

Community Support, Community Living, living community

Speaking about community care, community support, I will tell you about my experience as a father and a member of the community and the city in which I live.

I want to connect things that occurred the past year to the theme of this presentation, notions which I relate to the community in which I live.

Preparing this presentation increased the number of questions and enlarged the uncertainties and dilemmas for me.

I speak with you

?? about my daughter,

?? about something things that happen in the local community of Breda, with finding housing for people with learning disabilities,

?? about the discussion in my city about distributing the local funds for housing of schools and the role of the special school in this discussion,

?? about networking with people with learning disabilities, about starting a centre for day-activities for people with learning disabilities in city-districts.

Finally I will connect these stories to each other and present my and questions in looking and discussing about community support, emancipation and participation of people with a learning disability.

Rotterdam, 30 april 2003.

Peter Peeters

Community support, community living, living community

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1.

My story

So Berthe is our daughter of 10 and the sister of Anna and Stijn.

When she was born, Mérien, my wife and I were told, that Berthe has Down's Syndrome. The children's doctor emphasised that it was terrible what has happened to us and that we should be prepared for difficulties.

We were very disturbed and it wasn't easy to accept the impact of what happened should have to the lives of us and our two other children. That was our first reaction. We felt it in first as a scratch on our live, an expression we heard on a documentary about parents who were as much surprised by having a child with a learning disability as we were.

In the first weeks we experienced different things. We were trying to oversee the consequences of it all and finding a way to adjust the event in our lives and our ideas about future, happiness.

We realised, that the same things happened to us, the same emotions and rationalisations as there were at the birth of our two other children before, but also different and with an different impact.

What made it different and brought more concern was the fact, that Berthe has Down's Syndrome, a syndrome which meant a learning disability and possible physical problems.

From our professional background and studies we knew what kind of problems Berthe and we would have in the near and far future. The insecurity about her development and the grade of her disability and the knowledge about which obstacles she (also as being a girl) and we could encounter put us for the task to find a (new) balance in the lives of us and our three children.

We were, from our professional background, familiar to the structures of professional care by different services.

We knew the risks of growing depended and loosing responsibility to these services.

Having to deal with their structures of care and service.

React to their interference of a professional point of view in a structure in which prepared sorts of services were provided and in which it would be difficult to discover our own needs and define our own standards of support.

Family, friends in first said to us, that Berthe was lucky in having us as her parents, having our background and knowledge what to do en which services we should contact in finding help in raising our daughter. People talked about the well-taken-care-system in Holland and of course the musicality of people with Down's Syndrome.

We managed to find a balance, but we had to be aware, that services were not on our demand in a way, that we could define. Define what kind of service we needed in stead of choosing in the 'service-supermarket' which service- and care products were suitable for us. It's this sometimes constant awareness that costs the energy.

Our daughter is developing (as our other two children do too) very good. She is visiting a normal primary-school where she is attending a personal program and the usual program with the other children.

Berthe is growing up and people in our neighbourhood and at the school react to by saying the see, that she's so well integrated in the school and society. So although we've tried to bring her up just like our other two children people are looking at her as if she has been out of society, like coming from a sheltered home and now is trying to obtain her place in the community.

It looks like it is necessary that people first categorise her to a certain group and then allow en stimulate her to become a member of the community, like a school is.

Berthe visits the school now for the fifth year and we see, that the mental development of her stays behind to the other children of her age. The contact stays limited to her meetings with children in the neighbourhood and at the schoolyard.

Her best friend, after her sister, is Margriet, a girl with Down's Syndrome, who she has met in a pre-primarieschoolgroup five years ago. With her she has an equal relationship. Berthe likes to play with the children of her school-group, but she has little response, something from sheer necessity we have to accept. Although we would appreciate a more intense contact with children without a learning disability, we enjoin the way Berthe and Margriet getting along with each other. I will return to this subject later on in the presentation.

2.

Communication and dialogue and 'living community'

One of the city-districts in the place I live has an monastery in the middle of the community. This monastery, built in 1953, is no longer habituated by the monks. The owner is a local housing-service that owns several buildings and houses for rent in our city.

An institution for health-care for people with learning disabilities has made an agreement with the local service, that a part of the building will be rented and made suitable for housing a group of people with learning disabilities. People in the community were informed and because the inhabitants had already good experiences (is: no disturbance of the neighbourhood) with people with learning disabilities in their neighbourhood they didn't object to the plan.

But they were informed unofficially by hear-saying and inside information from within the foundation, that the nature of the disabilities of the people that should go living in the former monastery was more severe and problematical than was told by the representatives of the institution in their meeting with the community.

