Down Syndrome in Sweden:

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Easy Language Version

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Introduction

EU for Trisomy 21 is a group where parents and people with Down syndrome from all over Europe come together.

It's a place where everybody works together to support the rights of people with Down syndrome.

They also want to make sure that people with intellectual disabilities, especially people with trisomy 21, are noticed.

EU for Trisomy 21 tries to share information and work with European organizations to make sure that people with Down syndrome are treated fairly and their rights are respected.

In this document, we're looking at how well Sweden follows the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

We're interested in seeing if Sweden is putting the ideas from this Convention into action.

We found that although Sweden has laws to protect the rights of people with disabilities, they don't always follow through on them very well.

We want Sweden to do more to prevent discrimination against people with Down syndrome.

In our report, we talk about some specific parts of the UNCRPD related to equality, education, and health. We try to be fair by mentioning both the good things Sweden has done and the things to improve.

Equality and non-discrimination – Article 5

1. Positive measures

- Sweden has a law that stops people from treating others with disabilities unfairly.[1]
- Sweden also has a plan to make sure people with disabilities are treated fairly and included.[2]
- In some parts of Sweden, there are websites and centers where parents and others can learn about Down syndrome. This is good because it helps stop wrong information and the stigma around it.[3]

2. Ableism, source of discrimination

Ableism, as defined by Ms Devandas Aguilar, Special Rapporteur on Disability (2014-2020) in her annual report, is: "*a value system that considers certain typical characteristics of body and mind as essential for living a life of value. Based on strict standards of appearance, functioning and behaviour, ableist ways of thinking consider the disability experience as a misfortune that leads to suffering and disadvantage and invariably devalues human life.*"[4]

Lotta, mother of Moa, a Swedish girl with Down Syndrome opposes to this. She said that "*"It's too bad that the research and prenatal testing may make people with Down syndrome disappear. We need them to teach us about life. Who decides what's normal or not?*".[5]

In Sweden, the Down syndrome community became very small because of widespread prenatal screening. Since the 1970s, Sweden has used the KUB test, which combines ultrasound and blood tests,

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[1] https://www.riksdagen.se/sv/dokument-och-lagar/dokument/svensk-forfattningssamling/diskrimineringslag-2008567_sfs-2008-567/

[2] https://sweden.se/life/equality/disability-policy

[3] https://regionuppsala.se/infoteket/hamta-kunskap/fakta-om-funktionsnedsattningar/downs-syndrom/

[4] Ms Catalina Devandas-Aguilar, Report of the Special Rapporteur on the rights of persons with disabilities, 2020, A/HRC/43/41. §9. https://documents.un.org/doc/undoc/gen/g19/346/54/pdf/g1934654.pdf?token=XKh4YvcLcbmkbqCdBB&fe=true

[5] https://www.cedarsstory.com/hello-from-sweden/

to check for Down syndrome risk. If a risk is found, further tests are offered. Medical professionals often pressure pregnant women to take these tests, making them feel like it's mandatory, in order to detect as many cases as possible. It shows a very bad picture of a disability that people think should disappear.

The Swedish Medical Ethics Council (Smer) is afraid by the test called Non-Invasive Prenatal Testing (NIPT) in Sweden's healthcare. They think there will be fewer babies born with chromosomal abnormalities. They stated that "*this could mean that our view of human value will radically change. There is also a risk that we contribute to the increasingly limited acceptance of human diversity.*"[6]

Ableism means thinking some people are less important because they don't have certain abilities. Our society has difficulties to see the worth of people with disabilities.

The UNESCO International Bioethics Committee reported: "*A widespread use of NIPT, namely as general screening in order to detect abnormalities, followed by an abortion, is perceived by some people as an evidence of the will to avoid permanent pain in a lifetime, by others as a sign of a situation of the exclusion society gives to people affected by this illness, meaning indirectly that certain lives are worth living, and others less.*"[7]

In Sweden, between 1999 and 2015, 52.5% of babies who could have been born with Down syndrome were not born. In 2016, 73% of babies with Down syndrome were not born[8]. This increase happened because more parents were using tests before birth to check for Down syndrome, and doctors were encouraging them not to have the baby with Down syndrome. In addition, sometimes parents didn't have enough good information to decide.

Prenatal screening tries to seem neutral but often only gives parents one side of the story, which is biased against people with disabilities. When parents only hear about health problems related to Down syndrome, it makes it seem like having Down syndrome is a bad thing. This can make people with Down syndrome feel like they are seen as a problem instead of as equal human beings. It's like making everyone believe negative things about disabilities without showing the positives. This creates a mindset that is not accepting of disabilities.

