 2018

²⁹ WHO, 2001



Roger A. Hart's Ladder of participation

Roger A. Hart's Ladder of Participation is an older but popular model. Hart's ladder illustrates how participation can take place. The ladder shows a clear distinction between what participation is and what it is not. One main distinction is whether the participation is genuine or not. The goal is that participation shall help ensure that children and young people's views are heard and given weight, and that their views may form the basis for decisions that concern them.³²

When there is the opportunity for participation, it is the child who should establish the framework for his or her participation. The interaction between the individual and the environment greatly affects the child's involvement and experience of participation. According to Shier's model, this assumes that the child has the opportunity, ability and willingness to participate.

The opportunity for participation comprises all situations where children and young people can participate in society with help, support and service. Key arenas for social participation for all children and young people are kindergartens, schools, cultural and recreational activities, social media and public debate. As the child grows older, these shall also include working and organisational life and civil society in its entirety. The opportunity for participation may also refer to management, decision-making, planning, follow-up and implementation of support measures.

The ability to participate is linked to the child's ability to exploit these situations according to their functional status, abilities and skills within different areas of life.

The extent to which a child wants to participate depends on his or her dedication, involvement and preferences when presented with different options. A child's desire to participate and get involved may change over time, for example as a result of experiences after he or she has been given the opportunity to try out different activities.

The UN Committee on the Rights of the Child has identified some very useful basic requirements that should guide all processes.³³

1. Transparent and informative

Children and young people must be provided with full, accessible, diversity-sensitive and age-appropriate information.

2. Voluntary

Children and young people should never be coerced into expressing views against their wishes.

3. Respectful

Children's and young people's views have to be treated with respect, and children should be provided with opportunities to initiate ideas and activities.

4. Relevant

The issues on which children and youth have the right to express their views must be of real relevance to their lives and enable them to draw on their knowledge, skills and abilities.

5. Child-friendly

Environments and working methods should be adapted to children's capacities.

Involvement, participation and user involvement

The terms involvement, co-determination, participation or user involvement are terms that are often applied interchangeably, and their meanings often overlap. In a 2018 edition of <u>Nordic Welfare Research</u>³⁴, five scientific papers shed light on different aspects of the phenomenon of user involvement. All articles are based on new empirical studies. One important element highlighted in the articles is that the use of the term is diverse and fluid, and that the terminology does not have neutral value. It is therefore necessary to acknowledge perspectives of power in order to successfully understand and apply the terms. When use of the term is not neutral, issues relating to power, empowerment, authorisation etc. must be taken into account to ensure genuine participation and influence.

Individual and structural limitations have implications for the opportunities for participation. This means that the way we approach work on inclusion is important in order to achieve dialogue. Children and young people may be alienated by the words we choose to use in our communications. Deliberate use of terminology in all contexts (research, media, institutions and services) is essential.

The language we use may result in alienation and help assign adults the power to make definitions. The influence of the child is impaired, for example, when the person who is supposed to provide help or support the child uses a bureaucratic or academic language. Another typical imbalance in the power relationship occurs when there are conflicts of interest between the child's needs and the resources available to administration.

"You have to be strong to get your rights. The weakest children and young people with disabilities don't always get the help they need, but the strongest do. It's difficult to get the right help, if you don't speak the language of the system."

Nordic youth delegates

The level of insight into what participation entails can also represent limitations on our success in this process. Different services and individuals make use of different terminology, and this also applies to the differences between the Nordic languages. In Norwegian, one common term is "brukermedvirkning", which translates as "user involvement", while the Danish use the terms "brugerinddragelse" (user involvement) or "borgerinddragelse" (public involvement). In Swedish, "brukarinflytande" (user influence) is a widely used term. In Icelandic, "notendamiðuð nálgun" and "notendastýring" are used. The former can be translated as "targeting the user" and the latter as "user control". The term in Finnish is "käyttäjän osallistuminen" (user involvement)³⁵.

Participation, democracy and citizenship

For the individual child and individual young person, the processes of democratisation in the different countries have resulted in changes in the relationships between adults and children. The views on children and childhood changed in the 1970s and have continued to evolve ever since. Children are now considered competent actors in their own lives. They are both opinion makers and entitled to their own opinions.³⁶

Children in the Western world are also perceived as vulnerable and exposed. This has shaped the way parents and state facilitate for childhood. On the one hand, the child is a subject and participant, and on the other hand is an object governed by the assessments and decisions of others.

Neither is it obvious what is in the child's best interests and who has access to the child's perspective. There are no objective truths here. We are restricted, among other things, by our own limited horizon of understanding, and by different interpretations and different knowledge of what is in the child's best interests at any given time.³⁷ Nonetheless, experience gained over recent decades shows that children and young people who are involved show that they have important views, experiences and perspectives. The knowledge they bring has proved central in improving the everyday lives of children and young people and in reinforcing the rights of vulnerable people. Participation contributes to personal development, better decision-making processes and decisions, and it better enables society to protect children. Participation prepares children and young people for active citizenship and also increases their tolerance of and respect for others. Supporting participation and social involvement for children and young people contributes significantly to responsible and transparent governance both in administration and in all arenas where children and young people spend time.³⁸

³⁵ Egilson et al., 01 / 2018 (Volum 3)

³⁶ Warming, 2011

³⁷ Warming, 2011

³⁸ Landsdown, 2011



Input from youth delegates regarding a future with more meaningful and genuine participation

An independent life

"We need better opportunities to study and become more independent. There's a fine line between support and independence."

"We want more independence. If we can feel confident that the support from society is there, then we can start to believe that we have a chance to live a good and independent life."

"When you want to make changes in your life, it's important that changes are possible. It has to be easier to make changes in order to have influence over your own life."

"Individuals need to be able to make their own decisions without this involving so much extra work, and that help and support are provided [referring to rights and support that may be lost, for example, when moving]."

"Persons with disabilities have to contact people themselves and try to be more outgoing. It is important that children and young people with disabilities are open-minded and ask questions. They can inform others about how and what."



Accessibility

"It's important to always think about accessibility from the very start, in all matters. All public places must be accessible. We have to, for example, get rid of or adapt all the spaces and buildings that are designed with large glass surfaces. These confuse people with visual impairments. One example is the new schools or buildings with glass walls. All it takes are some curtains."

"Public transport is important. Transport accessibility has to improve. So that you can spend time with others – all the time."

Knowledge

"We need to learn more about how we can get involved in the political system. How to present our own views? How to get help communicating in the political arena?"

"We need to see more classes for disabled children and others together, in customary environments. We must start with toddlers, so that it becomes natural for everyone to go to school together. The first years of school must provide children with a good foundation they can take with them as they continue their studies."

- "Many young people are studying and doing other things that limit their time. We may need more time."
- "Higher education is the norm, and this should therefore be seen among children and young people with disabilities."

Socially

- "It's necessary to meet people with similar disabilities, but equally important to feel that we are 'not different'."
- "More and better information has to be provided about accessibility in relation to activities. It's difficult to participate in informal environments, where you have to create structures for participation yourself."
- "The way we can participate in youth organisations also requires discussion. It has to be possible to have a different approach to participation. There is a difference between participating and having joint influence. Everyone must be able to participate on their own terms. By participating in an organisation or association, you can get help to speak out—so that your voice is also heard."

Listening to and involving children and young people helps to improve decision-making processes and enhances the capacity of society as a whole to protect them.

How to create opportunities

Methods for participation and inclusion

The Nordic countries are carrying out both systematic and knowledge-based efforts to ensure participation for children and young people with disabilities in several arenas. Nonetheless, it is evident that we have a long way to go in securing their right to be seen, listened to and involved in a number of areas.

A selection of examples of good working methods are described in this section of the report, as well as a selection of key challenges faced by children and young people with disabilities. The material is input from the Nordic experts who have followed the project. These are areas where the experts believe it is essential to increase and improve the efforts to secure the rights of the child. The material covers communication tools to ensure involvement at home and contact with key help services, methods that contribute to participation at school and in the kindergarten, in their spare time and during the transition to adulthood, and examples of collecting the views and perspectives of children in research into living conditions for children.

One common element in the methods presented is that they have transfer value. They can be used in all the Nordic countries. The examples mainly comprise work on participation and involvement for children up to the age of 18.

How to communicate with and involve children who are deafblind

The UN Committee on the Rights of the Child stresses that children are able to express an opinion from the earliest ages. This requires recognition of non-verbal forms of communication, such as play, body language and drawing. In practice, participation shall be included in all early efforts, during screening, therapy and family support etc.

Guardians, persons close to the child and helpers all meet complex challenges in the work to ensure communication and participation for children with deafblindness. They have a substantial need for knowledge and guidance. The book <u>If you can see it</u>, <u>you can support it – A book about tactile language</u>³⁹ contains 19 different articles. These provide a knowledge-based introduction to the different aspects of what is known as tactile language and formation of opinion. The starting point is communication in the form of dialogue, through, for example, gestures, imitations, and other body language. The target group for the book is guardians and professionals.

Once the use of tactile language has been implemented, there still remains interaction with the child to develop the language and use it so that it is stored in the memory and becomes an integral part of the child's social skills. The knowledge in these books on deafblindness also targets people who work with children with cognitive and communicative disabilities. The book is unique and of great value for professionals both in the Nordic countries and internationally.

Tactile Working Memory Scale – A Professional Manual, ⁴⁰ describes the necessary knowledge-based methods and tools to identify and assess tactile working memory in persons with deafblindness. The working memory is the ability to remember something for a limited period of time, which is absolutely essential for recognition and experience.

In order to communicate with children with congenital deafblindness, we need a bodily-tactile perspective on working memory. The manual presents a scale that can be used by professionals to identify and assess tactile working memory in children and young people with deafblindness, and to design tools and strategies. This is the only book of its kind and is used by professionals around the world.

Children and young people with congenital deafblindness often have a hidden cognitive potential not detected by those around them. A professional assessment of cognition may uncover latent skills and, with appropriate strategies, the person with congenital deafblindness may be able to develop his or her full potential. <u>Revealing hidden potentials</u> targets professionals who participate in analysis and assessments of cognition in cases of congenital deafblindness in both children and adults.

How to talk with children about difficult topics

<u>Snakkemedbarn.no</u> is a digital knowledge and training portal (the name translates as talk with children) designed to guide adults in conducting conversations with children and young people they are concerned about, including when adults suspect neglect, violence and sexual abuse. The portal is an interactive platform aiming to increase professional knowledge, and primarily provide active competencies for all helpers who work with children. The portal includes simulated conversations with children and young people where you can choose options for the conversation and practice building trust.

If we are concerned about the well-being of children, it is essential to talk with them so that they can be helped and rescued from hazardous and difficult situations. The opportunity to have a safe conversation with an adult will make the child feel less alone and will contribute towards follow-up of the child so that they can have a better life. When taking efforts to detect bullying, violence and sexual abuse of children, it is important to know how to conduct a conversation with a child, with the best interests of the child in mind and on the child's premises.

The methods shown in the portal are based on research, knowledge and theories about a child's cognitive level and ability to express themselves verbally. Three key sources of knowledge are research knowledge, user knowledge and experience-based knowledge.⁴¹

The training platform has been universally designed for training in conversations with all children and young people. It can be challenging to use these conversation methods in dialogue with children with major cognitive disabilities.

The opportunity to attend school and early childhood education

Children and young people with disabilities still face many barriers when participating in kindergarten and school. A Nordic review study of the educational needs and social conditions for hearing-impaired children and young people in kindergarten and school revealed several challenges. Children and young people with disabilities have severely limited opportunities for participation both at school and in social life in general. One important obstacle in this context is that schools and kindergartens fail to sufficiently establish inclusive practices for children and young people with hearing-impairments together with their peers.⁴²

The consequences of this failure to ensure inclusion in schools and kindergartens affect the children. As a group, their grades are poorer, they face greater psychosocial challenges, are lonelier and struggle to obtain the feeling of being a member of a peer group that many others take for granted. Moreover, there is little evidence that they will be consulted when their educational programme is being planned, or during their education.⁴³

In a Norwegian research project that followed 661 families and their children with disabilities throughout their childhood, the researchers found that the ratio of children who attended school at the same pace as their peers without disabilities fell gradually as their school education progressed. In kindergarten, nine out of ten were part of the community of young children. By the end of a full education, only around three of ten were at the same stage as their classmates. 85 percent of the young people with disabilities in the selection for the research had been granted disability benefit by the time they were 19 years of age. The project explains the fall in numbers as a result of the emergence of new selection mechanisms that push children into segregated groups. Increased requirements on performance at school widen the gap between school expectations and student performance. As a result, a number of the pupils were taken out of the classroom for follow-up by special needs educators. The

⁴¹ Helsedirektoratet, 2018

⁴² Kermit, 2018

⁴³ Kermit, 2018

pupils who were taken out of classes had fewer friends. These mechanisms particularly affected children with mental disabilities. Their parents felt that they had little choice when it came to allowing their children to take classes with their peers. The learning capacity of the children was not taken into account. So, even though the children were entitled to a place in school, many found that the offer of special needs education was the only real option.⁴⁴

"Everyone must have the education they need. Education is important. We need to look at how to facilitate and create access to education that suits the individual. My wishes and needs. The fact that classes are getting bigger and bigger is also a big problem."

