Violations of Human Right of people with disabilities in the Netherlands

Paper by
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There are strong indications that human rights of people with disabilities in the Netherlands are being violated. We have found violations of the right to be free of torture or cruel, inhuman or degrading treatment or punishment; the right to have family life protected; the right to liberty and security of person; the right to live independently and to be included in the community; the right to personal mobility, the right to education and the right to have access to goods and services.

The violation of rights of people with disabilities in the Netherlands has become apparent in recent research reports and through media coverage of several cases of people with disabilities living in institutions who died as a result of (not getting proper) care or who have been segregated and/or chained during long periods of time. The extent of the violations of rights of people with disabilities in the Netherlands is not exactly clear. There is no systematic gathering of data and statistics on the rights of people with intellectual disabilities or mental health problems in the Netherlands, on their participation in society, their employment, their quality of life, their family life, their protection nor their use of health and support.
In this report we provide a brief summary of data that Foundation Perspectief collected, commissioned by the Fundamental Rights Agency in Vienna\(^1\), on the rights of people with intellectual disabilities and mental health problems. Other sources are data collected by the ANED network\(^2\) and the Dutch Coalition for Inclusion\(^3\). For this report we have taken the UN Convention on the Rights of Persons with Disabilities and the UN Covenant on Civil and Political Rights as the relevant framework in order to assess whether rights of people with disabilities in the Netherlands are violated.

The Netherlands signed the UN CRPD on 30 March 2007 in New York. Although ratification is not due before 2012, signing the UN CRPD means that the Dutch Government accepts the Convention. Furthermore, in the opinion of the Dutch Government, the UN CRPD offer no new rights but it ensures that existing human rights are to be made particular for people with disabilities. The minister of Foreign affairs wrote in a letter to parliament: “The Convention offers no new rights but aims to ensure that people with disabilities enjoy, on an equal footing with other people, the universal human rights and aims their equal participation in society.”\(^4\) According to this view the Rights of the UN CRPD are accepted in the Netherlands although the way they should be implemented has not yet been made explicit because ratification is still due\(^5\).

The right to be free of torture or cruel, inhuman or degrading treatment or punishment, security of person

Article 14 and 15 of the UN Convention on the Rights of Persons with Disabilities and art 7 of the UN Covenant on Civil and Political Rights grant the right to be free of torture or cruel inhuman or degrading treatment or punishment. For the Netherlands we can report the following.

Several incidents were reported about people with disabilities living in residential care institutions, indicating violations of their right to be free of inhuman or degrading treatment. We refer to some cases that were mentioned in general media: the case of Brandon (2010)\(^6\), a young man who was secluded and chained to a wall in his room in an institution “s Heerenloo for over a year; the case of Raymond (2011)\(^7\), a man with mental health problems who died in psychiatric hospital Dimence in his seclusion cell after several refusals by a series of doctors to treat his injuries; the case of Maljaars (2008)\(^8\) who suffocated in his seclusion cell in a psychiatric hospital in Amsterdam while being left

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\(^1\) Anna van der Zwan, Jose Smits, 2012 to be published as part of the Research Project on the Rights of People with Intellectual Disabilities and People with Mental Health Problems. website: http://fra.europa.eu/fraWebsite/attachments/disability-factsheet_EN.pdf

\(^2\) ANED, Academic Network European Disability Experts: www.disability-europe.net


\(^5\) M. Schuurman: Tekenen en dan…? Coalitie voor Inclusie 2010 ISBN 9789081704212

\(^6\) www.eo.nl 18 januari 2010 www.CoalitievoorInclusie.nl

\(^7\) www.eo.nl 18 januari 2010 www.CoalitievoorInclusie.nl

alone; and media coverage of several cases of serious neglect of people living in residential care in Amsterdam.

