



European study on the Specific Risks of Discrimination against Persons in Situation of Major Dependence or with Complex Needs

Country report the Netherlands

Dr. Martin Schuurman

November 2007

PART I: GENERAL RESULTS

Data on people with complex needs

In the Netherlands, there is no clear definition of people who are in situations of major dependence or with complex needs. As a consequence, there are no exact statistics about this group. The Dutch Association of Health Care Providers for People with Disabilities (VGN) distinguishes five specific groups of persons with complex needs:

- Persons with profound intellectual and multiple disabilities. This group has been estimated on ca. 9000 persons (information from Inspectorate).
- Deaf blind persons, between 4200 and 5100 (estimation of the National Expertise Centre of Deaf Blindness).
- Persons with severe behaviour problems, ca. 4350 (estimation by De Borg, cooperation body of specialised providers).
- Persons with autism, totally between 30.000 and 40.000 (estimation of the Dutch Society for Autism).
- Persons with non-congenital brain injuries. There are no statistics about this group as a whole. We know that each year from 600 to 1.200 children and youngsters get severe brain injuries from a traumatic incident, i.e. traffic and sports accidents (information of the Dutch Centre for Brain Injuries).

Being the total population of the Netherlands approximately 16 million people, the four first mentioned categories consists of approximately 0,3% of the population.

The Dutch policy on people with disabilities

In the Netherlands, with respect to persons with disabilities the so-called *compensatory approach* always has been dominant. This approach means that people get substituted and added what they are going to miss because of their disability. For example, when someone is expected not to be able to earn a salary in a normal paid job, he is offered a substitute income (social allowance) or substitute work (special jobs created for persons with a disability). Intramural care providers contributed their bit to it by offering their clients, from the moment they came into the organisation, all kinds of day activities and substitute work. In this system there are no stimuli at all to try to get proper work and get a position on the labour market.

In this approach the Netherlands seem to be quite unique. Other Western countries chose in much greater extent for the *non-discriminating approach*, which means that persons with a disability do as much as possible the same activities as other people do. The approach of non-discrimination is much more connected with participation and integration than the compensating approach, which is protecting in advance. That is why in the Netherlands the wish for integration of people with disabilities has never been so much rooted in society as it is in other countries.

Connected with this approach is the content which in the Netherlands is given to the concept of discrimination. The dominant interpretation of discrimination is linked with the individual level: discrimination is the specific, rejecting way others do react in daily life (on the street, in the supermarket, in public places, etc.) to people with a disability. For many parents of intellectually disabled children this even has been, and still is, one of the reasons to let their child live in a residential institution. With that, they in fact contribute to discrimination at the collective and societal level: they do stimulate social exclusion. Another consequence of the *compensatory approach* is that there has been no need for legislation with respect to disabled people and certainly not for specific groups like persons with complex needs.

Gradually the political vision on persons with an intellectual disability has been changed. Since the end of the nineties general government policy is to encourage people with disabilities to participate in social life as much as possible. This shift is influenced by the change of definition of (ICF model, AAMR) by which disability is being defined as a restriction of the possibility to participate. In the government view persons with a disability must be able to use the same facilities as anyone else and be as independent

as possible. The focus is no longer on the illness or disability but on the person with the disability, who must be enabled to lead his own life as much as possible. Care previously confined to institutions can now be provided at home, if the person (and/or his representative) wishes.

This vision also provides a powerful impetus for shifting the emphasis from residential onto extramural care, and in doing so meeting people's wishes to continue to live independently in their own environment as much and for as long as possible.

There are three main aspects in the Dutch government policy regarding people with disabilities. These aspects are complementary to each other and bring into practice the principle of the inclusive society for the individual person with a disability:

- To organize society in a way that all people can live and function. This means that we have to take into account the needs of persons with a disability in all domains of life.
- To offer special services to them who need these.
- At the level of realisation and execution: offer a reasonable accommodation, with individualized support.

The policy with respect to persons in situations of major dependence or with complex needs does fit with this general policy. Irrespective of the contents of the disability (deaf blind, autistic, severe multiple disabled, etc.), the concept of support is the same: basic support given by regular services => special care given by specialised providers and CCE's (Dutch Centres for Consultation and Expertise) => support of clients in getting clarified their demands and in going through procedures.

Regarding the legislation, article 1 of the Dutch Constitution states the prohibition of discrimination on any ground, including handicap or chronic illness. The Equal Treatment on the Grounds of Disability or Chronic Illness Act (WGBH/CZ) translates this general principle into application in daily practice. This act is a so-called modular one. It came into force, in 2003, with regard to 'vocational and professional education' and 'work'. The sector 'public transport' will come into force in 2010 for road-systems; for railway systems this will be 2030. The expansion of the WGBH/CZ to 'housing' is proposed to parliament, expansion in the fields of primary and secondary education and 'economic transactions' are under study. It is unknown when these modules will come into force. Generally, the act makes a distinction between meeting the demands of the organisation (work, school) and the specific facilities which are needed when the person is acting. For instance, when someone in a wheelchair applies to a job which asks him to move across the building and the employer does not engage this person because of his disability, he behaves against this act, because adaptations can be made.

