

# The Right to Live in the Community

## Seminar of the European Coalition for Community Living Brussels, 17 May 2006

### Practical Experiences with Closing a Large Residential Institution in Germany

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Ladies and Gentlemen,

Mrs. Bulic asked me to speak to you in this seminar about the experiences we have made and still make with closing down a large institution for people with learning disabilities in Germany. My name is Theodorus Maas, I was born in the Netherlands and went to Hamburg after my studies in 1970. Institutional care is what I did in different organisations in Hamburg. I am 61 years old, I am a member of staff of our board and my task is to represent the Protestant Foundation Alsterdorf, a NGO.

This Foundation is 150 years old and a classic so called “complex institution” for people with mental retardation. The umbrella organisations are the Diaconic Work in Hamburg as well as the BeB, a national organisation of care providers for people with handicaps all over Germany. The foundations budget has 200 millions Euros a year and we run a full range of services, e.g. housing for almost 2000 people with learning disabilities and psychiatric illness, sheltered workshops and daily activity centres for 800 people, 2 hospitals, a social paediatric centre, vocational education centres for professionals in nursing, speech therapy, as well as caring for people with handicaps, integrative schools in first and secondary level and a lot more.

New in our services is care for elder people, with or without handicaps and services for borderline people. The number of employees amounts 4000.

So you have got an impression of our Foundation.

My time to speak is twenty minutes. I focus on four items:

- Political framework and legislation, as well as funding
- Changes in awareness on the level of our board and management
- Employees in the field and the clients
- So called “Altlasten”: burdens from the past

#### **1. Political framework etc**

In Germany nowadays you will not find a public, wide spread general discussion about advantages or disadvantages of large institutional care. During the last parliament period there was an initiative for a search commission of the Bundestag on People in Institutions (Menschen in Heimen).

The commission was not realized.

In the last weeks we see a new effort to come to a commission of the Bundestag on the right of people with disabilities and elder people to live in the Community. We are looking forward to seeing it at work.

The numbers of people moving into the big institutions are growing.

Since the beginning of the eighties there is a law enforcing the ambulant (outdoor) services more than the residential care services, but the law stayed without effect for reasons of costs.

Even in the year 2005 87% of state funds came into the residential care, this number you can find in the official statistics of NRW.

Since a few years social politics push the extension of outdoor service structures, expecting reduction of costs. We are in doubt referring to this expectation.

The responsible officials in the social boards are looking at the people with mild disabilities and argue that they have not any need to live in institutions. That is right. We see however the risk of ghettos for the remaining rest with deep and complex disabilities, living in nursing homes, dissolved from rehabilitation programmes.

They do not realize that living in the community is a good aim only when the community has a real good social infrastructure with high quality services that meet the needs of people with disabilities, as well as private good functioning nets. This would mean planning and building living quarters with a lot of social work.

To the social political framework do belong the big umbrella organisations and they have a lot of influence on state social politics. These umbrellas and the institutes they represent do not really appreciate their own closing down. They would loose a lot of money and influence. They invest in new buildings and institutes. Characteristic for this situation is the nation wide Foundation Aktion Mensch (Action Man), funding programs of decentralisation of services for people with learning disabilities into community based structures with lots of money. The big institutions do not apply for its fund. I ask you: why not? They are not interested, I tell you.

Conclusion: as the Protestant Foundation Alsterdorf made the decision end of the nineties to close down her traditional structures and buildings in order to decentralize her services, she did it from her own motivation and conviction and not for reason of pressure from outside, e.g. politics. In our umbrella we do not only earn sympathy for that.

## **2. People in charge of responsibility**

One of the most crucial experiences we made in this field is the totally new view of things, of the people, who are the clients and of the way to deal with them. I consider willingly and gladly that this new way of thinking, this new view was mainly influenced by the experiences the board and the managers made during study trips in the north east of the US of America and in Sweden. We have seen with our own eyes and have heard from involved people their experiences and developments. We got clear impressions of the chances of community based services under renouncement of institutional care in big institutes. In a EU project in cooperation with a Dutch and a Belgian organisation we got to know about movements Community Care and Community Living. We made them our own, however in our way, not only copying them. Since that time,

end of the nineties, the ideas and visions in these movements give us orientation for our own development.

