The Netherlands: Health and Personal Social Services for People with Disabilities State Report

A Contemporary Developments in Disability Services Paper

This paper is one of a series of background papers describing how disability services are organised and delivered in selected jurisdictions, to help inform how such services might be organised and delivered in Ireland.

January 2011
The Netherlands: Health and Personal Social Services for People with Disabilities Country Background Paper

January 2011
<table>
<thead>
<tr>
<th>Abbreviated Terms</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AWBZ</td>
<td>Exceptional Medical Expenses Insurance Act for long term care</td>
</tr>
<tr>
<td>SER</td>
<td>Social and Economic Council of the Dutch government</td>
</tr>
<tr>
<td>WMO</td>
<td>Social Support Insurance Act to promote independent living for people with disabilities</td>
</tr>
<tr>
<td>ZZPs</td>
<td>Care Service Packages</td>
</tr>
<tr>
<td>CIZ</td>
<td>Centre for Needs Assessment</td>
</tr>
<tr>
<td>RIVM</td>
<td>Dutch National Institution for Public Health and the Environment</td>
</tr>
<tr>
<td>NZa</td>
<td>Dutch Health Care Authority</td>
</tr>
<tr>
<td>CVZ</td>
<td>Health Care Insurance Board</td>
</tr>
<tr>
<td>Zwv</td>
<td>2006 Health Insurance Act</td>
</tr>
<tr>
<td>SKGZ</td>
<td>Dutch Foundation for Complaints and Disputes</td>
</tr>
<tr>
<td>VGPN</td>
<td>Dutch National Disability Council</td>
</tr>
</tbody>
</table>
1. Introduction

This paper is one of a series of background papers describing how disability services are organised and delivered in selected jurisdictions. The objective of these background papers is to help inform how such services might be organised and delivered in Ireland. A composite report setting out key learning from across the six jurisdictions is also available (hyperlink). This composite report also draws on additional literature from the US and the National Disability Authority's (NDA) broader programme of work in the area of independent living for people with disabilities.

The jurisdictions were chosen after canvassing expert opinion on where there were opportunities for learning due to innovations in service procurement, design or delivery or evidence of quality. Data was collected for each jurisdiction under a common framework, although information was not always readily available across all elements of the framework for each jurisdiction. The sources of information included published and web sources, as well as interviews with three key informants, with different roles, in each jurisdiction. The draft paper was checked for accuracy and completeness with a national expert in each of the countries studied. Readers are advised that a key finding from this project is that disability service systems in all of the selected jurisdictions are in transition, and in some areas systems are undergoing rapid development. We welcome any feedback on any of the jurisdictions investigated that can update or enhance these background papers. The jurisdictions investigated include those set out below and can be found at www.nda.ie.
Table 1. Population of selected jurisdictions

<table>
<thead>
<tr>
<th></th>
<th>Ireland¹</th>
<th>England²</th>
<th>Scotland³</th>
<th>Netherlands⁴</th>
<th>Norway⁵</th>
<th>Victoria⁶</th>
<th>N. Zealand⁷</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Population 2009</strong></td>
<td>4.45m</td>
<td>51.81m</td>
<td>5.19m</td>
<td>16.48m</td>
<td>4.78m</td>
<td>5.42m</td>
<td>4.32m</td>
</tr>
<tr>
<td><strong>Ratio to Ireland</strong></td>
<td>1</td>
<td>11.6</td>
<td>1.2</td>
<td>3.7</td>
<td>1.1</td>
<td>1.2</td>
<td>1.0</td>
</tr>
</tbody>
</table>

2. Population

2.1 Population with a disability

It is estimated that the number of people reporting as having some degree of physical disability in Netherlands is 3.4m (22.5%) of the population. Out of this population 1.7m people have moderate to severe physical disability, including visual and auditory impairments.

The number of persons with an intellectual disability is estimated at approximately 110,000.

---


9 ibid

10 The figures and percentages cited in the SCP report are from 2007.

### 3. Provision of Health and Disability Services for people with disabilities

#### 3.1 Overview of Service Provision System

Table 2. Organisational Structure of Dutch Disability Services

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Ministry of Health, Welfare and Sport (VWS)</td>
<td>Responsible for the development and quality of the healthcare sector as a whole</td>
</tr>
<tr>
<td>The Netherlands Health Care Inspectorate (JGZ)</td>
<td>Responsible for the quality assurance of the system. The Inspectorate monitors the quality in health care institutions and reinforces the quality norms and laws for the health care sector. The Inspectorate also supervises the operation and development of the markets for health care providers and insurers.</td>
</tr>
<tr>
<td>The Dutch Health Care Authority (NZA)</td>
<td>Responsible for supervising all health care markets in the Netherlands. Produced system of indicators that control and measure the quality of health people are receiving.</td>
</tr>
<tr>
<td>The Dutch Federation of University Medical Centres (NFU) and the Dutch Hospitals Associations (NVZ)</td>
<td>Umbrella organisations that are responsible for medical quality assurance.</td>
</tr>
<tr>
<td>Regional health care insurers who run the regional care offices (32 offices)</td>
<td>Responsible for administering the Long Term Care Insurance (AWBZ) a mandatory insurance scheme for long term care. The management of the Long Term Care Insurance (AWBZ) comes under the auspices of the Ministry for Health and Welfare.</td>
</tr>
<tr>
<td>Municipalities (441 municipalities)</td>
<td>Responsible for administering the Social Care Support Insurance (WMO). This type of insurance is used to promote independent living and to fund accessible accommodations for houses, in-home household help, and transportation. It comes under the auspices of the Ministry for Internal Affairs and Rural Relations.</td>
</tr>
<tr>
<td>MEE Nederland (22 branches)</td>
<td>A national organisation that assists people with disabilities in accessing support, developing personal care plans and applying for assistance from the Long Term Care Insurance (AWBZ) or the Social Care Support Insurance (WMO). This programme is funded by the Health Care Insurance Board (College van Zorgverzekeringen, CVZ) from Long Term Care Insurance (AWBZ) funds.</td>
</tr>
</tbody>
</table>

In the Netherlands, the Ministry of Health Welfare and Sport funds health and social care supports for people with disabilities. The Ministry of Social Affairs and Employment funds income related supports, vocational and employment supports and educational supports are funded and provided through the Ministry of Education, Culture and Science.

3.2 Reform of the Health Care System

In 2006, major health care reforms took place after the Dutch government introduced the Health Insurance Law (ZVW)\(^\text{13}\). The two tiered system of social and private (voluntary) health insurance was replaced by one single mandatory private scheme (ZVW). This scheme provides coverage for a suite of services from medical and dental care to transportation costs for people in wheelchairs etc. The services covered by this scheme are detailed in Appendix C. In the new healthcare system the provision of healthcare has become more decentralised in the hands of the private independent health insurers\(^\text{14}\). If a person with a disability cannot afford any health care insurance for any reason (such as unemployment etc) the Dutch government provides insurance.

The objective behind these reforms was to create a more efficient system in terms of costs and quality\(^\text{15}\) and to change the supply driven system into a more demand driven system\(^\text{16}\). Market forces and client-centredness were two of the main issues that drove this reform. Service providers, health insurers or local commissioners and clients are perceived as being the key players in the market. Clients are expected to take more responsibility for their health and to be more aware of the cost of their health care insurance\(^\text{17}\).

In 2008 the Social and Economic Council (SER) of the Government proposed a series of reforms for the provision of disability services:

- A much more clear cut and unambiguous delineation and definition of entitlements
- An improvement in the needs assessment by, for example, introducing protocols, benchmarking and a permanent supervision of the assessment bodies
- A reduction in entitlements by transferring short-term rehabilitation services to the public insurance scheme for curative health (mental health)

---


\(^{15}\) ibid


services (under the Health Insurance Act, 2006) and by bringing the provision of social care under the responsibility of the municipalities (under the Social Support Act, 2007).

