ANED country report on the implementation of policies supporting independent living for disabled people

Country: Netherlands

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PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

The Netherlands has a tradition of promoting independent living for people with physical disabilities dating back to the 1960's. Government policy is aimed at making it possible for people to live at home and in their communities for as long as possible. Disabled people have not played a significant role in developing these policies, although the various patient and client organizations have been given opportunities to provide input at various stages of policy development. This policy has gained urgency in recent years as the population ages and expresses a clear desire to remain in the community for as long as possible. This, coupled with rising costs of providing healthcare in institutional settings, has led to new legislation emphasizing the importance of independent living. The Social Support Act (WMO), which took effect in January 2007, transfers the focus of providing support and care from the national level to the local governmental level. It encourages the use of informal caregiving networks by providing recognition and a degree of support to informal caregivers. Recipients WMO benefits are required to make an income-based financial contribution for the support they receive. An important cornerstone of the Social Support Act, as well as the more strictly medical-based AWBZ, which is the General Exceptional Medical Expenses Act (essentially an insurance scheme designed to cover the costs of providing care to disabled and elderly people), is the Personal Budget which can be used to finance many aspects of care and support, including housekeeping, personal care and activities. The Social Support Act is designed to fund adaptations to dwellings to make them more accessible and disability friendly, as well as to finance purchase of mobility devices and transportation. The Act is new and needs to be evaluated to determine if it provides sufficient support. The Equal Treatment Act for Disability and Chronic Illness was expanded effective March 15, 2009 to prohibit disability discrimination in the sale and rental of dwellings. While no cases have yet been decided under this Act, the intention is that this will support the efforts of persons with disabilities to live in the community in dwellings of their choice. The Disabilty Report 2007 indicates that several thousand people with a sensory impairment live in institutional care.

Persons with intellectual and psychiatric disabilities do not enjoy the same history of independent living. A great many people belonging to these groups live in intramural and semi-mural institutions financed under another law, the AWBZ. Intramural institutions are large institutions located in larger park-like areas away from the center of cities. Semi-mural arrangements take a variety of forms, but are generally small-scale, located in ordinary housing in the community, but operated by a larger residential facililty. A significant number of institutions provide a worrisome quality of care and choice to their residents. The national Healthcare Inspectorate has visited numerous institutions and made recommendations for improved performance. A vocal Coalition for Inclusion is a combination of advocacy organizations and care providers aiming to improve the quality of life, including prospects for self-governance in this sector of healthcare. The Resource Center Perspectief does independent monitoring on quality of life from the client's perspective, but it is difficult to see if there is real accountability for the quality of institutional life for persons with disabilities.

Initiatives to secure independent living in the Netherlands seem to come primarily from individuals. No wider independent living movement seems to have taken root in the Netherlands. Government efforts use the language of independent living, but are also seem very cost-driven. While there are building norms for making new construction physically accessible to all, older buildings are not required to be accessible and transportation lags as well (train transport need not be accessible until 2030). There is also a problem with data collection. There is a great deal of data, contained in a variety of databases and studies (many quite small), but it is not transparent or coherent. It is difficult to find information on how many people live in which kind of housing situation, how many institutions, as well as their size, provide housing to which people, how many people use which facilities to support independent living.

No easily accessible verview of needs and concommmittant services seems to be maintained. The decision of the Ministry of Health, Welfare and Sport VWS to discontinue publication of the Disability Monitor (published every 5 years since 1997 by the Netherlands Institute for Social Research at the request of the Minister of VWS) should be reconsidered. Joint ministerial efforts are to be applauded but more effective would be to consolidate information and policy development and monitoring under an authoritative government agency or department headed by a minister of disability.