Observations about practice

Several experts report there is a gap between the general policy of inclusion and the reality of daily life. It is a clear trend that people with mild disabilities make use of regular services and institutions (education, work, housing, etc.). More and more, parents of disabled children choose for living in communities by their child. However, the translation and implementation of the government policy in practice is not successful and is obstructed by a lot of barriers. More specific observations are:

- The connection with the theoretical framework of life course: the further in the life course, the more exclusion, the harder society reacts and the more damage it can give to persons with disabilities. Special points of attention are the moments of transition, particularly the transition from school to work, around the age of 18.
- Research has shown that compared to other citizens in society intellectually disabled persons are in general in a draw back position. Different aspects of this situation are very much connected to each other: no work means less money, which means fewer possibilities to leisure time activities, which means less access to 'normal' situations and contacts. Which, by the way, is something else than having no access to professional services.

- There is a general policy about inclusion, but no clear operational policy. In fact, there is no one who steers.

It is fully accepted that for persons with complex needs there are specialised facilities. The population in the Netherlands - generally speaking - prefers institutional care for persons with severe disabilities above living in the local community and use of regular services. Considerations and questions are: that institution more than regular services offer specialized support closely meeting the demands of persons with severe disabilities, that institutional care is on a high qualitative level and that there are lots of bad examples of living in the local community which were extensively discussed in press; good practices are less prominent in press.

At the same time, people experience persons with multiple and complex disabilities not living in a free situation. They are stuck because of the dependence from intensive support and care, which in the Netherlands makes it necessary to live in an institution. To live in society on a relatively independent way is reserved to people with mild intellectual disabilities. However, some parents with multiple and complex disabled children are able to create a position for their child in the society as well. These parents usually are highly educated and have more financial opportunities than others, or know better how to get funds. Besides, they know the way in the bureaucratic system and have knowledge about legislation and regulations.

It is felt that to all kinds of groups with complex needs tolerance is decreasing. There is a lot of embarrassment in practical work. And people are excluded from inclusion. Persons with Down syndrome or a mild intellectual disability are socially accepted, everyone likes to see them living and working. But when you really have to take into account the disabilities and identity of the other person – in case of someone with complex needs – there is much less acceptance. Like the autistic person with whom you precisely have to know how to organise the context.

Several experts do think there is a split arising between two groups of disabled persons in our society:

Persons who live relatively on themselves in society	Persons who stay in institutions
<p>This group consists of: persons with mild intellectual disabilities and Profound Multiple Disabled (PMD) persons with highly educated parents with financial possibilities.</p> <p>Characteristics:</p> <ul style="list-style-type: none"> • Care and support takes place from the principle of citizenship and inclusiveness. • Quality of life is a central concept. • Escape from the medical model. • Dispose of Personal Budget • PMD: (a) care and support are individual; there is a personal approach, (b) relatively high qualified staff, (c) lots of small-scaled initiatives, in which parents put money themselves (designing, repair, etc.). 	<p>This group consists of: persons with severe intellectual disabilities and Profound Multiple Disabled (PMD) persons with parents without high education.</p> <p>Characteristics:</p> <ul style="list-style-type: none"> • Medical model is embraced (gives grip). • The disabled person is seen as a patient. • Thinking and working are from the perspective of groups. People live in groups. • Low qualified staff. • There is no choice in housing. The institution says where you have to live.

In a very recent study of the Inspectorate to the quality of care in whole the sector of care to people with disabilities (November 2007) was found that in three quarters of the field action plans must be drawn up to improve the provision of care and services. The quality and quantity of personnel is worrying and these matters impact on the continuity of the care and services provided. In 48% of the residential/care locations in the visited organisational units, the Inspectorate considered an action plan to be necessary to address the risk aspect of continuity. The Inspectorate notes that a high

continuity risk is almost always accompanied by a high expertise risk. The Inspectorate asked 37% of the residential/care locations in the visited organisational units to draw up an action plan for this risk aspect.

The client's self-determination must be improved by obtaining a greater insight into his/her wishes and by a client-driven organisation. More than one quarter of the residential/care locations in the visited organisational units must take measures to improve the client's self-determination. The Inspectorate's measures and recommendations seek to create conditions for greater familiarity with the use of tried and tested methods for ascertaining the wishes of clients and for supporting them in making choices. It is also important to develop best practices for management methods and styles that will facilitate the client-driven organisation of care and services.

Directions for the future

Experts give many suggestions to improve the inclusion for persons with complex needs for care and support. The most important are the following:

- It is a good thing that in the Netherlands we now have the Equal Treatment on the Grounds of Disability or Chronic Illness Act. However, more important is the presence of a culture of acceptance. If there isn't such a culture, legislation can not be effective because there will be no situations the legislation can be applied to. Another comment on the WGBH/CZ is that it is not easy to do a plea of it. A lot of administration has to be done. You need to be quite assertive.
- To realize inclusion to persons with intellectual disabilities, we have to use legislation much more. We now mainly act on the basis of intentions, with great emphasis on the support of the process (i.e. how someone feels and experiences situations) instead of reacting on the facts and actual events.
It is important for the Netherlands that the European legislation is being extended, while that legislation is more fixed and rigid than the Dutch one.
- There should be more opportunities for experiments, especially at the basic micro level of support and services. There are lots of small, professionalized organisations which can support parents in their job. Some parents even make their own organisation around the care and support for their child. They have to get more support. Use of personal budgets must be stimulated and facilitated.
- We have to be able to explain why someone does *not* live and work in society, also when it concerns people with multiple disabilities and/or complex supportive needs. Providers have to make every effort to offer their clients daily activities which makes them real feelings to participate in regular life. People do integrate the best on school and at work. So we especially have to invest in these two domains.
- Speaking about participation and exclusion we also have to focus on the moments of transition, i.e. moments where someone goes into another stage of life. These are the moments that disabled persons are most vulnerable. An important transition is from education to labour (around the age of 18). It is obvious that disabled persons often can't meet the qualification demands of the working situation. This also has to do with the structure of special education. Disabled persons often do not get the certificates that are needed to qualify for a job.
- A basic condition is that the providers and the policymakers have the courage to decide to cut back on services, particularly schools and facilities which are not integrated in the community. This is the optimal way to promote the participation of special people in the community.