- A replacement of provider-based budgeting by client-based budgeting. Rather than clients having to follow the money – as in the current provider-based budgeting system – the money should follow the client. Clients would have the option to choose a personal care budget (as in the current system) and arrange all care by themselves, or to choose among providers contracted by regional care offices (to be replaced by individual health insurers in 2012).\(^\text{18}\)

- The client-based budgets should be based on the categorisation of clients in “care service packages” (abbreviated: ZZPs) by the needs assessment bodies. A “care service package” describes the type and amount of care needed by the client. For each “care service package” a budget will be calculated.

In June 2008, the Dutch government endorsed the above proposal which will be implemented over a number of years.\(^\text{19}\)

One of these recommendations have already been implemented. In 2008 Curative health services which used to be covered under the Exceptional Medical Expenses Insurance Act (AWBZ) was moved to the health care insurance scheme (ZVW).\(^\text{20}\)

### 3.3 Public Long Term Care Insurance

For people with disabilities there are two types of public long-term care insurance: the Exceptional Medical Expenses Insurance Act (AWBZ) introduced in (2006) and the Social Support Insurance Act (WMO) in 2007.\(^\text{21}\)

If a person with a disability cannot afford any public long-term care insurance the Dutch government provides insurance.

---


\(^{17}\) ibid


\(^{19}\) Schoonheim J (2009). ANED country report on the implementation of policies supporting independent living for disabled people in the Netherlands. ANED
Exceptional Medical Expenses Insurance/Long Term Care Insurance (AWBZ)

The Exceptional Medical Expenses Act/Long Term Care Insurance (AWBZ) is a mandatory scheme for long term care for people with disabilities and people who are elderly with long term health conditions.

Long Term Care Insurance (AWBZ) is funded by income related contributions that are collected through the income and payroll tax systems, along with the contributions for the other national insurance schemes (e.g. for unemployment and disability) and co-payments\(^{22}\).

Long Term Care Insurance (AWBZ) covers care needs for people with disabilities in their own homes or in residential homes e.g.:

- Personal care: e.g. help with taking a shower, bed baths, dressing, shaving, skin care, going to the toilet, eating and drinking
- Nursing: e.g. dressing wounds, giving injections, advising on how to cope with illness, showing clients how to self-inject
- Supportive guidance: e.g. helping the client organise his/her day and manage his/her life better, as well as day-care or provision of daytime activities
- Activating or behavioural guidance: e.g. talking to the client to help them modify his/her behaviour or learn new forms of behavior in cases where behavioral or psychological problems exist
- Medical and clinical treatment
- Cost of accommodation

Structure of Long Term Care Insurance (AWBZ)

If a person with a disability requires long term care they go to the Centre for Needs Assessment (CIZ) to be assessed to see if they are eligible for Long Term Care Insurance (AWBZ). This assessment is means tested and the person's contributions to their insurance, their care needs and their care budgets are based on this assessment. A person with a disability who is receiving social assistance/disability benefit will pay approximately €180 per month contribution towards their Long Term Care Insurance (AWBZ). If a person receives disability benefit and owns property or has additional income coming into the house their Long Term Care Insurance (AWBZ) contribution is higher\(^{24}\).


\(^{23}\) Schut, F.T and Van den Berg, B. (2009) Sustainability of Comprehensive Universal Long-Term Care Insurance in the Netherlands. Accepted for publication in Social Policy and Administration

\(^{24}\) Jose Smits, a key informant
If a person is assessed as being eligible for this type of insurance, they can choose between having a personal care budget or receiving care in kind. If a person is receiving a personal care budget, it is up to them to decide who is delivering their care, whether it is a residential home, an independent care worker etc.

If a person chooses care in kind they have some choice as to which care organisation delivers their care. Recipients go to their regional care office which is run by a health insurer company which is responsible for organising and purchasing care for people with disabilities using Long Term Care Insurance (AWBZ). There are 32 regional care offices in the Netherlands. The health insurers have a list of long term care providers that they recommend to a service user.

Under the Ministry of Health, Welfare and Sports the Dutch Health Care Authority (NZa) calculates the regional budgets i.e. (government concessions) for each regional office. If the regional office runs out of money they can discuss the situation with Dutch Health Care Authority. If a regional care office performs poorly then permission to operate the regional care office may be handed to another insurer. The diagram below details the structure.

Structure of Long Term Care Insurance (AWBZ)

---

Table 4 details the different groups of people that receive Long Term Care Insurance (AWBZ) benefits.

Table 3. Different groups of Long Term Care Insurance (AWBZ) beneficiaries by numbers and expenditures in 2007*

<table>
<thead>
<tr>
<th>Type of long-term care user</th>
<th>Number</th>
<th>Share of total number</th>
<th>Expenditure (billion euro)</th>
<th>Share of total expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elderly and chronically ill</td>
<td>360,000</td>
<td>69%</td>
<td>11.4</td>
<td>65%</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>100,000</td>
<td>19%</td>
<td>4.6</td>
<td>26%</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>15,000</td>
<td>3%</td>
<td>0.5</td>
<td>3%</td>
</tr>
<tr>
<td>Mental Health Difficulties</td>
<td>50,000</td>
<td>9%</td>
<td>1.1</td>
<td>6%</td>
</tr>
<tr>
<td>Total</td>
<td>525,000</td>
<td>100%</td>
<td>17.6</td>
<td>100%</td>
</tr>
</tbody>
</table>

* Excluding about 90,000 clients with a personal care budget (expenditure 1.3 billion euro)

Assessment of Care Needs
As detailed in the diagram below the CIZ assessment process for Long Term Care Insurance (AWBZ) is quite a detailed one.

- Step 1: CIZ examines what supports i.e. income, disability benefits, care supports.
- Step 2: CIZ analyses the various ways in which the care needs of a person maybe met. The CIZ will look at services that are not covered by Long Term Care Insurance (AWBZ) such as home delivery of shopping, childcare etc.
- Step 3: CIZ determines the gross need for Long Term Care Insurance (AWBZ) regarding the type of care that is necessary and the delivery of care i.e. Does the person need 24 hour care?
- Step 4: If the CIZ determines that a person is eligible for Long Term Care Insurance (AWBZ) the next decision is whether the person receives residential care in an institution or care in the home. The CIZ will discuss the options with the recipient of Long Term Care Insurance (AWBZ). If a person wishes to receive care in their home rather than go to a residential home than the person can try for “Full package at home”. This means that the person can get the same care in their home if it can be arranged at the same cost. However sometimes this can be difficult and some providers are not obliged to deliver this care.

CIZ Funnel model of Assessment for Long Term Care Insurance
AWBZ

Step 1
- CIZ examines the type of disability a person has
- The type of care that the person can access, whether it is provided by a family member and/or a professional carer
- Existing provisions for living whether a person is receiving social assistance (disability benefit) is working etc.

Step 2
The CIZ determines how the care needs of the person may be solved via:
Treatment/Rehabilitation/Reactivation,
Accommodations to person’s environment,
use of medical equipment etc,
Respite care, common provisions e.g. (Home delivery of shopping)

Step 3
CIZ gross determination of Need for AWBZ care
Type of care needed,
Frequency of care: daily, every two days etc

AWBZ needed

Care provided in the home (outside of the institution)
Care provided within a residential home.

Social Support Insurance (WMO)
The Social Support Insurance Act (WMO), was implemented in January 2007, as a response to the following issues:

- As the Dutch population ages, there is an increasing number of elderly people who state that they wish to live in their community and to live independently for as long as possible
- The increasing costs of healthcare provision in residential homes means that it would be more economical for more people to live independently in their own homes.

The Act emphasises the importance of independent living and transfers the provision of support and care from the national level to the local governmental level.

Long Term Care Insurance (AWBZ) is used for long term personal care while the Social Support Insurance (WMO) is used for domestic home help such as cleaning etc. The Social Support Insurance (WMO) is also used to pay for:

- accessible accommodations for houses such as: wheelchair ramps, railings and removal of thresholds, special toilets and showers.
- purchasing mobility devices (such as scoot mobiles and chairlifts)
- paying family members (informal carers) to provide care for a service user.

