Tidsskriftet Tidsskrift for Den norske legeforening

Persons with intellectual disabilities are still a pariah caste in Norway

PERSPECTIVES

TORSTEIN VIK

torstein.vik@ntnu.no
Torstein Vik, professor emeritus of paediatrics at the Norwegian University of Science and Technology. He is the father of a 46-year-old woman with intellectual disability.
The author has completed the ICMJE form and declares no conflicts of interest.

Supported by all political parties in Norway, a visionary reform was introduced in 1991. The reform implied that persons with intellectual disabilities should be enabled to live their lives as actively as other citizens. The architect was a doctor. Thirty years later, the reform has failed. Is it impossible for persons with intellectual disabilities to live dignified lives in Norway?

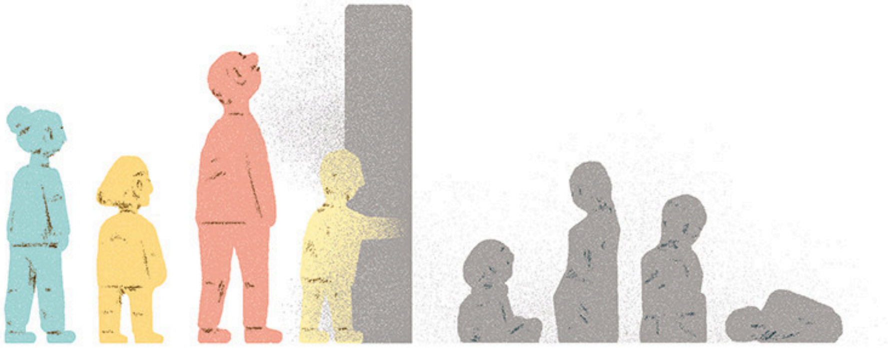

Illustration: Audun Gjerdi

In 1988, the Storting (the Norwegian parliament) adopted a reform that was intended to give persons with intellectual disabilities (hereafter referred to as intellectually disabled) the opportunity to choose where and how they would live, and to live active lives and participate in society like other people (1). The principles underlying the reform were based on two official government reports chaired by psychiatrist Ole Petter Lossius (1925–2007) (2, 3). The reform was introduced in 1991. The responsibility for its implementation was transferred from the county level to the municipalities, hence it was named 'The Responsibility Reform Act' (hereafter referred to as the 'responsibility reform') (1, 4). The main goals of the reform overlapped well with the goals for habilitation and rehabilitation of persons with disabilities as described in the International Classification of Functioning, Disability and Health (ICF), which was published ten years later (5), and in the UN Convention on the Rights of Persons with Disabilities (CRPD), which was adopted by the UN in 2006 (6).

Apart from the closure of large institutions, one of the reform's main objectives, and the transfer of responsibility to the local authorities, the reform got off to a bad start. Thirty years later, intellectually disabled persons are again placed in large residential care facilities reminiscent of institutions (7). Few are meaningfully employed, and their opportunities to participate in leisure activities are extremely limited (8). The main reason why the reform got off to such a poor start was that none of the good intentions were enshrined in law as rights (9). When politicians adopt budgets, the living conditions of persons with disability are no longer a matter close to their hearts.

In 2011, the overall responsibility for the living conditions of the intellectually disabled was transferred to the Ministry of Culture, which is also responsible for gender equality (8). Even though this reorganisation reduced the role of doctors, there are historical, moral and medical reasons why doctors should take particular responsibility to get the reform back on course.

The doctor's role – from humanism to eugenics

In Christian Europe, attitudes towards the intellectually disabled until the 19th century were characterised by an inhuman mindset and lack of respect (4). Persons with intellectual disability were regarded as inferior beings, worth less than animals (10). Many were kept chained and locked up together with mentally ill persons in huge institutions (11). During the French Revolution, the doctor Philippe Pinel (1745–1826) freed the captives from their chains, opened the gates and introduced more humane attitudes (11, 12). Another French doctor, Jean Marc Gaspard Itard (1774–1838) was among the first to start systematic education and training of persons with intellectual disability (13). In England, John Langdon Down (1828–1896) pioneered humane treatment, respectful attitudes, and education and training for this group of people (14).