Changes in organisations like our Prot .F. Alsterdorf in that size and with that far going reach are only possible, when the responsible persons at the top stay behind the ideas and changes, when they are backing them, even more, when they push them forward. They are bearing the responsibility for the organisation at the end and for its existence in the future. Against the backdrop of those unclear conditions in the surrounding framework I told you above you must see that this process of changing is connected to a lot of heavy risks. Most of all it is the risk of a big enterprise in the social market going a new way and doing this from own conviction and supported mainly, almost totally, by using own resources and power. We do not want to disappear from the market. Why should we? Other provider organisations would take over from us.

So we are looking for the transitions from former institutional care to become a provider of services based in the community. In our philosophy we argue that every initiative and every project has to correspond to the ideas and the vision we have as well as they have to fit to the economic and financial frames we see to be ours. The best project is useless, when it is missing necessary financing and the most lucrative project under aspects of earning money is only good when it meets the ideas of our vision.

The process of decentralization of housing and other services is elder than the board we have now. It started after the first scandal in our organisation as the papers published the conditions people with disabilities had to live in at the end of the seventies. The first steps of decentralization were reactions and not results of new visions. Remarkable anyhow is the fact that some of the people working on the front as we say were successful in getting through the movement even of people with heavy and deep learning disabilities and problematic behaviour away from the campus into the city parts of Hamburg.

It took a long time, till the end of the nineties and the beginning of our new century, until the management was convinced in order to make those decisions that did change our organisation in its structures and outfit. The new ideas are freedom, responsibility, autonomy, and individuality and last not least respect. You may remark the point of missing old Christian ideas like charity. The renouncement of these ideas does not come from proneness to modernity, it is the result of reflecting the image, the idea of man in liberal protestant tradition. In it man is free, responsible for himself and his life. Thinking in this way about people with learning disabilities and dealing with them, as we say on one level from eye to eye, taking them seriously and their interests in their way of life, this is the stuff of our conviction behind the changes. Without this vision we never could perform them. You need a vision. The persons at the top do so and they gave the start sign for the movement.

### **3. Employees and clients**

The richest resource in a service provider organisation is as you know staff, are the employees, more specially the front workers at the basis level face to face to the clients. This has some various aspects; one of them is the financial aspect. Staff covers more than 60% of the organisations budget, but there is another more important one. The front workers break down the vision of the organisation at the level of the clients, they make the vision perceptible.

On the basis of their direct services face to face and along the way how they perform their services you can judge whether the services are good or not, and the clients do feel that. These

remarks are quite general and obvious, but in times of deeper going changes you must see them critically.

I try to give an example. The vocational designation of the qualified worker in the field is in Germany the "Heilerziehungspfleger". There are three parts in this word. The first is "Heil", it is the word for the service, the doctor gives: to heal, to cure; the second part is "Erziehung", it means what parents do to their children: bring them up to adult persons, and the third part is "Pfleger", what a nurse does: nursing care. All the three parts do not really fit to the new view on people with handicaps. The new field worker should not do what the doctor does, people with handicaps is not per se sick or diseased, and adult people has no need to be brought up, they are already. The same with nursing care: some need it and some do not. The new type of field worker is the one to deal with the client from eye to eye at the same level and the subject is the concept, the plan of life to be realised together in partnership with the client, with his net, his or her relatives and friends etc. And not anymore in the institution with 24 hours care around, regardless whether there is any need or not, but rather in the living area, where all the people wants to be and is going to. We speak about participation in our society, living in the community. The crucial questions may be: how do I get to the doctor, which sports company gives membership, where are the friends to play soccer, where can I go shopping, where is the house fitting to my wishes, where do I find a job? You see arising a totally new awareness of this professional picture; we speak about building bridges, the part of mediator, the capacity to negotiate, to arbitrate, to give motivation etc. The new employee, we call him "assistant" in Germany.

