

ANNEX VIII: BELGIUM

Belgium is a kingdom near the North Sea. The official population on 01/01/2000 was 10,239,085 inhabitants. As a state it has a federal structure. There is the Flemish Region with 5,9 million inhabitants. The Walloon region has 3,3 million people (including a German-speaking Community of 70,000 persons). The Brussels Capital Region has almost 1 million inhabitants.

This paper will focus on the situation in the Flemish Community, which is generally the best organised region with regard to services for people with a label of “intellectual disability”. Flanders lies in the northern Dutch-speaking part of Belgium. Brussels is its capital, Brussels is also the capital of Belgium.

The Flemish Government and Parliament are responsible for ‘person-related issues’ within the Flemish Community (i.e. the inhabitants of the Dutch language area and the Dutch speakers in Brussels). These are policy areas in which the provision of services to the people is closely related to the language in which they have to be carried out, for example welfare, public health, education and culture. The Flemish Government is also responsible for ‘territorial issues’ such as the economy, infrastructure, agriculture, environment and employment, within the Flemish Region (i.e. the territory comprising the Dutch language area: provinces of West and East Flanders, Antwerp, Limburg and Flemish Brabant).

Although Belgium is internationally known for its ‘community care’ for persons with “mental health problems” in Geel, this paper will illustrate that, in contrast, a very specialised care system has been developed for persons with “intellectual disabilities”. This specialised system was developed starting from psychiatric institutions like the ‘Ghuislain Institute’ in Ghent (founded in 1857) where children and adults with “mental health problems” and “intellectual disabilities” were brought together in the first modern psychiatric hospital for the country. Dr. Ghuislain, the head-psychiatrist, worked together with the Brothers of Charity to ensure improved quality of life of persons who were marginalized in an industrial society. More and more these kinds of institutions appeared and were so well organised that the inhabitants of Flanders had less and less contact with the people living in these ‘asylums’.

BACKGROUND

- (1) What definitions of Intellectual Disability are typically used in your Member State?
Is there an ‘official’ definition?
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In Flanders the term ‘person with a mental handicap’ is still used. Here ‘handicap’ does not equate to the definition used in the third level of the former (1980) WHO-definition (i.e. in danger of discrimination), but rather to the medical definition of ‘impairment’ (e.g. Down Syndrome). In accordance with neighbouring countries, more and more the negatively coloured word ‘mental’ (‘mentaal’) is being replaced with ‘intellectual’ (‘verstandelijk’). People also try to avoid the use of the older terminology of ‘handicap’. If they work with someone they take into account the interaction of problems on the individual level with the barriers and the threatening discrimination as organised in the organisation of our society. It has to be said that due to the Flemish culture of ‘special care and special systems’ the individual level still gets more attention than the barriers in society.

With regard to service provision (either through Flemish Agency¹ or the special school system) it seems more and more obvious that people get a label as a way to solve an administrative problem. Who is disabled and who is not depends as much on the criteria for access to specific provisions (and it is even dependent on the availability of services) as on any general criteria. To be entitled to a Flemish Agency provision e.g. the candidates have to be a ‘disabled person’ as it is

defined by the legislation of the Agency. In accordance with the Decree of 1990 someone is disabled if he or she is confronted with a situation of long-lasting and substantial limitations of his/her possibilities of social integration due to reduced intellectual, psychological, physical or sensory capacities.

(2) What is the historical context in which services have developed in your Member State?

Within history we can observe that religious groups took the first responsibility to work with person with (intellectual) disabilities. Within the 20th century service providers took an organisational form of ‘not for profit organisations’. These organisations are organised through a board that takes the responsibility for the management of this organisations that gets his subsidies from the Government. The Flemish Agency pays the subsidies and controls the good management and quality of services. This control system tries to make sure that the not for profit organisation uses its budgets in agreement with it’s goals.

94% of the care system is organised through such private not for profit organisations, the rest are organisations of the Provinces or large communities who get subsidies from the government.