The neighbourhood discovered that the future neighbours had severe behavioural problems like aggressive, destructive, suicidal, criminal behaviour. The neighbourhood was especially triggered by the fact, that a person who had robbed a shop in the city-district and that some persons had sexual, paedophilic problems and behaviour were going to live in their habitat. In first, the institution denied the facts the people had discovered, what increased the resistance and decreased the chance of a participating live of the group in the former monastery.

A few (almost militant) inhabitants of the district started an homepage concerning the problem and mobilised the people who live in the neighbourhood of the former monastery. The relationship between the residents in the city-district and the institution was disturbed and there was no trust in the reliability of the institution. People stated, that they agree in facilitating housing for people with learning disabilities, but suggested that another institution should be participating. Seeing, that there was no other institution the problem was enormous, accounting the fact, that the waiting-list for people who wanted to live outside the institution was long.

At the end the parties involved came to terms with each other and there will going to live 39 people with learning disabilities in a part of the complex; people who don't have behavioural problems. The group of people with the behavioural problems will stay in the institution and the question is raised if it should be so, that also these people, who will need intense and individual care and guidance ever will integrate and participate in a community. It raises the question at what (emotional, social and financial) expenses institutions and local authorities want to realise this kind of integration and participation.

Every year the city-council has to decide in what way the budget for the housing of schools in the city will be distributed. Every school has its own list of wishes. The number of children who want to visit a school in a city-district is increasing and that means, that they present plans for extension. Other schools need to be renovated.

They all want a part of the budget and as always the budget is not sufficient to satisfy all requests. So the city-council always is placed into a dilemma and has to be wise. Probably not every school-board will be happy with their decision.

One of the demands comes from the school for children with learning disabilities the number of pupils has increased the last years. The school is situated at several locations in the city and it is the wish of the schoolboard to situate all departments in one building. The costs (estimated 15 million Euro) are, related to the budget of the city (54 million Euro) enormous. The problem for the city is, that the school has become the largest in Holland and children in the age of 4 till 18 of the own and surrounding schooldistricts visit the school. But.

The cities from which these pupils are coming don't have to participate in facilitating the housing.

In order to influence the members of the city-council all kinds of actions were initiated by the teachers, the parents and the children of the school. The ultimate action seems to be, that the overall board of the school (in fact a big foundation) to which other primary-schools belong decided to abandon several co-operated relationships with other primary schools in the city. In the continuation of the discussion they suggested (and emphasised by letting attend children with learning disabilities at meetings of the committee of education of the city council and the city-council meetings) that budget proposals for renovating other schools should be replaced to their school for children with learning disabilities.

If the city-council should decide that they honour the request that will mean, that an other should be closed, because the housing is not save enough anymore. The schoolboard is focussing the discussion and decision to the issue of sympathising between children with learning disabilities and children without learning disabilities.

In the book *Netwerken van mensen met een verstandelijke handicap* (networks of people with learning disabilities) Ad van Gennep & Bertho Smit, the two authors, stated about reinforcing the (social) network of the clients that in the case you try to contact people who could be a member of the network you maybe encounter some difficulties. One of the facts could be, that the people you contact could see your question, the help you ask, as the job of the professional. In that case you should explain, that the activities you suggest has the purpose to make the live of your client more interesting, that it stimulates his social contacts and makes it possible to participate in society as normal as possible.

In their survey about Networks of people with learning disabilities they try to state on what grounds it is possible to create or reinforce networks. Their startingpoint is, that people with learning disabilities can't start that by their selves. Usually the professional or concerned family can help them in making a map of present members of a network and the members or kind of members of a network someone wants to have.

When reading the book it strikes me, that the authors stated that often there will be a (kind of) professional help will be needed. Furthermore they discovered that the preference of people with learning disabilities to whom they like to be member of their network concentrates to other people with learning disabilities, mostly encountered in day-activity centres or group homes; that members of family, they only have seen two or three times in their lives were wanted in their network.

The professionals were not mentioned at all or were mentioned close by in the network. In both ways it brings the professional in a position to think about.

Startingpoint in creating or reinforcing a social network is the capability of the person concerned to maintain his network self-reliant.

In the way Van Gennep and Smit talked about networking they emphasise, that it is important to accept, that the network of a person with learning disabilities isn't inferior if the members are in majority other people with learning disability although we should realise that they won't experience social and emotional that what they would experience if their network would be more divers.