Nordic youth delegates

Similar findings relating to obstacles have been made in relation to Danish school pupils.⁴⁵ Children with autism spectrum disorder or ADHD find the teaching environment in schools so challenging that many are reluctant to go to school. Over time, absence from school impairs enjoyment, resulting in the child spending longer periods of time at home, without any education. Another Danish study found that a school environment with a low level of facilitation and inclusion led to poorer well-being for the children, higher absence and lower school grades when compared with their peers.⁴⁶ The Ombudsperson for Children in Norway⁴⁷ and the Ombudsman for Children in Sweden describe similar circumstances. ⁴⁸ Many pupils who receive special needs education do not achieve a proper yield from their education and have a poorer psychosocial school environment than other pupils. When children are allowed to speak out, they describe a situation at school where they are met with low expectations, classes that are insufficiently adapted to their needs, and inadequate academic challenges.

⁴⁴ Wendelborg & Tøssebro, 2014

⁴⁵ Nielsen et. al, 2017

⁴⁶ Mortensen et al., 2020

⁴⁷ Barnombudsmannen, 2016

⁴⁸ Barneombudets fagrapport, 2017

"Expectations on children and young people with disabilities are too low. There are too many prejudices and ignorance regarding what is required to, for example, work with people with disabilities."

Nordic youth delegates

Children and young people with hearing-impairments who participate in classes together with hearing children struggle more at school and feel excluded. Data from two empirical studies of children with cochlear implants shows that children often pretend to understand, strive to behave as if they do not have hearing-impairments, and adopt a variety of strategies to hide their difficulties in understanding their peers. These are challenging and exhausting strategies that indicate that children are experiencing stigma.⁴⁹

Facilitating participation in schools and kindergartens

The right of children and young people to participate and be included is incorporated into the different countries' practices and curriculum for kindergartens and schools. This is a comprehensive process, and only a small selection of examples is presented in this document as a means of inspiration and to illustrate the diversity and complexity of this work.

Methods for a better school environment

The Swedish Agency for Participation (MFD) has carried out safety surveys together with pupils with disabilities. Pupils with disabilities are more vulnerable than their peers. They often have a greater need to seek out privacy and get rest. The surveys carried out by the MFD clearly show that pupils with disabilities want and are able to help shape the school of today and tomorrow. The method they have developed for the safety surveys aims to help ensure that children are able to communicate what works at school and what does not work, based on their own experiences. The report Skapa en trygg skola, Genom trygghetsvandringar med elever med funktionsnedsättning (Create a safe school by means of safety surveys with pupils with disabilities) provides an introduction to how schools can work to ensure a safe environment that improves the premises for motivated pupils and learning for all pupils.

Betri vinir

Betri vinir – Free of Bullying is a preventive anti-bullying programme for children aged 0-9 on the Faroe Islands. The programme comprises educational material with guidelines for specific and targeted work that helps to strengthen a sense of community among children, contributes to participation and inclusion and prevents bullying and exclusion. The material is packaged in a suitcase and is available in three versions targeting children of different age groups, 0-3 years, 3-6 years and 6-9 years. The Free of Bullying project was launched by The Mary Foundation in Denmark, and has been adapted to conditions on the Faroe Islands by Barnabati, The Mary Foundation and Save the Children. The project name in Faroese is Betri vinir. <u>The method has been evaluated and found to</u> <u>produce good results</u>. It is Denmark's most widespread anti-bullying programme, and is also used in Iceland and Greenland, amongst others.

Lego Braille Bricks

<u>The LEGO Foundation</u> has started a project named <u>LEGO Braille Bricks</u>, in which they have embossed Lego bricks with braille. Letters are also printed on each brick. This allows sighted and blind pupils and family members equal conditions for interaction. The combination of play and learning contributes to inclusive learning for blind and visually impaired children who need to learn braille.

Educators in kindergarten and school can use the bricks when teaching blind and visually impaired pupils. The purpose is to learn braille in a playful way and make it possible to collaborate with fellow pupils. Pupils can share a Lego base plate to create words with the bricks, or use their own base plate, then compare what they have written in a visible and accessible way. The Lego set comes with guidelines describing different exercises using the bricks.

By the end of 2020, around 20 countries, including all the Nordic countries, will receive Lego boxes as donations from the LEGO Foundation.⁵⁰ Each country is responsible for distributing the boxes to educational enterprises for blind children between the ages of 4 and 10.

SSI is an instrument for interviews

<u>SSI</u> (school setting interview) is an interview instrument which, based on the student's perspective, identifies the need for adaptation in school. It was first introduced in Sweden under the name BAS (Bedömning av anpassningar i skolmiljön). SSI is intended for children and young people from about 7 years of age and up.⁵¹

⁵⁰ The idea to create LEGO Braille Bricks was first proposed to the LEGO Foundation in 2011 by the Danish Association of the Blind, then again in 2017 by the Brazilian Dorina Nowill Foundation for the Blind. The concept has since been further developed in close cooperation between associations of the blind in Denmark, Brazil, the UK and Norway. The first prototypes have now been sent to these countries for testing. The LEGO Foundation in Denmark is responsible for producing the Lego boxes.

⁵¹ Lindström et. al, 2020

Several functions in the school environment affect pupils with disabilities and serve either as support or barriers to school participation. The purpose of the interview tool is to chart the students' perspective⁵² in order to ensure efficient and targeted facilitation, in co-operation with occupational therapists and other key academic bodies.

The tool has been designed to facilitate planning of support and adaptations in the school environment in consultation with the pupils. SSI comprises 16 questions about everyday school activities in which pupils may need adaptations to be able to participate. SSI can also be used by special needs teachers, special needs educationalists and other professionals who focus on the pupil's activity and participation in school. The instrument has been tested for reliability and validity, with good results. Linköping University_has carried out research on the working method and the tool.

Participation and influence in school life

A number of universal guidelines and learning resources to ensure participation and influence in the countries have been implemented. The diversity of methods is extensive, and we have included a selection of relevant websites below for further reading.

In Sweden, guidelines for work on participation are described in, for example Curriculum for the Preschool: Participation and influence of the child (LPFÖ 18). A number of good guidelines have also been developed for educationalists and teachers.⁵³

Similar tools can be found in Finland. The <u>National core curriculum for early</u> <u>childhood education and care 2018</u> for 0-5-year-olds describes guidelines for work on participation, equal treatment and equal opportunities. The <u>National</u> <u>core curriculum for pre-primary education</u> in Finland also includes work on participation. This highlights the importance of ensuring children's participation and influence in schools as this lays the foundation for a democratic and sustainable future.

The National Agency for Special Needs Education and Schools in Sweden has published <u>Delaktighet – ett arbetssätt i skolan</u> (Participation – one working method in schools). This publication contains descriptions of good working methods that support the pupils' right to participation and the right to an equal education.

Denmark's digital learning portal for teachers, educational employees and managers, describes a number of experiences and working methods for inclusion and participation for children and young people. Inclusive learning environments relate to how children and young people can learn, thrive and develop at school.

In Norway, <u>Statped has a website</u> providing teaching aids, tools, approaches and technology to facilitate development and learning when children, young people and adults have special educational needs.

⁵³ Skolverket, 2020

Young people with disabilities often refrain from participating in leisure activities because they are afraid of encountering a hostile reception. 5

Being with friends in your spare time

Accessible meeting places are required for a wide range of needs, and where the threshold for participation is low for children and young people regardless of finances, social status and disabilities. The Convention on the Rights of the Child recognises this; all children have the right to rest and leisure, to engage in play and recreational activities and to participate freely in cultural life and the arts. This implies that participation in recreational arenas shall be possible for children and young people with disabilities. This includes a country's youth clubs and youth centres, culture, sports and all children's and youth organisations.

"It is important for us to spend time with friends in cultural settings. It is important to create accessibility, such as being able to participate and use the same entrances as others for recreational activities. This is a matter of spending time with friends, not in parallel settings."

Nordic youth delegates

Within both international and Nordic research on participation for children and young people with disabilities, we see the same trends – they participate to a lesser extent in most areas of everyday life and in social and cultural groups, when compared with their peers. Children and young people with invisible or less visible disabilities in particular find that they do not have sufficient access to recreational activities.⁵⁴ For young people and young adults, participation is even more limited when compared with their peers without disabilities.⁵⁵

Recreational arenas are important places for friendship and recreation. The variation in participation and the ability to participate is vast between different groups of children and young people. Children and young people with disabilities participate more often in more sedate recreational activities, which lack variety and often take place at home.⁵⁶

A survey conducted by the Swedish Agency for Youth and Civil Society (MUCF) identified a clear link between children and young people's mental health and their opportunities to participate in meaningful activities in their spare time. Young people who are satisfied with their spare time have less symptoms of mental illness, and most of the young people in the study say that they have good opportunities to participate in different types of recreational activities. However, some groups experience obstacles more often than others. These are primarily young people with disabilities, born abroad and young LGBT people.⁵⁷

Young people with disabilities often refrain from participating in recreational activities because they are afraid they will not be welcome. Around four out of ten young people also report that recreational activities cost too much. The MUCF recommends that more should be done on health-promoting factors and economic opportunities that can help give more young people the opportunity to participate in meaningful activities in their spare time. Among other things, they propose that the Swedish authorities investigate whether public actors' premises, such as schools, can be used to provide a higher number of and more inclusive meeting places.

Methods for inclusive play

In an effort to provide inspiration for inclusion of children in a game or activity, the Knowledge Centre on Disability in Denmark has created a database where users can search among more than 150 games, toys and activities that can be customised to allow everyone to participate.

The database is designed so users can search among different games and activities, and refine the search. You can search for games indoors, outdoors or in water. The games vary from dance and drama to running. The number of participants and any props for use in the game can be entered into the search engine.

Body, movement and relationships are key to the work of the Knowledge Centre on Disability. Participation in sports and movement lay the foundations for learning and development that strengthen the individual's participation

⁵⁴ Kissow & Karlsson, 2018

⁵⁵ Grue, 2001

⁵⁶ Kissow & Karlsson, 2018

⁵⁷ Myndigheten för ungdoms- och civilsamhällesfrågor, 2020

and social involvement. Social participation in an arena has an impact on other areas of life and can provide better opportunities for education, employment or voluntary work.

The centre works with participation in four focus areas:

- 1. Adapted sports, exercise and outdoor activities
- 2. Health, rehabilitation and movement
- 3. Education
- 4. Work

ALLEMED, a tool against exclusion

ALLEMED (ALLIN in English) is a dialogue tool and a tool against exclusion, developed by an NGO in Norway. The purpose of the tool is to help more people contribute toward inclusion of all children and young people in recreational activities, thereby preventing exclusion among children and young people. ALLE-MED is a free tool for action to include all children in their spare time regardless of their financial situation, background and ability. There are two versions of the tool, one for the municipal sector and one for the voluntary sector.

The tools are used to generate debate and raise awareness of exclusion among children and young people, and the goal is to come up with concrete ideas on how to work to find solutions that give all children and young people the opportunity to participate in organised recreational activities.

It can be difficult to gain an overall picture of activities for children and young people in their own local environment. Information about low-threshold and facilitated offers does not always reach the target audience. The bank of information for inspiration contains, e.g., examples of how different municipalities and organisations have taken measures to make their services known. The tools can be used for parent-teacher meetings or board meetings, during a seminar for coaches or at meetings for managers etc. The ALLEMED website features movies, inspiration and tools.

Inclusive sports

Children and young people who have visual impairments do not always have access to inclusive physical education or active recreational pursuits. The Swedish Association of the Visually Impaired has carried out a three-year collaborative project⁵⁸ on sports, activity and health for children and young people who have visual impairment. The project has produced material aimed at different target groups.