PART 2: LEGAL AND POLICY CONTEXT

Physically disabled people have a long history of independent living in the Netherlands. Government policy aims at enabling disabled persons to live independently as long as possible. (SCP Rapportage Gehandicapten 2007, p. 139, Actieplan Ministries VWS and VROM, Beter (t)thuis in de buurt, 2007-2011, December 2007) As the population ages, and also as the result of deinstitutionalization, the demand for support to facilitate independent living has grown. The Ministry of Housing, Spatial Planning and the Environment (VROM) has made a number of recommendations to increase the number of accessible dwellings in the future, including single story dwellings without stairs and thresholds. It is estimated that by 2015 at least an additional 395,000 single story dwellings will be needed. (SCP 2007, p. 140.) A number of laws support independent living for disabled adults in the Netherlands, some of which are very recent or have been recently amended. The general thrust of the new legislation is to decentralize the administration of the support necessary to enhance independent community living and also to support the informal networks people with disabilities need and fall back on in order to remain in their own homes and live independently. Municipal authorities are now entrusted with delivery of household support, transportation, the provision of support devices and making accommodations to dwellings

The Social Suppport Act, effective January 2007 (Wet op maatschappelijke ondersteuning, WMO) combined aspects of earlier laws designed to provide support to disabled persons (including the former Disability Facilities Act WGV and the funding for household help formerly provided exclusively by the AWBZ or General Act on Extraordinary Healthcare Costs). The WMO is administered at the level of municipal government and facilitates adaptations to homes (for such things as wheelchair ramps, railings, removal of thresholds, special toilets and showers) as well as mobility devices (scoot mobiles and chairlifts, e.g.), in-home houshold help, and transportation.

Both the WMO and the newly revised Act on Extraordinary Healthcare Costs (Algemene wet bijzondere ziektekosten, AWBZ, revised version entered into effect on January 1, 2009) provide Personal Budgets (Persoonsgebonden budget, PGB). The WMO PGB is available to people living independently. The AWBZ PGB is available to persons living in intramural or semi mural institutional care and enables the recipient to arrange for aspects of their care on their own. A disabled person can qualify for a PGB (personal budget) pursuant to the Social Support Act to finance the stimulation of development and activities in the home to support independent living. PGBs are often pooled by recipients to finance independent group living arrangements, such as the 63 Thomas houses located throughout the Netherlands which are set up for people with intellectual disabilities.

Another important development which could enhance prospects for independent living is extension of the Dutch Equal Treatment Act for Disability and Chronic Illness (Wet gelijk behandeling op grond van handicap en chronische ziekte, WGBH-CZ) to the area of housing. Effective March 15, 2009 the Equal Treatment Act now prohibits landlords and sellers of dwellings from discriminating on the basis of disability. (The WGBH-CZ took effect in 2003 for the areas of employment and adult vocational and professional education, and as of August 2009 the Act will also take effect for primary and secondary education). The WGBH-CZ applies to rentals of dwellings as well as to sales of homes and apartments, but explicitly exempts prospective landlords and sellers from making accommodations to dwellings. This exemption was made so as not to create a possible additional incentive to discriminate against renting or selling a dwelling to someone with a disability. Necessary accommodations are to be made pursuant to the Social Support Act or WMO, upon request to the municipal government. The Dutch Equal Treatment Commission has jurisdiction to hear cases of housing discrimination and to issue non-binding, but in practice very persuasive, decisions. No cases have been decided by the CGB to date in this area.

Disability-sensitive building norms have been codified in the national Building Code (Bouwbesluit 2003). The Bouwbesluit 2003 is a general administrative order of the Ministry of Housing, Spatial Planning and the Environment (VROM) and contains a variety of construction norms for new buildings, including a requirement for wheelchair accessibility. Older buildings do not have to conform to these norms, however, and a documented explanation for the low level of community inclusion of persons with disabilities in the Netherlands attributes this to the often difficult to enter buildings and transportation (especially trains).

In addition, rental support (huur toeslag)is also available for disabled persons and priority in occupying scarce municipal social dwellings can be given to disabled persons.