PART II: SPECIFIC RESULTS

1. Prenatal Diagnosis and counselling

By the extended possibilities for family planning, parenthood in modern societies becomes increasingly a question of individual decision-making. Prenatal diagnosis and reproduction technologies permit to include characteristics of the foetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions on children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counselling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this realised?

Description

In order to give pregnant women the opportunity to make their own choice in case of bearing a foetus with a disorder, pregnant women are entitled by law to have invasive prenatal diagnostic tests (chorionvillusbiopsy, amniocentesis and cordocentesis) and/or non-invasive prenatal investigation (advanced ultra sound test). Above the age of 35 the tests are given, under the age of 35 on request (indication). The law also dictates that information on genetic risks and prenatal diagnostics has to be given.

There are excellent facilities for genetic counselling at the Centres for Clinical Genetics.

Abortion is allowed subject to the provisions of the Termination of Pregnancy Act (WAZ) of 1984. This law dictates that careful consideration must be given to the following items:

- a woman and her physician must agree that her circumstances are compelling;
- the doctor must inform her on other possible solutions;
- to give a woman time for reflection, there must be a lapse of at least five days between her first consult with her doctor and the actual termination of the pregnancy;
- abortion is prohibited once the foetus is viable outside its mother's body. The absolute limit is after 24 weeks. In practice, however, the limit is 22 weeks.

The aim of the act is to balance two potentially conflicting interests: on the one hand protecting the life of the unborn child, and on the other helping women who are in a difficult position as a result of an unwanted pregnancy. Having a foetus with a serious disorder is an accepted reason for termination of the pregnancy.

Risks of discrimination

If the items of the law are executed careful and integer, there will be no risks of discrimination of people with severe disabilities or complex support. However, if at any point there is no full carefulness (for example: not complete information given to the woman, pressure on her to have abortion or not) there really will be risks for discrimination.

2. Early childhood

To have a baby is for most families a life situation of uncertainty and need for orientation. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents in a situation with specific challenges and dependencies. Often psychological stress in their daily life makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutic or medical treatment is necessary, parents cannot refer to their own educational experiences but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services at a very early age of the child are decisive factors both for the personal development of the child and for the successful coping process of parents. How is this realised?

Description

Distinction can be made between tracing intellectual disabilities and the early care if a disability has been detected. The Netherlands have an excellent network of Municipal Health Centres where preventive activities are carried out: the heel prick (4-8 days after birth, CHT + PKU test) and the Infant Welfare Centres and the Child Health Centres, where by periodic investigations and tests developmental disorders are indicated. In case of positive scores on the tests and/or indication of an developmental disorder by the infant doctor, special teams (VTO-teams) take care of the assessment and diagnostics.

In the care giving so-called early intervention teams play an important role. These multidisciplinary teams must coordinate care and support. The Dutch Association of Health Care Providers for People with Disabilities (VGN), together with other organisations, made a plan in which a model for early diagnostics and assessment and early intervention has been worked out. It's a plan for individual, timely, structured and long term support at home, called 'Early, continuous and integral; chains of timely detecting, diagnostic, care, education and support to children with disabilities and their families'. The aim of this plan is to detect children with disabilities as early as possible, to diagnostic adequately and to offer an efficient and effective care and support to themselves and their parents.

From birth, special services are available for intellectually disabled persons and his/her parents: pedagogic homecare, developmental programs, child day care centres for disabled children, special schools, special clubs, et cetera. The care and support are at a high level. Very important is that the specialised support of child and family can start as early as possible.

The support and care for persons with complex needs is in transition. It is going from a well-considered model into a system of individual authority. There still is a lot of improvement on individual authority to make.

Risks of discrimination

In the system of early intervention it is crucial that persons with severe and multiple disabilities and complex needs can enter the chain of detection and intervention as early as possible. Not everyone has the same chance; well educated and informed parents have an advantage to other parents.

Another risk of discrimination concerns the connection between the process of intervention and the idea of inclusion. In spite of the increasing possibilities for parents to keep their disabled child at home, from the beginning the focus is on specialised services and there is a strong tendency to hospitalisation. Families go along with that. As young parents with a child with an intellectual disability, you will be shown the route of exclusion. From birth we separate people. It would be better to realise the conditions that a disabled child and his family can stay together and the child can attend regular schools. Regular schools have to take their responsibilities. So the practical model of early detection and intervention should be more supportive to the idea of inclusion. In any case, we still need more attention for early diagnostics and assessment. For the well-being of the person involved, it's most important to find out the kind of support one needs in the social context in which one lives. With respect to persons with severe behaviour problems we can say that there is a strong connection between early diagnostics and assessment and the intensity of the behaviour. The longer it takes before the right diagnosis is made, the bigger the chance that the behaviour gets more problematic.

3. Childhood: education and care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare for school and give children the opportunity to get in contact with peers. Young girls and boys can broaden their field of experience and enhance social skills.

Children with severe disabilities have the same need to get in contact with peers, to make friends outside the family and to experience themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this realised?

Description

There are children with multiple and complex disabilities who attend regular preschool institutions like inclusive or special kindergartens, but there are not many. Mostly they stay at home, while still being in the process of diagnostic investigation and search for the right intervention.

