
Summary

The title of this report, *På høy tid* (High Time), also summarises its main message: The rights of persons with disabilities in Norway are not – and for far too long have not been – fulfilled. Adaptations in order for persons with disabilities to live a good and safe life, and for them to experience genuine equality, are inadequate.

In order to do something about this, the Commission recommends a significant overarching change, in addition to proposing concrete measures in a number of different areas of society.

The overarching change concerns the understanding of disabilities. For a long time, disabilities – from developmental disabilities to mobility impairments – have been primarily viewed as a health problem and a health challenge among most people. The Commission instead wishes to focus on a *rights-based* approach, where the individual is understood as possessing fundamental rights that the authorities and society as a whole shall ensure. The individual with disabilities is not primarily a patient or a user of services, but an individual and a citizen with rights and opportunities. It is not the first time this has been pointed out, but it is high time that this is realised, and that such an understanding characterises society.

The chapters in the report are mainly structured in the same way. First, a description of the current situation is provided as well as a review of what research and previous reports have concluded. This is followed by an assessment by the Commission and recommendations for measures that should be implemented. The recommendations by the Commission are preceded by a short text about the Commission's wishes and visions for the area. All chapters contain illustrative texts from fiction and public debate, as well as important input that the Commission has received.

A common thread in the report is that a better and clearer connection must be created between the measures offered to persons with disabilities. Agencies that do not communicate well with each other, transitions that do not work well enough, a lack of clarity in communication and, in general, what we often refer to as a silo mentality characterise too many of the services that are provided and prevent full equality. We must ensure that persons with disabilities are not marginalised in society. This must be done both by changing attitudes and by ensuring that schemes actually work, not least by ensuring that they are better coordinated and are based on real needs and sound knowledge.

With the exception of the first three chapters, which do not contain assessments or measures, we will here summarise chapter by chapter some of the findings and measures that the Commission has arrived at. For a full overview, the reader is referred to the individual chapters, and in particular the Commission's assessments and proposals for measures.

Chapter 1: Introduction and mandate provides an introduction to the Commission's basic mindset, a definition and discussion of concepts and terminology, as well as a philosophical and practical consideration of ideas, values and visions related to how we create a good life for all of society's citizens, with particular emphasis on persons with disabilities.

Chapter 2: The Commission's work and members reviews the Commission's mandate and composition and provides an explanation of how the Commission has worked.

Chapter 3: Human rights and legal framework reviews current human rights and other legislation with relevance for persons with disabilities, with an emphasis on everyone's equal rights and the principle of non-discrimination.

Chapter 4: Core issues for persons with disabilities reviews key issues related to the realisation of the rights of persons with disabilities, including the importance of working to change attitudes and having the CRPD framework incorporated into Norwegian legislation and practice (the CRPD is the UN Convention on the Rights of Persons with Disabilities). Proposed measures in the chapter concern CRPD incorporation, the terminology used for persons with disabilities, the fight against silo organising and mentality, better coordination and follow-up, e.g., in the Norwegian Labour and Welfare Administration (NAV) system, and the need for more knowledge and assessments of the conditions of persons with disabilities in Norway. The National Council for the Equality of Persons with Disabilities must be restored and the municipal councils strengthened, with a permanent right to participation in the municipal councils for the chairperson and deputy chairperson. The scheme involving User-Controlled Personal Assistance (UCPA) must be revised and further developed, so that improved, expanded and more comprehensive assistance schemes and services for persons with disabilities can be put in place.

Chapter 5: More than disabled! focuses on the demanding challenges that come with belonging to several minority groups or social categories in society, and at the same time being a person with disabilities. This type of situation is characterised by what is referred to as *intersectionality*. The chapter discusses identity-based discrimination, as well as challenges and opportunities linked to various identities and the combination thereof. The Commission emphasises that more knowledge is needed about the experiences of persons with disabilities who belong to several minority groups. Furthermore, the Commission highlights the need for individual consideration of each individual in their life situation, and it is emphasised that persons with disabilities must be included in public diversity policy and be able to benefit from it.

Chapter 6: Families expecting a child with disabilities addresses demanding issues, including a possible termination of pregnancy. The Commission emphasises the importance of sufficient information and considerable support. It is important that the space for normality and acceptance in society is not restricted, and that society gives full acceptance and support to everyone who is expecting or has a child with disabilities, or who has disabilities themselves. People in the difficult situations discussed here must be able to make genuine and well-informed choices. Among other things, the Commission recommends a state-funded, comprehensive and national follow-up service with peer support and guidance for pregnant women/couples expecting a child with disabilities. It must be ensured that all foetal diagnostic centres have a social worker or family therapist available to provide satisfactory support for pregnant women and couples who are faced with a choice, and a welcome/measures package should be prepared for pregnant women who are carrying a child with disabilities.