These incidents are the top of the iceberg, is our conclusion based on reports of the Dutch Health Care Inspectorate, reports on quality of care in institutions by Stichting Perspectief and a formal evaluation of the Psychiatric Hospitals Compulsory Admissions Act (Dutch acronym BOPZ) by Landeweer. Deaths of patients, serious neglect and degrading treatment are regular. The Health Inspectorate has noted that these cases could be prevented if care institutions would change their treatment policies but not all institutions are willing or able to change their policies. These conclusions are based on the following:

Landeweer e.a. describes in the evaluation report of the Psychiatric Hospitals Compulsory Admissions Act that in 2005 17,000 people with mental health problems or intellectual disabilities were forcibly admitted in institutions and were subject to coercive measures. This number of 17,000 was double that of the number in 2000. The number of imposed coercive treatment was 31% higher than in 2000. Landeweer could find no clear explanation of the increase. The report notes differences in the numbers per regions, again without a clear explanation. Landeweer also noted that institutions do not report each forced admission and each applied coercive measure such as segregation, to the Heath Care Inspectorate although reporting is obliged.

A report of the Health Care Inspectorate confirms the findings of Landeweer. According to the Health Care Inspectorate 20% of people living in residential care institutions are regularly locked up in their room at night, 30% are subject to forced medication to keep them calm and 12% are regularly tied to their bed at night. During the period June 2007 – May 2008, 7 people died of suffocation in their bed ties. This was regarded as unusually high by the Health care Inspectorate as the average death toll of these ties is two a year. The Inspectorate notes considerable differences between comparable institutions. In some such restrictive measures are not applied, in others more than average.

Noorthoorn e.a. collected information on the application of restrictive measures in 23 psychiatric hospitals in an investigation commissioned by the ministry of Health, Welfare and Sport on the effect of policies on reducing restrictive measures. Noorthoorn reports a decline of 17% of total seclusions...
and 20% decline of the numbers of total hours spend in seclusion cells by patients. In another report, Noorthoorn e.a. concluded that 1 in every 4 patients in Dutch psychiatric hospitals spends a period of on average 16 days in an isolation room. Frequency and duration of seclusion periods of patients in psychiatric hospitals is longer than in surrounding European countries.

A report on the prevention of seclusion by the Health Care Inspectorate (2008) states that in one third of psychiatric hospitals it is regular practice to systematically prevent seclusions of new patients on the day of arrival. In one third of hospitals recommendations by the Inspectorate to prevent seclusion were sometimes followed and sometimes not followed. One third of the hospitals ignored the recommendations of the Inspectorate to prevent seclusion.

The minister of Health, Welfare and Sport wrote in a letter to Parliament that 151 persons with disabilities were kept in seclusion for over a year during the period 2004-2008.

Perspectief found the following during evaluation of quality of care in some residential care facilities for people with intellectual disabilities.

“A young man has been tied to his bed for 20 hours a day during four months. The hours he was not tied were spent doing practically nothing. His behavior was controlled by electro aversive therapy. His parents experienced deep pain to see what their son had to go through ... They thought he was treated like an animal ... His personality has changed as a result ... It led to a deep sense of worthlessness.

“Someone is tied to a wall and is very limited in his freedom of movement. Another wears tubes around her arms and is seated in everybody’s sight in order to become more restful. For some their bedroom is a room with only a mattress. From 9 o’clock at night everybody remains in their closed bedrooms. And one has to sleep naked.”

“Around 11 o’clock all music, and lights are out. These people went on holiday together as a group to a place where such confinements were not possible. Their attendants were surprised to see that special measures were not missed during this holiday. Back from holiday nobody took consequences from this experiences and the special measures were imposed again.” (report on quality of care in a group home for 6 people, April 2006).

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18 Fragments from evaluation reports by stichting Perspectief, in a letter, July 25, 2007 to the secretary of Health, Welfare and Sport.
Protection of Family life and support for children to ensure life in a family.

Both the UN Convention on the Rights of Persons with Disabilities and the UN Covenant on Civil and Political Rights grant protection of family life and that states should secure such support that children with disabilities are not forcibly separated from their families. In the Netherlands an unknown number of children are admitted in residential care institutions. There are statistics on the number of children declared eligible for residential care: in 2010 that was the case for 3600 children with disabilities. Residential care can be given as an individualized budget, in order to provide the necessary support within the family so it cannot be said with certainty that all 3600 children eligible to residential care actually live in institutions. Nevertheless it is clear that children with disabilities do live in institutions in considerable numbers. The General Act on Extraordinary Healthcare Costs (AWBZ) implicitly supposes that people in residential care live in groups. The financing of care facilities is explicitly based on group living. The General Act on Extraordinary Healthcare Costs does not contain the right to care and support to enable family life. There is one family who had to appeal before the high Court of Appeal in order to gain a (high enough) care budget to help them finance care for their child with a severe disability within their family.