People are means tested for their eligibility regarding Social Support Insurance (WMO) by the CIZ in the same process as people being assessed for Long Term Care Insurance (AWBZ). If a person is determined as being eligible they must then go to their municipality who is responsible for providing the services. Municipalities received a budget from the Ministry for Internal Affairs and Rural Relations, for home help services. The Social Support Insurance (WMO) is funded by income related contributions.

3.4 Policy framework for independence and community living in the Netherlands

There is no national strategy addressing disability issues in the Netherlands. However a key informant indicated that each of the 13 ministries (central government departments) are responsible for having policies dealing with disability issues.

---

29 Schoonheim, J. (2009). ANED country report on the implementation of policies supporting independent living for disabled people in the Netherlands. ANED
30 Zichtbare Zorg is a Health Care Transparency Programme established at national level, by the Ministry of Health, to standardise the development, monitoring and maintenance of quality indicators across the health care sector, going forward
In 2003 the Act on the Equal Treatment of People with Disabilities came into effect. The Dutch government introduced this Act to provide people with disabilities with the legislative means to legally enforce their equal rights. The Dutch government also stated that this Act was an indication that:

"the idea of equal treatment (of people with disabilities) has now been made a key factor in its policy and must therefore be implemented in practice.\textsuperscript{32}\"

The Dutch government's policy approach on the equal treatment of people with disabilities focuses on the inclusion and equal participation of people with disabilities within society. In practice this means that people with disabilities have access to education, employment, healthcare, public spaces, and supports to live independently etc. The government also states that it is society's responsibility and the personal responsibility of people with disabilities to create a more inclusive society.

Since the 1960's the Dutch government has had a tradition of promoting independent living for people with physical disabilities. The Social Support Insurance (WMO) Act in 2007 exemplifies this policy in that it emphasises the importance of independent living and transfers the provision of support and care from the national level to the local governmental level, i.e. the municipalities\textsuperscript{33}.

In the last decade the Dutch government has introduced policy measures (see section 4.8) to increase the number of people with disabilities participating in employment (including mainstream, fulltime, part-time, and supported employment). In 2008 the government introduced an inclusion programme \textit{Everyone is Included} that focused primarily on the people with disabilities accessing the employment market. In 2008, the government committed €165m. euros to this programme which has risen to €205m. in 2011\textsuperscript{34}.

4. Housing, Accommodation and Day Services for People with Disabilities

4.1 Residential Services

Table 4 below sets out the quantum of current residential and home care provision in the Netherlands.

**Table 4. Current residential and home care provision in the Netherlands**

<table>
<thead>
<tr>
<th>Clients</th>
<th>Residential Care</th>
<th>Home Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>22%</td>
<td>5%</td>
</tr>
<tr>
<td>Elderly with physical problems</td>
<td>43%</td>
<td>63%</td>
</tr>
<tr>
<td>People with intellectual and physical disabilities</td>
<td>26%</td>
<td>14%</td>
</tr>
<tr>
<td>People with mental health difficulties</td>
<td>9%</td>
<td>18%</td>
</tr>
<tr>
<td>Total % of people with disabilities</td>
<td>35%</td>
<td>32%</td>
</tr>
<tr>
<td>Total</td>
<td>253,000</td>
<td>335,000</td>
</tr>
</tbody>
</table>

Source: VWS/CVZ, 2008

As detailed earlier out of 253,000 people in residential care, approximately 35% (89,000) are people with disabilities. Out of 335,000 people receiving home care supports in their own homes that are delivered by an institution approximately 32% (108,000) have disabilities.

Nursing homes and other institutions that provide residential care are independent non-profit private organisations that receive funding from the government.

There are many types of “care in kind” or residential/institutional services in the Netherlands such as group homes and community homes. If a person with a disability chooses care in kind, the institution liaises with the healthcare insurer and supervises the provision of different services to people within the residential service e.g. physiotherapy, speech and language therapy.

The institution receives a care provider budget for each person in the institution. The service user can decide whether to use this money for a personal care budget.

---


36 ibid

37 Applica & CESEP & European Centre (2007) Study of the Compilation of Disability Statistical Data from the Administrative registers of Members States.
Each service provides different levels of care depending on the service user's needs. Some people require 24 hour care and others receive support only when needed e.g. in the mornings and the evenings. A scale for residential services is currently used to determine the level of care a person needs such as: 'intermittent', 'limited', 'extensive' or 'pervasive' support\textsuperscript{38}.

A new change in long term care and support means that financial arrangements for institutional care are individualised. A key informant confirmed that the personalised budget is allocated based on a standardised needs assessment. Budgets are allocated using standardised costs for services, and that with regard to institutional accommodation, these costs are set on the presumption of group living arrangements, rather than individual accommodation\textsuperscript{39}.

\begin{table}[h]
\centering
\begin{tabular}{|l|c|c|}
\hline
Care in Kind & Total Costs (billion euros) & Average amount per client \\
\hline
Residential & €14.9m & €58,500 \\
Home care & €5.9m & €22,000 \\
\hline
\end{tabular}
\caption{Costs of Care in Kind}
\end{table}

\begin{flushright}
Source: VWS/CVZ, 2008\textsuperscript{40}
\end{flushright}

\subsection*{4.2 Housing}

The Ministry of Housing, Spatial Planning and the Environment deals with rent policy, rental allowance, housing production and renovation, and urban development\textsuperscript{41}. People with disabilities can apply for and receive rental allowance and they are also given priority in terms of occupying scarce municipal social housing\textsuperscript{42}.

\textbf{Types of accommodation for people with disabilities}

People with disabilities live in residential homes, or with their families, or in their own homes. There are also other housing opportunities for people with disabilities in the Netherlands.

\textbf{Clustered housing}

Stichting Fokus is a non governmental body that provides housing specifically for people with physical disabilities who can live independently and who

\textsuperscript{38} Jose Smith key informant from Academic Network of Disability Experts (ANED)
\textsuperscript{41} Ministry of Housing, Spatial Planning and the Environment website http://www.vrom.nl/pagina.html?id=37413
require care on an on call basis only\textsuperscript{43}. A person must require a minimum of 5 hours personal support/care a week in order to qualify for a Fokus home. The organisation has 1300 adapted buildings in 90 locations throughout the Netherlands for people with severe physical disabilities. The organisation has over 2,100 employees. These homes are completely accessible and on call assistance is available 24 hours a day. Each location has a cluster of 12 - 20 houses and a project manager that leads a team of 20 personal care assistants\textsuperscript{44}. People who wish to use this service pay for it using their Long Term Care Insurance (AWBZ).

"Thomas Houses" is another initiative that provides supports for people with intellectual disabilities to live independently. The initiative is run by an independent company called ARGO that is affiliated with the University of Groningen. ARGO provides research and consultancy services on improving health care services to healthcare providers, the Dutch government and umbrella organizations in the healthcare sector. "Thomas Houses" typically provides support for 6-8 people with intellectual disabilities to live in a house\textsuperscript{45}. Two care givers are assigned to each house to support the needs of the residents. The caregivers live in or beside the house. In 2010 there were 80 Thomas Houses in the Netherlands and the demand is increasing\textsuperscript{46}.

The total cost of living in a Thomas House depends on the individual person’s care needs. Each month a service user receives a customer account that displays the full cost of rent, service and food etc. Service users pay for living and care costs using their personal care budgets\textsuperscript{47}.

Table 6 shows guidelines for rent and service charge for a Thomas House in 2009.

\textbf{Table 6. 2009 Guidelines on individual monthly charges in a Thomas House}

<table>
<thead>
<tr>
<th>Service</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Room rent</td>
<td>€350 per month</td>
</tr>
<tr>
<td>Personal care services</td>
<td>€150 per month</td>
</tr>
<tr>
<td>Meals</td>
<td>€200 per month</td>
</tr>
<tr>
<td>Total</td>
<td>€700 per month</td>
</tr>
</tbody>
</table>

Source: Thomas House website http://www.thomashuizen.nl/wat_is_een_thomashuis.aspx

\textsuperscript{43} Stichting Fokus website http://www.fokuswonen.nl/317-Missie-van-Fokus.html.