In this stage the role of parents is a central one. They have to take up steering and coordination; they have to organise the care, to fix and order, to communicate, to study regulations, etc. That's why it is very important that the specialised support of child and family can start as early as possible. Umbrella organisations made a plan in which a model for early diagnostics and assessment and early intervention has been worked out (see before).

For the well-being of the person involved, it's most important to find out the kind of support one needs in the social context in which one lives.

Risks of discrimination

We may expect that the shift to more integration in the preschool phase the coming years mainly will be related to children with mild disabilities, not to children with severe and multiple disabilities. In terms of inclusion, there are some groups of disabled persons, like children with Down syndrome or autistic children, who more and more participate in regular kindergarten and primary schools. There is a chance that children with severe and multiple disabilities will fall behind further.

4. Childhood and youth: school

Schools are responsible for children's education and the transfer of knowledge on different subjects. Beyond this, school is an important part of young people's socialization process by offering the chance to enhance social skills and deepen social contacts with peers. Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support to participate in school education, such as barrier free access or well-trained teachers with the intention to cooperate with other professionals.

But especially for them school often exercises a segregating function. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate?

Description

Next to the regular schools, in the Netherlands there is a extended system of special primary education. It comprises schools providing special education for disabled children and children whose education requires a special approach, catering for either the primary or secondary age group or both. Education of this type is divided into four categories:

- Category 1: schools for the visually impaired, who may also be multiply disabled.
- Category 2: schools for deaf children, partially hearing children and children with severe speech disorders, who may also be multiply disabled.
- Category 3: schools for physically disabled children, children with severe learning difficulties (ZMLK) and chronically sick children (LZK) with a physical disability, who may also be multiply disabled.
- Category 4: schools for severely maladjusted children (ZMOK), chronically sick children who are not physically disabled and children in schools attached to paedological institutes (i.e. institutes associated with a Dutch university which give guidance to special schools).

Children and youth with severe and/or multiple disabilities with intensive need for care until recently were not qualified for the category 3 schools. Consequently, they were left to special day care facilities. This has been changed; now there is education legislation which gives the possibility for attending special or even regular schools. By law children and youth with disabilities and/or severe problem behaviour have the opportunity to choose for mainstream schools with extra assistance or for special schools. Children and youth with severe and/or multiple disabilities have the same choice. They are entitled to get a financial budget (the so-called 'back pack').

In terms of inclusion there are some groups of disabled persons (for example people with Down syndrome) who more and more participate in regular primary school. As the schools are hardly prepared to provide differential education, attending regular secondary school is already much more difficult. The older one gets, the more difficult it becomes. So it is important to make use of regular schools as long as possible. When one gets involved in specialized education, it is hard to get back.

Risks of discrimination

School is one of the most important domains for inclusion. In the Netherlands the legislation was changed in order to give also people with complex needs the opportunity to attend mainstream schools. That was the intention of the 'back pack policy': all children, no matter their level of disability, should be able to go to school. Nevertheless, several years after the introduction of the new law, many children with profound multiple disabilities (PMD) are still looked after by day centres. The educational policy itself may have complicated a successful transfer, the authorities did not force schools to meet any requirements with regard to use of products (curriculum, checklist), to extra training of personnel, or to the acquisition of essential facilities.

The accessibility to regular education for PMD children still is difficult and mostly impossible. Even the access to special education often is problematic because here also limits of level are practised: in the curriculum only little attention is being put into communication, which exceptionally is the most suitable point of impact into the PMD person. Also in the special education the cognitive aspects are considered the most important ones. So in practice, the traditional separation of groups keeps alive. The further you come in the chain of day centres and schools (day-care centre => special basic school => regular basic school => regular secondary school) the less accessible the organisation is. Even the new legislation did not change the situation really.

There are some groups, like people with behaviour problems, which do not make a chance to be included at all. As their behaviour is troubling others they are excluded.

5. Childhood and youth: housing/network, family support services

According to the varieties of modern family life, children grow up in different environments. These environments can be understood as a social network including all kinds of relationships to individuals or institutions. The family's living conditions in this phase of the life course are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families.

Some children and young people live in a foster family, others in children's home. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

Description

The current policy is that that children with severe and/or multiple disabilities should grow up in their birth families. So they live with their parents, often in combination with stay in a day care centre.

So parents and other relatives have an important role in the support and care for their disabled child or family member. As their strengths and supportive power are limited it is sometimes hard for the parents to keep their disabled child at home. Luckily nowadays there is all kind of provisions that help the parents to keep the child at home as long as possible. There is for example family support that provides services and aid to the parents and the family members who support them and there are guesthouses where children can stay on a temporary base that is specially accommodated for disabled persons. Very important is that the specialised support of child and family can start as early as possible.

While care and support for disabled persons who live relatively independent usually are split up at providers' side, parents have to take up steering and coordination. They have to organise the care, to fix and order, to communicate, to study regulations, etc. However, often they don't have the power and money for that.

Against this background we may say that parents do play an important role in participation and inclusion of persons with multiple and complex supporting needs. They know their child very well and can be helpful with the interpretation of the needs and demands of their child.

At the other hand, parents usually react conservative to ideas of participation and living in the community. Often the reason is that they already went through a lot of things with their child and became cautious to changes. In realising inclusion it is wise to make contacts with young parents and not to put much energy anymore in elder parents.