⁵⁸ A collaboration between the Swedish Association of the Visually Impaired, the Swedish Sports Confederation, the Swedish School of Sport and Health Sciences in Stockholm and Parasport Sweden with funding from the General Heritage Fund.

- Rörelseglädje och hälsa barn 0–5 år (Joy of movement and health children 0-5 years) (PDF)
- Rörelseglädje och hälsa barn och ungdom 6–18 år (Joy of movement and health children and young people 6-18 years) (PDF)
- Idrottens möjligheter och hinder (The opportunities and limitations of sports) (PDF)
- Information folder describing the material (PDF)
- Historic sports project (PDF)
- All brochures in DAISY format (zip)

The material can be used as inspiration for inclusion of children and young people in physical education and to find joy of movement in everyday life. The project has developed a <u>Handbook for teachers</u>, to inspire teachers and others to provide more inclusive physical education and to increase participation by visually impaired children. The website also has a film, as a substitute for printed text.

All children and young people have the right to participate as active citizens in society at all levels. They must be able to participate in democratic processes, and they must have the opportunity to influence their own daily lives.



Having a say

The ability and willingness of society at large to facilitate general awareness is of great importance. Children's participation in society emerges as a result of the experiences they themselves acquire by being assigned and taking responsibility. Children and young people with disabilities have the right to participate as active citizens in society at all levels. They shall be allowed to take part in democratic processes, and they shall have the opportunity to influence their daily lives and development of society.

Participation can provide the individual with both a sense of belonging and access to social networks. Participation is in itself beneficial for the health, good physical and mental health is often a key prerequisite for active participation in society. Various sample surveys have uncovered that people with disabilities run a higher risk of health problems, often have lower education and income, and participate to a lesser extent socially and in working life than others.⁵⁹

In more recent research relating to children, the child's experience of being met, seen and respected is emphasised as fundamental to the development of self-worth and identity. How the child experiences being listened to, the extent to which he or she can have a say, and whether the child is noticed affects the child's quality of life here and now. ⁶⁰ This focus on childhood here and now has an impact on how we see and understand the child. When involving children and young people with disabilities in decisions about support, rehabilitation or facilitation, it is thus not only the fact of providing help to the child that is important. For the child, it is equally important to be met with respect and to feel that he or she is taken seriously. The opportunity to lay the foundations for our own lives gives us a sense of self-esteem and self-worth.

Unfortunately, it is also the case that more children and young people with disabilities are in difficult life situations than their peers. International research has found that children and young people with disabilities are three times more likely to experience bullying, violence and sexual abuse than other children. Both in the Nordic countries and internationally, they are more exposed to bullying than others and are more often involved in cases where they are taken into care due to neglect and violence in close relationships.⁶¹

In a Norwegian public inquiry into cases where children have been victims of violence, sexual abuse and neglect, one of the central areas where these children are failed was that those who work with and meet children on a daily ba-

⁵⁹ Statens folkhälsoinstitut, 2011

⁶⁰ Warming, 2011

⁶¹ Montefusco, 2016

sis talk about children they are concerned about, but not with them.⁶² Another committee found that the child's best interests are not always a fundamental consideration when formulating health and care services for children with intellectual disabilities and their families. They also found that more children with intellectual disabilities do not receive a sufficient service in children's and respite care.⁶³

One of the most important methods for discovering that children are having difficulties is to facilitate good conversations with the child in a way that makes the child feel safe enough to speak out. The main objective is to develop good conversations in terms of quality, where we can learn how the child is feeling and what he or she needs. This requires both competencies and enough time.

Toolbox for participation

Children and young people have participated in the work to identify key skills and methods required when working with people with disabilities in Finland. The VamO participation project⁶⁴ aims to develop good working methods to strengthen and further develop expertise within social work for Finland's Handicap Service.⁶⁵

The working methods have been developed by professionals in collaboration with researchers at the University of Lapland, Rovaniemi and collected in a <u>toolbox</u> to be used in order to listen to and involve children and young people with disabilities. The aim of the toolbox is to ensure that children and young people with disabilities are listened to and are allowed to participate in the formulation and facilitation of their own services. The toolbox can be used by anyone who works daily with children and young people with disabilities. The toolbox is available online in <u>Handbook on disability services</u>, a knowledge-based portal for policy-makers and employees.

One good example is <u>Talking Mats®</u>. This method has been designed to contribute to conversations and participation for children and young people with disabilities. To make a Talking Mat, you need a door mat, printed images and a piece of Velcro. The images shall be chosen to suit the subject of the conversation, such as recreation, skills or housing, as necessary.

The subject to be discussed is placed in the centre of the mat with an assessment scale at the top adapted to the subject of the conversation, such as good to bad. The questions must be open, not leading. Ask, for example, "What do you think of this?" rather than "Do you like this?"

The method was developed and registered at the University of Stirling in

⁶² NOU: 2017:12

⁶³ Barne-, ungdoms- og familiedirektoratet, 2020

⁶⁴ Heini et al, 2019

⁶⁵ Nordlund-Spiby et al., 2019

Scotland. In Finland, Tikoteekki provides training on how to use the talking mat, and the Papunet website contains more information and examples of videos on how the mat can be used.

The Najorti scheme, spokesperson for the child

The Najorti scheme gives children in Greenland a "children's expert" when meeting the authorities. The objective of the scheme is to ensure that children and young people are accompanied by an adult when their social and care issues are to be discussed. Specifically, a najorti participates with a child in meetings with the municipality. The najorti assists the child in having his or her say and being allowed to give statements in his or her own case. To date, experience shows that the scheme has helped more children make greater demands on the adults surrounding them. In the new child support law⁶⁶, local authorities are now obliged to offer a child a najorti when the municipality plans to discuss cases involving respite measures in the home. This is a new scheme in Greenland, and it includes all children, both with and without disabilities.

Child impact analysis

The Family policy programme for the province of Åland describes how the province shall utilise and apply child impact analyses in its work. The Government of Åland has stipulated that the administration shall identify methods by which to incorporate the impact analyses in relevant decisionmaking processes. The rights of the child perspective shall be applied when preparing budget proposals. The perspective shall be taken into account in all cases affecting children directly or indirectly, and the impact on children shall be assessed. Save the Children in Åland has received support for developing and providing training in the work to carry out child impact analyses for the municipal sector. The training is under way.

The child as an informant, research on quality of life

In the LIFE-DCY research project at the University of Iceland⁶⁷, children and young people with disabilities participate in charting their own quality of life and participation in different fields.⁶⁸

The LIFE-DCY research project has two goals. Firstly, Children's Quality of

^{66 &}lt;u>Greenland Parliament Act (Inatsisartutlov) no. 20 dated 26 June 2017 relating to support</u> <u>for children.</u>

⁶⁷ Ólafsdóttir et al., 2019

⁶⁸ The LIFE-DCY study team

Life is evaluated based on their own descriptions and those of their parents. The second goal is to find common features, differences and contradictions in reports that may affect variations in quality of life and participation for children with disabilities.

The method design used was complex sequence analyses. In brief, this entailed the following: During phase one of the project, the charting phase, the KIDSCREEN-27 method was used. Kidscreen is a recognised method for obtaining children's assessments of their own quality of life in different areas. The findings were compared to the parents' assessments and assessments made by children without disabilities and their parents.

By applying PEM-CY, "participation and environment measures", the research team then studied the guardians' assessments of children's participation in different social settings. A total of 209 children with disabilities and their parents, as well as a control group comprising 335 children without disabilities and their parents, participated in the charting phase.

The aim for phase two was analysis of the qualitative information consisting of the views of the children and their parents. Fourteen case studies were conducted with children with disabilities. Four group interviews with young people with disabilities were also carried out. The subject of these interviews was the young people's reflections on childhood and adolescence.

The methodological approach facilitated comparison of findings within and between the data sets, to reveal similarities, differences and key indicators of quality of life as interpreted by children with disabilities, and also how these subjects are interconnected.

The theoretical understanding used in this study can help uncover different aspects of childhood and disabilities that affect knowledge and power, and contribute to more knowledge about how ideas about childhood and disabilities are constructed. A number of articles in the project have been published, and more are in the pipeline.

Becoming self-reliant

Young people with disabilities, like all other young people, want to be selfreliant. They want a life with active participation in society and working life. Many of them experience the opposite. For many, the consequences are marginalisation and loneliness due to insurmountable barriers.

"We want a more independent and selfreliant future. If we can feel confident that the support from society is there, then we can start to believe that we have a chance to live a good and independent life."

Nordic youth delegates

The transition from young person to adult involves moving away from home, starting studies or work, forming new relationships and higher demands to make your own decisions. Young people with disabilities have and face greater challenges in the transition to higher education and in the transition to adulthood.⁶⁹ Challenges in finding work, housing and a sense of belonging are part of the reason why they have lesser opportunities to become independent than their peers with no disabilities. There is a significant need for a more successful support system around this transition. These challenges faced in the transition to higher education, employment and own housing are clear in the statements made by the youth delegates. When these obstacles stack up, the situation may seem impossible. The teaching institutions are described as inflexible and inaccessible. Both the design of the physical environment and



Increased participation in the labour market has long been a key political aim in the Nordic countries, but remarkably few people with disabilities have ordinary (non-adapted) jobs.

the need for individual adaptation of studies are difficult.⁷⁰

A survey on participation in working life for persons with disabilities studied the features of the education offered in upper secondary school⁷¹. The researchers found that young people with disabilities do not to a large extent participate in mainstream teaching. The most common education offered to pupils with intellectual disabilities is a combination of training for working life, ADL (everyday life training) and training in basic skills in common core subjects. It is evident that the school's expectations on pupils with disabilities are influenced by what the school believes the young people can expect once they leave school. If the school expects that the young people, as adults, will be enrolled in day activities provided by their municipality, then the academic content and expectations on that pupil may be far lower than if the school expects the pupil to gain employment.

Increased participation in working life has been an important political goal in the Nordic countries. Nonetheless, very few participate in ordinary work. A major study from Norway shows an increase in the ratio of people with intellectual disabilities who do not have daytime activities, and that only a small number of people with disabilities are covered by measures to integrate persons with reduced working capacity into ordinary working life.⁷²

A Nordic qualitative study⁷³ evaluated compliance with Article 19, the right

- 71 Wendelborg & Tøssebro, 2017
- 72 Wendelborg & Tøssebro, 2014
- 73 Brennan et al., 2018

⁷⁰ Tidemann et al., 2020

to live independently, in the UN Convention on the Rights of Persons with Disabilities. The findings of the study suggest that significant reforms and a shift towards a rights-based approach to welfare services are necessary. Behind the Nordic countries' reputation as forerunners in relation to independent housing and personal assistance, there remain challenges that cannot be sufficiently solved without involving services based on rights. Some of the issues raised are inflexible services, poor access to information about personal assistance and power imbalance. Control of the services mainly lies with the system and professionals.

Living a good and independent life

Fountainhúsið or Fountain House is a meeting place and a voluntary work community for young people and adults (18-67 years old) who have or have had mental health problems. At Fountainhúsið in the Faroe Islands, the mentally ill can participate in meaningful activities or tasks. The goal is for more people to learn skills that can help them become fully or partially independent. Fountainhúsið emphasizes the individual's resources and opportunities, rather than illness or disability. The Fountain House model is both a psychiatric rehabilitation service and a work-oriented low threshold initiative.

The model is in use in several of the Nordic countries and around the world. Fountain houses shall be managed in accordance with common international standards. They are based on voluntary work and equality at work. The houses are owned and managed by the members and pay full respect to the potential of each individual to participate.

The Fountain houses are governed by 37 international guidelines to ensure compliance with the houses' main principles. The goal is also to certify a Fountain House every three years according to an <u>international standard</u>, in agreement with Clubhouse International.

"We need to find a new perspective on obstacles. It is important that society starts to see children and young people with disabilities as a resource and enables us to be just that, by providing us with education and work."