\textsuperscript{44} ibid


\textsuperscript{46} Thomas Houses website http://www.thomashuizen.nl/wat_is_een_thomashuis.aspx

\textsuperscript{47} ibid
4.3 Care Support for people with disabilities

Home care for people with disabilities is provided by a residential support service, whether a person is living in rented accommodation, their own home or in a residential home. As detailed in Table No. 4, there are more people with disabilities (108,000) receiving home care in their own homes while 89,000 people with disabilities receive this care in a residential home.\(^{48}\)

Table 4 shows that more elderly people with physical problems, approximately 210,000 receive care outside of a residential home compared to 109,000 people who receive the services in residential homes.

There is no data available for how many people pay for home care services using their personal care budget.\(^{49}\)

4.4 Respite and Carer Supports

There are 200 carer support centres throughout the Netherlands. In addition to providing carers (professional and informal) with a range of services e.g. information, advice on financial, informal and practical support, these centres also provide respite care using volunteers. Xzorg is the national umbrella organisation for the carer support centres.

Respite care is provided by a mixture of professional carers and by volunteers and/or family members (informal carers). It can be provided in the person’s home or by an institution. The time frame is flexible ranging from a few hours a day to a couple of weeks. There are also care hotels and hostels that provide respite care for temporary stays for children with disabilities. Under the Long Term Care Insurance (AWBZ), some nursing homes and residential services also provide respite care such as day care or short term stays.

There are organisations that also provide holidays for carers and for people receiving care. While the carers are on holiday, professional care workers provided by LOT, the Dutch Red Cross and other organisations take care of the person in need of care. Meals on wheels services and handymen services are also provided as part of respite care services. There is a care broker system that help carers in paid employment obtain services, allowances and other assistance that enables them to stay in paid employment.

Carers can be compensated for loss of earnings from the cost of care through:


• Income tax measures (which have a very high threshold and are not often used)
• Income support
• A paid career break (care leave)
• Insurers (e.g. compensation for respite care)
• Measures by local authorities
• Payment by the care recipient who has opted for a personal budget and can use it to pay his/her carer a wage
• There are also certain types of leave in the Netherlands that enable carers to continue working while also caring for someone
• Calamity leave: In an emergency situation a carer can take a few days leave to get a situation under control
• Short term care leave: a maximum of 10 days. An employee can use this leave when a family member is ill and there is no one else to care for them.

The Act on Financing Career Breaks enables employees to reduce their working hours to at least 50% for a period of 2 – 6 months that can be extended up to 10 months to take care of a terminally ill family member. They receive an allowance for the hours that they provide care. This system is not often used.\(^50\)

### 4.5 Preschool for children with disabilities

Preschool children between the ages of 0-4 can attend mainstream day care centres where they can receive the specialist services they require e.g. rehabilitation services, speech therapy etc. These day care centres are financed by the Long Term Care Insurance (AWBZ), and are free to children with disabilities. Pre-school children with disabilities are also eligible for social development support in their own homes.\(^51\)

Most staff in mainstream play groups/day care centres have received training in early intervention measures. Cross sectoral early intervention teams consisting of paediatricians, speech therapists, social workers etc work with staff in preschool day care centers to provide the supports.\(^52\) The educational system in the Netherlands does not provide any early intervention services for preschool children with disabilities.

---


4.6 Care supports in education for children with disabilities

Early intervention regarding a child's education needs, is not a guaranteed right in the Netherlands. The educational system does not provide early intervention services to pre-school age children (0-4) because children cannot be enrolled in schools before their 4th birthday\(^5\). The only time children with disabilities are exempt from education is if they are in institutions and they are considered to have low developmental abilities\(^6\).

The Ministry of Education, Culture and Science is responsible for providing educational services for children with and without disabilities in mainstream and special primary and secondary schools, in addition to vocational and higher education\(^5\).

Children with disabilities in the Netherlands undergo an extensive assessment process by the CIZ (Centre for Assessment), that determines their educational and other support options. Depending on the level of their disability, some children may be placed in a mixed school system (mixture of mainstream and special schools) organised by local networks.

Children with severe disabilities, particularly those with intellectual disabilities, are placed in special schools with little or no mainstream activity. In 2005 there were waiting lists for children seeking to be placed in the special education system because of the extensive testing process that precedes admission into the system\(^6\). In 2003, the Dutch Education Inspectorate stated that 126 students were waiting to be placed in primary and secondary schools and 776 students were still waiting to be assessed and referred\(^5\).

Since August 2003 children who are assessed as requiring special education support are eligible for pupil specific funding called the "back pack". Parents can use this funding to cover the costs of educational supports their children may need if they are in the mainstream educational system. The Dutch

\(^6\) ibid
\(^5\) Ministry of Education Culture and Sport http://english.minocw.nl/
government also introduced the “Back to School Together” programme that promoted a more inclusive approach to education\textsuperscript{58}.

Research shows that there are a number of barriers for children with intellectual disabilities attending mainstream schools in the Netherlands:

- The back pack funding system that promotes inclusion only caters for 25\% of the population of children with intellectual disabilities\textsuperscript{59}. The funding is lower for children with intellectual disabilities than for children with other types of disabilities.
- This back pack funding is only applicable to some schools, so that parents' choices are limited regarding the type of schools they can send their children to\textsuperscript{60}.
- The funding provided by the state to mainstream school networks to support children with intellectual disabilities is insufficient to meet the children’s needs. This funding enables the student to pay for extra support that they may need from a special needs teacher to enable them to complete their education\textsuperscript{61}. Many parents with children with intellectual disabilities therefore enrol their children into special schools\textsuperscript{62}.
- Schools can determine the type of curricula used in the classroom alongside general objectives specified by the government. The Education Inspectorate discovered that, in many schools, materials and lessons were not suitably adapted for children with intellectual disabilities. In-service training for teachers is optional and many teachers only receive limited training in how to adequately teach children with disabilities\textsuperscript{63}.
- School inspectors also reported that curricula and materials in special schools have also proved to be inadequate\textsuperscript{64}.

Key informants stated that school management and teachers in mainstream schools have raised objections to the Dutch government's plans for developing a more inclusive educational system. Research shows that special education teachers and some parents of children with special education needs have also raised similar objections. These groups are not against the

\textsuperscript{58} ibid
\textsuperscript{60} ibid
\textsuperscript{61} http://www.european-agency.org/country-information/netherlands/national-overview/complete-national-overview
\textsuperscript{63} ibid
\textsuperscript{64} ibid
principles of integration. They believe that children with special education needs benefit from being in a segregated setting where they can receive the specialist teaching and counselling services they need\textsuperscript{65}.

A key informant for this background paper indicated that a school cannot refuse to have a child. However there have been cases where a school has stated that they cannot support some children with disabilities and the children have not been accepted at the school. If a child with a disability is home from school for more than a year the parents have to send them to a special school. A key informant estimated that there are between 3,000 - 4,000 children and young people with disabilities in day care institutions because mainstream and special schools cannot provide services for them\textsuperscript{66}.

Research shows that children with autism, for example, are the largest group of children who do not attend school\textsuperscript{67}.

**Table 7. Netherlands: Pupils with SEN in special schools by disability type (2005/2006)\textsuperscript{68}**

<table>
<thead>
<tr>
<th>Intellectual</th>
<th>Mental Health</th>
<th>Learning difficulties</th>
<th>Sensory</th>
<th>Physical</th>
<th>Multiple</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>-</td>
<td>23%</td>
<td>33%</td>
<td>5%</td>
<td>4%</td>
<td>9%</td>
<td>27%</td>
<td>67,000</td>
</tr>
</tbody>
</table>

Source: Netherlands, Ministry of Education, Culture and Science

Studies undertaken by the Social and Economic Council (SER) of the Dutch government (2007)\textsuperscript{69} recommended that the Dutch government should:

- Improve the basic education for young people with disabilities, particularly those with intellectual disabilities and experiment more with inclusive education
- Providing assistance for young people leaving school to find jobs and internships

SER made these recommendations after highlighting the link between special schools and the increase in young people with some work capacity receiving

\textsuperscript{65} Applica & CESEP & European Centre (2007) Study of the Compilation of Disability Statistical Data from the Administrative registers of Members States.