The family support runs along three lines:

- MEE-organisations, which offer support in giving information (social map), in clarification of the support demand, references, organising contacts with other parents, etc.
- Facilities from the Exceptional Medical Expenses Act (AWBZ).
- Facilities from Social Support Act (Wmo). By this act, municipalities are legally obliged to provide care services for the elderly and the disabled - transport, wheelchairs and special facilities in houses as well as support to families. Patients can apply to a special municipal agency for care services or for an allowance with which to purchase the care themselves. This has led to greater flexibility and a more demand-driven approach among care providers. 'Participation' is the objective of the *WMO*. Social support policy must be based on enabling people, including vulnerable individuals, to participate in mainstream society.

A specific important item in support of families is the transport. If you want to participate in the society you need to be mobile in some way. For persons with PMD mobility requires very specific transport. The regulations are insufficient. For example: if a PMD person who lives in an institution wants to attend a regular school, it formally is conceived as a kind of day activity. So you do not get the transport paid because day activities (transport included) are a part of the total amount the institution for this client get. The part 'transport' in this total amount is so little that travelling to regular social activities for a person is impossible.

If the person lives with his parents, transport is very complicated as well. You can't use the public transport; special taxi transport often is not available. So you have to organise specific solutions (as make an elevator in your own car).

Care providers react different with respect to participation of their youngsters:

- Some providers give individual Active Support, which can stimulate participation and inclusion, others use traditional methods of group support.
- Sometimes the organisation has the opinion that the development of their client is without any perspective. Then the decision has been made to replace the

development goals by the goal of quality of life: to give the person a life as good as possible in a residential setting.

- Others combine solid care with an open view to society. The aim of participation is realised from an attitude of carefulness and staying very close to the needs and wishes of the clients. So activities of participation are carefully tuned to the individual needs and abilities.
- Sometimes the ambitions are high, as in the case of the Very Intensive Care (VIC) Workhomes. There the recovery to a normal daily life is seen as a perspective for clients with severe problematic behaviour. To realise that, the method is geared to a recognizable and normal course of daily life based on creating a supportive climate.
- Sometimes, parents take the care in their own hands, helped by the possibility of personal budgets. For instance, they create a company of supportive professionals and volunteers by which their multiple and complex disabled child can have a supported living in the society, far from the residential institutions.

Risks of discrimination

Family support services, with exception of transport, are at a high level and by that they can influence the opportunities for participation on a positive way. However, there is a tension between the intention of inclusion and the assessment of the effects on the person. Parents as well as professionals realise that society nowadays is fast and much focussed on production. People with complex needs are vulnerable in such a society. Moreover, society is not eager to meet them, which is something they feel and know well, especially when they get older.

We have to develop care and support further in the direction of individualistic packages of support for clients.

6. Childhood and youth: leisure time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this realised?

Description

Most leisure time activities for children and youth with severe and/or multiple disabilities are organized privately or are connected with the stay on the day care centre, usually with great involvement of volunteers.

Leisure activities for this group, as well as for the group of disabled people as a whole, are not covered by regulations of equal treatment legislation. The Equal Treatment on the Grounds of Disability or Chronic Illness Act has not been expanded to this sector yet. There also are no regulations for accessibility of public areas where everyone uses to spend their free time (buildings, shops, cafes, cinemas, etc.). Many shops even do not have a slope for wheel chairs. Mostly also outside activities (parks, beaches, etc.) are not accessible to these persons.

Risks of discrimination

There are almost no possibilities for children and youth with severe and/or multiple disabilities to participate in the leisure time activities which are available for the other young Dutch citizens. In this domain there is discrimination.

7. Youth and young adults: vocational training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this realised?

Description

Persons with severe and/or multiple disabilities and complex needs do not attend regular schools for vocational training. In the Netherlands there are five special institutes in which these persons are being equipped for normal jobs. As a consequence of the government market policy these organisations have to collect their own money from the market, which made them coming in trouble.

Vocational training is one of the fields the Equal Treatment on the Grounds of Disability or Chronic Illness Act (WGBH/CZ) came into force until now. By this act (2003) discrimination between students and pupils with and without a disability on schools for vocational and professional education is prohibited. Particularly with respect to accessing school; in classes, during traineeships and exams; in providing information on career choices; in making adjustments in order to be able to follow the course.

Risks of discrimination

In spite of the non-discrimination legislation in this sector, persons with severe and/or multiple disabilities and complex needs are being discriminated. Regular vocational training is not available for them. Consequently, the discrimination legislation can not be effective for this group because there are no situations the legislation can be applied to.

8. Children and adults: social security/health care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. Especially to have a basic social security and to have access to health care services if necessary is a central need for all people. In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approving services create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this realised?

Description

With respect to *health care*, the Health Insurance Act (Zorgverzekeringswet) and the Exceptional Medical Expenses Act (AWBZ) constitute the basis of the health care insurance building in the Netherlands. The Zorgverzekeringswet is a private health insurance with social conditions. The system is operated by private health insurance companies; the insurers are obliged to accept every resident in their area of activity. A system of risk equalisation enables the acceptance obligation and prevents direct or indirect risk selection. The insured pay a nominal premium to the health insurer. The entitlements that exist under the AWBZ have been defined in terms of functions. Six broadly-defined functions create considerable freedom for arranging indicated care in consultation with a care provider: personal care, nursing, supportive guidance, activating guidance, treatment and accommodation.

By AWBZ, the entire special costs for persons with severe and/or multiple disabilities are paid: care, accommodation, and support. Relevant regulations belonging to this act are:

- During 2007 care providers will be obliged to make a care and support plan for every client. In this plan, the needs for care and the delivered care and services have to be fit to each others concretely.