> ***«When politicians adopt budgets, the living conditions of persons with disability are no longer a matter close to their hearts»***

With the emergence of eugenics in the late 19th century, doctors unfortunately helped attitudes take a turn for the worse (15–17). Eugenics was regarded as important for public health and recognised as a research specialty in the United States, England, Germany and Scandinavia (16). Some Norwegian doctors who adopted these theories included Halfdan Bryn (1864–1933), president of the Norwegian Medical Association and chairman of the Royal Norwegian Academy of Sciences, the husband and wife researchers Alette (1873–1951) and Kristian Schreiner (1874–1957), and Ingeborg Aas (1876–1958), liberal politician, public health promoter and pioneer of mother-and-child clinics (15–17). In the United States, American doctors lobotomised John F. Kennedy's mildly intellectually disabled sister Rosemary in 1941 (18). The lobotomy rendered her totally incapacitated, and she was hidden away (18).

The ideas of eugenics culminated with the murders of persons with intellectual disability in Nazi Germany (19). However, abuse and maltreatment continued in the post-war years (16). In the Nordic countries, persons with intellectual disability were subjected to physical abuse, unethical research experiments and forced sterilisations until the 1970 s (4, 16, 20). This took place while they were isolated from the general population in large institutions (4).

A humane reform that failed

In the 1970 s and 80 s, the psychiatrist Ole Petter Lossius chaired the work on two official government reports (2, 3). The reports' conclusions were that persons with intellectual disability should be permitted to decide for themselves where and how they wanted to live, that there was no reason for them to be isolated in large institutions, and that they should be provided with individually adapted education and training, and employment, as well as access to leisure activities like other citizens. These conclusions overlap impressively well with the intentions in the ICF classification and the CRPD convention, published 20–30 years later (5, 6). We can safely say that Lossius and his co-workers were ahead of their time.

> ***«The main reason why the reform failed is that the good intentions were not enshrined in law as rights»***

Unfortunately, when the reform was introduced in 1991 things went wrong from the start. A number of reports and official assessments have repeatedly documented that none of the main goals have been achieved (7, 8, 21)(21–23). In 2006, the Norwegian Board of Health Supervision revealed that persons with intellectual disability were subject to abuse and undue coercion (23). In 2007, the Directorate of Health published a report that questioned the implementation of the reform (21). A report from the Norwegian University of Science and Technology in 2011 showed that large residential care facilities had again become common (7). A new Report to the Storting in 2012 expressed concern (22), which spurred another official report with the title *På lik linje [On equal terms]*, published in 2016 (8). Yet again, the conclusion was that the goals of the reform were still far from being achieved (8). So far, *På lik linje* has only helped generate another, still pending, report to the Storting. There are good reasons to argue that the Responsibility Reform Act represented a humane reform that has failed. The main reason why the reform failed is that the good intentions were not enshrined in law as rights.

Relatives bear the burden

As early as in 1994/95, the doctor and lawyer Aslak Syse warned that without rights, the reform would fail and the families would have to '... bear the burden of a care reform that was intended to benefit everybody' (9). Since 2012, based on their personal experiences many well-known Norwegian authors have described what life is like as parents of a child with intellectual disability and how this can be a strain on the entire family (24–28). The abovementioned reports and official assessments, the literary descriptions and my own experience as a father have shown that Syse was right.

Without human rights

In the *På lik linje* report, the living conditions of persons with intellectual disability in Norway in 2016 were not only measured against the intentions in the Responsibility Reform Act, but also against the CRPD convention (8). The convention was ratified by Norway in 2013, but it has not yet been incorporated into Norwegian law (29). When measured against the convention, the rights of persons with intellectual disability in Norway fell short on a total of fifteen counts (articles) (8). These included articles on general human rights as well as on ordinary living conditions. *På lik linje* concluded that Norway failed to comply with the articles that concern education (Article 24), health (Article 25), habilitation and rehabilitation (Article 26), work and employment (Article 27), participation in political and social life (Article 29) and participation in cultural life, leisure activities, entertainment and sports (Article 30). All these areas were key targets in the Responsibility Reform Act and in the two official government reports (1–3).