\textsuperscript{66} Jose Smits, a key informant

\textsuperscript{67} ibid

\textsuperscript{68} Applica & CESEP & European Centre (2007) Study of the Compilation of Disability Statistical Data from the Administrative registers of Members States.

disability benefit. These recommendations were seen as a possible solution to activating young people towards employment\textsuperscript{70}.

**Transition from education to employment**

Educational supports for students with intellectual disabilities in secondary and vocational schools such as extra supports provided by special needs teachers, have been reduced, and there are plans to modify other benefits that would limit the already reduced funding available for such students\textsuperscript{71}.

Research in the Netherlands has highlighted the link between young people attending special schools and an increasing number of young people receiving a disability benefit entitled the Wajong. Young people with disabilities receive this benefit when they are 17 years of age\textsuperscript{72}.

A study undertaken by the SER in 2007\textsuperscript{73} estimated that there would be an increase in Wajong recipients from 156,000 in 2006, to possibly 360,000 in 2040. This study also found that of the 156,000 recipients, 26\% were in some form of employment, yet, 50\% of the recipients were considered by the SER to have some work capacity. The SER recommended that the Dutch government should activate these recipients toward employment by:

- Improving the basic education for young people with disabilities and experiment more with inclusive education
- Providing assistance for young people leaving school to find jobs and internships
- Increasing supported employment opportunities for young people.

In their report on employment of people with disabilities (2009) the Academic Network of Disability Experts (ANED) cites two plans the Dutch government issued in response to the SER report.

The core objectives of these plans, which are still in the process of being implemented, are:

- Young people with disabilities are assessed for the Wajong benefit based on their capacity to work.

\textsuperscript{70} ibid
People with a higher work capacity receive a lower benefit but as an incentive for them to work, are allowed to keep part of their benefit in addition to their earnings. People who are unable to work receive the highest level of benefit, which is 75% of the minimum wage.

All Wajong recipients are now being offered an individual participation plan, that will provide them with assistance to find a job or provide them with training which leads to an actual job offer. If recipients refuse to comply with the participation plan their benefits can be terminated.\(^{74}\)

Develop a disability awareness raising campaign for employers and employees to create inclusive workplaces.\(^{75}\)

### 4.7 Transport to Disability Services

The Equal Treatment Act for people with disabilities did not extend to include the area of transportation until 2010. However, people with disabilities do receive discounts for using public transport. There are special tariffs for people with disabilities in the Netherlands. Regional and local authorities pay the difference.

In the Netherlands, "special" transport such as taxis, etc are allocated for use by people with disabilities. There is also a regional transport system for people with disabilities operated by the municipalities called the Valys-system. It is paid for by the Dutch government.

There are also six national programmes facilitating individual door-to-door-transport for people with disabilities. These minibuses and taxis transport people with disabilities to school, social welfare appointments and social/recreational activities. These programmes are paid for by the Dutch government.\(^{76}\)

### 4.8 Day & Employment Services

**Day care services**

While there is no legislation or regulations setting out an agreed definition of the day supports for people with disabilities in the Netherlands, the needs assessment process set out the range of supports that can be provided such as personal care, medical care, or attendance during activities. Providers of day supports are required to provide the care specified in each needs assessment.

The Ministry for Health, Welfare and Sport funds day care and activity centres for people with disabilities of all ages. The majority of people who use day

---


\(^{75}\) ibid

care and activity centres are older people with intellectual disabilities and children with intellectual disabilities.

**Employment services**

The Dutch government's policy on employing people with disabilities has focused on determining adults' capacity to work and reducing the number of adults receiving disability benefits. In 2006 the Dutch government implemented a policy change regarding employment and employment disability benefits that distinguished between:

- People who were entitled to disability benefits because they were permanently disabled. Their benefits were structurally increased.
- People who are considered to be capable of finding some kind of work. To assist this group to get employment, financial risks for employers were reduced and supports for individual job seekers were improved. The result was a sharp decrease in employees filing for disability benefits from 60,000 to 21,000 in 2006. However it's not clear whether the decrease in applications is due to an increase in employment rates for people with disabilities.

The Dutch government's policy regarding disability benefits sought to provide financial incentives for recipients to pursue work by:

- Tightening the eligibility requirements for recipients to receive higher benefits
- Providing employers with subsidies to hire people with disabilities
- Providing educational and integration support to people with disabilities who have a work capacity. The UVW (the government's co-ordinating body) is responsible for mapping employee's competencies and matching employees with reintegration companies to provide reintegration training, individual training support and job coaching.

**Sheltered Employment**

Sheltered employment is the most common form of employment in the Netherlands for people with disabilities. In the Netherlands sheltered employment is financed by the government and managed by the municipalities.

---

78 ibid
79 ibid
In 2006, over 99,000 people were in sheltered employment\textsuperscript{81}. Some people were employed by private companies under the supervision of sheltered employment providers. In 2006 there were 16,000 people on waiting lists for sheltered employment compared to 6,000 in 2002\textsuperscript{82}.

A majority of people with intellectual disabilities in employment are employed in sheltered employment. A 2005 report stated that out of 73,000 people with intellectual disabilities:

- 41% were employed in sheltered employment
- 4% were employed in supported employment in the open market
- 21% were at adult day care facilities doing unpaid employment duties\textsuperscript{83}.

**Impact of activation policies**

According to Schoonheim and Smits (2009), the activation policies that the Dutch government have implemented have not yet proven effective regarding improving the employment prospects of people with disabilities. They report that employers' attitudes towards hiring people with disabilities has not changed. They also state that barriers that prevent people with disabilities entering the labour market such as bureaucracy and effective support for people with intellectual disabilities have not been dealt with. Schoonheim and Smits (2009) recommend that in order to improve employment opportunities for people with disabilities there is a need to:

- Develop an accurate and complete statistical database on the employment position of people with disabilities, disaggregated based on the type and severity of disability, the support needed, the support utilised, gender, age, and ethnicity. Statistics to be updated annually
- Focus on employment opportunities for people with disabilities in institutions and day care centres
- Impose a 5% hiring quota for employers and monitor employer progress on this employment quota. While there is currently no quota system in the Netherlands, the Government has urged employers to adopt a voluntary 2% hiring target for people with disabilities, but it is unclear if this system is monitored in any way.\textsuperscript{84}

\textsuperscript{81} They work for private companies in the open labour market but they are supervised by their sheltered workplace and their contract would be with sheltered workplace
\textsuperscript{82} ibid
\textsuperscript{84} ibid
4.9 Supports to Independent Living

Social Supports Insurance, (WMO)
The Social Supports Insurance Act (WMO) introduced in 2007, emphasises the importance of independent living for people with disabilities. Under this Act, people with disabilities can now use their personal care budget to pay family/ friends who care for them. This makes it easier for people with physical, intellectual and other disabilities to live at home and in their communities for as long as possible. The Ministry for Health, Welfare and Sport estimates that 1.6m people are caregivers to a family member.\textsuperscript{85}

Under the Social Supports Insurance (WMO) Act, each of the 441 municipalities in the Netherlands has a central information point that will provide people with disabilities and their families with assistance in applying for personal care, adjustments to their home, mobility devices, housekeeping help etc.\textsuperscript{86}

Other legislation
Prior to the Social Supports Insurance (WMO) Act, the Dutch government introduced two pieces of legislation that respectively: support the right of people with mental health difficulties and intellectual disabilities to live at home; and promote the provision of accessible public buildings and houses.