The right to independent living and personal mobility

Article 19 of the UN CRPD is on independent living in society with equal choice for people with disabilities to choose freely where and with whom to live and access public services in society. In the Netherlands there is support to enable independent living and access to public services for people with disabilities based on mainly two acts: 1967 General Act on Extraordinary Healthcare Costs (AWBZ) and the 2006 Social Support Act (WMO). Income benefits and rent benefits are available for people with disabilities. The Act on Equal Treatment on Grounds of Disability or Chronic illness covers the ground of employment, education and housing.

For people with physical disabilities and minor intellectual disabilities participation is monitored by Research Agency Nivel. The monitor shows that people with physical disabilities have a lower participation rate in employment, leisure activities and public transport.

People with more severe intellectual disabilities and mental health problems are not monitored by Nivel or other Agencies such as the Dutch Central Bureau for Statistics.
No systematic gathering of data is done on the life of people with intellectual disabilities and mental health problems.

Based on some research reports we know that people mental health problems who are dependent on professional support and care, lead a very isolated life. According to a meta-analysis survey of the findings of four different surveys, among 3,000 people with mental health problems, at least 35% of them experience unfulfilled wishes when it comes to having friends, a sense of purpose in life, work or useful activities, and intimate relationships. The researchers state that these findings give a representative image of the state of care and support to people with mental health problems in the Dutch population who need professional care. According to Van Weeghel, professor of rehabilitation and participation, only 12% of the 110,000 people with mental health problems who receive care in the Netherlands have paid work. Of this group under psychiatric care, 50% have no other structured daily activity. Most are socially isolated. According to van Weeghel, isolation is as much a result of barriers in society as it is of their mental health problem.

People with high need for support (eligible for residential care) meet barriers in Dutch legislation which hinders their participation in society and an independent life. One such barrier can be found in the 2006 Social Support Act (WMO). Local municipalities are responsible for providing support based on this act. When deciding on individual requests for support local municipalities may take into account provisions that can be provided based on other Acts such as the 1967 General Act on Extraordinary Healthcare Costs (AWBZ). This can and sometimes does lead to refusal of support such as support in regular school or housing adaptations if a person is eligible for special school or residential care. It does not matter whether a person actually applies for or is provided with these other provisions. In one court case a young woman was denied housing adaptations because she could have moved to an institution.

A barrier which hinders a large number of people is found in the General Act on Extraordinary Healthcare Costs. This act recognizes two groups within eligibility criteria. One group is not entitled for residential care and receives support based on individual needs. One group is considered to be in high need for support and is then eligible for residential care. People with disabilities cannot choose themselves to belong to either of these groups. The choice is up to the independent Agency CIZ who decides on care eligibility in all cases.

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31 Research for Fundamental Rights Agency: Stichting Down Syndroom knows examples of parents who did not receive support on a regular school because they had the theoretical option of a special school. Barrister M. Vermaat (http://www.woudenberg.nl) handled a case of a woman who was refused support by local council because she had the option to move to residential facilities.
32 U Barrister M. Vermaat (http://www.woudenberg.nl) handled a court case of a woman who was refused support by local council because she had the option to move to residential facilities.
People who are entitled to residential care receive support based on the assumption people live in groups and share their support. The General Act on Extraordinary Healthcare Costs does not contain a right to support to enable independent living arrangements or for children the right to live within the family. The assumed group living and sharing arrangements is part of the financial regulations and the formal eligibility criteria for residential care.\textsuperscript{33}

The national government does not endorse a formal policy or use specific measures to promote community or independent living for people with disabilities. The policy aim is to make it possible for people with disabilities to live at home and within their communities “for as long as possible”.\textsuperscript{34}

The result is that residential care budgets can be lower for residential care per person (because support is shared in groups) than care budgets for people who are considered able to live independently. The Health Care Insurance Board CVZ ruled in a verdict in an appeal case in which new financial arrangements for residential care lead to a lower care budget the before for people living independently: “being eligible for residential care means that less care at home if possible then for the same person living in an institution.”\textsuperscript{35}