With respect to guardianship, Dutch law recognizes three different forms of legal guardianship which in general would apply to persons with a intellectual or psychiatric disability, but not to people with physical disabilities. The three forms are full guardianship in case of incapacity, financial management and mentorship for decision-making (e.g., re: health decisions). This scala seems to satisfy the need for support. It is not clear how many people are under one or other form of supervision (only for full guardianship is their a registry), nor how satisfied people are with the guardianship system in place. An informative website of an organisation called Mentorschap Netwerk provides readily accessible information on mentorship to prospective mentors and mentees (www.mentorschap.nl).

No formal, organized independent living movement exists in the Netherlands. The so-called umbrella organization VGPN is the speaking point for the European Disability Forum, but seems to operate more as a postal address than a real advocacy group. The website of the international Independent Living movement does not list an independent center for the Netherlands, nor a contact address. Pressure for deinstitutionalization would seem to come from individual initiatives and client and patient membership organizations, including the national umbrella disability organization CG-Raad (Dutch Council on Disability and Chronic Illness). The CG-Raad represents primarily the interests of physically disabled persons, however. The interests of persons with intellectual and psychiatric disabilities have traditionally been represented by other organizations, such as the recently reorganized KansPlus. In this sector, institutional living is also much more prevalent than for physically disabled persons, due to the needs of the population as well as to the attitudes of parents and professionals (Kwekkeboom).

PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

The move toward deinstitutionalization began in the Netherlands in the 1960's but did not move as quickly as in other countries nor equally quickly across all sectors. Today approximately 1,7 million people with moderate to severe physical disabilities (also including visual, auditory and sensory impairments) are reported to live independently. The numbers of persons living in semi- and intramural residential housing is not known exactly, but according to the Netherlands Institute for Social Research (Scp) only a very small population of physically disabled people live in intramural settings. (Table 6.1 Disability Monitor 2007). This monitor shows 2,400 registered places in four large institutions for persons with auditory and/or visual impairments and some 4,300 places in semi-mural dwellings (gvt's and focus homes) for people with motor and sensory impairments. The capacity in both the intramural and semi mural sector has grown somewhat over the past ten years but is explained by the fact that for financial reasons some people are registered with an institution, but actually live in the community in some supervised form. In addition, many people with physical disabilities, but particularly elderly people, live in nursing homes or care homes. In 2004 approximately 100,000 people lived in care homes and 60,000 in nursing homes. (Disability Monitor 2007)

The figures are quite different for people with intellectual disabilities and chronic psychiatric problems, both groups having faced greater obstacles in the process of deinstitutionalization, as described by Kwekkeboom and Weert in a 2008 study commissioned by the Netherlands Institute for Social Research. Of the approximately 120,000 persons with intellectual disabilities in the Netherlands, a significant number live in institutional settings. A 2002 study (known as the PSV study, summarized in de Klerk, Disabiility Report 2002) revealed that of the 1,000 adults with an intellectual disability included in the study, 40 % lived in intramural settings, 30% in semi-mural settings, and 30% at home with parents or other family members. A recent report of the national Healthcare Inspectorate (Igz) contains quality of life and care findings for 96 institutions for persons with intellectual disabilities, of the "135 large institutions for intellectually disabled persons with (large-scale) intramural care." (IGZ, Toets op de risico's in the 24-uurzorg voor mensen met een verstandelijke beperking 2006-2007). Research reveals no available overview of institutions indicating their size or specific population. It does appear that intramural placements are increasing, albeit slowly, possibly in reaction to the difficulties sometimes encountered in community living, including isolation and fear of bullying (a fear perhaps held more by parents and professional caregivers) (OSI Monitoring Report 2005, Rights of People with Intellectual Disabilities) . The size of the group of persons with chronic psychiatric disorders who structurally receive care was estimated in 2002 to be 47,000, some of whom live in intramural settings, some in sheltered settings and others independently (Kwekkeboom, 2006).