More than by the question how people with disabilities manage their life in times of changes, the management is occupied by the challenge to change the staff awareness of these new functions and parts to play. Sometimes we are convinced that this is the big point in the process of changes. It is still going on and it will not end so fast. The education centre in Alsterdorf is offering further training to the employees in the crucial areas. This means not only to learn some new techniques, you also need a new self-image, new competence and reliability in order to get new self-confidence and self-assurance. Every front worker is placed before this crucial question: do I really want this new job or should I better leave? The new way of assisting and supporting clients is not yet good practice, but we have got an idea of the aim and we do the steps in the right direction.

We speak about people with learning disabilities. In our organisation they do not seem to have big problems with the changes in their life following decentralisation and de-institutionalisation. Nevertheless I must remark that the clients did not force the decision of deinstitutionalization. The new shape of the open market place in Alsterdorf with its supermarkets, with medical care practices, as well as workshops, restaurants open for all the citizens goes back to the management decision for reasons mentioned above. The consequences for the clients at the other side, especially referring to housing and the important questions of quality: where to live? Rather in some part of the city, or outside of Hamburg in the countryside, or even staying in Alsterdorf? Live together with whom? Which kind of apartment? Etc. Those questions had to be discussed extensively to the people, their relatives and legal guardians. They were discussed during a period of almost one and a half year. The discussions took place based in the setting of person centred planning. Everyone could pronounce her or his wishes, interests, suggestions and ideas, competences etc. As far as possible these suggestions were taken in consideration and realised. Even those who wanted to stay in Alsterdorf got new apartments in the new houses there.

The experience we made is that it is worth to invest intensively used time in preparing the clients and their relatives. You can prevent by this way perhaps not any but a lot of complaints and deceptions afterwards.

Additional to this I want to point out that the people in question once they moved from the central campus do not yet live totally on their own in their apartments in the various living quarters of Hamburg, independent on support. Of course not, they need a lot of support further more.

Our organisation, as well as other providers, offers gradual services, step by step and in degrees and stages. First step is living in your own apartment under one roof together with some other people with disabilities, may be ten or twenty. The next step can be to move in another house some streets around the corner. There you live as a neighbour of people without disabilities but, when you do not feel good, when you feel alone, you can go back to find someone to speak to or to get some support in the former house you moved from.

The social board offensive to more ambulant service providing will push our organisation to still more flexibility in services, according to the needs of the clients. This is a big challenge for our organisation.

#### **4. Burdens from the past**

The last aspect in these remarks is referring to the so-called “burdens from the past”, “Altlasten” as we say in Germany.

It is a very specific experience and nevertheless quite understandable too that you can not wipe of, with one strike of your hand, the history of one hundred and fifty years.

You may change your name in order to make clear that you have changed your vision and your way of service providing. It takes a lot of time before people gets awareness of it. You stay in their mind the old Institution, the Anstalt.

More specially I want to speak about the sins from the past, represented in the big buildings on the campus, the houses facilitating living places for hundred, hundred seventy, even for 216 people in former days. 1700 people with disabilities were living in Alsterdorf. The people moved away and the buildings remained, not always completely paid off to the end. What to do with them? Usually they are, not only in Alsterdorf, not well maintained, some of them quite neglected.

Our experience is that you need a lot of fantasy in order to find a way out. Our way, one of our ways was to make a deal with the employees and the works council as well as the union in order to collect the money needed to give a new destination of use to these buildings, some of them were broken down and new buildings were needed for market purposes. Our employees made renouncement of rise of their wage and gave the money in a fund on investment. It was their contribution to the future of the organisation and the security of the jobs.

You are on your one, when you close down your institution. And when you are successful, you may have some people giving support to you, but if not it is your own risk. For that reason the board of our organisation is courageous, no doubt, but also going carefully, step by step.

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