Chapter 7: Families with children with disabilities is about the family's encounter with the support services. The Commission emphasises that the situation of many families with children with disabilities is unsustainable. Many do not receive the assistance they are entitled to. Their rights, which are emphatically stated in several articles of the CRPD, as well as in Norwegian legislation, are breached every day. The Commission has clear expectations that the children's coordinator role, which became a statutory requirement as of 1 August 2022, will improve the situation for families with children with disabilities. The Commission proposes, among other things, that sufficient earmarked funding must be ensured for the children's coordinator positions, that the children's coordinators who are to follow up families with different minority backgrounds have sufficient multicultural competence for the task, and that the children's coordinators are given the opportunity to be coordinators for the entire family. Research on, and follow-up evaluation of the children's coordinator role must be ensured. The competence of coordinators and service providers must be ensured. Outdated

guidelines must be updated, and families and children with disabilities must be approached with clear and plain language and comprehensible digital systems. The right to a care allowance for parents who are unable to participate in working life due to caregiving duties for their own children must be strengthened and secured. The National Relatives Guide must contain requirements for measures to be offered to siblings, as relatives. Public funding of peer support carried out in organisations must be strengthened. The services for families with children with disabilities must also be made available to parents with a minority background.

Chapter 8: Upbringing, leisure time and participation for children and young people with disabilities addresses the right to participation for children and young people with disabilities, with particular emphasis on inclusion through universal design. The chapter takes its point of departure from the UN Convention on the Rights of the Child's emphasis that all children and young people have the right to rest and leisure, play and recreational activities. In addition to the right to participate in recreational activities, and not least sports, the chapter also addresses the importance of being able to participate in the practice of faith and in cultural life. The Commission emphasises that a more universally designed society will help increase the visibility of children and young people with disabilities. It can contribute to the necessary changes in attitude, so that the rights of children and young people with disabilities are better realised. The Commission recognises the important inclusion efforts of many passionate individuals in sports, culture and leisure, but emphasises that this work must be given better frameworks. It is necessary to enhance the awareness and competence of both municipal managers, including school managers, and managers in non-profit organisations regarding how children and young people with disabilities can be included and segregation can be combatted. Increased support for assistance schemes is needed. The Commission's vision is that all children and young people with disabilities should be active and contributing individuals through a good, rewarding and inclusive everyday life and leisure time.

Chapter 9: Primary, lower secondary and upper secondary education takes its point of departure from everyone's equal right to education. The Commission's review shows that, for most, segregated teaching and little participation in ordinary classes lead to alienation and increased otherness. Pupils with disabilities generally do not receive enough challenges or sufficient learning outcomes and progression in their education. The current school system also does not ensure that pupils with disabilities enjoy genuine equality and participation in everyday school life. Low expectations in school prevent full learning outcomes for pupils, and a lack of diplomas, competence assessments and grades create problems for many pupils in relation to later opportunities in working life. There is inadequate information flow and coordination in the transitions between school levels. It is also a significant problem that many unskilled assistants and teachers are assigned to coordinate and teach pupils with disabilities. In general, it is important to have school managers who clearly and consistently ensure that persons with disabilities enjoy their full rights in school. The Commission wants universal design of schools – including access to learning materials adapted to the pupil – to be ensured by 2030. Career guidance must be offered to all pupils in primary, lower secondary and upper secondary school, regardless of disabilities. All vocational programme subjects must be made accessible so that free choice of school in upper secondary education is a genuine possibility for pupils with disabilities. Pupils' needs and wishes in the transition between school and work must be strengthened. School authorities and the Norwegian Labour and Welfare Administration (NAV) must be required to collaborate to ensure that all pupils with the right to an adapted education on the pathway to working life receive necessary and suitable assistance.

Chapter 10: Higher education is about the right to equal access to higher education of persons with disabilities. It is an expressed wish in society that people who want and have the talent to

do so should be able to pursue higher education. Far too many persons with disabilities feel that they are excluded from this goal. The chapter describes barriers that prevent persons with disabilities from making free educational choices based on their own interests and qualifications. It is also economically unprofitable that fewer people enter into working life and remain in the workforce. Research shows that higher education is the best way to get persons with disabilities into work. Simpler and better schemes must then be created so that persons with disabilities can complete higher education. The Commission believes that NAV must use the work assessment allowance scheme to a greater extent to provide support for higher education and do so in a flexible manner that safeguards individual interests and wishes. A possibility of early admission should be offered to students who require adaptation, so that the adaptation is in place before the commencement of studies. The possibility of financial support for persons with disabilities who do not complete their studies in the standardised period of time should be strengthened. The Norwegian State Educational Loan Fund and NAV must facilitate financial frameworks that make it possible to complete a study programme, and the additional grant for students with disabilities must be increased. Disability benefits should be possible to combine with higher education according to individual assessment. The Norwegian State Educational Loan Fund's rules for converting grants into loans must equate income from national insurance benefits such as work assessment allowance and salary. The Commission wants all study programmes and course descriptions to be reviewed with regard to the special challenges that persons with disabilities may have during implementation. Persons with disabilities must also be given a genuine opportunity to study abroad.