Many not for profit organisations are also dependent on ‘fund raising activities’ to build up their budgets. The National Lottery and individual gifts with tax reduction certificate are the structural possibilities. Service clubs such as Lions and Rotary act as interesting partners in the fund raising sector. Most organisations use this system of fund raising to keep their budget in balance or to prepare new investments/projects.

The administrative category of ‘persons with a handicap’ developed in the Flemish context from 3 important historical factors.

In Belgium education for all children is compulsory (basic law of 1914) and as a result, the Government and school boards were confronted with children who did not fit into the regular school system that focused on preparing children to develop their intellectual capacities and to work on the regular labour market. Out of this tension arose a basic law on special education in 1970.

In the sixties and seventies, starting from the special school system, a care system for people with disabilities was organised in an attempt to do better than ‘the medical model’ of old psychiatric institutions. A very specialised network of (mostly residential) facilities was organised to make sure that certain children and adults received the protection, care and support they needed, taking into account their problems to adapt to the expectations of an industrial and post-industrial society.

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On the other hand, members of society want to get protection from people with all kinds of problems. The network of services is organised in a ‘categorical’ way (every facility claims a certain ‘target group’, working as if they could define a certain profile). So people got away from the medical model and ‘total institutions’ and entered the world of specialised, categorical services. This brings us to the point that these special services seem to be very hard to change.

Because of the fact that the labour market plays an essential role in a capitalist society, the perspective of ‘having a job’ plays a central role in the life of most citizens. Persons with a label of ‘intellectual disability’ live in a conflicting position to the ‘productivity discourse’. ‘Income replacement allowance’, the category ‘unable to work’, the position of the phenomenon of

¹ The Flemish Agency for Persons with a Disability is the Flemish Administration in charge of legislation and budget concerning services to persons with disabilities.

‘sheltered workshops’, new trends like ‘job coaching and supported employment’ in relation to the idea of an ‘active welfare state’, are topics that are in the centre of contemporary discussions. After years of debate the Flemish Government decided to move all initiatives concerning work for people with a label to the Ministry of Work (instead of Ministry of Family and Welfare in former years).

(3) Are there specific legal rights afforded to people with intellectual disability?

Education, disability specific service provision, etc.

Situations where rights may be revoked on the basis of incapacity?

Prolonged Minority.

Persons with disabilities have, in general, the same rights as other Belgian citizens. However, Belgium has a law on ‘prolonged minority’ (law of June 1973) which applies to people with intellectual disabilities. Until the beginning of the nineties, this was seen as the main way to protect people (especially people with so called ‘severe mental handicap’). The diagnosis of ‘severe retardation’ in this situation is organised via a medical doctor and is based on following elements:

- the “retardation” has to be ‘severe’,
- the “retardation” has to be inborn or has to be manifest in early childhood,
- the situation has to have a bad prognosis.

In addition to these criteria, it has to be clear that the person is not in a situation to take care of himself and to manage his/her goods/property.

This protection makes sure that the parents (or a legal guardian) keep the parental authority they would have if their son or daughter, were under 16. This means that people with the status of ‘prolonged minority’ cannot get married, cannot start a business co-operation and they can’t donate or get goods out of a will.

In the beginning of the nineties, the Government came under pressure about this law (based on the argument that people either have rights or do not), and passed a law in 1991 on ‘temporary government over persons’. With regard to persons with ‘mild retardation’ the court can decide to organise a specific package of protection decisions for a certain period. In most cases the protection goes back to budget matters or questions about ownership. A lawyer can be appointed to become a kind of mentor to follow the specified field. For people with severe disabilities the status of prolonged minority was maintained.

In practice, however, some services also try to negotiate with their ‘clients’ to organise a system of a ‘double signature’ on documentation concerning the budget of someone with a label of intellectual disability. This system makes sure that the ‘client’ cannot take money of his account without the double check of his or her professional guidance. This system is organised from a pragmatic point of view, but from a legal perspective it is obvious that this system is in a “grey area”.

Compulsory schooling for everybody?