> ***«As doctors, we have an extended responsibility for the living conditions of people with intellectual disability»***

In March 2019, the UN Committee on the Rights of People with Disabilities criticised Norway for not yet having incorporated the CRPD convention into national legislation (29). The committee argued that the lack of rights was the main cause of many of the problems that people with disabilities in Norway encounter, including the large variations according to the municipality of residence (29). *På lik linje* outlines eight measures intended to get the reform back on track. The first measure is to incorporate the CRPD convention into Norwegian law. As late as in March this year, the Storting rejected such a proposal for the third time (30).

Failure in overall governance

Until 2011, the overarching responsibility for the living conditions of intellectually disabled persons rested with the Ministry of Health and Care Services. In that year, the responsibility for coordination was transferred to the Minister of Equality, who at present is also the Minister of Culture. The overall, governmental responsibility for health, education, employment, social benefits and housing was delegated to the appropriate ministry, while the practical responsibility for the reform still rested at the municipal level (8). The intention behind this reorganisation stemmed from the desire to emphasise the equality aspect. However, one of the conclusions of *På lik linje* was that this reorganisation has functioned poorly, because the main goals of each ministry have been given higher priority than cross-sectoral concerns for equality (8). Although the reform was already about to fail in 2011, the splitting up of responsibilities and weak overall governance finally brought the reform to a grinding halt.

Doctors and politicians both need to act

Participation and active lives are the general goals for all habilitation and rehabilitation of people with disabilities (5). This means that we as doctors have an extended responsibility for the living conditions of persons with intellectual disability. This applies to GPs, various specialists and especially to doctors in public positions, such as vice mayors, health directors, county medical officers and the chief health administrators in the Ministry of Health and Care Services and the Directorate of Health.

«The politicians must stop talking about equality and start acting»

Since this article was first submitted, the Directorate of Health has published new guidelines for good health and care services to persons with intellectual disability (31). For doctors, the guidelines may be a good starting-point, although they may not go far enough in relation to the ICF. Politicians must stop talking about equality and start acting. A starting point could be to enshrine the intentions in the Responsibility Reform Act as rights in law, in line with the CRPD convention. It is a shame that this well-considered and visionary reform, whose architect was a doctor, has failed.

LITERATURE

1. Søbye E. HVPU-reformen: Intensjoner og forløp. Samfunnsspeilet 1994; nr. 1: 32–5.

2. NOU 1973:25. Omsorg for psyksk utviklingshemmede: Målsetting og retningslinjer. https://www.nb.no/nbsok/nb/a5d6bc71ae6e89136bcabea6f0052565?lang=no#51 Accessed 21.5.2021.

3. NOU 1985:34 Levekår for psykisk utviklingshemmede. https://www.nb.no/items/69e6860a20edca97a70a86451a340d5e?page=0&searchText=NOU%201985:34%20Levek%C3%A5r%20for%20psykisk%20utviklingshemmede Accessed 21.5.2021.

4. Fjermeros H. Åndssvak! Et bidrag til sentralinstitusjonens og åndssvakeomsorgens historie. Oslo: Universitetsforlaget, 2009.

5. International classification of functioning, disability and health (ICF). Geneva: World Health Organization, 2001. https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health Accessed 21.5.2021.

6. Konvensjon om rettighetene til mennesker med nedsatt funksjonsevne. Oslo: Barne-, likestillings- og inkluderingsdepartementet, 2013. https://www.regjeringen.no/globalassets/upload/bld/sla/funk/konvensjon_web.pdf Accessed 21.5.2021.

7. Kittelsaa A, Tøssebro J. Store bofellesskap for personer med utviklingshemming. Trondheim: NTNU Samfunnsforskning AS, 2011. https://naku.no/sites/default/files/files/Store%20bofellesskap_rapport.pdf Lest 21.5.2021.

8. NOU 2016:17 På lik linje. Åtte løft for å realisere rettigheter for personer med utviklingshemning. https://www.regjeringen.no/contentassets/b0baf226586543ada7c530b4482678b8/no/pdfs/nou201620160017000dddpdfs.pdf Accessed 21.5.2021.