Networking of people with learning disabilities has being researched concerning living. There is little research about the relation between networks and work or day-activities. It is stated normalisation of the living-circumstances and day-activities of people with learning disabilities is necessary to make social contacts especially with other people (without a learning disability). But normalisation (however you will define it) is not enough. There is more needed. They suggest:

- ?? Do not focus on training of social skills only
- ?? Only participating on social activities is not enough
- ?? Living in group homes creates social network with other people but mostly with people learning disabilities
- ?? Professionals should initiate the creating and / or reinforcing of social networks.
Important is to make contact with the persons who wants to create stabile relationships
- ?? Friendship is the best base for social networks. They cannot be forced. So it's important to stimulate people to go to places or create opportunities where they can meet other people and hope there will start relationships.

4. Establishing centres for people with learning disabilities in city-districts.

Talking with one of the managers of a institution for care and services for people with learning disabilities we discussed about the importance of founding a day-activity centre in the middle of a community.

What would be the reason to try to find a place close to the community of for instance in a city district ?

First of all it would make it possible to let the visitors of the centre make contact with the neighbours or other people who are in contact with the centre.

But why should we encourage and spend money in trying to invite people with learning disabilities to a centre with only people with learning disabilities to make contact with ?

How could the visitors of the centre experience participation in the community when the centre doesn't have any meaning for the community ?

In times in which money is not so available as it used to be, it brings up the question why spending the money in establishing a day-centre on an expensive place in the city, when you can create an equal centre at the outskirts of the city for less money, but with the same quality of service, when there are not enough arguments to do it otherwise.

Furthermore it seems, that the inhabitants of a city-district or neighbourhood are not so much interested or committed to the people who work at the centre that they want to do more than saying hello to them.

Now I'm exaggerating I know, but it helps to come to my point, that emancipation and participation is nor something you can enforce on the site of people with learning disabilities, neither on the site of the community.

It happens to be so, that people can be mostly focussed on their own situation and doesn't have the intention to invest or get involved in the well being, social contact, social network of people with learning disabilities on a structural basis. In fact people may think, that they pay taxes to provide services and think that care and service is a professional job for which you attend courses en specific education. Volunteers *assist* in this work.

So if you want to participate in a community, a social network you'll have to be of importance or significance for the community.

Solutions could be found in building a day-centre in which you able other city-services or services that are important for the community, like medical service, law-counselling but also a kindergarten. Invest in giving service to the community, that support the cohesion of the community, the neighbourhood.

In interaction between the day-centre and there users and the people who make use of the building and the services within, there could develop participation of people with learning disabilities in the community and social networks or relations based on friendship could grow and will be of importance to the community and to the people of the centre.

In contrast to what happens if people who has more choice in way of living, place of living, place of working, networks for social interaction can chose for themselves, people with learning disabilities often needs a kind of guidance. Coaching in finding their independence, self-determination and in that they will encounter disappointments, because other people are not always interested in you because you have a learning disability, are because you have a learning disability. Coping with these kinds of experiences is important.

I think my point of view to community support is clear. In the first place I'm a parent and in second a professional and a lecturer.

Our daughter is now 10 years old. I realised myself, that talking about community support always seemed to be associated to adults, in our context adults with a learning disability.

People seem to think that support is belonging to the domain of the professionals.

You cannot take community support for granted. It demands an investment of the people involved.

And how about, homeless people, elderly people, drugs-addicted people, refugees,....

Communication and an open dialogue in the case of the people with a learning disability, that should be going to live in a part of the monastery influences the acceptance, in first the non-acceptance and will have its repercussions on community support. Should they accept the choice the institution made at all times, or should we accept, that it's the reality, that people do not accept.

With the school, presented in the first part of my presentation, the city council is involved, the representatives, the alderman are involved, the other school, their children and parents are involved. The impact of the action to the living atmosphere between the schools, within the community can influence the public opinion in both ways.

Knowing, that emancipation, participation and solidarity is something that is not coming for free, it is a logical decision of the school board to push of to other primary schools ?

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Is it ?

In interaction between day-centres in a community (and their users) and for example civil service providers who are hosted in the building, there could develop participation of people with learning disabilities in the community and social networks or relations based on friendship could grow and will be of importance to the community. This could influence living community in a positive way. Should service-providers for people with a learning disability always first invest in the community ? Is that community support ?

But ,

I am involved, because my daughter is involved.

So, my point of view is a subjective one, but I would ask you: I think everyone's point of view, perspective in participating in a discussion about community support, community living, living community, isn't subjective.

Should community support not be subjective, personal involved ?

Thank you.