People are protected from involuntary placement in psychiatric hospitals as well as in institutions for persons with intellectual disabilities via the Act Regulating Placement in Psychiatric Hospitals (Wet BOPZ) of 1994 amended many times over the years, which the government intends to replace by a new law currently being drafted. Involuntary placement is possible if one is considered a danger to him or herself, to others or to her environment, and no other measure has been shown to effective to prevent harm. The placement of persons with an intellectual disability is also regulated under the same act, which permits involuntary placement if the person cannot live on his or her own. Internal and external complaint procedures are available to those who oppose institutionalization. It is unclear if the procedures provide sufficient safeguards to people with disabilities. The Ministry of VWS is working on legislation to replace the Wet BOPZ in which the specific needs of the patient/client facing hospitalization or institutionalization will be the point of departure in making placement decisions.

Statistics Netherlands (CBS) reports annually on the volume and costs of healthcare in the Netherlands, most recently in Gezondheid en zorg in cijfers 2008. For the year 2006 CBS reports that in the disability care sector, 30,045 men and 23, 685 women made use of AWBZ financed residential care (Table C.8). The Ministry of VWS reports a higher figure, that almost 66,000 persons live in institutions for disabled persons (letter of State Secretary for VWS dated 2009 and available at VWS website).

A study of AWBZ expenditures between 1980 and 2005 indicates that in 2005 in total 586,000 people made use of some form of nursing and care under the AWBZ. 62% were living at home and utilized some form of extramural care. 38% lived in a nursing or care home. The collective expenditures for care and nursing were almost 10 billion EUR in 2004, with 64% going to intramural care.

For the psychiatric care sector in 2006, Statistics Netherlands reports that 11,115 men and 7,610 women made use of AWBZ financed residential care (Gezondheid in zorg in cijfers 2008, Table C.8). From the 'production and capacity' figures (Table D.8), 40,735 intramural places with treatment are reported, and 22,047 places without treatment in intramural settings. The amount of money paid to the various providers of disability care totalled 6,581 million EUR in 2006 and 6,762 million EUR in 2007 (Table D.2). For the mental health care sector, 4,208 million EUR was paid to providers in 2006, and 4,497 million EUR in 2007. The total AWBZ expenditure in 2007 was 21 billion EUR, which is 40% of the total healthcare expenditure (AWBZ – Feiten en Cijfers, Min VWS). Part of the AWBZ expenditure finances Personal Budgets to facilitate independent living. The cost of financing Personal Budgets from the AWBZ (and presumably not from the Social Support Act WMO) was reported to have risen from 1.1 billion EUR in 2006 to 1.5 billion EUR in 2007 (Gezondheidszorg balans 2008).

It is not clear if major investments are being made in building large institutions, but the general trend toward smaller-scale arrangements would seem to dictate not. However, further research would be necessary to know for sure.

PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY

People who wish to remain in their own homes are to be supported in the first place by their informal networks, especially family, but also neighbours, friends and volunteers. Each municipality is to have a central point (WMO loket) to provide information about and assistance for applying for housekeeping help, personal care, mobility assistance and/or adjustments to the home to make it more accessible. In addition, a national program called MEE Nederland (www.mee.nl) has 22 branches with 3,300 employees who work throughout the country to assist people with any kind or degree of disability in devising support, including designing a personal care plan and applying for assistance via the AWBZ or Social Support Act (WMO). MEE is financed by the Health Care Insurance Board (College van Zorgverzekeringen, CVZ) from AWBZ funds. MEE Nederland reports that it assisted some 100,000 clients in 2007.

To qualify for a Personal Budget or other AWBZ financed care, a person must have a care referral ('indicatiestelling') from a care referral centre (CIZ or Centrum Indicatiestelling Zorg). Effective January 1, 2009, the AWBZ has changed its financing of care provided by institutions from funding based on institutional capacity. Now a person who is eligible for care will receive a 'zorg zwaarte pakket' (ZZP, or a Weighted Care Package) which will provide a certain amount of financing depending on the degree of impairment and intended treatment or support. There are 52 categories of ZZP. Application for this is facilitated by MEE among others.