Nordic youth delegates



Some advice from the expert group regarding work for and with children and young people

- Build up the strengths of the individual child. Create inclusion, recognition and quality of life here and now. This is how we promote participation and improve quality of life for more children and young people.
- Children need early support in expressing their views, so that they learn that their voice also matters. Many children with disabilities are not expected to have their own opinions in preschool or school.
- The most important working method is found in how we think when ensuring participation. We need to seek the child's perspective – and voice. It is only when we place the child at the centre that we can take active measures to ensure genuine participation and influence.
- Contribute to increased knowledge among parents, personnel and authorities
 - about how to talk with and about children with disabilities
 - about how to facilitate dialogue
 - about how children must be heard and taken seriously
 - about children's best assessments when the child has a disability
- Provide a lot of support and guidance to guardians and persons close to the child. They need increased competencies in the use of different methods for dialogue and participation.
- Prevent loneliness. Loneliness is harmful to all children, and friendship is important for well-being and development. Socialising boosts a child's development, and social networks have a protective function.
- Support informed choices. Facilitation and assistance must be adapted to the individual's needs. The child's knowledge of his or her own life and needs must be taken into account. Parents, support persons and teachers all need more knowledge about how to see opportunities and not limitations, and how the child can become more confident in their own strengths.

Final considerations

Empower children and youth

In an international context, the Nordic region has made significant progress in the work to comply with the UN Conventions and follows an active and inclusive welfare policy. In spite of this, it is evident that children and young people with disabilities are not secured sufficient participation and influence in several areas.

Children and young people with disabilities do not have the same opportunities and conditions as their peers in kindergarten, school, in their spare time or in the transition to an independent adult life. The expert group behind this report has concentrated on highlighting how to work better in these areas specifically. They have also provided knowledge of several of the major challenges and obstacles faced by children and young people. In this report, we have highlighted research contributions that describe key challenges. This does not, however, provide a comprehensive picture of the challenges in the field.

Several of the areas identified by current research as key challenges in different and important areas of children's lives require further investigation. First of all, a study is required to identify how we can work better and more purposefully both nationally and in the Nordic region.

Inclusion and participation are both a process and a goal in ensuring that all children are seen, heard and involved. This is a matter of meeting the individual's prerequisites and needs in the best possible way. It also requires a society that at all times facilitates diversity and inclusion.

This precisely encapsulates one of the main challenges in the work on participation – to constantly remember that the objective is inclusion and participation for all. The goal is a Nordic region where all children and young people are seen and heard in all arenas and in all contexts.

The youth delegates have explained that they too often experience being questioned or ignored. They demand to be listened to more, to be respected, and to be empowered in their own lives.

"It's important that young people are heard and taken seriously when they talk. That we are regarded as people with special knowledge and experience." "When you want to make changes in your life, it's important that changes are possible. It has to be easier to make changes in order to have influence over your own life, an independent life."

Nordic youth delegates

No children and young people should be left behind

The work to ensure participation and inclusion for all children and young people requires knowledge-based efforts. We need to know what works. This is also an ongoing process. It involves constantly meeting the assumptions and needs of each person in the best possible way. It also requires a society that at all times facilitates diversity and inclusion. This means that we have to work purposefully to succeed.

The procedure that determines whether we have a sustainable future is Leaving No Child Behind (LNOB). The promise to not leave anyone behind lies at the heart of the sustainable development goals. So, what does this vision mean for our work for childhood in the Nordic region? How shall we work systematically and purposefully to promote social sustainability in various sectors such as kindergartens, schools and important social arenas in the sports, cultural and recreational sectors?

First and foremost, this work requires the elimination of obstacles and inequalities that undermine the potential of individual children, but also for all children and young people in the Nordic region as a whole. The UN's tools and guidelines are necessary in this process, both in order to operationalise and to follow up on the obligations.

The work includes identifying who is being left behind and why, identifying effective measures to address fundamental causes, monitor and measure progress and ensure accountability in relation to LNOB nationally and in the Nordic countries.⁷⁴

⁷⁴ What does it mean to leave no one behind? A UNDP discussion paper and framework for implementation July 2018

"Policymakers and those in power, such as politicians at national and local level, should play a more active role in the work on participation for all. A systematic approach is important. They should talk more to the young people and gather their views."

Nordic youth delegates

The commitment to work purposefully and systematically is followed up via the Nordic co-operation. Several of the Nordic initiatives are described in the Nordic Vision 2030 action plan and the <u>Nordic Action Plan on Disability</u>. Among other things, there is a need for more Nordic co-operation on knowledge development and analysis, development of knowledge-based and targeted efforts and more knowledge sharing. The co-operation shall comprise several sectors, including civil society organisations, the private sector, Nordic research networks and youth organisations.

Participation for children and young people, and the Nordic co-operation

Efforts to ensure increased participation for children and young people with disabilities in the Nordic countries must be based on participation. In other words, Nordic actors must involve children and young people in both knowledge sharing, debate and method development within the field.

"We need more co-operation between youth organisations for children and young people with disabilities. It is important that we unite in the Nordic countries, so that we can strengthen our voice."

Nordic youth delegates

Such co-operation will be a natural part of the goal to increase co-operation on participation for children and young people in the Nordic countries, between authorities, institutions, the voluntary sector and youth organisations. NORD-BUK, the Ombudsmen for children, the Nordic Welfare Centre and non-profit organisations are key players in this co-operation.



Input from youth delegates: suggestions on how Nordic co-operation can contribute to better opportunities in the future

"We need more co-operation and contact between the countries, for young people. We also need more co-operation on different disabilities at EU level."

"We can find inspiration in the success stories from other Nordic countries if we cooperate more."

"Today, the level of co-operation in the Nordic countries differs. In Norway, for example, summer camps are very common. Almost all parties arrange political summer camps for young people. In Finland, there are none. If we work together at an organisational level on challenges involving participation, we can achieve a lot, but this will probably involve a significant effort."

"It is positive for Nordic co-operation that we also involve the Baltic states, so that they take part and learn, and vice versa. Estonia, for example, thought that the Nordic countries were very far ahead, but it has emerged that we have many similar challenges."

"More conferences and programmes can be initiated to mobilise children and young people with disabilities in the Nordic countries (empowerment)."



It is important to increase awareness of the methods that contribute to genuine participation.

"It has to be easier to study and work throughout the Nordic region for people with disabilities. One example is Nordjobb. Among other things, regular checks should be made of how national systems integrate with each other, and if they are transferable, especially when it comes to education and studies, to make it easier for young people with disabilities to study or work elsewhere."

Knowledge of the Nordic region's work on Article 12

The gap between the opportunities available to children with and children without disabilities shall be reduced nationally and internationally. To achieve this, we need knowledge-based and targeted work on compliance with Article 12. A Nordic co-operation will represent an important contribution.

Nordic co-operation on Article 12 should be based on the recommendations of the UN committees to the Nordic countries. This work can be supplemented by a comparison of recommendations relating to relevant articles in the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. Systematic and knowledge-based work can, for example, be based on methods used in the work on existing indices on convention follow-up⁷⁵ internationally, or separate and delimited Nordic overviews may be developed. Subsequent analyses of the recommendations can be used to highlight common challenges and lay the foundations for methodical and targeted Nordic co-operation.

Monitoring living conditions for children and young people

At the time of writing, we do not have Nordic indicators to monitor efforts to reduce the gap between the opportunities for participation and development for children and young people with and without disabilities. Such indicators are required in order to discover whether the work we are doing actually helps improve their conditions.

Many organisations have underlined the importance of improving access to data and statistics on living conditions for people with disabilities (including the UN, WHO and the EU). On this basis, a <u>Nordic co-operation</u> has been initiated to develop comparable statistics regarding disabilities. The project is part of the Nordic Council of Ministers' action plan for co-operation on disabilities, and the assignment has been delegated to the Nordic Welfare Centre and Nordregio.

Nordregio is carrying out a mission from NORDBUK to compile statistics on children's living conditions in the Nordic countries. This assignment does not currently comprise indicators for monitoring the living conditions of children and young people with disabilities in the Nordic countries.

Systematic co-operation on sustainable practice

There is a need to study in more detail what methods and practices we use to ensure involvement and participation, in order to identify which procedures actually work.⁷⁶

⁷⁵ For example: KidsrightsIndex

⁷⁶ Arnason, 2018

The scope of practice and methods to provide children and young people with disabilities with the opportunity to participate and develop is extensive, and the quality of the practice varies.⁷⁷ Among other things, it is important to gain more knowledge of which methods contribute to genuine participation, so that the individual feels that he or she is both seen and included.

A systematic knowledge development can be based on scientific methods such as field studies, action research or case studies, or the execution of systematic practice development.⁷⁸ One method of mapping and systematic development of knowledge about good practice has been developed by VIVE in Denmark. The method consists of a typology that is designed to describe good (promising) practices.⁷⁹ The Nordic Welfare Centre has applied this typology in a report on early efforts for immigrant children, young people and parents in the Nordic countries.⁸⁰

- 77 Kissow & Karlson, 2018
- 78 Kissow & Karlson, 2018 p 46-47
- 79 Cramer Jensen el al., 2016
- 80 Määttä & Gärdegård, 2020



The work to assure participation and inclusion for all children and young people requires a knowledge-based approach.



Actors in the Nordic countries

There are numerous social actors with responsibility for contributing to compliance with Article 12 of the Convention on the Rights of the Child. National, regional and local authorities shall ensure compliance with the Convention. Civil society and voluntary actors also play an important role. They work in a number of arenas that allow children and young people to participate socially, develop their creativity and gain experience of democracy and citizenship.

The overview presented in this chapter is not exhaustive but, includes many of the most important players in the countries and the Nordic region. We also briefly describe the role played by the different actors in ensuring participation for children and young people with disabilities. The overview has been prepared in consultation with the Nordic expert group that has monitored the work.

Nordic Council of Ministers

The Nordic governmental co-operation has a common vision that the Nordic region must be the best place in the world for children and young people. <u>Chil-</u> <u>dren and Young People in the Nordic Region: – a cross-sectoral strategy for the</u> <u>Nordic Council of Ministers 2016-2022</u> covers all children and young people in the Nordic countries aged 0-25 years. The strategic focus areas are:

- Enhanced support and inclusion for disadvantaged children and young people
- Continued collaboration with and support for civil society
- Improved knowledge-sharing and efforts to enhance skills

In order to ensure that participation by children and young people is carried out in a way that safeguards the rights of children and young people, a memorandum on guiding principles has been developed that lays the foundations for all Nordic activities; <u>When involving children and young</u> <u>people in the work of the Nordic Council of Ministers: Principles and</u> <u>approaches.</u> The memorandum shall be used to ensure that the work is based on a number of guiding principles, with a joint minimum level for the involvement of children and young people, and above all else, in a way that protects and safeguards the safety of children and young people.



Input from youth delegates about actors who need to contribute more

"The local community and local authorities play an important role in the work to ensure inclusion. They have to cooperate more to ensure that all services are more universal. Especially in the network around schools and recreational activities."

"Recreational activities are so important. We need meeting places where both disabled and nondisabled young people can meet. These meeting places need to be more accessible."

"Governments should hire more people with disabilities. Universal design is essential for this to happen. Governments should also be held more accountable for the services provided by local authorities and municipalities. People should have access to the same services, support and rights regardless of where they live."

"Policy makers should talk more to the young people and gather their views."

"More disabled politicians need to commit to and get involved in the work on participation, including at municipal level." "The local community is an important player because parents, children and young people need a local support system and a community that is willing to be inclusive."

"Teachers should be more encouraging and invite students and parents to collaborate, and make sure to include students with disabilities in all activities, including after-school activities. They need to understand that children can participate socially and be more involved."

"Teacher training is important. Teachers should know more about inclusive teaching methods. Teaching helpers/assistants at school also need training. And they should have a degree/education in the field."

"It is important that assistants allow pupils/students to be independent. Assistants must not take over, they must understand their role and not intervene socially. The pupils need to have the social space more to themselves and to be allowed to be themselves. The assistant is not the pupils' friend."

"The media should be more active in portraying diversity and people with disabilities. Journalists should be trained in how to portray, talk with and about children and young people with disabilities. For example, the media must avoid pitfalls such as portraying disabled people as 'special' and 'heroes'. This promotes neither inclusion nor equality."



"Dpos [Disabled people's organisations] are important players, as they offer networks and are a support system that shows others that they are not alone."

"It is difficult to achieve any concrete results in co-operation with other social actors such as the Ombudsperson for Children. There is often uncertainty about children and young people as a target group, especially if this includes children with disabilities."

"Parents are an important player. They need more support. They are often left on their own. They should, for example, receive training in when to let go, so that the child can be more independent and make their own decisions."

"The Nordic Welfare Centre is an important player. They can help promote mobility and how to influence mobility in the Nordic countries. A roadmap should be developed on how to take a [study] semester abroad, and an online portal with information on accessibility."