In building regulations\textsuperscript{36} for residential care facilities group living of 6 persons is the preferred options but group living for 7 to 8 persons is allowed in new facilities and group living arrangements for 10 persons is allowed in older facilities. National Government policy opts to provide every person in residential care facilities for people intellectual disabilities with a private bedroom. In 2010 this private bedroom had yet to be provided to 4445 persons.\textsuperscript{37}

Person eligible for residential care can opt for an individualized care budget. This allows to provide care in independent living arrangements. Every individualized budget for residential care is 75% of the budget that individual would receive within a care facility. A budget is therefore 75% of the budget for group living in residential facilities.

Care providers do provide mainly group living arrangements. Kwartel\textsuperscript{38} estimates that 152,000 people younger than 65 years of age, get long term care based on the General Act on Extraordinary Healthcare Costs. Of this group 70,000 are deemed to be dependent on residential care. In another study Klerk (2002)\textsuperscript{39} estimated that 40% of people with an intellectual disability lives in large residential care settings, 30 % live in small group homes of care providers in the community and 30%
live with parents or other family members. Independent living is rarely seen with people with severe intellectual disabilities.

A study by Perspectief\(^{40}\) shows that persons with intellectual disabilities who moved from large residential setting to group home living in the community, could only partially decide where to live, were in majority not allowed to choose their home mates and were never allowed to choose for independent living. Nivel\(^{41}\) reported that people moving from large residential setting to small group homes did not regard themselves better or worse off. They did complain about the forced sharing of their housing, about the noise, the lack of privacy and not enough friendly ties with their home mates.

The result of above mentioned lack of formal policies endorsing independent living, the assumption in financial regulations that care facilities are to be shared through forced group living, the building regulations, the lack of the right to opt for adequate support in independent living arrangements is that people with more severe disabilities cannot live independently and have poor access to participation in the community. The group for whom group living is the only offered option is to be estimated around at least 70.000 people with intellectual disabilities. There is no systematic data gathering on people with severe intellectual disabilities and mental health problems.

**The right to personal mobility**

Article 20 of the UN CRPD asks states to take measures to ensure personal mobility and provide adequate support for a reasonable price. Transport providers in the Netherlands are not required to provide accessibility to disabled passengers. The Equal Treatment Act on Disability and Chronic Illness 2003 contains a preliminary provision on public transport, but the specific article has not yet been activated.

In 2011 a Code of Accessible Transport\(^{42}\) and a time schedule\(^{43}\) was published based on an agreement between national government and local and regional (transport) authorities and it is as follows: in 2015 70% of all bus travel should be fully accessible for passengers with a disability; in 2011 all buses will have a low floor; in 2015 half of the bus stops should have a platform, as low as the bus floors; in 2015 all train stations must be accessible for people who are blind or deaf; in 2020 70% of train stations (serving 90% of all train passengers) should be fully accessible; in 2015 travel information,
including information on delays, should be accessible. Personal assistants, required by people with intellectual disability or any other disability, may travel with them for free. This agreement shows that full accessibility will not be reached soon. Special transport is provided to people who cannot access public transport. Local municipalities provide local transport along their own eligibility criteria. Long distance special transport is provided by national government and is limited to 750 kilometers per year and as of 2012 to 450 kilometers per year.

**Access to public goods and services**

Article 9 of the UN CRPD concerns equal access to build environment, public goods and services. The Equal Treatment Act on Disability and Chronic Illness 2003 does not cover the grounds of public buildings, goods nor public services. The Building Code 2003\(^\text{44}\) governs usability (including accessibility) of new or renovated buildings open to the public. Regulations vary from ruling the height of ceilings (at least 2.6 metres) and the width of passageways (at least 1.2 metres). A specific demand on accessibility is that buildings with a total floor surface over 500 m\(^2\) should have at least one toilet that is fully accessible with the exception of bars and restaurants, which should have a fully accessible toilet when the floor surface is over 150 m\(^2\). The Building code contains no sanction in case regulations are violated. There is no research known whether this regulation leads to results.

