

Patient- and client organizations and education in The Netherlands

In the Netherlands there is a rather strong movement of patient and client-associations. We have associations for the physically disabled, the mentally disabled, for people with chronic illnesses, like asthma, parkinson, diseases of the hart a.s.o.

They are recognized as a counterpart of the central and local governments, the boards of institutions and lately also the big insurance companies who finance the care.

About 30 years ago the national government started to subsidize these associations for this role.

It needs a lot of information and training to be able to play this role. We still have to fight for real recognition. And because of the crisis there are big cuts in the subsidies of the government.

Associations

Many of these associations were formed already 50 years ago and at that time their aims were different: parents or clients came together to support each other and find information and help. The recognition by the government and the boards of institutions came later.

My experience lies mostly with the associations and client-councils for the mentally disabled. But the structure and activities of the organisations of patients are mostly the same.

I am the stepmother of a daughter who has the Down Syndrome.

She is now almost 55. And since 30 years she lives in an institution. Nowadays these institutions are not big buildings in the woods but they are decentralized. They have houses for 8 up to 24 clients on several locations in the region.

I will tell you about several types of associations and client-organizations at the local/regional and national level.

And about 3 types of education, that we find in these organizations, namely

- education to further personal knowledge and development
- education to further the knowledge and skills to deal with authorities like the board of an institution,
- education to be able to work together in the board of an association or in a client council

The national level

There are 5 national associations of parents of mentallydisabled persons: KansPlus which is a nonreligious association, SIEN and some other associations on a Christian basis. There are also associations of parents/relatives for special syndromes like Down and Autism.

The aim was and is to give mutual support (lotgenotencontact), to get information about the best care for their children, to organize day activities and sheltered homes for their children and to influence the government to get better care.

They have national bureaus with a small staff and regional member-groups. They used to be subsidized by the national government. But as I said nowadays there are big cuts in these subsidies.

KansPlus f.i. has 10.000 members and 1000 volunteers. Part of the income of KansPlus are membership-fees. The local/regional member-groups organize information meetings and social activities for mutual support.

The national bureau has a Knowledge and Advice Centre (Kennis- en adviescentrum)

This is a helpdesk and gives information and advice for individual members and member-groups and you can hire their professionals for regional information-meetings.

At the national level 15 associations and organizations form the **Platform VG**, that is the Platform for mentally disabled People. This Platform mainly influences the government. And it makes Newsletters on the many new developments in laws and regulations and the cuts in budgets that we are confronted by nowadays.

Parent-associations within institutions

But there is also an other type of associations, namely at the level of the institutions for the mentally disabled.

For instance the parents and relatives of clients (as we call them) in the institution where my daughter lives, formed an association about 30 years ago, the Ouder-/Familievereniging (OFV). The aim was to support each other (mutual support), get information about the policy of the institution and to influence this.

The OFV (since a few years I am the chairperson) organizes information meetings f.i. about the plans of our institution for new buildings, about a method Gentle Teaching that forms the basis of the care in our institution, or about the system to registrate mistakes in the institution. We also pay attention to the brothers and sisters (broers en zussen, brussen) of clients. They have there own experiences and problems with having a mentally disabled brother or sister. Often they have to take over the role of their parents to be the representative of the client as the counterpart of the institution. And their special position is often neglected.

We had a booklet made in which 12 brothers and sisters were interviewed about their lives with a mentally disabled brother or sister. And we organized a big meeting in which participated more than 100 brussen. They shared their experiences and concerns and they got information about several topics like genetics (can my children also become mentally disabled), how when I have to become the representative of my brother and sister) (the law on succession, guardianship or financial manager for your brother or sister)

At the end there was a theatre-play by a group of mentally disabled people. This group is guided and trained by a centre for amateur-art. (Centrum voor de Kunsten)

Client-councils within institutions

During the years the function of the parent-associations within institutions changed, because since 1995 there is a law called Law on the participation of clients in care institutions. (WMCZ). This is a general law which concerns homes for the elderly, mentally and physically disabled.

This law was introduced in order to strengthen the position of clients in those institutions. According to this law client-councils (clientenraden) where installed.

In institutions for the mentally disabled these client-councils mostly consist of parents or other relatives. The members are chosen by the clients or the relatives.

(I am a member of the client-council of the institution where my daughter lives.)

The association of parents and relatives in our institution (OFV) still exists.

The difference in function is roughly speaking that the OFV is for the individual interests of the parents/relatives and their mutual support and the client-council for the collective interests of the clients and to give advice to the director..

The client-councils within institutions of course need information and training to be able to perform their role to be a real counterpart of the director of the institution. This is offered by bureaus like Vraaggraak (Ask whatever you want) wich is a branch of KansPlus and also by conference centres. The client-council is financed by the institution and so are these courses.

Regional Platforms

In most regions, like in mine there is a Platform of organizations for the mentally disabled.

In our VGPlatform both KansPlus, some other parent-associations and the client-councils of the institutions for the mentally handicapped in our region participate.

We organize information- and discussion-meetings, and we further the collective influence of the mentally handicapped and their relatives on local municipalities, f.i. in the WMOclient-councils (about which I will tell you later on) and in the participation-councils of sheltered workshops.

We organize these meetings usually in cooperation with an expert of one of the client-associations like KansPlus or SIEN and with MEE which is a regional non-patient organization for advice (about which I will tell you later)

The topics are f.i.