The national building code (Bouwbesluit) introduced in 2003 by the Ministry of Housing, Spatial Planning and the Environment (VROM) sets out accessibility guidelines for new buildings e.g. all buildings must be wheelchair accessible. However older buildings do not have to be accessible. The Equal Treatment Act for Disability and Chronic Illness was expanded and made effective in March 15, 2009 to prevent discrimination against people with disabilities in the sale and rental of houses. The objective of the Act is to assist people with disabilities to live in the community in housing of their choice.\textsuperscript{87} The Equal Treatment Act also ensures that people with disabilities cannot be forced to live in an institution.

Personal Care Budget
Key informants for this background paper and research evidence suggests that the introduction of the personal care budget (see s.5.2) has been an important support for independent living for people with disabilities. It

\textsuperscript{87} Schoonheim, J. (2009). ANED country report on the implementation of policies supporting independent living for disabled people in the Netherlands. ANED (Academic Network of European Disability Experts) www.disability-europe.net/
provides them with the means to decide on and to purchase the types of care services they wish to have.

5. Entitlement, Choice and User Involvement

5.1 Entitlement

Health insurance and public long-term care insurance are mandatory in the Netherlands for people with and without disabilities. Therefore everyone is entitled to health and social services. Appendix B details the services for people with disabilities covered by health insurance.

For people with disabilities there are two types of public long-term care insurance the Long Term Care Insurance (AWBZ) or the Social Supports Insurance (WMO) that promotes independent living. A more detailed summary of these two types of insurance is provided in section 2.4. In order to determine what type of health insurance and care services a person with a disability requires, they must first be assessed by Centre for Needs Assessment (CIZ). This national organisation is responsible for conducting needs assessment, which are health based i.e. based on a person's health rather than mean-tested.

The type of care a person receives and their choice in service providers is dependent on their disability.

While people with disabilities may use the same type of public long-term care insurance as in Long Term Care Insurance (AWBZ) or Social Supports Insurance (WMO), there are different service providers for people depending on their disability.

When a child is diagnosed with a disability between 0-4 years of age the parents and families contact their local MEE Nederland office which will inform them of the different service options that are available to them in terms of adaptations, transport etc. and answer other questions they may have.

The type of care a child with a disability requires depends on their disability. Children are assessed based on IQ tests and/or clinical observation. This assessment is carried out by an organisation that is independent from the

---

88 ibid
89 In 2008 the CIZ has one main office, 6 district offices and 30 local offices in Schut, F.T and Van den Berg, B. (2009) Sustainability of Comprehensive Universal Long - Term Care Insurance in the Netherlands. Accepted for publication in Social Policy and Administration
90 As detailed in Table 2 MEE Nederland is a national programme assists people with disabilities in accessing support, developing personal care plans and applying for assistance from AWBZ or the WMO. This programme is funded by the Health Care Insurance Board (College van Zorgverzekeringen, CVZ) from AWBZ funds
health insurance and health care providers. This assessment also provides parents and/or legal guardians with options as to how they would like the care to be funded in the form of a personal care budget or from a healthcare insurance provider\textsuperscript{92}.

If the parents of a child with a disability decide to place their child in residential care then institutions are obliged to provide the necessary care\textsuperscript{93}.

5.2 Personal Care Budgets

The personal care budget is a form of direct payment for people with disabilities in the Netherlands. People who have Long Term Care Insurance (AWBZ) or Social Supports Insurance (WMO) can choose to use a personal care budget\textsuperscript{94}.

When a person with a disability opts for a personal care budget they are receiving 75\% of what their care in kind would cost. It is paid directly into their bank account by the CIZ’s care liaison office. The person can purchase the type of care they wish. The CIZ’s care liaison office checks in with the personal care budget users to ensure that they can account for their expenditure\textsuperscript{95}.

Under the Social Supports Insurance (WMO) informal care provided by family and friends is now recognised. A person is defined as a caregiver if they care for someone for longer than 3 months. A person with a disability can use their personal care budget to pay for informal care by a family member. In 2009, the Ministry for Health, Welfare and Sports estimated that 1.6m people looked after a family member or a friend with a disability. Local governments are encouraged by the Ministry of Health to provide training for non-professional care givers and to have back-up procedures in place that will enable carers to take adequate time off\textsuperscript{96}.

\textsuperscript{92} ibid
\textsuperscript{94} Schoonheim J (2009). ANED country report on the implementation of policies supporting independent living for disabled people in the Netherlands. ANED (Academic Network of European Disability Experts) www.disability-europe.net/
\textsuperscript{96} Schoonheim, J. (2009). ANED country report on the implementation of policies supporting independent living for disabled people in the Netherlands. ANED (Academic Network of European Disability Experts) www.disability-europe.net/
Table 8. Key data on personal care budgets, 2005

<table>
<thead>
<tr>
<th>Number of Budget holders</th>
<th>77,883</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age distribution</td>
<td></td>
</tr>
<tr>
<td>18-55</td>
<td>32.5%</td>
</tr>
<tr>
<td>56-65</td>
<td>12.6%</td>
</tr>
<tr>
<td>66-75</td>
<td>14.3%</td>
</tr>
<tr>
<td>76-80</td>
<td>8.7%</td>
</tr>
<tr>
<td>Type of Health problem</td>
<td></td>
</tr>
<tr>
<td>People with heart conditions</td>
<td>67%</td>
</tr>
<tr>
<td>Elderly people with Alzheimer’s and or dementia</td>
<td>1%</td>
</tr>
<tr>
<td>Mental difficulties</td>
<td>14%</td>
</tr>
<tr>
<td>Physical disabilities</td>
<td>14%</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>11%</td>
</tr>
<tr>
<td>Sensory disability</td>
<td>1%</td>
</tr>
<tr>
<td>Net budget amount in euro*</td>
<td></td>
</tr>
<tr>
<td>&lt;2,500</td>
<td>27.7%</td>
</tr>
<tr>
<td>2,500-5,000</td>
<td>24.9%</td>
</tr>
<tr>
<td>5,000-25,000</td>
<td>30.5%</td>
</tr>
<tr>
<td>&gt;25,000</td>
<td>16.9%</td>
</tr>
</tbody>
</table>

*Net of co-payments by budget holder. The average gross personal care budget was about 14,000 euro, of which about 1,000 euro was paid by the budget-holder out-of-pocket.

7% of long-term expenditure covered by Long Term Care Insurance (AWBZ) is used for personal care budgets. More than 10% of long-term care users opt for the personal care budget.

Every year the Dutch government puts a ceiling on the total amount that can be spent on personal care budgets. Since 2005 the demand has exceeded the agreed budget. In 2007, the government implemented a total annual budget increase of 35% (Ministry of Health 2007). In 2008, it was estimated that total cost of personal care budgets was €1.3bn, an average of €14,500 per service user.

Personal care budgets are used for:
- Assistance with everyday activities such as getting up, having a shower
- Paying informal care by relatives, neighbours and friends, (which was previously often provided for free)
- Purchasing brokerage services as an increasing number of brokers charge a fee to assist people with disabilities in applying for a personal care budget

---


• To purchase supports from home health care agencies\textsuperscript{100}
• Supports for someone with a disability trying to reintegrate into the workplace after being absent from work due to their disability\textsuperscript{101}
• Weekend and respite care\textsuperscript{102}

Per Saldo is an umbrella organisation established and run by people with disabilities using personal care budgets. It is a not for profit voluntary organisation that provides information, publications and advice on everything to do with personal budgets\textsuperscript{103}. It also provides support and representation (including legal representation where necessary) for its members through its service department. It represents people with disabilities if they have issues with needs assessment, the allocation of the budget or making arrangements with help providers and organisations.

Per Saldo is also an advocacy organisation that is campaigning on a number of issues such as:
• Better PGB scheme for care, help and support under the Exceptional Medical Expenses Act (AWBZ), with more straightforward implementation, realistic tariffs and simpler accounting.
• The widespread introduction of personal financing in a variety of areas, e.g. for education, for the provision of aids and facilities, and for reintegration into the labour market.
• An integrated participation budget putting the control of the whole of people's lives back into their own hands\textsuperscript{104}.