The Belgian constitution provides that everyone has a right to education with respect for fundamental rights and freedoms. With a view to secure this right to all children, education is compulsory. Compulsory education starts on 1 September of the year in which a child reaches the age of 6 and lasts 12 full school years. It finishes at the end of the school year in which the pupil reaches the age of 18 or when she/he – irrespective of age – has gained the certificate of

secondary education. Students with special needs can get official permission to stay at school in special schools until the age of 21.

However compulsory education does not mean compulsory schooling – children do not have to go to school to learn. They can also be educated at home.

Children who are unable to attend school, mainly because of serious impairments, can be exempted from compulsory education. Till now official statistics show that only a very small group of children – 0.03 % - get a measure that sets them free from compulsory education.

Most of these children attend ‘day care centres for children who cannot attend school’. These projects are subsidised by the Flemish Agency , not through the Ministry of Education.

(4) What is the estimated prevalence figure for intellectual disability in your Member State?

Both in terms of an estimated 1-3% of the population who have an IQ less than 70, and in terms of known service users.

Is there any published material on prevalence studies?

Belgium and its Flemish speaking part in global follow the trends of most industrialised countries.

All the available statistics are delivered by the organisations in the care system: so, one, reliable overview is not available. Someone can be registered e.g. within his school career and leave the statistics when becoming an adult, to re-enter the field after some years within the Flemish Agency with a demand for support as a ‘new client’.

(5) What databases/sources are available in your Member State that might provide information on prevalence?

Medical or social benefits, disability databases etc.

Data are collected by the administration, the Flemish Agency. Most data are linked to ‘service types’, as shown in table 1. As a consequence no specific data are collected or available concerning the prevalence of people with intellectual disabilities.

Table 1: total population according to the type of service provision on 30/06/2003

| | n | % |
|--|---------------|--------------|
| <i>for minors:</i> | | |
| Boarding school | 4.194 | 14,3 |
| Boarding school for children unable to attend school | 368 | 1,2 |
| Semi-boarding school | 3.252 | 11,0 |
| Semi-boarding school for children unable to attend school | 418 | 1,4 |
| Observation- and treatment centre | 320 | 1,1 |
| <i>for minors as well as adults:</i> | | |
| Short Stay Service | 803 | 2,7 |
| Foster Care | 766 | 2,6 |
| Living with support of a private person | 123 | 0,4 |
| Family Support Services | 3.428 | 11,6 |
| <i>For adults:</i> | | |
| Day Care Activity Centre | 3.891 | 13,2 |
| Supported Employment | 104 | 0,4 |
| Supported Living | 1.892 | 6,4 |
| Group Homes in the society | 515 | 1,7 |
| Residential services for those who work | 1.134 | 3,8 |
| Residential services for those who cannot work – occupational type | 3.849 | 13,1 |
| Residential services for those who cannot work – nursing type | 4.209 | 14,3 |
| Independent living | 196 | 0,7 |
| Total | 29.462 | 100,0 |

Source: www.vlafo.be

SERVICE PROVISION

(6) What is the criterion for eligibility for intellectual disability services?

With regard to service provision (either through Flemish Agency or the special school system) it seems more and more obvious that people get a label in an administrative way. Who is disabled and who is not depends as much on the criteria for access to specific provisions (and it is even dependent on the availability of services) as on any general criteria. To be entitled to a Flemish Agency provision e.g. the candidates have to be a 'disabled person' as it is defined by the legislation of the Agency. In accordance with the Decree of 1990 someone is disabled if he or she is confronted with a situation of long-lasting and substantial limitations of his/her possibilities of social integration due to reduced intellectual, psychological, physical or sensory capacities.

(7) What type of service provision is currently offered to adults with intellectual disability?
Educational, day service, residential, etc.

1/Global policy.

In the Flemish speaking part of Belgium, the policy for the social integration for persons with disabilities is developed through the Ministry of Work and the Ministry of Equal Opportunities. This Ministry has a close co-operation with the Flemish Agency for Persons with Disabilities, which is the administrative body. The policy and management board exists of a mixture of care providers, family organisations and unions. This mixture provides a series of distinct influences on the policy papers of the Ministry.