NORDBUK

The Nordic Committee for Children and Young People (NORDBUK) is the Council of Ministers' advisory and coordinating body on issues related to Nordic and international children's and youth policy. The committee consists of representatives of both authorities and youth organisations from Denmark, Finland, Iceland, Norway and Sweden, as well as government representatives from the Faroe Islands, Greenland and Åland.

NORDBUK's mission is to collect and disseminate knowledge about children and young people's living conditions in the Nordic region. They shall promote integration of issues involving children and young people in the Nordic Council of Ministers and support the organisation and participation of children and young people in democratic processes.

NORDBUK manages a programme, NORDEN 0-30, which allocates funds for projects and is administered by <u>Nordic Culture Point</u>. The programme supports children and young people's own projects and organisation. Its purpose is to strengthen their influence and participation in political, cultural and social activities. The target group is young people up to the age of 30.

The Ministers for Nordic Co-operation (MR-SAM) in the Nordic Council of Ministers

<u>MR-SAM</u> is responsible for the overall political governance of the Nordic co-operation. Most of the work targeting children and young people in the Nordic Council of Ministers takes place within the different political sectors such as culture, social and health issues, employment, equal opportunities, education and regional politics. Governance of the cross-sectoral strategy for children and young people in the Nordic countries is carried out via NORDBUK, which is tasked with following up implementation of the strategy.

The Council of Nordic Cooperation on Disability <u>The Disability Council</u> is an advisory body for the Nordic Council of Ministers. The members of the council are appointed by governments and disability organisations throughout the Nordic region. The council works cross-sectorally.

<u>The Nordic Council of Ministers' disability action plan 2018-2022</u>, has three target areas:

- **1. Human rights:** To support and strengthen the work on national implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities.
- 2. Sustainable development: Use universal design to enhance inclusion, promote equality and combat discrimination against people with disabilities in all parts of Nordic society by integrating strategic thinking about the disability perspective into work on sustainable development.
- **3. Free mobility:** Promote free mobility and remove barriers to cross-border freedom of movement that affect people with disabilities in particular.

Nordic Welfare Centre

<u>The Nordic Welfare Centre</u> is an institution within the Nordic Council of Ministers' social sector, which helps develop more knowledge and co-operation on both political and practical improvements nationally, regionally and locally in the five Nordic countries, as well as the autonomous areas of Åland, Greenland and the Faroe Islands.

The Nordic Welfare Centre's mission is to contribute to the development of welfare initiatives in the Nordic region. The upbringing and living conditions of children and young people are a core part of our work. In line with the Nordic Council of Ministers' strategy for children and young people in the Nordic countries, we shall integrate a child rights and youth perspective into our work, and thus increasingly highlight and take into account the voices of children and young people.

The Nordic Welfare Centre is the secretariat for the Council of Nordic Cooperation on Disability (the Disability Council).

We administer a support scheme for the Nordic Council of Ministers of approximately SEK 1.5 million. The funds are allocated annually to organisations working with disabilities in the Nordic region to support co-operation, projects and joint activities.

We present examples of successful integration projects and manage a project that highlights early efforts for children, young people and their families who have recently arrived in the Nordic region.

Our <u>website on Integration in the Nordic region</u> has been designed to simplify coordination between governmental authorities, municipalities, non-profit organisations and ministries regarding integration and immigration. The Nordic Welfare Centre is the project manager, in co-operation with Nordregio.

We have our own deafblind section with responsibility for Nordic co-operation on increased knowledge and competence development.

Nordregio

<u>Nordregio</u> disseminates and prepares facts and statistics about the Nordic region and the Nordic countries. Their publications include <u>State of The Nordic</u> <u>Region</u>, with facts and figures showing the current situation in key socioeconomic sectors, such as demographics, including facts about children and young people, working life and economy.

Nordic co-operation on statistics on living conditions for children and young people

NORDBUK has commissioned Nordregio to prepare comparative statistics on children's living conditions in the Nordic countries. The assignment is part of the Nordic Council of Ministers' strategy for children and young people. The statistics will enable monitoring of developments in the child population systematically and over time.

Nordic co-operation on statistics, living conditions and disabilities

The Nordic Welfare Centre and Nordregio have initiated a co-operation on proposing indicators to monitor the follow-up of CRPD and Agenda 2030 in the Nordic region. The project is a continuation of the Nordic Council of Ministers' action plan on disabilities.

By the end of 2020, the institutions proposed a number of indicators and models for working methods as part of the effort to monitor developments at the Nordic level leading up to 2030. Activities and results are presented on <u>the Nordic Welfare Centre's</u> website. The report also describes the national statistics that are available for a number of priority areas for people with disabilities.

The Ombudspersons for Children in the Nordic countries

From the very outset, the Ombudspersons for children have led the way in giving children and young people freedom of speech, and speak on their behalf in public. As part of their establishment, the Ombudspersons for Children were tasked with monitoring the countries' practices in following up the UN Convention on the Rights of the Child. The Ombudspersons for Children have an informal Nordic co-operation and hold annual meetings.

Denmark: <u>The National Council for Children</u> Norway: <u>The Ombudsperson for Children</u> Sweden: <u>The Ombudsman for Children</u> Finland: <u>The Ombudsman for Children</u> Iceland: <u>The Ombudsman for Children</u> Åland: <u>The Children's Ombudsman</u> Greenland: <u>MIO (National Advocacy Center working for Children's Rights)</u> Faroe Islands: <u>Umboðsmaðurin</u>



THE NORDIC COUNTRIES, FAROE ISLANDS, GREENLAND AND ÅLAND

Denmark



Authorities and ministries

<u>The Danish Ministry of Social Affairs and the Interior</u> coordinates the disability policy and is responsible for, among other things, family policy, vulnerable children and young people and the policy on voluntary work. The Ministry contributes to and participates in the elements of UN co-operation that involve social affairs, including the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.

<u>The Danish Ministry of Social Affairs and the Interior's Benchmarking Unit</u> is an independent unit under the Ministry that compiles benchmarking analyses relating to the work of the municipalities and regions on solving tasks. The purpose is to promote potential for improvement and good practice.

<u>The National Board of Social Services in Denmark</u> is responsible for developing a sound knowledge base and guidelines for authorities, municipalities and others who provide social support and services to citizens with disabilities. They are in close contact and dialogue with relevant organisations in the field regarding initiatives, efforts and knowledge development. The Board cooperates with trade associations on the development of aids, and they head <u>the council</u> for Assistive Technology Data – Denmark (ASSISTDATA).

Den nationale videns- og specialrådgivningsorganisation, VISO, is an authority under the National Board of Social Services. Their task is to provide knowledge, expertise and advice to municipalities, citizens and regional and private actors.

<u>The Appeals Board</u> oversees municipalities and regions to ensure compliance with the rules for public authorities on employment and social affairs. They process complaints relating to special needs education, discrimination, disability, etc.

Taskforce – Handicap for funksjonshemming offers municipalities short communication and learning courses and regional theme days that provide

knowledge and insight into a specific topic. The purpose of the co-operation is to strengthen the municipalities' case management on disabilities for both children and adults.

The Danish Institute for Human Rights shall promote and safeguard human rights and equal treatment in Denmark and abroad. In relation to disability, the Institute shall promote and monitor the implementation of the UN Convention on the Rights of Persons with Disabilities.

The National Council for Children in Denmark is a governmental council tasked with ensuring the rights of children and young people. The Council shall raise current issues for debate and speak on behalf of children in public debate.

98 municipalities and five regions

KL – Local Government Denmark is the association and interest organisation for the 98 Danish municipal councils. Their task is to ensure that the municipalities have a sound framework enabling them to prioritise welfare, and the finances for local development of the municipality.

Both the National Board of Social Services in Denmark and the organisation <u>Børns Vilkår</u> help the municipalities in developing <u>methods to involve children</u> <u>and young people in processing of their own cases</u>. Børns Vilkår is a voluntary organisation that works to promote the rights and living conditions of children. They offer counselling for children, relatives and professionals who work with children and families.

All pupils at primary school have <u>the right to form a pupil council</u>, if the school has at least five form years. If the pupils do not form a pupil council themselves, the school management should encourage them to do so.

Civil society

Sammenslutningen af Unge Med Handicap is an umbrella organisation in Denmark for and with young people with disabilities They have around 4,000 members with all types of disabilities, divided into 12 member organisations.

<u>The Danish Youth Council</u> is an umbrella organisation and interest group for 78 socially involved organisations for children and young persons. Scouts, student organisations, pupil organisations, ecclesiastical associations, environmental organisations and the political youth parties are among the members.

The Disabled People's Organisations Denmark (DPOD) is the umbrella organisation for Danish disability organisations. They work nationally and at





municipal level to ensure good political dialogue and more knowledge. They also play an active role in Danish development co-operation, distributing work and knowledge of the UN Convention and international goals. They govern 35 <u>member organisations</u> and cover all types of handicap, for example, the Danish ADHD-Association, the National Association of Autism, CP Denmark, the Muscular Dystrophy Foundation.

The Danish Disability Counsel is the national counsel for the Danish government and disability organisations. They monitor compliance in Denmark with the obligations under the UN Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. They advise politicians, authorities and other stakeholders.

The National Association for Disabled Persons in Denmark is an organisation for persons with disabilities and intellectual disabilities. They work to promote the members' right of self-determination and co-determination.

The National Council for Volunteering (Denmark) advises the Minister of Social Affairs and the Interior and the Danish Parliament (Folketinget) on issues involving the role of the voluntary sector. The council's objective is to contribute to public debate about the role of the voluntary sector in the development of the welfare society. They collaborate with The Danish Institute for Voluntary Effort, which is a national and voluntary knowledge and analysis centre and a mouthpiece for the socially disadvantaged.

Kofoeds School provides help with self-help. They offer the unemployed and socially vulnerable people education, support and the opportunity for an active daily life.



Research and statistics

Statistics Denmark Handicap barometer The Danish Institute for Human Rights The Danish Center for Social Science Research Roskilde University, Research Centre for Life with a Mobility Disability University College South Denmark, inclusion and exclusion Knowledge Centre on Disability Ålborg University, Autism, ADHD, Psychiatry Aarhus University, Danish School of Education

Finland

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Authorities and ministries

<u>Sosiaali- ja terveysministeriö</u>, The Ministry of Social Affairs and Health is responsible for coordinating policy for persons with disabilities

Opetus- ja kulttuuriministeriö, The Ministry of Education and Culture is responsible for research, education and teaching for infants, art, culture and youth etc.

Terveyden ja hyvinvoinnin laitos, THL, The Finnish Institute for Health and Welfare charts and monitors welfare and health in the population and develops measures to promote health. On the basis of their research and development work, they offer expertise and solutions applied by policymakers in the government, municipalities and regions, social and health care actors, researchers and citizens in relation to health promotion work. The Institute is an independent expert in the Ministry of Social Affairs and Health. In addition to a unit working with children and young people at THL, there is also a team called Funktionshinder i samhället (disabled in society), who work with issues related to people with disabilities of all ages.

Valvira – Sosiaali- ja terveysalan lupa- ja valvontavirasto, the National Supervisory Authority for Welfare and Health, is a national agency operating under the Ministry of Social Affairs and Health. Valvira monitors social care activities nationwide and oversees the regional authorities. Valvira's objective is to create a uniform licensing, governance and supervisory practice nationwide.

<u>Aluehallintovirasto</u>, The Regional State Administrative Agency is a regional control, licencing and supervisory authority for social welfare. The Agency oversees both municipal and private social, health and care services.

Vammaisten henkilöiden oikeuksien neuvottelukunta , VANE, The Advisory Board for the Rights of Persons with Disabilities is the national coordinating mecha-



nism for the implementation of the UN Convention on the Rights of Persons with Disabilities and policy in this area. It consists of representatives of organisations for persons with disabilities, labour market organisations as well as ministries.

Kansallinen ihmisoikeusinstituutio, The Finnish National Human Rights Institution, comprises the Human Rights Centre and its Human Rights Delegation and the Office of the Parliamentary Ombudsman. All actors are independent and autonomous. Ihmisoikeuskeskuksen ihmisoikeusvaltuuskunta, The Human Rights Centre's Human Rights Delegation, is a national cooperative body. The delegation consists of 20-30 experts in various fields. Ihmisoikeuskeskus, The Human Rights Centre, is an independent expert body that monitors the implementation and follow-up of international human rights conventions in Finland. The Centre's tasks include information, education and research. Eduskunnan oikeusasiamies, The Parliamentary Ombudsman of Finland, monitors the activities of the authorities and ensures that basic human rights are observed. The Ombudsman conducts investigations on the basis of complaints and conducts inspections at various institutions on its own initiative.