- This has to do with the introduction of a new financial system. Clients who have an indication for care and accommodation will receive financial facilitation which corresponds with one of 45 sets in which the size of care and services is expressed (ZZP's). At the basis of this set and the demands of the client, provider and client together have to make the translation into concrete agreements about daily services. These agreements have to be admitted in the care and support plan. In this way, the client is given more direction about his own life.
- From April 2007 it has been possible for persons with an indication for care and accommodation to receive the whole package of care and support from the AWBZ at home (so-called full package system). By this, people with disabilities are being offered an alternative for residential stay and support.

Over the past decade the government has made an important change in the care system with the introduction of the client-linked budget. This personal budget increases people's options so that people can take more responsibility for their own situation and have care that is better suited to their needs. Care can be deployed more flexibly, for instance at home instead of having to relocate to a specific care institution.

With respect to *social security* three acts are of great importance. Together they form a safety net for vulnerable people, like persons with severe and/or multiple disabilities. The creation of this safety net can be considered as belonging to the compensatory approach of this country (see part I). (a) The Disablement Assistance Act for Handicapped Young Persons (Wajong) makes provision for a minimum benefit for young handicapped persons. (b) Regulations governing Contributions towards the Upkeep of Disabled Children living at Home (TOG) provides for an additional allowance, apart from child benefit, to parents for the upkeep of a disabled child living at home. (c) The Work and Benefits Act (WWB) provides a minimum income for all persons residing legally in the Netherlands with insufficient financial resources to meet their essential living costs.

Risks of discrimination

Generally, the access for persons with complex needs to medical services is good; the access to public services is not. Because the responsibility of the (medical) care has been placed in the hands of the caregivers, they decide about how you are treated. This is different for other citizens.

Having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. The new financial system – by which clients who have an indication for care and accommodation receive financial facilitation which corresponds with one of 45 sets in which the size of care and services is expressed (ZZP's) – is worrying. Because of the financial restrictions of this system organisations are being driven to become intramural institutions again. Smaller groups and households are more expensive, so economically it is more effective to keep the clients residential. This tendency is also shown in the language of workers: you can hear them speak again about 'working on the group' and 'the size of the group'. So the new system seems to initiate processes of social exclusion.

The accessibility of care services and support for persons with multiple and complex needs depends on which provider you have to do with. Actually, there are providers who prefer not to have persons with complex needs as clients, because of financial reasons: they are too expensive for them. The more severe and complex the disabilities are (multiple disabilities, behaviour problems, and severe physical disabilities) the less supply from providers and services is available.

Discrimination is also been observed in other areas of care and welfare. In the psychiatric care there is a lack of knowledge about the specific disabilities and impairments of persons with complex intellectual disabilities. They feel treated without respect.

9. Adults: work

Having work or day occupation is for financial and other reasons a very important indicator for social inclusion and quality of life. Going to work does not only structure people's days and weeks and has an important impact on the development of a person's identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities transition situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like barrier free infrastructure to enable their access. How is this realised?

Description

The government's aim is to get more disabled people out of sheltered work environments into jobs with regular employers (supported employment). That is why the Sheltered Employment Act (Wsw) has been changed. The first phase of modernisation of the Wsw took place in 2004 when the Centres for Work and Income started to assess who is eligible for a job in a sheltered workplace. That used to be the responsibility of local authorities. In the second phase the aim is to increase the number of disabled people who find work outside of sheltered workplaces. This means finding supervised jobs with regular employers or placement in service of a sheltered work company. Municipalities have the task to realise that.

In fact, mainly persons with mild disabilities take advantage of this policy. Only few persons with severe and/or multiple disabilities have a job in a regular setting or have training for such a job. Mostly, they stay or work at special day care centres, which are connected with care providers. These providers have a strong tendency to protect their clients. For example: at the residential institution there is a well functioning bakery but the step of starting a bakery in the village is not done.

With persons with multiple and/or complex disabilities you need employers who enjoy working with this group. There are a lot of jobs which persons with severe disabilities are able to carry out: for instance in garages, playing grounds, etc.

The facilities for day activities are going to be decreased, as a consequence of the new financing system (by which the size of care and services is expressed in one of 45 sets of heaviness). In that system day activities are going to be assessed lower (i.e. cheaper) than housing facilities.

Risks of discrimination

Work is one of the domains people do integrate the best. So we especially have to invest in this domain.

We see contradictions between the unanimous accepted vision and goals of participation and inclusion in labour situation (legislation included) at the one hand and the practice at the other. This is in particular with regard to people with complex needs. We want participation of these persons in the regular labour process and at the same time no concrete actions have been carried out. In contrary, institutions of support for this complex group (job coaching, training) have to finish their activities because of financial problems which are the result of ministerial withdrawal of financial resources (because of the market principal that they have to fund their own activities). This gap between policy and practice makes discrimination going to increase.

In residential services for people with complex needs, staffs prescribe what people must do; they know what the best is for them. Day activities mostly do not aim development of the individual person, they consists of some music, whirlpool bath, hanging around. Workers and managers think in terms of groups; for example the group of autistic persons who need structure. People are sorted out to types of disabilities.

Work is one of the two domains the Equal Treatment on the Grounds of Disability or Chronic Illness Act has been come into force. Because of the very low participation of persons with complex needs in regular work, this law can not be effective for this group because there are no situations this legislation can be applied to.

10. Adults: housing

Becoming an adult also means to make up your mind about how you would like to live: Stay in the natural family for a while, live alone, with a partner or family, with a friend or in other forms. Having privateness, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live is very important for people in our societies. For people with complex needs it is a big challenge to find their way to life. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disability do not only need good support services but also need counselling to realise their ideas and style of private living. How is this realised?