After a baby with Down syndrome is born, the ableist thinking still happens. In a study with 165 Swedish parents who had young children with Down syndrome, it was found that right after their child was born, 70% of them didn't feel like they got enough helpful information from the doctors and nurses, and 56% felt like they didn't get enough support. The parents complained that the medical staff didn't communicate well, there wasn't enough privacy, they heard too many negative things, and they wished they could have connected with other parents of kids with Down syndrome earlier.[9]

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[6] Report of the Swedish Medical Ethics Council (Smer) "Analysis of foetal DNA in the woman's blood: Non-invasive prenatal testing (NIPT) for trisomy 13, 18 and 21 - ethical aspects", page 33. https://www.smer.se/wp-content/uploads/2015/10/Smer-2015_1-webb-PDF1.pdf

[7] Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights, UNESCO, October 2015. http://unesdoc.unesco.org/images/0023/002332/233258E.pdf.

[8] Report on Birth defects and chromosomal abnormalities, 2016. https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2018-3-13.pdf

[9] https://researchportal.hkr.se/ws/portalfiles/portal/40958244/FULLTEXT01.pdf

This shows that in Sweden, the healthcare system discriminates against people with intellectual disabilities, both before they are born and after.

3. Recommendations (Equality and non-discrimination – Article 5)

To align with Article 5 of the Convention on the Rights of Persons with Disabilities, Sweden should consider the following recommendations:

1. Sweden should understand that prenatal tests make people with Down syndrome feel rejected and are a type of discrimination. Sweden should draft new guidelines concerning prenatal test to avoid prenatal discrimination. We want the rules to follow what the Convention on the Rights of Persons with Disabilities says, which is about treating everyone fairly and equally.
2. Sweden should teach healthcare workers how to talk better to parents about Down syndrome. They should give parents the right information. Healthcare workers should talk about the possibility to learn, to work and to live a happy life. Down syndrome, it is not just health problems.
3. Please, more campaigns to make people understand that discriminating against persons with Down syndrome is wrong. Please, try to change how people think about Down syndrome. Please, make an environment where people with Down syndrome are supported and celebrated for their special qualities.

Education – Article 24:

1. Positive measures

- In Sweden, all children go to school starting when they are 6 years old. They stay in school for at least 10 years[10].
- Sweden proposes financial support for adults with intellectual disabilities who are receiving education or are on an internship[11].

2. Reality and Challenges

Even though school is required starting at age 6, not many children with Down syndrome can go to regular primary schools. In Sweden, people with Down syndrome usually go to separate schools, not the same ones as everyone else. This separates them from others and doesn't help a cohesive community. It would be better if children with Down syndrome could go to regular schools like everyone else.

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[10] https://www.svenskadownforeningen.se/kunskapsbank/skola-och-utbildning/grundskola/

[11] https://www.spsm.se/stod-och-rad/sok-statsbidrag/privatpersoner/bidrag-for-vuxna-som-far-anpassad-utbildning-pa-komvux/

School is important not only to learn academic knowledge but also to learn how to live in a heteroclite group with other citizens. The best way to experience diversity is to share school with persons with disabilities. That is why, it is important not to exclude persons with intellectual disabilities from regular schools, but rather, ensure that they have their rightful place there. It would be better if children with Down syndrome could go to regular schools like everyone else.

People with Down syndrome also face discrimination in education because they don't have good access to learning the Swedish language easily. The Language Act of 2009 helped with minority languages and Swedish Sign Language, but it didn't focus enough on AKK (alternative and supplementary communication). This means there weren't specific plans to help people with intellectual disabilities, especially with Down syndrome, learn better.[12]

When people with Down syndrome are also in special conditions like being a refugee, an immigrant, or from poorer backgrounds, it's much harder for them to learn Swedish. They have to deal with their disability along with differences in culture, language, and financial means. Without specific help like AKK (alternative and supplementary communication), they are pushed aside even more. This makes it hard for them to get a good education, make friends, and have the same chances as others, making discrimination even worse.

For people, being able to communicate and understand language is really important. It helps with talking to others, learning new things, thinking, and being part of a democracy. But in Sweden, there aren't clear rules or guidelines on how children with Down syndrome can make sure they learn language properly. This means the Swedish authorities haven't done enough to help them with this important right[13].

Lastly, even though Sweden helps people with intellectual disabilities with education aid, it's not enough. The Special Education School Authority (SPSM) said that the money given to support students with disabilities in colleges and universities is too low and needs to be increased[14].

Lack of accessibility to Education of Ukrainian Refugees with Disabilities.