Lapsiasiavaltuutettu, The Ombudsman for Children in Finland, is an independent and autonomous authority. The Ombudsman monitors whether children's rights are observed by policymakers and in legislation.

<u>Yhdenvertaisuusvaltuutettu</u>, The Non-Discrimination Ombudsman, is an independent authority responsible for the Non-Discrimination Act and the National Non-Discrimination and Equality Tribunal.

<u>Tasa-arvovaltuutettu</u>, The Ombudsman for Equality, monitors the Equality Act in Finland.

<u>The Ombudsman for Accessibility/the Handicapped</u> is a non-statutory position and can therefore vary in terms of organisation according to location. In many municipalities, representatives of disabled persons and accessibility representatives have merged into one unit. <u>Vammais- ja kehitysvammapalvelut</u>, The municipalities' handicap/disability service, is municipal and tasked with providing services for persons with disabilities.



310 municipalities, 18 regional councils and Åland, which is autonomous

<u>Kuntaliitto</u>, The Association of Finnish Municipalities, is the interest association and development partner for the municipal sector. They offer expertise and information services. The regional associations, health service and municipal affiliates are also covered by the Association's activities. All municipalities shall have a <u>Youth Council</u> or equivalent participation body for young people (Municipal Law 410/2015). Participation and democracy for schoolchildren in e.g. Finland is offered via the pupil councils, <u>Basis for curricu-</u> <u>lum for the</u> basic education, Finland (2014). Other activities include "support pupils and mentoring" and involvement in voluntary work.

NUVA, the Union of Local Youth Councils in Finland, is an educational, communication and interest body for all youth councils.

<u>Erityishuoltopiirit (the special care district)</u> is responsible for facilitated care for persons with intellectual disabilities. The municipalities normally facilitate necessary services via the respective special care district.

Civil society

<u>Allianssi</u>, the Finnish National Youth Council is the umbrella organisation for the Finnish youth sector and its members include more than 130 national youth or educational organisations.

<u>Vammaisfoorumi ry</u>, The Finnish Disability Forum is an umbrella organisation for 30 disability organisations in national and international co-operation, especially in the European Disability Forum.

KVANK, the delegation for housing for persons with disabilities, is a co-operation network for organisations that work for people with disabilities and their relatives, and for actors in the public sector. The delegation promotes the implementation of the UN's rights for persons with disabilities.

ETENE, the National Advisory Board on Social Welfare and Health Care Ethics, is tasked with processing ethical issues within the health and social care sector. They take initiatives, make statements, provide expert help, raise social debate and provide information on national and international ethical issues.

SOSTE is a nationwide umbrella organisation for about 200 social, health and care organisations and some 10 other cooperative organisations.

Examples of Swedish-speaking organizations involved in disabilities in Finland:

<u>SAMS</u> is an umbrella organization with several member organizations that includes activities for children, young people and families. This includes amongst others Interest organization for Swedish speaking with intellectual disabilities.

Member associations within <u>FMA - Funktionsrätt med ansvar</u> includes for example <u>finlandssvenska teckenspråkiga</u> (Finnish-Swedish sign language). Others member organisations are Förbundet finlandssvenska synskadade (vi-



sually impaired) and Psykosociala förbundet rf (psychosocial disabilities).

Swedish-speaking organisations in Finland: <u>Valteri Skilla</u> (Valteri School Skilla), Folkhälsan, child welfare association, Lärum (teaching aids).

A homepage in the Finnish Handbook on Disability Services gives an overview of Finnish disability organisations; Vammaisalan järjestöt.

Vammaisten lasten ja nuorten tukisäätiö, The Vamlas Foundation, promotes participation and equal opportunities for children and young people with disabilities.

Vammaisperheyhdistys, Jaatinen ry, is an association for families with children and young people with disabilities.

Erilaisten oppijoiden liitto is a federation of 14 member associations.

<u>Tietotekniikka- ja kommunikaatiokeskus Tikoteekki</u> is a centre for information technology and alternative and replacement communication.

<u>Mannerheimin lastensuojeluliitto</u>, The Mannerheim League for Child Welfare, is an organisation that is open to everyone. It promotes the wellbeing of children and families, increases respect for childhood and sees that children's views are taken into account in decisions that concern them.

<u>Väestöliitto</u>, the Family Federation of Finland is an organisation within the social and health care industry. They provide services and conduct research in areas such as family, population and reproductive health. They publish, among other things, the Familjebarometern or family barometer.

Barnavårdsföreningen (The child welfare association) is a national non-profit child welfare organisation. The association has an orphanage, several kindergartens and afternoon activities for school pupils. They offer support and advice to children and families who experience challenges in everyday life.



Research and statistics

<u>Statistics Finland</u> <u>Suomen vammaistutkimuksen seura</u> – VATU, Finnish Society for Disability Research Professorship in Disability Studies

Faroe Islands

Authorities and ministries

<u>Almannamálaráðið</u>, The Ministry of Social Affairs, is responsible for social policy, family law, gender equality and housing policy. They are responsible for the coordination of disability policies and the implementation of the UN Convention on the Rights of Persons with Disabilities.

<u>Heilsumálaráðið</u>, The Ministry of Health, is responsible for health policy, preventive measures and research in the field of health.

<u>Uttanríkis- og Mentamálaráðið</u>, The Ministry of Foreign Affairs and Culture, is responsible for foreign policy in addition to education, research and culture. This area of responsibility comprises day care institutions, primary school, lower secondary school, university, sports, voluntary work and television and radio.

<u>Almannaverkið</u>, The Department of Social Services, offers help and advice. They are responsible for benefits, including care for a child with disabilities or long-term illness and counselling on individual rights.

Familjufyrisitingin, The Family Administration, administers services and provides advice on issues involving family and law of persons. The Administration is under the Ministry of Social Affairs.

Barnaumboðsmaðurin, the Ombudsman for Children, oversees whether authorities and institutions listen to the views of children and young people and whether their rights are respected. The Ombudsman has the right to process cases of their own accord if they suspect that the rights of the child are not respected.

Barnaverndarstovan is divided into eight areas, each with its own child welfare service.



<u>Sernám</u> is the National Pedagogical-Psychological Counselling Centre and is responsible for coordinating special needs educational services and counselling for parents, institutions and schools working with children and young people. Sernám provides special needs educational advice and support and aims to strengthen all children and young people aged 0-18 socially, physically, personally, linguistically and cognitively. Their staff have expertise relating to speech and hearing, physiotherapy and occupational therapy, education and psychology. They work preventively with investigations and treatment.

Barna- og ungdómspsykiatriin is child psychiatry, under the hospital sector. They are responsible for providing dignified, fast and cohesive diagnostics, treatment, care, health counselling and rehabilitation in co-operation with children, young people and their families.



29 municipalities and six regions

Kommunufelagið is the association for the municipalities and safeguards the interests of the municipalities and coordinates their work. On the Faroe Islands, there are a total of 124 villages and towns divided into 29 municipalities, all of which are members of Kommunufelagið. The association provides advice and guidance to municipal politicians and municipal employees. The municipalities are responsible for the living conditions of children and young people, child and youth policy, institutions for children and leisure schemes.



Civil society

<u>MEGD</u> is the umbrella organisation for 24 member organisations that work with the disabled. MEGD's main work relates to disability policy issues and challenges, based on the UN Convention on the Rights of Persons with Disabilities. The 24 member organisations have around 3,000 members.

Barnabati works with children's rights, on the basis of the Convention on the Rights of the Child. They work to improve upbringing and living conditions for children and young people. Their aim is for all children to have equal rights to develop and receive the support and care to which they are entitled. Barnabati provides information, guidelines and specific advice to children and young people, <u>Tú og eg ráðgevingin</u>, to help, for example, build self-image for children and young people. They offer mentorship, <u>Mentorskipan</u>, for young people. A mentor is a volunteer adult who still remembers what it is like to be young.

<u>Føroya Ungdómsráð</u> is an umbrella organisation for children and young people. They represent around 4,000 children and young people under the age of 30, from 51 local communities. They offer, for example, a variety of recreational activities for children and young people; drama, music, Faroese dance, choirs, political youth policy, human rights, children's camps and scouts. They address issues concerning young people and encourage young people to participate actively and to influence society in co-operation with the authorities.

<u>Spyr meg</u> is an interest group under Javni, and works to ensure that people with mental disabilities have an independent voice based on the term "independent living". The organisation Javni works for equal rights in all cultures in Faroese society.

<u>SSP samstarv</u> is an interdisciplinary collaboration between schools, social services and the police to promote the well-being of children and young people aged 0-18 years. SSP prevents crime and cooperates with Barnaverndarstovan, which is affiliated with the local child welfare services.

<u>Gigni, heilsufrøði til ungi</u> is tasked with promoting the health of children and young people (0-18 years). In primary schools, all pupils are examined once a year, and receive counselling, guidance and are taught about health, development and well-being. The organisation advises students, parents and teachers.



Greenland



Authorities and ministries

Naalakkersuisut, the Government of Greenland, has been ordered by Inatsisartut, the Parliament of Greenland, to develop an action plan⁸¹ for compliance with the Convention on the Rights of the Child. The Parliament of Greenland has also ordered the Government of Greenland to draw up an action plan for monitoring the UN Convention on the Rights of Persons with Disabilities in 2022.

Isumaginninnermut, Ilaqutariinnut Inatsisinillu Atuutsitsinermut Naalakkersuisoqarfik, The Minister of Health, Social Affairs and Justice in Greenland coordinates disability policy in Greenland.

Inatsisartut ombudsmandiat, The Ombudsman for the Parliament of Greenland, monitors compliance with law by self-government and the municipalities. The office has specific contact persons for children.

Tilioq, <u>the institution for spokespersons for the disabled</u>, is an institution that works to secure and promote the rights of persons with disabilities. Tilioq is a politically independent institution under Greenland's self-government authorities. The institution comprises a spokesperson for persons with disabilities and a secretariat with three employees. The spokesperson is the manager of the secretariat and is employed and appointed by the Government of Greenland.

<u>Meeqqat illersuisuat</u> or MIO is a National Advocacy Centre working for Children's Rights. MIO comprises a Spokesperson for Children who heads a secretariat with six permanent employees. The spokesperson is employed by the Government of Greenland and acts as a Spokesperson for Children for a period of three years. A children's council has been appointed to assist the Spokesperson for Children in developing strategies for children.

Inuusuttut inatsisartui, the Youth Parliament, is organised by the Bureau for Inatsisartut (the Parliament of Greenland). The purpose of the youth parliament is to provide young people between the ages of 18 and 24 with the opportunity to learn about and practice democratic processes. The participants are selected by the Bureau for Inatsisartut on the basis of several established criteria.

MISI is a municipal psychological educational advisory unit for parents and professionals relating to all children 0-18 years of age, with an emphasis on children with special needs.

<u>Pissassarfik</u> is a nationwide centre for the disabled under the <u>Agency for Pre-</u> <u>vention and Social Affairs</u>. Persons of all ages with disabilities can apply via the municipalities to visit the centre. The centre offers facilitated procedures providing habilitation and rehabilitation for persons with disabilities. The primary aim of the treatment is to help the individual become more self-reliant, and to increase quality of life.

Five municipalities; Kommuneqarfik Sermersooq, Kommune Kujalleq, Qeqqata Kommunia, Kommune Qeqertalik and Avannaata Kommunia.

Civil society

<u>Sorlak</u> is a federation for the children's and young person's organisations in Greenland. Sorlak was the first children's and young person's organisation in Greenland and works to promote children's rights and boost their opportunities for participation and influence.

Kalaallit Meerartaat, The Association for children in Greenland, works on projects to ensure that children and young people in Greenland have a safe childhood, have the opportunity to gain an education and to get involved and be heard in matters that concern them.

There are a number of organisations for children in Greenland, but none that focus on children with disabilities. Below are links to several organisations working with children:

- Kalaallit Røde Korsiat (Red Cross)
- Red Barnet Grønland (Save the Children)
- UNICEF in Greenland
- Børnerådet's organisation



NIIK and Kalaallit Nunaanni Innarluutillit Piginnaanikitsut Kattuffiat, KNIPK are two nationwide umbrella organisations for disabled persons. A web page providing a complete list of associations for persons with disabilities is provided on Tillioq homepage.