Family members and other informal support network members are now formally recognized in government policy and the Social Support Act (WMO) as important to enabling persons to remain in the community. The Ministry of VWS estimates that 1.6 million caregivers take care of a disabled family member, friend or neighbour. One is defined as a caregiver if he or she cares for longer than 3 months for a person in need of such care. Local governments are encouraged to provide training for non-professional caregivers, to reward them with a 'compliment' (set at 250 EUR in 2008), and provide other services to enable caregivers to take a rest when necessary. The Personal Budget may also be used to pay family members and other non-professional caregivers.

In order to qualify for WMO (Social Support Act) one must be assessed by the local authority, and to qualify for AWBZ benefits one must be assessed by a centre for care referral (CIZ). Both procedures involve application, possible interview and review of medical and diagnostic records. Government officials trained to make these particular eligibility and level of funding decisions make them. Applicants can apply via internet and telephone, with or without the help of others, and are required to submit their medical and diagnostic records. All decisions are subject to administrative review.

Pursuant to the Social Support Act municipal governments are responsible for providing community support to people with disabilities. This responsibility includes monitoring the quality of services provided (WMO, article 3, para. 4, set out in letter of State Secretary VWS to Lower House of Parliament, July 10, 2008). The WMO also makes the Quality of Institutional Care Act (Kwaliteitswet zorginstellingen) applicable to household support. The Healthcare Inspectorate (IGZ) is charged with monitoring compliance with the Quality of Institutional Care Act which has as its chief requirement 'responsible care'. Thus both municipal governments and the national IGZ are charged with monitoring the quality of WMO and AWBZ support services. It does not appear that municipal governments have yet operationalized a monitoring system, nor that the IGZ is yet monitoring the quality of household support delivered by professional caregivers. (Letter to 2d Chamber from VWS Secretary Bussemakers of July 10, 2008, Kwaliteitskader Huishoudelijke Verzorging in de WMO.)

The IGZ is formally charged with monitoring the quality of intramural and semi-mural care. An important independent body monitoring the quality of life of disabled persons in a wide variety of settings (including residential care and schools) from a client-centered perspective is Perspectief Kenniscentrum voor inclusie en zeggenschap (www.perspectief.org) which has conducted over 1,100 in-depth quality of life interviews over the past ten years.

4.1: PERSONAL ASSISTANCE SERVICES

Both the Social Support Act (WMO) and the General Exceptional Medical Expenses Act (AWBZ) make it possible to receive in-home support in a variety of forms. Disabled people who qualify for a Personal Budget are allowed to purchase the care they see fit, and accountability is required to be given afterwards in an annual reporting system. One has discretion and control over how the Personal Budget is spent as long as the expenditures can be accounted for and fall within the general guidelines of the ZZP. The budgets are not open-ended but are awarded in one of 21 different category of support and concomitant financial level, depending on the impairment and support required (resulting in a 'weighted care package' or ZZP). This means that disabled persons themselves can hire the people they choose, if they choose to do so. This kind of budget requires administration by the recipient or his or her guardian or mentor and additional support is available by MEE and/or the Association of Budget Holders Per Saldo (which has 23,000 members and a very informative webpage).A Personal Budget enables individuals to contract their own care providers (including family members), which is seen as very positive (and was intended to lower costs by fostering competition with institutional care providers), but also requires the individual to do his or her own paperwork which is perceived as too much work and/or responsibility by some.

Personal Budgets or PGBs are available to finance care for all kinds of disabilities, including physical, intellectual and psychiatric disabilities. PGBs under the AWBZ are aimed at people with moderate to severe disabilities and finance their care (in instituions) and to improve and maintain their self-reliance (which is defined in terms of 5 different domains: social self-reliance, movement and ability to get around, behavioural problems, psychological well-being and orientation and memory problems). WMO Personal Budgets are intended to compensate milder disability and provide support in housekeeping and other services such as adaptations to the physical home environment and transport. Eligibility requirements are complicated.