Description

With regard to living, the Dutch government takes as the starting point that everyone with a disability should live in the local community with the support he needs. However, the government does not want to oblige people to do that. Institutional living offers efficient and effective support in many cases. Many persons choose for these arrangements. In the perspective of the parents organisations, freedom of choice is important; but the efficiency and quality of treatment in a specialized setting might overrule this general principle.

A small amount of persons with severe and/or multiple disabilities lives relatively independent in a special assisted living centre or with friends or family, having adaptations in the house and special intensive support (Active Support).

Most people do live in residential settings. This support is financed by Exceptional Medical Expenses Act (AWBZ). These persons can not do anything for themselves what they would like to do. And they live with many regulations. Like the formal distinction between leisure and work. For example, someone rides horseback (which is leisure) and would love it to do after the riding small jobs, like caring for the horses, brushing them, etc. That is not possible because that would be work, which is another category than leisure. For fear of making mistakes, workers in institutions act strictly in line with the current regulations. They don't want to take much risk. For example, if someone wants to go out for a walk with a client he only may leave the institutional ground when he is authorised to give the medicine in an urgent situation (even when the last five years the person didn't need that medicine). It means that a nurse has to go with him. Practically it means that the disabled person doesn't come outside the institution at all.

Summarised, there are three reasons why participation and inclusion are blocked:

- Good practices do not get imbedded.
- Staff is feared to be tackled to their conduct; so they protect themselves against 'irresponsible actions'.
- Disabled people permanently are overprotected. The reflex of staff to challenges is: 'let's not do it, they are not able to do this.'

People with complex supportive needs usually live in groups because then their life and support are easier to control and to manage. So human beings are made subordinated to the system. They are put together on the basis of demands. Each person has numerous possibilities to develop, has for instance wishes and opinions about going to work. But the organisation says: 'No work, first we are going to manage the housing.'

This culture of control is not restricted to residential living, also in case of community living the organisation wants to control. For example, when disabled people live in adjacent houses in the community, the fences between the gardens are removed because of the whole will be being better controllable. Staffs are very good in seeing hurdles on the road.

Residential institutions have problems with using the demand of the client as starting point. Their orientation often is to control everything. Confirmation of this is given by the results of the project 'phased and stratified supervision' of the Inspectorate.

Good practices of participation and inclusion show that factors of success are:

- Personal involvement and inspired leadership (in spite of legislation and regulations).
- Everyone, regardless his position in the organisation, respects the client. Dialogue is experienced as a real dialogue.
- Methods (assessments, image making) and attitudes to get to know somebody are applied.
- There is cooperation between the disabled person(s), family and professional workers. There is partnership.
- There are guaranties that the vulnerability can be small, especially financially. (A risk factor is that the personal budget can be reduced easily when the evaluator – in his subjectivity and ignorance – makes such a judgment).
- There is no thinking in terms of groups: persons do not need to be equal, everyone is an individual human being with capacities and disabilities.

Especially small and medium-sized providers do succeed in participation projects. These organisations usually has been semi mural, not residential, are flexible in anticipating on environment and needs for support (who is this client, what does he want?), have the vision that behaviour problems are related to not having listened to the person and have an excellent regional network.

Another category of successful practices are the small-scaled services which are created by (groups of) parents.

Risks of discrimination

In the Netherlands, the most people with complex needs (persons with severe and multiple intellectual and/or physical disabilities) live in intramural institutions. They are basically excluded from society. In these institutions, even the day activities often are located at the place of living, so people don't come outside their residential setting at all. And if day activities are elsewhere, people are transported by special vans.

There should be more opportunities for experiments, especially at the basic, micro level of support and services. For example, there should be given more facilities to parents to practice their role as the 'director' of their profound multiple disabled child. There are lots of small, professionalized organisations which can support parents in their job. Some parents even make their own organisation around the care and support for their child.

Our house, the place where we eat and sleep, is the basis of our life. If you start with placing someone in an institution in the forest, the city is far away. Some persons with complex needs even form a relatively easy group. For instance profound multiple disabled children: they have not the behaviour problems other groups of persons with intellectual disabilities have, they are not that disordered. They need a lot of care with respect to daily life, which you can organise on individual level quite well. However, there is no regulation for individual living. So also in this, there is discrimination.

The level of control is related to the way of living of clients: the more they live in big groups the more control is needed. So we should finish living in institutional groups. Inclusion is the key to less control.

11. Adults: education and leisure time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to everyday-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional career. Sometimes people participate in adult

education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this realised?

Description

Most leisure time activities for people with severe and/or multiple disabilities are organized privately or within the residential organisation they live, often with involvement of volunteers. The activities are not covered by regulations of equal treatment legislation. There also are no regulations for accessibility of buildings people are used to spend their free time (shops, cafes, cinemas, etc.). For instance, lots of shops do not have a slope for wheel chairs. Also outside activities (parks, beaches, etc.) mostly are not accessible.

In situations of independent living it often turns out that it is very difficult to get in contact with other people and to build up your own network. In fact, you are not equal to other people. There are no equality and mutuality between people without and with disabilities. Exceptions are situations in which non disabled persons make an agreement with a disabled person to go out regularly, for instance once a week (buddy projects). Together with labour and education, leisure time is the domain on which the most profit can be made. Leisure time usually offers a lot of opportunities to develop. For that, you don't need necessarily to participate in the activity physically; also in the role of observer you can participate, enjoy and learn.