Greenland's Council on Human Rights represents a number of organisations and individual authorities and public institutions. Evaluation and monitoring of human rights is carried out in co-operation with Denmark. Naalakkersuisut, the Government of Greenland, has stated their wish that the Danish Institute for Human Rights in Denmark acts as a national human rights institution for Greenland and Denmark. The institute assists the council with teaching related to various human rights issues, and the council provides the institute with good knowledge of the situation in Greenland.

One of the most important steps in the co-operation is a report on the status of human rights in Greenland. In addition, the institute also provides consultation responses on new legislation for Greenland with relevance to human rights.



Research and statistics

Børnetalsmanden, or the Spokesperson for Children (MIO), has prepared several reports from trips to various areas in Greenland. Some of these reports describe living conditions for children and young people with disabilities. <u>Reports</u> from trips carried out by Tilioq (the Spokesperson for Disabled Persons).

Iceland

Authorities and ministries

<u>Mennta- og menningarmálaráðuneytið</u>, the Ministry of Education, Science and Culture, is responsible for cultural, research, education and youth policy, among others. The Ministry is also responsible for support for youth organisations, research relating to young people and sports.

<u>Heilbrigðisráðuneytið</u>, the Ministry of Health, is responsible for public health, health institutions and hospitals, health insurance and patient rights, among other things.

<u>Félagsmálaráðuneytið</u>, the Ministry of Social Affairs, is responsible for issues related to living conditions and rights for persons with disabilities in addition to employment, refugee, migration, family and housing policy.

<u>Tryggingastonun</u>, the Social Insurance Administration, is a government authority responsible for, among other things, social security, health and child support schemes.

<u>Gæða- og eftirlitsstofnun félagsþjónustu og barnaverndar</u>, the Quality Inspectorate for Social Services and Child Protection, is a government authority with responsibility for inspection of social services and child protection.

<u>Réttindagæsla</u>, is a guardian of rights, assigned responsibility for monitoring the status of persons with disabilities and helping them protect their rights in all situations.

Barnaverndarstofa, the Government Agency for Child Protection, is an independent institution under the supervision of the Ministry of Social Affairs. The Agency works with various issues related to the activities of the municipal child protection committees and oversees the running of specialised treatment centres for children. <u>Umboðsmaður</u>, the Ombudsman for Children, shall ensure that public authorities and all those who are in contact with children take full account of the children's interests, needs and rights. The Ombudsman shall highlight and make suggestions for improvements where deemed necessary.

<u>Greiningar- og ráðgjafarstöð ríkisins</u> is the State Diagnostic and Counselling Centre. They offer support, advice and guidance for children and young people with disabilities and their families.

<u>Þjónustu- og þekkingarmiðstöð fyrir blinda, sjónskerta og daufblinda ein-</u> <u>staklinga</u>, the National Institute for the Blind, Visually Impaired and Deafblind, is a centre providing services within the field of rehabilitation and education. The centre is responsible for a national database on visually impaired and blind people.

Samskiptamiðstöð heyrnarlausra og heyrnarskertra is the Communication Center for the Deaf and Hearing Impaired. The centre works with research on Icelandic sign language, the development of curricula and interpreting services between Icelandic sign language and Icelandic.

Heyrnar- og talmeinastöð Íslands, the Hearing and Speech Institute of Iceland, is a knowledge centre in the field of hearing and speech impairment. The centre offers diagnosis and treatment, sales and services of hearing aids and aids.



76 sveitarfélög or municipalities and eight landsvæði or regions

The municipalities cooperate via <u>the municipal association</u>, <u>Samband</u>, and just over half of the most populated municipalities have youth councils. The Government has established a workinggroup for monitoring the sustainable development goals, with observers from the <u>municipalities and youth councils</u>.

<u>The Youth Act No. 70/2007</u> aims to support the participation of children and young people in organised youth work. The law defines youth work as all organised social and recreational activities where children and young people work together in their spare time for ideals, goals and interests that they value.

Link to websites in the larger municipalities and their services for people with disabilities.

Barnvæn sveitarfélög, Child Friendly Cities, is a national initiative via co-operation between UNICEF Iceland and the Ministry of Social Affairs, with the aim of encouraging the municipal case workers to actively apply the Convention on the Rights of the Child in all proceedings concerning children and young people. This year, 40 percent of all children in Iceland live in municipalities that implement the Convention on the Rights of the Child systematically. In 2021, this figure will increase to 50 percent of all children in Iceland.

Civil society

Landssamband ungmennafelga, The National Youth Council of Iceland (LUF), and former The National Association of Youth Association (LÆF), is the umbrella organisation for youth organisations in Iceland. They have 30 member organisations that are common in that they are democratic, NGOs, which operate nationally and are led by young people.

Mannréttindaskrifstofa Íslands, the Icelandic Human Rights Centre, promotes work for and relating to human rights by gathering and distributing information in Iceland and internationally. The centre also carries out research and dissemination. The centre has, for example, administered an EU project, <u>The Human</u> <u>Rights Education Project (HREP)</u>, which has developed teaching materials on human rights for worldwide use.

Öryrkjabandalag Íslands, ÖBÍ, Aðildarfélög, OBI, is The Icelandic Disability Alliance, an umbrella organisation covering 43 associations for people with disabilities. Many of these works to promote the rights and conditions for children and young people with disabilities, such as the Icelandic ADHD Association, the Cerebral Palsy Society of Iceland, the Icelandic Autistic Society and the Tourette Association in Iceland.

The youth group in the Icelandic Disability Alliance is a forum where young people can promote their interests within the Disability Alliance.

<u>**Proskahjálp</u>**, Throskahjalp, is The National Association of Intellectual Disabilities in Iceland, an umbrella organisation for 20 associations working with human rights, including the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. <u>Átak</u> is one of these associations and the only one run by persons with intellectual disabilities. Throskahjalp works closely with two consultation groups, the youth committee and the grassroots group.</u>

Link to several national and international organisations for children.

Research and statistics

Hagstofa Íslands, Statistics Iceland

Rannsóknarsetur í fötlunarfræðum/The Centre for Disability Studies





Háskóli Íslands, the University of Iceland

<u>Greiningar- og ráðgjafarstöðvar ríkisins</u>, Icelandic State Diagnostic and Counselling Centre

University of Akureyri Research Centre

<u>CFC, Child Friendly City index</u> for the well-being of children is currently being developed, and this is a collaborative effort between the Ministry of Social Affairs, UNICEF and Kópavogur municipality. The index is based on the four fundamental principles of the <u>Convention on the Rights of the Child</u> (right to education, equity, health and wellbeing and security and protection. The index is to become national and include all municipalities in Iceland.

Norway



Authorities and ministries

<u>The Ministry of Culture</u> is responsible for government policy and administration in the areas of culture, equality and discrimination, copyright, media, sports and voluntary activities. They are the national point of contact for the UN Convention on the Rights of Persons with Disabilities and have the overall responsibility for nationwide implementation of the convention.

The Ministry of Children and Families is responsible for the upbringing and living conditions for children and young people, family and married life, religion and philosophy and for consumer policy. The Ministry is responsible for coordinating the implementation of the Convention on the Rights of the Child and for reporting to the UN Committee on the Rights of the Child in co-operation with 11 other ministries. The Ministry has commissioned the Norwegian Directorate for Children, Youth and Family Affairs (Bufdir) to prepare a report promoting the views of children and young people on what it is like to grow up in Norway. The report is an attachment to Norway's national report to the Committee on the Rights of the Child.

The Norwegian Directorate for Children, Youth and Family Affairs (Bufdir) is

governed by the Ministry of Children and Families and the Ministry of Culture. Bufdir is a professional body involved in the areas of child welfare, children, young people and upbringing, adoption, family welfare, equality and non-discrimination, disabilities and violence and abuse in close relationships. Bufdir leads a project to increase knowledge of the UN Convention on the Rights of Persons with Disabilities in the municipalities. The aim is to improve knowledge among employees in municipal services and administration of the convention and how they can apply it in their daily work. They have developed Jegvet.no, a digital learning resource, for use in kindergarten and school, to give all children knowledge about bullying, violence and abuse.



<u>Ung.no</u> is the public information channel for young people and is run by Bufdir. Young people can use the website for quality-assured information from the public authorities including, for example, a question-and-answer function.

<u>Statped</u> is a governmental special needs educational service for municipalities and county councils. They work to further develop top competence and aim to enable children, young people and adults with special educational needs to take an active part in kindergarten, education, work and social life. The educational and psychological counselling service <u>PPT</u> is an important partner for Statped. The service provides special facilitation for children, pupils, trainees, apprentices, candidates for experience-based trade certification and adults.

The Ombudsperson for Children is the spokesperson for children and young people. They work to promote children's rights and are responsible for ensuring that children and young people's opinions are heard. In particular, the Ombudsperson shall monitor that children's interests are safeguarded in legislation and that Norway complies with the Convention on the Rights of the Child. In 1998, an addendum was added to section 3 of the Act relating to the Ombudsperson for Children: "In particular, the Ombudsperson shall monitor compliance with legislation to protect the interests of children, including whether Norwegian law and administrative practices fulfil Norway's obligations under the Convention on the Rights of the Child."

The National Institute on Intellectual Disability and Community (Norwegian acronym NAKU) is managed on behalf of the Ministry of Health and Care Services. The service has been established to build and disseminate competence relating to various aids, including adapted physical activity, to promote activity and participation in all venues for children and young people with disabilities. The service shall initiate cross-sectoral interaction where the ability to participate in recreational activities must have the same priority as traditional habilitation and rehabilitation services.

<u>The Equality and Anti-Discrimination Ombud</u> shall combat discrimination and promote equality irrespective of gender, ethnicity, skin colour, national origin, descent, disability, language, religion, sexual orientation, trade union membership, political views and age. The Ombud offers free advice on rights and obligations, to aid in solving problems independently. If this fails, you can appeal to <u>Diskrimineringsnemnda</u>. They are tasked with monitoring the nationwide implementation of the UN Convention on the Rights of Persons with Disabilities.



356 municipalities (as of 2020) and 11 counties

According to the Local Government Act, as of 2019 all municipalities and county authorities are required to have a <u>council for people with disabilities, a</u> children and youth council and a council for the elderly. A set of Guidelines for

youth councils and Guidelines for councils for persons with disabilities have been published.

The Norwegian Association of Local and Regional Authorities, KS is the interest organisation for the municipal sector. They coordinate a universal design network that collects information and publications providing good examples. The ABSOLUTT development programme aims to provide the municipalities and county authorities with increased understanding and knowledge of their responsibilities for kindergartens, schools and upbringing.

The Ombudspersons for pupils, apprentices and against bullying are regional ombudspersons tasked with safeguarding the rights of children and young people in kindergarten and primary school, as well as pupils and apprentices in upper secondary education. They have published, for example, the booklet entitled Children's right to participation in kindergarten.

All Norwegian schools must have a <u>pupil council</u>, as stipulated in the Education Act. <u>Elevmedvirkning.no</u> is a website developed by pupils, for pupils of all ages and at all schools.

<u>Sjumilssteget (The Giant Leap)</u> is a national initiative via the county governor's offices, aiming to encourage case workers in county governor's offices and municipalities to make active use of the Convention on the Rights of the Child in all cases concerning children and young people.

Civil society

The Norwegian Children and Youth Council, LNU, is a cooperative body and an umbrella organisation for 98 children and youth organisations in Norway.

The Norwegian Association of Youth with Disabilities is an umbrella organisation, representing 37 organisations and groups for young people with disabilities and chronic disease. Their goal is equality and societal participation for youth aged 12 to 36 with disabilities and chronic disease.

<u>Youth Work Norway</u> is a democratic non-profit children and youth organisation for users, employees and volunteers in municipally supported recreational clubs, youth centres, cultural centres for young people, and similar open meeting places. Their common feature is that they are controlled by the users and open to everyone.

Norges Handikapforbunds Ungdom is an organisation by and for young people with disabilities. They work to ensure full equality for everyone.

In Norway, there are two umbrella organisations for disability organisations: The Norwegian Federation of Organisations of Disabled People (FFO)



is Norway's largest umbrella organisation with 84 member organisations for people with disabilities and chronic diseases and their families. <u>The Norwegian</u> <u>Forum of Disabled Peoples' Organizations</u> (SAFO) is an umbrella organization for the <u>Norwegian Association for the Disabled (NAD)</u>, the <u>Norwegian Association for Persons with Intellectual Disabilities (NFU)</u> and <u>the Norwegian</u> <u>Association of the Deafblind (FNDB)</u>.