Research and key informants have stated that the personal care budget provides people with disabilities with a choice and the potential to be creative in their service provision because they can decide on the types of service they wish to purchase themselves. The number of people with disabilities, choosing to use personal care budgets is slowly increasing\textsuperscript{105}.

\textsuperscript{100} Schut, F.T and Van den Berg, B. (2009) Sustainability of Comprehensive Universal Long-Term Care Insurance in the Netherlands. Accepted for publication in Social Policy and Administration
\textsuperscript{102} ibid
\textsuperscript{103} ibid
\textsuperscript{104} Per Saldo website. http://www.pgb.nl/persaldo/english/?waxtrapp=tdtvrMsHcwOhcPjBCAU
5.3 User Involvement

A key informant for this background paper indicated that people with disabilities were involved in Social Supports Insurance (WMO) advisory boards at local level. Local authorities also have consultative platforms for people with disabilities.

People with disabilities are also represented on the several advisory bodies that assist the government. These advisory bodies consist of councils of people with specialist knowledge who advise the minister on request or on pending issues. Examples of advisory boards in the Dutch government are: Health Council, the Election Council and the Transport Safety Board. Occasionally the government may decide to appoint a temporary committee to advise it on a particular matter.

The following organisations advocate for the inclusion of people with disabilities into mainstream Dutch society:

- The Dutch National Disability Council (VGPN) is a non-profit organisation made up of disability organistaions and individuals with disabilities that represent the interests of people with physical and intellectual disabilities, mental health difficulties and chronic diseases. It is primarily an advovacy organisation on behalf of the interests of the disability community in the Netherlands\(^\text{106}\). It is affiliated with the European Disability Fourm

- The Dutch Council on Disability and Chronic Illnesses (CG-Raad) promotes the rights of people with physical disabilities.

- Kanplus promotes the inclusion of people with intellectual disabilities and mental heath issues into society\(^\text{107}\).

The Dutch Coalition on Disability and Development (DCDD) does advise the Dutch government on promoting the inclusion of people with disabilities in societies worldwide through co-operation and development. This group is made up of individual members and international disability organisations.\(^\text{108}\)

---

106 Dutch Coalition on Disability and Development website
http://www.dcdd.nl/default.asp?3079


108 Dutch Coalition on Disability and Development website
http://www.dcdd.nl/default.asp?3079
6. Summary of Key Learning Points

Legislative changes in the Netherlands have been key in underpinning system reform in the health sector with the aim of promoting choice and person centred services.

Personal Care Budget

The Personal Care Budget as detailed in section 5.2 is an example of an existing person centred service that provides people with disabilities with the right to chose the type of care they wished to receive and who would care for them\(^{109}\).

Quality and transparency in healthcare provision

Recent legislation regarding the NZA (the national authority that controls the market) has provided the Netherlands with a system of indicators that control and measure quality of health care. The system also aims to improve the transparency of the market and pricing system for health care provision in the Netherlands\(^{110}\).

Strengthening Advocacy and Services User Voices

According to Schoonheim, there is a need to improve the central funding of advocacy supports in the Netherlands to enhance the engagement of non-statutory and representative bodies in the policy making process\(^{111}\).

Employment

In 2006, the Dutch government's policy regarding disability benefits re-oriented its focus to highlight people’s capacity rather than their incapacity to work. The government sought to provide financial incentives for recipients to pursue work by:

- Providing employers with subsidies to hire people with disabilities
- Providing educational and integration support to people with disabilities who have a work capacity.
- Tightening the eligibility requirements for recipients at the higher level of benefits

Despite these incentives there are still barriers to people with disabilities entering the open labour market\(^{112}\).

---


\(^{110}\) A key informant from Zichtbare Zorg


References


Applica & CESEP & European Centre (2007) Study of the Compilation of Disability Statistical Data from the Administrative registers of Members States.


Dutch Coalition on Disability and Development website
http://www.dcdd.nl/default.asp?3079

EC Europa (2008) Mental Health Briefing Sheets, Fact and Activities in Member States:


Ministry of Health, Welfare and Sport website

Ministry of Housing, Spatial Planning and the Environment website
http://www.vrom.nl/pagina.html?id=37413


Per Saldo website.
http://www.pgb.nl/persaldo/english/?waxtrapp=tldtrrMsHcwOhcPjBCAU


Schut, F.T and Van den Berg, B. (2009) Sustainability of Comprehensive Universal Long - Term Care Insurance in the Netherlands. Accepted for publication in Social Policy and Administration


State of the Accessibility of Public Transport Systems for People with Disabilities in the Netherlands (NL) www.cbs.nl


Thomas Houses website http://www.thomashuizen.nl/wat_is_een_thomashuis.aspx

APPENDIX A: List of Key informants

Jacqueline Schoonheim is a researcher of disability and education law, and a lecturer of private law at Maastricht University

Ms. Jose Smits member of ANED (Academic Network of European Disability Experts)

Senior Policy & Public Affairs Advisor from the Dutch Ministry of Health, Welfare and Sport who wishes to remain anonymous

A key informant from Zichtbare Zorg who wishes to remain anonymous. This organisation is a Health Care Transparency Programme established at national level, by the Ministry of Health, to standardise the development, monitoring and maintenance of quality indicators across the health care sector, going forward
Appendix B: How health and personal services are overseen and monitored in the Netherlands

The Dutch health care sector is undergoing significant ongoing reform at present. Services are now, in the main, arranged and provided as 'standard service basket' entitlements based on mandatory private insurance (and, where applicable, a system of assessed need) under the 2006 Health Insurance Act (Zorgverzekeringswet, Zvw). Government retains ultimate responsibility for the:

- accessibility
- affordability
- durability (sustainability)
- solidarity (cohesion)
- choice
- quality
- efficiency and
- quality of health care.

(Dutch Ministry of Health, Welfare and Sport).

The new care system in the Netherlands - including the Zvw is administered by the Ministry of Health, Welfare and Sport, in collaboration with a range of 'regulatory' bodies. These include, for example:

- The Dutch Health Care Authority (NZa): the supervisory body for all healthcare markets in the Netherlands. NZa oversees the implementation of insurance legislation in healthcare and produces an annual audit report on the state of the acute health care market
- The Health Care Insurance Board (CVZ) which:
  - co-ordinates the implementation and funding of the Zvw and the long term care, Exceptional Medical Expenses Act (AWBZ) and
  - has a monitoring role in relation to:
    - adherence to the regulations of international conventions and
    - the feasibility and efficiency of Government plans.
- The Dutch foundation for complaints and disputes (SKGZ) which incorporates an Ombudsman's role and handles patient complaints and disputes in relation to insurers
• The Dutch National Institute for Public Health and the Environment (RIVM) which
  - produces an annual 'Dutch Health Performance Report' and other reports such as waiting times for services
  - operates a consumer health information portal that provides a range of information including information on selecting a health insurer and health and personal services providers
  - has a particular role in relation to people at risk of social exclusion.

In addition, local Government continues to have some responsibility for managing a number of elements of the national social benefits package on behalf of citizens on social income support. Local authorities negotiate collective contracts and commission community development services in respect of this budget (the 2006 Social Supports Act refers).

The Dutch Government has put a number of quality and performance safeguards in place at national level, including, for example:

• prescribing the content of standard package of essential health and personal care referred to as 'standard service baskets', consisting of preventative, standard and long term care provisions
• taking measures to ensure access, quality and solidarity
• developing a comprehensive new instrument in consultation with key stakeholders to monitor the performance of the overall healthcare system on a regular basis
• issuing regular Health Care Performance Reports (Zorgbalans) from 2006\(^{113}\).

Other Government initiatives in the area of monitoring include commissioned reports from:

• CIZ - to assess user satisfaction with Long Term Care Insurance (AWBZ) and

• NIVEL - to investigate quality of life in nursing and residential homes.

**Licensing & Regulatory Framework**

• A system of voluntary hospital registration, performance measurement and incentivisation has been established by IGZ.