According to Swedish law "all asylum-seeking children have the right to attend school [15]". However, when refugees come to Sweden, there haven't been enough actions taken to make sure that people with disabilities, especially, can go to school like they should.[16]

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[12] https://www.aftonbladet.se/debatt/a/21y8zx/sa-diskriminerar-vi-barnen-med-downs

[13] https://www.aftonbladet.se/debatt/a/21y8zx/sa-diskriminerar-vi-barnen-med-downs

[14] https://www.svenskadownforeningen.se/nyheter/2020/regler-behover-ses-over-for-allas-ratt-till-hogre-utbildning/

[15] https://www.migrationsverket.se/English/Private-individuals/Protection-and-asylum-in-Sweden/While-you-are-waiting-for-a-decision/Education.html#:~:text=All%20asylum%20seeking%20children%20have,permit%20before%20beginning%20any%20studies.&text=All%20asylum%20seeking%20children%20and,to%20attend%20preschool%20and%20school

[16] https://www.gp.se/debatt/krisberedskapen-maste-inkludera-aven-de-med-funktionsnedsattning.22652d16-e35b-4600-968c-0d461698c240

Also, there is a problem with getting interpreters for deaf people from Ukraine who came to Sweden because of the war. They don't have sign language interpreters. This makes it hard for them to access education. [17]

3. Recommendations (Education - Article 24)

To align with Article 24 of the Convention on the Rights of Persons with Disabilities, Sweden should consider the following recommendations:

- **Make regular school accessible** for persons with Down syndrome. We urge the Swedish government to give more money to programs that help make schools inclusive for people with Down syndrome. This means giving money for special training for teachers. With more money, we can break down barriers and have a school system where everyone is included.

- We call on the Swedish government to **increase funding to programs that help people with Down syndrome learn language.** This means making better ways to learn language, giving special tools, and training teachers to help. With more money, we can make sure the language-focused plans from the Language Act of 2009 actually work. This will help people with Down syndrome get fair access to education and communication.

Health – Article 25:

1. Positive measures

- In every part of Sweden, there are healthcare services, but some doctors might not know a lot about Down syndrome.

- In Sweden, there'= is a social policy called LSS. It stands for the Law on Support and Service for People with Certain Disabilities. This law helps people with intellectual disabilities who struggle in daily life and need support. People can apply for assistance.[18]

2. What can be improved

Doctors often don't have enough knowledge about Down syndrome and might struggle to properly care for patients with intellectual disabilities.

In Sweden, parents of children with Down syndrome feel that dental staff often don't know how to handle kids with this condition. They also found that medical staff don't know about other ways to

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[17] https://www.dn.se/sverige/brist-pa-tolkar-som-kan-ukrainskt-teckensprak/

[18] https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/12/Sweden_Act-concerning-Support-and-Service-to-Persons-with-Certain-Functional-Disabilities-LSS.pdf

communicate, like using pictures and signs. This information comes from a survey done by researchers at Jönköping University's School of Health and Welfare.[19]

Sweden has welcomed Ukrainian refugees, like other countries in Europe. But those refugees who have disabilities find it hard to get healthcare. According to a recent report by UNHCR about Ukrainian refugees in Europe[20], in 2023, 49% of families with at least one person with a disability had difficulties getting healthcare. This is much higher than the 32% of other families. The difficulties include long waits and high medical costs.

The report also states that these groups become even more vulnerable as they stay displaced for longer.

Certain types of care and assistance are available for Ukrainian refugees with disabilities in Sweden, however many lots of types of care are still hard to get, especially for people with physical or intellectual disabilities. For instance, Olga Ostapiuk couldn't get an electric wheelchair when she asked for one from the area. Instead, she got one on loan from a non-profit organization, as was reported by Swedish radio[21].

Starting from October, 2023, Ukrainian refugees have permission to stay in Sweden until at least March 2025, thanks to the EU's temporary protection plan under the mass migration directive. This means they get some benefits, like emergency care. However, help for people with disabilities isn't always guaranteed.

Advocates, like Nicklas Mårtensson, who leads the organization Funktionsrätt Sweden, believe the rules for Ukrainians with disabilities need to change. He thinks that the help they get through the mass migration plan isn't enough because it was only meant to be temporary for about a year. Since Ukrainians will be staying longer in Sweden, he says they need more help.

3. Recommendations – Article 25 of the CRPD

To align with Article 25 of the Convention on the Rights of Persons with Disabilities, Sweden should consider the following recommendations:

- Develop and implement **guidelines for healthcare providers** to ensure persons with intellectual disabilities, including Down syndrome, receive **the highest attainable standard of health**. This includes **training for healthcare professionals** on the specific needs of persons with Down syndrome.

- Implement **regular health assessments** for persons with intellectual disabilities to proactively address their healthcare needs and prevent the exacerbation of existing conditions.

- Launch **public awareness campaigns** to reduce stigma associated with intellectual disabilities and foster a more inclusive and understanding society.

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[19] https://ju.se/en/research/news/news-archive/2022-11-11-dental-care-staff-found-lacking-when-treating-children-with-down-syndrome.html

[20] 20 Report from the UNCHR, November 2023. https://data.unhcr.org/en/documents/details/104828

[21] Radio Sweden, 20 October 2023. https://sverigesradio.se/artikel/ukrainaren-olga-bad-om-elektrisk-rullstol-regionen-sa-nej