<u>The Forum for the Convention on the Rights of the Child</u> is a network of organisations, institutions and individuals concerned with the rights of children in Norway and internationally. The network consists of close to 50 members. The aim is to contribute to the exchange of information and experiences about working with children, and to be a source of inspiration for further development of the understanding of children's rights.

Beitostølen Healthsports Center (BHSS) is a re-/habilitation institution in the specialist health services that provides services to children, young people and adults with various diagnoses, disabilities and functional levels.

Valnesfjord Health Sports Centre is a private, non-profit foundation that offers specialised habilitation and rehabilitation.

Forandringsfabrikken (The Change Factory) is a knowledge centre that gathers summarised knowledge from children. They promote children and young people as experts on the systems in which they are involved. Around 300 young people are active in The Change Factory, acting as Child Care Pros, Mental Health Pros or School Pros.

In addition, there are many organisations working for and with children and young people, several of which are also international, such as UNICEF, Save the Children and the Red Cross.



Research and statistics

Statistics Norway Sciencenorway.no Nordland Research Institute Proba Karde Beitostølen Healthsports Center NTNU Social Research OsloMet The Norwegian Directorate of Health

Sweden



Authorities and ministries

<u>The Ministry of Health and Social Affairs</u> is responsible for coordinating disability policy, in line with the UN Convention. Several other ministries and political areas are covered by the policy. A group made up of representatives from different ministries meets regularly and exchanges experiences and discusses current affairs.

<u>The Ministry of Employment</u> is responsible for the implementation and follow-up of the policy on the rights of the child, in accordance with the Convention on the Rights of the Child. This includes all activities that affect children and young people, such as education policy, migration policy, cultural and welfare policy. The Government has formed a delegation on the rights of the child (Barnrättsdelegation); a forum for dialogue between the government and civil society organisations. They have participated in the work to ratify <u>the Conven-</u> tion on the Rights of the Child in law in Sweden in 2020.

<u>The Ministry of Culture</u> is responsible for issues related to culture, democracy, the media and national minorities. The Ministry is also responsible for civil society, sports and youth policy.

<u>The National Board of Health and Welfare</u> is a government agency under the Ministry of Health and Social Affairs. They are responsible for, among other things, identifying and developing statistics and knowledge in areas such as mental health, disabled persons and children and young people.

<u>The Equality Ombudsman in Sweden</u> monitors, among other things, the rights of persons with disabilities and produces checklists and materials for kinder-gartens and schools that are in the process of promoting equal treatment.

The National Agency for Special Needs Education and Schools, SPSM, is

Sweden's largest body of knowledge within special needs education. In order to ensure that preschools, schools and adult education provide education that satisfies the needs of children, young people and adults, regardless of their ability, they offer free support in the form of knowledge and skills development throughout Sweden. One example is their publication <u>Delaktighet – ett arbetssätt i skolan</u> (participation – a working method in schools).



The SPSM is part of the Swedish government mission <u>Kunskapslyft Barnrätt</u> <u>i praktiken</u> (education initiative Rights of the Child in practice). SPSM has a <u>youth network</u> run by young people with disabilities.

The Ombudsman for special needs education is under the SPSM and shall help special needs pupils gain knowledge of and insight into their rights. Pupils in special needs schools can contact the Ombudsman directly for support, advice and guidance. The scheme was introduced in 2018, and the role is being developed in co-operation with the school authorities.

The Swedish Agency for Participation, MFD, is responsible for follow-up of the UN Convention on the Rights of Persons with Disabilities. They are responsible, among other things, for the <u>Barnrätt i praktiken</u> initiative and have developed films about the convention for children. On behalf of the Government, the MFD has prepared a report on the implementation of Agenda 2030.

The Swedish Agency for Youth and Civil Society, MUCF, is a government agency tasked with addressing youth and civil society issues. They develop and communicate knowledge about the living conditions of young people and about civil society. They develop knowledge on key issues such as participation and democracy, school, health and education for young people. One example is the publication <u>Det vore ju kul om de frågade nån gång: Ungas möjligheter</u> <u>till inflytande på lokalt nivå – Fokus 19</u> (It would be nice if they ever asked us – Young people's opportunities for influence at a local level – Focus 19).

The Ombudsman for Children in Sweden is a government agency tasked with representing children regarding their rights and interests on the basis of the UN Convention on the Rights of the Child (CRC). The Ombudsman for Children monitors how the CRC is complied with in society and pushes for its implementation in Sweden's municipalities, county councils/regions and government agencies. They shall draw attention to faults in the application of the CRC and propose changes to laws and ordinances.

<u>Funktionshindersdelegationen</u> (the disability delegation) is a government agency. It is the national co-operation counsel for the Swedish government and disability organisations. The delegation consists of representatives from the Swedish Disability Rights Federation, Nätverket Unga för Tillgänglighet (Network of young people for accessibility) and a number of representatives outside the Swedish Disability Rights Federation. The delegation is led by the Minister of Health and Social Affairs.



290 municipalities and five regions

The Swedish Association of Local Authorities and Regions, SKR, works on issues relating to disabilities. The SKR assists municipalities and local authorities/ regions in the ongoing development work.

<u>Sweden's youth council</u> covers youth councils and other agencies that have an influence for young people in Sweden. They have around 50 active member associations. There is no record of how many of Sweden's municipalities currently have an influence body for children and young people.

Civil society

<u>LSU – The National Council of Swedish Youth Organisations</u> – is an interest and co-operation organisation that brings together national children and youth organisations. A non-partisan and non-religious organisation that works to strengthen the democratic and civil rights of young people.

Stiftelsen Allmänna Barnhuset is a government foundation that is tasked with supporting and developing methods and knowledge that will help to strengthen disadvantaged children and young people. The foundation's target group is practitioners, researchers and policymakers.

<u>Nätverket för Unga för Tillgänglighet</u>, NUFT, comprises a network of organisations for young people with disabilities. Today, NUFT serves as an arena for information dissemination. NUFT coordinates representation in various projects and delegations and has previously coordinated interest policy initiatives.

The Swedish Disability Rights Federation and the Federationen Lika Unika are two umbrella organisations for disability organisations in Sweden.

The Swedish Association of the Visually Impaired is an umbrella organisation for several federations such as the Swedish Association of the Hearing Impaired, the Swedish Association of Disabled Children and Young People, the Swedish Association of the Deaf, which are outside the Swedish Disability Rights Federation.

Research and statistics

Statistics Sweden The National Board of Health and Welfare The Swedish Agency for Participation The Department of Education, Stockholm University Forte.se – Swedish Research Council for Health, Working Life and Welfare Centre for Disability Research, Uppsala University Swedish Institute for Disability Research Center for Research on Welfare, Health and Sport (CVHI) Research field for disabilities and rehabilitation, Malmö University Funka.com









Authorities and ministries

The Government of Åland with the entire administration has a cross-sectoral responsibility to ensure compliance with the UN Convention on the Rights of Persons with Disabilities. The Government shall introduce impact analyses for decision-making processes involving children. Currently, the new curriculum for primary and lower secondary schools in Åland (effective from August 2021) underlines that pupils shall be given opportunities to have a say, and the rights of children with disabilities have been strengthened.

<u>Åland's health care association</u> is responsible for all health services in Åland, ranging from mother and child health, specialist health services to end of life care. They are responsible for the school health service and student health service. <u>The child and adolescent psychiatric (BUF) clinic</u> is an outpatient centre for children and young people aged 0-17 and their families. A <u>BUF</u> team carries out investigations of children who have a physical, mental, communicative or intellectual disability. The team is made up of child and adolescent psychiatrists, psychologists, paediatricians, speech therapists, occupational and physiotherapists and a habilitation coordinator.

The municipal social services were assigned the task of joint coordination of social services, apart from care for children and the elderly, with the implementation of Åland law (2016:2) on Municipal Social Services, which came into force on 1 January 2020. The service is covered by the framework of a municipal association that comprises all Åland municipalities. They offer a range of services for disabled people, such as housing, activities, counselling and information on services in and outside the province of Åland. By January 2021, all municipalities must have established a common social care district.

<u>The Office of the Åland Ombudsman</u> is an independent authority governed by the Government of Åland. The Office is tasked with promoting equality and equal opportunities, in addition to promoting the rights of the child, clients and patients. Other tasks include counselling individuals, independent investigations

and information for policymakers and authorities. The Office has been assigned the following functions:

The Children's Ombudsman shall ensure that children's rights are respected, and shall gather the views of children by mapping, carrying out surveys and personal meetings and communicating their opinions to policy-makers.

<u>The Åland Non-Discrimination Ombudsman</u> accepts and issues notifications of anti-discrimination law violations and provides advice concerning prevention of discrimination for individuals.

<u>The Ombudsman for Patients and Clients</u> is tasked with providing information about rights and helping clients and patients make complaints related to health and social services. Complaints include, for example, services for children and young people with disabilities.

<u>Åland's environmental and health care authority</u> is responsible for the preventive services and for supervising, testing and providing information in relation to health and environmental matters. One of the areas for supervision is the public and private social and welfare services.

<u>Åland's police authority</u> is responsible for a children's home model for co-operation between authorities when there is suspicion of violence and child abuse. The model promotes collaboration to protect children, investigate abuse and provide qualified support to the child.

15 municipalities

Kindergartens and schools play important roles in all municipalities.

<u>Åland's kommunförbund</u> is the association of municipalities and is a politically led interest and employers' organisation.

Civil society

<u>Rädda barnen (Save the Children Åland)</u> carries out activities based on the Convention on the Rights of the Child and works to improve living conditions for children. One example of their work is the Impact Analysis for Children, a tool for policymakers to allow them to work systematically on participation for children. Save the Children Åland has received support from the Government of Åland to educate the municipalities in the use of the impact analysis tool. The training process is under way.





Åland's disability association, with its 13 member organisations, is the co-operative organisation for patient and disability associations in Åland. The association's tasks include monitoring and acting on disability issues, informing, supporting and assisting member associations. The association aims to highlight disability issues and improve the conditions of the disabled, by being active opinion builders and making a difference. The association's work is based on the UN Convention on the Rights of Persons with Disabilities. The disability association has a number of member organisations, including <u>De Utvecklingsstördas Väl</u> (welfare for the disabled) in Åland, the association for parents of children with special needs, Reseda (Åland interest group for mental health), Åland's autism spectrum association, Åland association for the visually impaired etc. As of today, there is no specific public registered association for or by children and young people with disabilities in Åland.

<u>Ung Resurs</u> is a non-profit organisation that aims to help young people between the ages of 15 and 29 find a place of study, work or other meaningful activity. The organisation works with several clients and network partners.

<u>Ungdomshuset Boost</u> is a youth centre primarily for young people. They provide young people with support and guidance for studying, work and employment. Boost is a cooperative centre where several different authorities and organisations are represented.

<u>Ålands Idrott</u> is an umbrella organisation for 69 member organisations and includes the entire sports movement in Åland. The largest group of members relates to sports for children and young people. One important goal for the organisation is to influence the municipalities so that children's and youth sports develop in the desired direction. The goal is for everyone to be able to participate.



Research and statistics

Åland is covered by the research conducted by the Finnish Institute for Health and Welfare.

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Support material

Nordic Council of Ministers

Are you wearing the right glasses? A guide to integrating a child rights and youth perspective in the work of the Nordic Council of Ministers

Do rights! Nordic perspectives on child and youth participation

Children and Young People in the Nordic Region – a cross-sectoral strategy for the Nordic Council of Ministers 2016-2022

When involving children and young people in the work of the Nordic Council of Ministers – Principles and approaches

Council of Europe Child safeguarding policy

The Nordic expert group

Anne-Merete Kissow researcher, Videnscenter om handicap, Denmark

Ann-Marie Stenhammar representative for Funktionsrätt Sweden/investigator, Sweden

Bryndis Snæbjörnsdóttir representative, Throskahjälp, Iceland

Cecilia Ekstrand representative, Swedish Association of the Visually Impaired

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Þórdís Viborg expert, ÖBI, The Icelandic Disability Alliance, Iceland All children and young people have the right to participate, to have their say and to be heard in all matters that concern them. This report centres on how to assure this right to a greater extent for children and young people with disabilities in the Nordic countries. In the report, we highlight some of the barriers to participation that children and young people commonly encounter in different arenas. Nordic youth delegates provided input and a Nordic expert group contributed knowledge on current research and methods for promoting inclusion and participation for more people. A number of key stakeholders in society play an important role in the work to ensure that participation is accessible to children and young people with disabilities. Our objective with the report is to describe a selection of key players and their roles, both in the Nordic region as a whole and in the individual countries.