- Friendship and sexuality, on which we had three different meetings among which
 - . the wish of mentally disabled persons to have a child, (f.i. a mother came with her daughter who had a boy friend and she wanted to have a child. The mother felt this was not a good idea, because the daughter could not understand how difficult it is to raise a child and the mother would be the one who would have to solve the problems).
 - . an other information meeting was about lover boys, how to recognize them, how to deal with them.
- Other topics : How after school: possibilities for work and day-activities
- Changes in the laws concerning the mentally disabled
- Their financial position, what do they have to pay the institution in which they live, what other costs do they have and what is their income.

WMO client-councils

There is also an other type of client-councils: at the municipal level we have the WMO-clëntenraden.

To explain this I have to tell a bit about the way of financing the care.

In the Netherlands we have the AWBZ that is the General Law on Special medical Costs.

According to this law the costs of care are paid for by the government for people who will need care for the rest of their lives, costs that can not be included in a personal insurance.

This involves care for mentally and/or physically disabled people, many elderly people a.s.o.

Around 2005 part of the AWBZ was decentralized to the municipalities and put into the WMO which is the Law on Social Support. This involves f.i. housekeeping, special transport, means and tools like a zimmer frame (rollator). And from 2014 on also day care activities, guidance and other provisions that are organized by instutions will be part of the law on social support.

The idea is that everybody has to be able to participate in society. According to the AWBZ people had a **right to receive these provisions**. According to the WMO the municipality has the obligation to **compensate people for their disabilities**.

The municipal government has to make sure that citizens participate in the policy-making concerning the WMO. That is why most municipalities installed a WMO cliëntenraad (WMO client-council) consisting of citizens who have experience with the several fields which the WMO concerns, like mentally or physically handicapped people, the elderly, youth, homeless people (dak-en thuislozen), drug-addicts a.s.o.

The WMO client-councils can get training courses, f.i. in

- . how to work together as a team and understand an integrated approach (and not just work in the interests of your own group of clients),
- . in concepts that are important in this law like the concept of compensation,

- . how to make a good advice, how to deal with the municipality,
 - . how to reach the people for whom you are a member of the client council.
- F.i. the client-council of which I am a member organized a research-project in which slightly mentally disabled persons were trained to interview other mentally handicapped people about what they missed in their lives, like how to make friends, how to participate in sports and other free-time activities. This project was called Zeg 't Ons (Tell us). This method could also be used for other groups.

MEE

And I have to mention MEE. This is just a name which something like act together. This is not a patient-organization, but an organization that gives information and advice for people who are disabled or chronically ill. It has a professional staff. It is subsidized (till 2015) by the national government. (After 2015 they will be decentralized and paid for, after budget-cuts, by the municipalities) and has bureaus at the regional level. It means that these bureaus are in the vicinity of people and that their services are free. They give advice in one or two meetings but not for a longer time. If more help is necessary they refer to an institution that can give guidance and care.

MEE also gives training-courses for which a fee has to be paid.

F.i. for parents of a disabled child:

- . How to communicate with a child that cannot speak
- . How to raise your mentally disabled child
- . Tea-meetings for Turkish or Moroccan mothers or for African parents

For slightly mentally disabled people

- . Social skills,
- . Friendship and sexual relationships (f.i. a girl who wishes to have a child is given the chance to train with a doll that can really move and cry and she is confronted with the needs of a child that grows up)
- . The ability to stand up for your self /to defend your self
- . how to make clear what you want and do not want.
- . How to handle money (household-budget)

MEE is an institution which is mostly of interest for disabled people who do not live in an institution and want to find their way in society and in the field of work and provisions for care. Because of their expertise they are also of importance within the field of education for clients and their relatives.

Dinie Goezinne,
Board member Learn for Life

Presentation for project SLS , June 2, 2012

Structure of associations and other organizations for the mentally disabled at the national and regional/local level in The Netherlands

National level

national associations of (parents of) mentally disabled persons among which KansPlus, SIEN, syndrome-associations and LFB small staff of specialists give information and advice on an individual basis concerning the care and financial and juridical matters

14 of these associations and L!R!S (the bond of regional platforms for the mentally disabled) form together the

PlatformVG (Platform for the mentally handicapped)

Staff of 3 fte and some specialists for projects like decentralization of the AWBZ (The Law on special medical costs)

Counterpart of the national government for the collective interests of mentally disabled people

Regional/local level

- Regional member-groups of the national associations (no staff, no subsidies, they get part of the membership-fees) (information meetings, mutual support)
- Parent/relative-associations in institutions for the mentally disabled (membership-fees, no staff, no subsidies) (information meetings, mutual support)
- Client-councils in institutions for the mentally disabled (financed by the institutions) (give advice to the director of the institution)

Together these 3 types form **Regional Platforms** for the mentally handicapped people (VGPlatforms)

(mostly no subsidies and no staff, only volunteers)

WMO cliëntenraden (Client-councils for the Law on Social Support)

The members must give advice to the municipality in order to further the participation in society of every citizen. They come mostly from special groups like (parents of) mentally or physically disabled, chronically ill, the elderly, youth, homeless, drug addicts, people who take care of others for a longer time on a voluntary basis (mantelzorgers)

MEE

Professional organization with regional bureaus for information, advice and training courses for mentally and/or physically disabled people and their parents/relatives.

(subsidized by the national government, will be decentralized to the municipalities in 2015.)

Dinie Goezinne, presentation for SLS, June 2 2012