\(^{113}\) These reports complement Public Health Forecasting (Volksgezondheid Toekomstverkenningen, VTV) Reports, published once every four years by the National Institute for Public Health and the Environment (RIVM) which aim to evaluate policy and to help set new priorities where necessary.
• Otherwise a system of professional and management-based regulation applies.114 "Government is devoting less and less attention to the requirements for providing health care (e.g. norms and conditions for recognition and regulations for training), and more to the quality of the health care process. There are two important new pieces of legislation in this respect: the Individual Health Care Professions Act and the Care Institutions (Quality) Act." (IGZ Fact Sheet, 2002).

The Care Institutions (Quality) Act establishes a number of key requirements that all providers of care must fulfil.
  - Service providers must provide 'responsible care' i.e. care that is characterised as being of a good level, effective, suitable, patient oriented, and geared towards the real needs of service users
  - Service providers must make clear what they are doing to achieve and maintain 'responsible care'
  - Service providers must - to the greatest extent possible - systematically protect and, improve the quality of care they provide ... this includes taking measures such as establishing and monitoring a system of quality control
  - Service providers must publish an annual report indicating the quality control policies they have adopted and report on the quality of care they deliver.

• Under the Health Act, all serious incidents, adverse effects and crises must be reported to IGZ.

• The Individual Health Care Professions Act (Wet BvG) regulates the provision of care by professional practitioners, focusing on the quality of professional practice and patient protection.

• People with mental health difficulties and mental health service users are supported through, for example:
  - the Law on Contracts for Medical Treatment (Wet op de Geneeskundige Behandelingsovereenkomst) which set out health professionals' responsibilities to provide good quality care. It also safeguards patient rights.
  - the General Complaints in Healthcare Act and Psychiatric Hospitals (Compulsory Admissions) Act and the Client's Right of Complaint (Care Sector) Act (Wet klachtrecht cliënten zorgsector) which, in the case of the former, require that complaints mechanisms are established on a statutory

114 "Management-based directs regulated organizations to engage in a planning process that aims toward the achievement of public goals, offering firms flexibility in how they achieve public goals." Cary Coglianese and David Lazer"2002.
basis in relation to each institution and, in the case of the latter, provide for appeals through official complaints committees.

- the Participation (Clients of Care Institutions) Act (Wet medezeggenschap cliënten zorginstellingen) - which requires that the voice of clients is heard within residential and in-patient settings through mandatory client councils to be set up with legal competence to advise service providers on matters related to health service quality.

**Inspection of Services**

IGZ is an independent, statutory body that has an important role in relation to ensuring that health and personal social care providers comply with laws and regulations. Its main focus is safety and effective client-centred care.

IGZ operates a mandatory inspection system based on its own risk assessment of self-report monitoring data submitted by service providers in respect of agreed quality indicators. It has significant powers of enforcement, including those of direction, sanction and initiation of further investigation under criminal law where it finds reasonable grounds for suspecting breaches of the law.

The inspectorate reports - both on request and at its own initiative - to the Minister of Health, Welfare and Sport. It is legally obliged to follow any orders the Minister decides to issue with a view to regulating inspection policy.

IGZ is subdivided into three sub-inspectorates:

- preventive and curative health care
- mental health care (covering paediatric and general psychiatric hospitals, centres for drug and alcohol addiction and services for people with intellectual disabilities and nursing homes for the elderly)
- pharmacy and medical technology (medical devices and assistive technology).

It also has a special role in the supervision of involuntary placement and treatment in psychiatric institutions and inspects about 10% formally each year - including examining medical records and treatment team and patient and/or representative interviews.

IGZ carries out general supervision through regular visits to designated centres to ensure that the quality of care is up to prescribed standards\(^{115}\).

\(^{115}\) e.g. the system of performance measurement for hospital quality inspection that has been developed by the Inspectorate
The inspectorate is currently developing a new, three-phase, risk-driven approach to inspection as follows:

1. identifying institutions with higher risks - initial assessments are made by the Inspectorate on the basis of information collected via an electronic inspection questionnaire completed by all institutions 
2. conducting on-site inspection of the institutions  
3. conducting assessments of quality of care against required standards. 

Investigations into reports of serious problems, adverse events or other crises in the provision of care and other services will continue in parallel with this approach - and reports on these investigations and key quality assurance and risk reduction themes will continue to issue as appropriate.

The Inspectorate will also continue to publish an annual report on developments in healthcare and its work.

It is worth noting two significant initiatives in which IGZ has recently become involved:

1. "Basisset" which focuses on:
   • transparency mainly using process indicators for accreditation
   • selective overseeing using risk analysis
   • inviting hospitals to cooperate with the enforcement tasks of the Inspectorate
   • quality assurance of indicators by involvement of scientific communities.

2. The introduction of Transparency Lists to enable clients and insurance companies to choose between health care services based on bottom up ZN (Insurance Sector) Transparency Sets - Purchase Guides indicators that are quality assured through the involvement of all stakeholders in their development.

5) Other developments of note

Further Government initiatives:

In 2003, the Ministry of Health, Welfare and Sports launched a Sneller Beter (Better Quicker) programme to increase efficiency, improve quality and encourage innovation and embed transparency as a quality improvement tool across hospitals, clinical specialists and general practitioners.

A similar programme, Zorg voor Beter (Making it Better), was established for the long-term care sector to improve the client centredness and more
general quality of health and personal services provided within the scope of the Long Term Care Insurance (AWBZ). This E36.6 million programme is co-ordinated by the National Health and Healthcare Research Fund and implemented by Vilans and TNO Quality of Life.

Other national programmes are being rolled out on specific themes including dementia services, fall prevention and safe medication.

Notably, national innovation and quality improvement schemes increasingly include initiatives that aim to improve mental health services.

The Ministry of Health, Welfare and Sport has also established a framework to support local government in respect of the 2006 Social Support Act (WMO) developing policies based on the composition and demands of citizens within their catchment areas.

In June 2008 the Dutch Government endorsed a number of further reforms in the area of health and personal social services relevant to people with disabilities that had been recommended by the Social and Economic Council. These include:

- decoupling of service and support financing from accommodation subsidisation
- increased real control over personal budgets for people with disabilities with services offering clearly defined care service packages (ZZPs) setting out details of service provision for each service user
- opportunities for further standards development in the area of needs assessment and definition of entitlements.

Other opportunities for standards development have been identified for early attention in relation to the quality of job coaches.

Other quality initiatives include the following:

The Association of Dutch healthcare insurers has developed a common code of conduct. This code of conduct presents guidelines for proper insurance behaviour and deals with the aspects of quality and accessibility. The code of conduct can be viewed at:

A Health Care Transparency Programme (Zichtbare Zorg) has been established at national level, by the Ministry of Health, to standardise the development, monitoring and maintenance of quality indicators across the health care sector, going forward, however. The Programme Bureau currently works on behalf of fifteen steering groups working across the health and personal health care sector. A formal system of service provider/data registration applies.

The Bureau published a consultation document 'Framework for Quality Indicators' in early 2010. It received responses from a variety of
stakeholders including service providers, consumer organisations and umbrella groups and one health care insurer.
Appendix C: Services covered by Dutch health insurance

- Medical care and services by medical and nursing professionals
- GP services
- In-patient hospital costs
- Dental care up to the age of 18 (for others specialist dental care only)
- Medical – assistance devices including dentures, glasses for people with a serious visual impairment; walking aids/wheelchairs/Zimmer frames
- Pharmaceuticals: Prescription drugs only
- Obstetric and maternity (pre/postnatal services up to age of 6 months) care
- Paramedical care
- Physiotherapy
- Rehabilitative care: Fully covered for first 365 days
- Emergency ambulance
- Chronic intermittent ventilation (use of equipment in own home requires authorisation)
- First three sets of IVF treatment
- Audiological advice for people with hearing impairments
- Genetic testing including counselling for people at risk
- Transportation for people confined to wheelchairs, people who need out-patient haemodialysis; and people who are visually impaired
- Haemodialysis

Primary and out-patient mental health care, up to a maximum of eight sessions; co-payment of 10 Euro per session\(^\text{116}\)

---