Chapter 11: Work, employment and career opportunities analyses both opportunities for and barriers to participation in working life for persons with disabilities. For many, work is a source not only of income, but of joy, participation and respect. Therefore, it is important that as many people as possible are integrated into working life, while those who are unable to work receive the support they need to live a fulfilling life. The Commission's proposed measures reflect a vision of a working life that is inclusive and flexible, and where both employees and employers experience the joy and great benefit of a working life in which everyone can participate. In many ways, we have fallen short in Norway. There are many reasons why far too few persons with disabilities are included in working life, including a lack of universal design, structural barriers, inadequate arrangements, bad attitudes and lack of knowledge. An arrangement such as not performing work capability assessments for persons who have already received a decision regarding secured income in the form of disability benefits means that many do not even get the opportunity to make an attempt at working life. The chapter otherwise contains many good examples to follow, from which the Commission believes lessons can be learned. The Commission proposes that a government funding scheme be established from which employers can apply for funds to rebuild their own premises in order to adapt for employees with disabilities. It should be evaluated how to better combine national insurance, work and education, so that it becomes more profitable to work. The flexibility to alternate between disability benefits and work must be continued and strengthened, and it should be evaluated whether wage subsidies can replace disability benefits in those cases where partial disability benefits are granted. The scheme involving functional assistance must be expanded and strengthened. The working life participation of persons with disabilities must also be part of the partite cooperation in working life at all levels.

Chapter 12: Housing focuses on the right to have a safe home. A safe home is both a place where you can be yourself and live your life in a good way, as well as a place where the surrounding conditions are adapted so that you receive the follow-up you need. The

Commission is aware that many municipalities are in a difficult financial situation, but that is precisely why it is essential to have clear, statutory requirements that counteract large differences based on which municipality or part of the country you live. The new Social Housing Act must be revised so that it clarifies the municipality's responsibility for providing suitable housing. The municipality must provide necessary and appropriate assistance to obtain adequate and suitable housing for persons who are unable to safeguard their own interests in the housing market. A limit must be introduced on the size of shared housing and how many co-located dwellings the municipality can establish, so that the dwelling feels like a home and not an institution. There should be new conditions for grants and loans from the Norwegian State Housing Bank. Grants from the Norwegian State Housing Bank must be given in a sufficient order of magnitude so that the individual can purchase an accessible dwelling and have the option of having their own assistant's room if the person in question needs it. Ownership in the housing market for this target group must be strengthened by developing new models. The housing benefit limit must be revised annually so that persons receiving disability benefits are still entitled to housing benefits when national insurance benefits are adjusted. The income limits should at all times be regulated so that everyone who receives 100 per cent disability benefits and receives national insurance amounting to less than 3.5 G (basic amount in the National Insurance scheme), qualifies for housing benefits. Schemes involving permanent financial incentives should be introduced to ensure that refugees and asylum seekers with disabilities are housed in suitable dwellings quickly.

Chapter 13: Community participation for adults with disabilities is about the opportunity to be able to participate on an equal footing with others. Being a person with disabilities to accessibility should not mean that you are unable to be an active participant in society, or that you experience marginalisation. Beautiful and important visions that "everyone should be able to participate" and that "everyone should be able to develop themselves", must in fact apply to all members of society. Universal design is also a key concept in this context. The increasingly all-encompassing digital schemes and aids in society must not lead to a digital class divide or to services, in practice, becoming inaccessible to many. An information and public awareness campaign should be launched which draws attention to the challenges faced by persons with disabilities. The goal must be to create a general acceptance to secure rights for this group just as for others. The police's competence regarding hate crime against persons with disabilities must be strengthened. Freedom of expression of persons with disabilities must be strengthened and safeguarded, including by increasing their knowledge of freedom of expression, as well as ensuring that information about these rights is included in guidelines and information letters for those who are to provide assistance to persons with disabilities. The right of persons with disabilities to exercise their faith and religion must be ensured. There is a need for more research on the sexuality of persons with disabilities and need for and use of sexual technical aids. In terms of community participation, there is a need for more up-to-date and relevant research-based knowledge, not least regarding the living conditions of persons with disabilities over time.

Chapter 14 Administrative and financial impacts reviews the administrative and financial impacts of the Commission's proposals for measures and recommendations.