Risks of discrimination

There are almost no possibilities for adults with severe and/or multiple disabilities to participate in the leisure time activities which are available for the other Dutch citizens. Persons with intellectual disabilities have less access than other people to free time, networks, friends (who actually do not exist), nature, etc. In this domain there is discrimination and exclusion.

12. Adults: partnership and parenting

According to social changes the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions bring into life. Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. Again in their parenting they are dependent on special support.

Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this realised?

Description

There is no policy with respect to partnership in general (living with others, to choose other people as a neighbour, buddies, volunteers, etc.). With respect to parenting of people with intellectual disabilities there is discussion and debate about the division of responsibilities between the individual disabled person and society. Government policy is that parenting has to be discouraged in stead of that it must be accepted (which obliged to build up a system of support).

Professionals and interest groups (parents organisations) have suggested to develop legislation by which persons with intellectual disabilities could be obliged to have contraception.

Risks of discrimination

By discouraging parenthood in stead of focussing on systematic support and coaching during the important stages (decision taking of pregnancy, the pregnancy, after the birth) discrimination and exclusion are stimulated.

13. Adults: exercising civil rights

One developmental task of the adult age is to know and to exercise citizen's rights. This comprises the rights that a state concedes to its people in order to secure protection and political participation, e.g. basic human rights and voting.

Especially for people with severe (intellectual) disabilities civil rights still cannot per se be taken for granted. Additional support is needed to exercise democratic rights like voting. It can also not been taken for granted that people with severe disabilities or complex needs are regarded as capable to be mandated for political positions. How can people with severe disabilities exercise their citizen's rights?

Description

The principal foundation of Dutch government's policy on people with a physical, intellectual or sensory disability is that they have the same rights and duties as any citizen. It is not taken for granted that by being intellectual disabled the autonomy (i.e. the competence to take decisions by your own) can be perceived as felt away. As much as possible the autonomy of the individual has to be the point of departure. The ability to give informed consent legically is an important turningpoint.

For people with severe (intellectual) disabilities the citizenship often is reduced to rights and duties within the context of their concrete living situation. They should have control and authority about the basic matters in their daily life as much as possible. It is self-evident that in order to exercise this they must get all the information they need. In practice, the civil rights of people with complex needs are not an important topic in the care and support to these people; civil rights of this group mostly are taken for granted.

In an indirect way, the Dutch government since a couple of years tries to guarantee the civil rights of people with disabilities by the Equal Treatment on the Grounds of Disability or Chronic Illness Act (WGBH/CZ). This is a so called modular act, which up till now has come into force in the domeains of work and vocational education. In 2010 the sector 'public transport' has been planned to come into force, which means that from then discrimination also will be prohibited with respect to: acces to public transport, the use of travel information (timetable), all public transport (bus, train, tram, trolley) and buying a ticket. The law does not apply to aircrafts, boats, privat bus transport and taxis. There is not yet a culture of acceptance of this law. If there isn't such a culture, legislation can not be effective because there will be no situations the legislation can be applied to. Another comment on the WGBH/CZ is that it is not easy to do a plea of it. A lot of administration has to be done. You need to be quite assertive.

There are initiatives in expanding the WGBH/CZ further. Together with the Ministry of Housing, Spatial Planning and the Environment, the Ministry of Health, Welfare and Sport has made a proposal to extend the act to 'housing'. The Lower House introduced a private member's bill into Parliament in order to extend the act to all the education and to make the module 'public transport' coming into force in 2008 already, which probably not will be effectuated. The Ministry of Health, Welfare and Sport has started a study to explore if whole the economic area can be classed under this act.

Risks of discrimination

In two ways people with complex needs are excluded with respect to civil rights. Firstly, there is no broad awareness of the existence of these rights for this group. Rights are taken for granted. Secondly, the Equal Treatment on the Grounds of Disability or Chronic Illness Act, which is meant to protect the rights of (also) people with complex needs, isn't extended far enough to be a real guarantee for the protection of the civil rights.

What we need is that permanently and consequently all new legislation and regulations beforehand will be examined on the consequences for people with complex disabilities (and disabled persons in general) in terms of accessibility and inclusion. By being proactive we prevent discrimination in advance instead that we have to protest afterwards. The question behind it is: are we, as a society, willing to apply this law also to persons who are so far away from labour, education, free time facilities, etc.?

14. Adults: ageing/end of life

Ageing contains a lot of new challenges: Retiring, organizing one's day in a new way, coping with the loss of abilities) and summarizing or agreeing with one's life. Regularly, more support is needed in day-to-day life and social dependencies are increasing. Often this means that familiar life settings have to be changed because care needs cannot be covered anymore by the given arrangement.

Most people don't want to leave their familiar setting even when their care needs are becoming very extensive. They prefer arrangements which are based on home care services that are reliable and flexible. When people come to think about the end of their life there is the wish to die in dignity. How is this realised?

Description

As far as we know (no statistics are available) for persons with complex needs the stage of ageing doesn't include big changes in living supporting system. The support which is needed in day-to-day life doesn't increase so much, because it already was at a high level.

To die in dignity is something which is possible for these persons in the same way it is available for anyone else. When for dying in dignity euthanasia is wished, it is possible to realise, under the strict condition of the law. In the Netherlands, euthanasia is understood to mean termination of life by a medical practitioner at the request of a patient. This definition also covers assisted suicide. It may only be carried out at the explicit request of the patient. It allows a person to end his life in dignity after having received every available type of palliative care (which can be defined as: 'An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by treatment of pain and other problems, physical, psychosocial and spiritual' – definition of WHO).

Risks of discrimination

There are no particular risks of discrimination of people with severe disabilities or complex support needs.