It has to be said that all the services that are offered by the Flemish Agency have a supplementary character. The Agency is only active on the domains where the global policy and services do not fulfil their inclusive role. More and more we observe a trend of inclusive policy, non-categorical service, for example, social housing projects, provide a service for all citizens. The Flemish culture with its parallel care system can be situated in the first stages of a paradigm shift from a categorical/specialist system to an inclusive system.

The most recent policy paper, stated that everybody who is 'in need' for support should get the opportunities to get the support to participate in the community. The Flemish Agency and the Ministry have chosen to introduce a shift of accent from the residential care for persons with disabilities to the persons and their natural networks themselves. One of the most important elements within this shift is the introduction of 'a personal budget'.

Other issues arising from the recent policy include 1) an attempt to get rid of the old idea of 'total packages of care' and replacement of those packages with individually evaluated levels of support for each person. Within the system we can observe experiments with 'case-management; 2) an attempt to make consistent the different options that are offered by service providers within the same region; 3) a resolve by the Government and the administration to work on the transparency and simplification of bureaucratic rules. It is essential to ensure that services can take initiatives with respect to what people ask for even if the request falls outside the 'little bureaucratic rules'; 4) the necessity for large service providers and parents associations to ensure that some of their staff members are given the opportunity to study and implement the distinctive new ideas and waves in the field. Within the Flemish Community we observe also the recent influences and growing power of self-advocacy movements.

2/ Specific services.

The Flemish Agency gives subsidies to residential services as well as to services in the community. Since 2000, the Agency has also organised a system of 'personal budgets', a system which allows persons with disabilities to organise their private care packages and as such they

become the employer of their support and care-givers. In 2001 316 budgets were allocated (the amount of budget varied from 7,436 Euro to 34,705 Euro for one year). Of these people 118 persons (37%) had a label of intellectual disabilities. The majority of people with intellectual disabilities are therefore using other forms of services.

- Services in the community.
These are services that are offered in the community to ensure that families and persons with disabilities can participate in the community and can have a good 'Quality of Life'.

Services of supported living e.g. give psycho-social support or assistance in activities of the daily life. Persons with a label of 'intellectual disability', 'physical or sensorial disability' can get a limited package of support.

- Semi-residential services
Those services are given to persons who get support in the day-time, but stay with their family in the weekends and the evenings.

For adults we can find e.g. day care centre programmes. Those centres give support on several domains but their specific expertise is situated in the domain of adapted activities for adults who cannot work on the regular labour market.

- Residential services
Adults can get support in a wide variation of residential services. Those who work can live in residential services that are designed for them. In residential services for those who cannot work people get a home situation and an activity programme. People with an intensive need of support can live e.g. in nursing homes.

Group homes in the community are situated in between services of supported living and residential services for those who work. Those group homes are situated in the community, close to a residential facility. Persons with disabilities can also participate in daily activities as organised by the residential facility. (Residents of the group homes pay the costs for housing and living themselves, they don't work with the 'hotel cost system' of residential services.)

Persons with disabilities get the support they need in services or residential facilities without paying for the staff members. The only cost has to be seen as a kind of 'hotel cost'. Everybody who lives in a residential facility has an amount of 'assured pocket money'. This is an amount of money service providers cannot claim.

The fact that citizens with intellectual disabilities get an amount of pocket money is contra-productive for the integration of some of them. It is cheaper to live in a residential facility with pocket money than to go and look for a house on the free market and to get support at home. People who live in the society and use a day care centre or supported living arrangements do not get that pocket money.

Traditionally the services of the Flemish Agency were organised on a 24hr basis. Since the beginnings of the nineties more and more services in the community are organised. Through group homes in the community the Flemish Agency offered less intensive support packages, which was thought to be able to work more on a demand and supply strategy. However, we already mentioned the negative side-effect of the pocket money system. Some families decide to leave their family member in a residential facility because of this financial system and, in addition, many (older) parents hesitate to bring their children in the community because they fear that the support possibilities will not be sufficient in confrontation with the demands of the society. As a result, even in 2001, the majority of the budget was still allocated to residential services (approximately 400,000,000 Euros) compared to community care services (approximately 14,000,000 Euros).