Websites are not required to be accessible to disabled people in the Netherlands. An awareness raising campaign by national government ended in 2005. National government is striving to make its own websites fully accessible in 2011. A privately run and privately funded Dutch Foundation for Accessibility\(^\text{45}\) makes the Web Content Accessibility Guidelines available in Dutch and offers technical support to web builders. The foundation regularly monitors how many websites are accessible. Their monitoring shows that around 50% of website information by national government is fully accessible. At the local level the situation is worse; only 2% of municipalities offer accessible websites, according to a monitor published in June 2011. Of around 3500 official web builders in the Netherlands 100 work according to the Web Content Accessibility Guidelines.

**The right to education**

Article 24 of the UN CRPD concerns the right to education. Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live.

Since 2003 the Dutch special schools are no longer allowed to refuse pupils with intellectual disabilities on the ground of not being educable or being below a certain developmental level.\(^\text{46}\)

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\(^{45}\) Monitor Accessibility Websites [http://www.accessibilitymonitor.nl/](http://www.accessibilitymonitor.nl/)

\(^{46}\) Tadema, A. C. (2007). From policy to practice : developments in the education of children with profound intellectual and multiple disabilities, Groningen, proefschrift RUG.
Nevertheless it is estimated that 2500 children with severe disabilities are exempted of compulsory education and receive care in daycare centers. The right to education is thus denied to this group.

The Equal Treatment Act on Disability and Chronic Illness 2003 has prohibited discrimination on the ground of disability in vocational education since 2003 and extended its scope to primary and secondary education since 2009. On the basis of the Equal Treatment Act schools are required to admit students who can meet the academic requirements and for whom adaptations are within reason and the means of the specific schools. Primary schools cannot ask for academic requirements. Parents can opt for mainstream or special primary schools. In a study by De Graaf 30% of parents with Down Syndrome in special schools said they only choose special schools because mainstream school had refused to admit their children.

Secondary schools can ask academic requirements or intellectual level of new pupils and usually do. Meeting academic requirements means that almost all secondary schools will not admit pupils with intellectual disabilities. According to an interpretation in 2005 of the Minister of Education, laid down in answers to written questions from members of parliament, schools for secondary education are by law required to refuse pupils who do not meet all academic requirements. Not many children with disabilities visit mainstream school. In 2010 80% of pupils with an intellectual disability and 66% of all pupils with mental health or behavioural problems went to separate special schools.

Pupils with a disability have had since 2003 the right to receive a pupil bound budget based on the Pupil Bound Budget Act 2003 when they choose a regular school. These pupil bound budgets will be abolished as of 2013, according to a proposed new Appropriate Education Act. This Act rules that parents may express their wish for either mainstream or special schools but that school boards will have discretionary freedom to decide if a specific child with a disability is to be educated in a regular or a special school within the district. The school board will furthermore decide to which schools the means for support for students with disabilities will be allocated. School boards can thus influence the choice where students with a disability will receive their education.

The Equal Treatment Act prohibits discrimination on the ground of disability in employment and vocational education since 2003. Provisions for support in vocational education and employment are

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52 Appropriate Education Act http://www.passendonderwijs.nl/
provided based on the Act on Reintegration of Labour-disabled 2005\textsuperscript{53}. The Equal Treatment Commission ruled in a verdict\textsuperscript{54} that the scope of the Equal Treatment Act for persons with disabilities and chronic illness (WGBH-CZ) does not cover general education for adults. In this particular case a young man was refused for a language course by the general vocational provider in the Netherlands (ROC, regional vocational training centre) on the grounds of his disability (he cannot speak).

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\textsuperscript{53} Act on Reintegration of Labour-disabled: Wet Werk en Inkomen naar Arbeidsvermogen. 

\textsuperscript{54} Verdict of the Equal Treatment Commission on Education for Adults (Wed, Jun 29, 2011 9:43 PM) 
http://www.cgb.nl/oordelen/oordeel/221687/de_commissie_mag_niet_oordelen_over_de_vraag_of_onderscheid_op_grond_van_handicap_is_gemaakt_bij_de_toelating_tot_een_opleiding_nederlands_als_tweede_taal__nt2_opleiding__