9. Syse A. Rettssikkerhet og livskvalitet for utviklingshemmete. Rettigheter, vern og kontroll som rettslige virkemidler. 1. utg. Oslo: Ad Notam Gyldendal, 1995.

10. Vik T. Utviklingshemmede i Europa. Paidos 2020; 38: 160–3.

11. Weissmann G. Citizen Pinel and the madman at Bellevue. FASEB J 2008; 22: 1289–93. [PubMed][CrossRef]

12. Skålevåg SA. Philippe Pinel. Store norske leksikon. https://snl.no/Philippe_Pinel Accessed 21.5.2021.

13. Groff ML. Jean Marc Gaspard Itard. Psychol Clin 1932; 20: 246–56. [PubMed]

14. Ward OC. John Langdon Down: the man and the message. Downs Syndr Res Pract 1999; 6: 19–24. [PubMed][CrossRef]

15. Jacobsen N.. Norsk rasehygiene. Nor Tannlegeforen Tid 2008; 118: 516–20.

16. Kyllingstad JR. Eugenikk. Store norske leksikon. https://sml.snl.no/eugenikk Accessed 21.5.2021.

17. Aas I. Hvordan kan samfundet beskytte seg mot åndssvake og sedelighetsforbrytere? Oslo: Olaf Norlis Forlag, 1932.

18. Söderfeldt B. Den gömda Kennedydottern - och synen på funktionsnedsättningar. Lakartidningen 2016; 113: D6R4. [PubMed]

19. Beddies T, Schmiedebach HP. "Euthanasie"–Opfer und Versuchsobjekte. Kranke und behinderte Kinder in Berlin während des Zweiten Weltkriegs. Medizinhist J 2004; 39: 165–96. [PubMed]

20. Brusevold IJ. Vipeholmstudiene: Store norske leksikon. https://sml.snl.no/Vipeholmstudiene Accessed 21.5.2021.

21. Jakobsen T. Vi vil, vi vil, men får vi det til? Levekår, tjenestetilbud og rettssikkerhet for personer med utviklingshemning. Raport IS-1456. Oslo: Helsedirektoratet, 2007. https://naku.no/sites/default/files/IS-1456_17307a.pdf Lest 21.5.2021.

22. Meld. St. 45 (2012–2013). Frihet og likeverd. Om mennesker med utviklingshemming. https://www.regjeringen.no/no/dokumenter/meld-st-45-2012--2013/id731249/ Accessed 21.5.2021.

23. Rettssikkerhet for utviklingshemmede. Oslo: Helsetilsynet, 2006. https://www.helsetilsynet.no/globalassets/opplastinger/Publikasjoner/rapporter2006/helsetilsynetrapport2_2006.pdf/ Accessed 21.5.2021.

24. Nilsen O. Tung tids tale. Oslo: Samlaget, 2018.

25. Nilsen O. Yt etter evne. Få etter behov. Oslo: Samlaget. 2020.

26. Ystgaard HM. Den tause sønnen. Oslo: Spartacus, 2019.

27. Gabrielsen L. Entré. Oslo: Gyldendal, 2020.

28. Vaage LA. Syngja. Oslo: Oktober, 2012.

29. Concluding observations on the initial report of Norway: Committee on the Rights of Persons with Disabilities. Geneva: United Nations Digital Library, 2019. https://digitallibrary.un.org/record/3848336 Accessed 21.5.2021.

30. Piene B. Stortinget sier nei til å ta funksjonshemmedes rettigheter inn i loven. Adresseavisen 9.3.2021. https://www.adressa.no/nyheter/innenriks/2021/03/09/Stortinget-sier-nei-til-%C3%A5-ta-funksjonshemmedes-rettigheter-inn-i-loven-23618871.ece Accessed 21.5.2021.

31. Helsedirektoratet. Gode helse- og omsorgstjenester til personer med utviklingshemming. https://www.helsedirektoratet.no/veiledere/gode-helse-og-omsorgstjenester-til-personer-med-utviklingshemming Accessed 9.7.2021.

Publisert: 27 August 2021. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.21.0428
Received 22.5.2021, accepted 10.8.2021.