3/ Work.

Till april 2006 to be entitled to employment provisions, a person had to undergo an evaluation from a multidisciplinary team to show that capacity to hold employment is reduced in relation to the demands of the open labour market. Applicants with an intellectual disability had to prove that the attempts they have made to find a job on the regular job market continue to fail. Once eligibility is established people can access a variety of provisions, e.g. vocational training, sheltered employment and supported employment.

In Flanders about 13,000 people with a disability find a job in a sheltered workshop. About 60 to 70% of the employees have a label of 'intellectual disability'. Although these workshops were established to train people to find a job on the open market, research shows that in the middle of the nineties less than 1% of the workers were able to find a job on the open market. In addition, it is only since 1999 that employees in these workshops get the legal 'minimum income' out of their job – until then they worked for about 80% of the minimum income.

It is important to mention that a lot of people with an intellectual disability who get the extra label 'not able to work' enter a career in a day care activity centre. A lot of those centres offer industrial activities and job coaching projects. Activities in the community are available and people who 'cannot work', work there but they cannot get an income from this work.

Since 1999 and after many experiments, supported employment services have been available in Flanders. They have the task to guide people from a process of vocational training/extra-schooling, job analysis and solicitation and on-the-job training to a job in the open labour market. The vocational training is often organised through one of the 13 (in 1999) Vocational Training Centres that are specifically organised for people with disabilities.

Since april 2006 the services that give support to the persons with a label concerning employment are transferred to the Ministry of Work.

4/ Life Long Learning and Leisure.

There are also some organisations for Life Long Learning that play an interesting role in the so-called empowerment process.

In Flanders exist several Organisations for Life Long Learning for adults with a mild to moderate intellectual disability. Their educational courses cover a broad range of subjects e.g. nature, society, art and self-expression, relationships and sexuality, budgeting, self-image, internet, gsm and pc. Few courses relate to the physical health of adults with intellectual disabilities, e.g. such as healthy cooking or 'My body changes, what can I do?' and 'Me old, no kidding?' for people over the age of 50.

Adults with intellectual disabilities could also be included – at least in theory – in life long learning initiatives for the general public.

Leisure organisations, some of them are organised in an inclusive way, others for our specific 'target group', try to add to the physical and mental wellbeing of people with intellectual disabilities, by creating opportunities for adults to participate in different kind of social activities e.g. such as sport, travelling, day-trips, and movies or theatre.

5/ Waiting Lists.

In Flanders 'waiting lists' still exist as there is a structural deficit of 'places' e.g. in the (residential) services. The Agency has recently set up 'central waiting lists', with which the policy makers try to close the gap between people with a request for services and those who organise services and facilities. Table 2 shows the number of persons for different kind of services, registered with an urgent need of support at the end of 2005.

Table 2: number of persons with an urgent need of support, registered at the end of 2005 for different kind of services

| | 31/12/05 |
|--|-------------|
| Day Care Activity Centre | 720 |
| Semi-boarding school | 271 |
| Day Care Activity Centre/Supported Employment | 147 |
| Semi-boarding school for children unable to attend school | 39 |
| Group Home in the society | 405 |
| Residential services for those who cannot work – occupational type | 1093 |
| Supported Living | 964 |
| Residential services for those who cannot work – nursing type | 654 |
| Residential services for those who can work | 247 |
| Boarding school | 538 |
| Family Support | 1925 |
| Independent Living | 114 |
| Foster care - living with support of a private person | 25 |
| Observation- and Treatment Centre | 81 |
| Foster Family System | 52 |
| Total | 7275 |

Source: www.vlafo.be

(8) What sources of income are available for people with intellectual disability?

Benefits – provide some index of national minimum wage as a reference point

The income situation of persons with intellectual disabilities is organised on the federal level, especially for people who cannot get an income out of labour. The ‘income replacement allowance’ and the ‘integration allowance’ are two important elements that will be discussed in this paper.