It is unclear if there is support for personal assistance services for independent living that are controlled by disabled people themselves or by their representatives, beyond the control individuals have over their Personal Budgets.

4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

As noted above, the Social Support Act (WMO) is intended to provide, at the local government level, the support needed for people with disabilities to live as independently as possible. This is called 'compensation for a disability,' and is financed by the Ministry of VWS from public funds. Such compensation is possible via a Personal Budget for household help, personal care, personal training and therapy, but also with adjustments to make dwellings accessible, and to provide mobility devices and transportation. With respect to work and adult education, employers are expected to make 'reasonable accommodations' to make study and work possible. Financing is available in detailed in the ANED report on employment. The Equal Treatment Commission is empowered to hear complaints in this area. In the area of childhood education, 'backpack financing' is available to fund (minimal) adjustments to school classrooms to facilitate mainstream education. This is described in the ANED report on education.

To qualify for assistance under the Social Support Act an individual must meet eligibility criteria set out in the law and applied by local governments who either have their own intake specialists or use the assistance of CIZ specialists (set up for making referral decisions for AWBZ funded care). The WMO is intended for people with a disability or chronic illness. Municipal governments maintain a variety of contacts with care providers. There are many professional care providers in the Netherlands, providing a wide variety of care, from household help to personal care to active stimulation and day activities. They are often organized in networks at a regional or provincial level, such as WMOAdviesgroep . An strong support group for Personal Budget recipients exist to provide detailed information and supports to budget holders: Per Saldo, www.pgb.nl.

A Personal Budget is not financially unlimited. A Personal Budget financed by the AWBZ requires payment of a personal contribution per month and will be limited by the Weight Care Package (ZZP) category to which the applicant is assigned based on disability and need. For 2009 the highest annual ZZP is 117,340 EURO (sensory impairment); the care packages for care sector intellectually disabled range from 22,005 EUR per year to 83,415 EUR (Per Saldo Overview Personal Care Budget ZZP rates 2009).

WMO financing is less per individual and will be determined by the municipal government in which the recipient lives. WMO support also requires payment of a personal monthly contribution. Moving to another municipality will require a new application for benefits and very likely a different outcome as each municipal government can exercise discretion in how it provides support to disabled people living in the local community.

The Netherlands Institute for Social Research has been requested to analyse expenditures made by local governments on household help under the WMO. In its recent report, Definitief advies over het Wmo-budget huishoudelijke hulp voor 2009 (see bibliography) on expenditures for expenditures in 2008, it confirms that 1.322 million EUR is budgeted for 2009. This is an increase of 6.15% over 2008. It is not clear how many people received household help, nor is it clear how many people receive other benefits under the WMO at the moment.

The CAK is the agency charged with collecting the individual contributions required for AWBZ and WMO care. They report that in their Jaaroverzicht 2007 that in 2007 280,000 people receiving care while residing in institutional settings paid an individual contribution, and individual contributions were collected from 660,000 people living independently who received some form of WMO support.

PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE

Disabled people are entitled to participate in discussions about the Social Support Act, which is the key law and policy for supporting independent living.

An excellent example of good practice in independent living is provided by Stichting Fokus, www.fokuswonen.nl, which provides 1300 adapted Fokus dwellings in 90 locations around the Netherlands to persons with severe physical disabilities. Fokus homes have been adapted completely to the mobility needs of the resident, with 24 hour on-call assistance available for support (a minimum of 5 hours personal support per week is required in order to qualify for a a Fokus home).

A project to support independent living initiatives of disabled children and their parents is Inthe Landelijk Steunpunt Wonen (National Support for Living on Your Own), http://www.woonzelf.nl/index.html, . This project supports the many initiatives now ongoing in the country.

This section should be supplemented by the CG-Raad for collective and or community –based independent living initiatives.

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