Persons with the label of ‘Intellectual Disability’ often cannot get an income from employment. Currently, a person is entitled to an “income replacement allowance for the disabled” when his/her condition causes a diminution of his/her earning capacity to one third or less of what a non-disabled person can earn in any job of the labour market. There is no distinction made between degrees of disability and in general this benefit is meant for disabled persons who never worked or work very irregular hours due to the presence of a long-lasting and serious

impairment. In confrontation with the situation on the labour market we can observe that the medical doctors of the Ministry of Health, who are responsible for this evaluation, base their ideas about work capacities more on the observable impairments and functional limitations than on a confrontation between the capacities and the demands of the market.

The “integration allowance” is based on a definition that refers to the ability to perform activities of the daily life independent, the ability to communicate, personal hygiene skills, etc. Disability is measured with a scale especially designed for this evaluation. The allowance is intended to cover the ‘extra-costs’ resulting from functional impairments, but is often simply used in part as an additional income for people who get an income replacement allowance. Both assessments are often carried out together.

HEALTH SERVICES & UTILISATION

(9) What health services are currently offered to adults with intellectual disability?

People with “intellectual disability” attending residential facilities receive an annual medical check-up. A specific health check is available for people with Down’s Syndrome that includes screening for hearing, vision, cardiovascular disease and Alzheimer’s disease. Data are collected in personal files for follow up.

(10) Is there a body of research in your Member State on the health of adults with intellectual Disability?

Cite main researchers and areas of research they investigate (not the specific studies themselves - just direct the reader to where information can be found)

The Department of Paediatric Dentistry and Special Care of UZ-UGent has collected data on the oral health status of people with intellectual disability.

Source: Gizani, Declerck et al. 1997²; Martens, Cauwels et al. 2001³; Kint, Martens et al. 1991

(11) Is there any data on life expectancy among this population in your Member State?

No data available.

(12) Can you provide comparative information on the following for both people with intellectual disability and the general population – prevalence of epilepsy, forms of health promotion such as screening for blood pressure, blood cholesterol, breast screening, cervical screening, testicular cancer screening, testicular cancer screening? Are there other forms of health promotion screening available to people with intellectual disability (such as medication use, oral hygiene, contraception etc.) and how is this information available – in written form, pictures, television adverts etc.?

² Gizani S., Declerck D., Vinckier F. et al (1997) Oral health condition of 12-year-old handicapped children in Flanders (Belgium). *Community Dentistry and Oral Epidemiology*. 25, 352-357.

³ Martens L., Cauwels R., Marks L. (2001) Tandheelkundige risicogroepen in de dagelijkse praktijk VI: de gehandicapte patiënt. *Belgisch Tijdschrift voor Geneeskunde*. 75, 353-358.

Initiatives of prevention and health promotion have not been directed to or adapted for people with intellectual disabilities in Belgium.

Research (Boddez 2001) suggests that older women with intellectual disability have limited knowledge about menopause and prefer active forms of acquiring information on this matter.

(13) Is there any disability specific training for health professionals – such as modules on undergraduate programmes etc?

GP, Dental, Psychiatry.

Till 2006 Faculties of Medicine in four universities in Belgium provided scientific specialisation training in disabilities (a two-year part time study) leading to the award “Graduate in the Advanced Studies in Disabled Persons’ Care.

The course focused on physicians working in the field of disabled persons’ care. During the initial training for medical doctors information was disseminated regarding the prevalence, causes and treatment of disabilities and disabled persons. However a systematic approach of these problems was not integrated in the curriculum. This specialised training integrated aspects from the medical sciences, the behavioural sciences and juridical sciences to enhance the competence of medical doctors in dealing with disabled persons.

This course is since 2006 replaced by a course on master level on Handicap Studies organised by the University of Antwerp.

A specialisation is available to dentists leading to the award “Graduate in the Advanced Studies in Child Dentistry and Special Dentistry”.