The Right to Live in the Community
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The Need for De-institutionalisation and Community Living in Europe: Challenges and Achievements

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Dear Colleagues,

As somebody who has experienced the exclusive and discriminatory structures and behaviours of our society myself, I am more than happy that this workshop is taking place today. It's good to see that a strong European movement for a life of disabled people in the community rather than in unnatural and excluding settings like in institutions is developing and gaining strength.

The fact that we still have to discuss the need for community living and for de-institutionalisation of disabled people is for itself a sign what a long way we still have to go. In some countries we have made enormous progress for community living – in others we are just at the beginning with such a movement. As someone who lives in Germany I am probably from a country which is sort of in the middle of this process. We have on the one hand many institutions in which disabled people have to live and we spend way too much money from the so called funds for the integration of disabled people, which go to institutional care instead to the support of community living of disabled people. The latest numbers of the year 2004 show for example that 93 % of the so-called funds for the integration of disabled people went into institutions. Only 7 % of this money was spent for supporting disabled people living in the community. This is a shame and it is a shame that almost daily we have to read in the newspapers about the development of new institutions and new sheltered workshops. On the other hand we have in Germany many disabled people who made their way out of institutions and live in the community with the assistance they need. A variety of services have developed and a movement for self-determined living is gaining strength. Nevertheless there are still many people who have to live in institutions without any alternatives.

A growing number of information from countries like Sweden, where institutions for disabled people have been mostly overcome, from Norway, where the life of disabled people in the community is widely supported, from the Netherlands, where models of direct payments for the assistance and support disabled people need, are practised, give us hope and show us what's possible. All those systems are probably far away from being perfect, but they give hope for an inclusive society for all. News from central and eastern European countries about big institutions with conditions for disabled people, which we believed are a part of history, are the other side of the picture and the systems, which we have to face and to challenge.

Talking about the way disabled people want to live, we could dive deeply into big theories. We could look at all sorts of research, which has been done and probably could be done in the future. We certainly could ask doctors, professionals and many other people who have clear

opinions and all sorts of reasons why the situation is like it is – that many disabled people still should live in institutions. But we can also look at the way we ourselves want to live.
Who from us wants to move straight away in an institution?

Who from us wants to live in double-rooms or even with more people together in one room, like it still is in many institutions, and to adjust to strict plans, when to get up, what meals we get served and so on.

If there are any, please feel free to contact me afterwards.

So, why should it than be best for disabled people to live in institutions? Only because they need certain types of assistance to manage their lives? We all need assistance in many areas of life and find creative ways to deal with those challenges. We bring our car to the repair-shop, we go to the restaurant, so that we don't have to cook all the time ourselves, we use trains and busses because we don't want to walk all the way and quite a number of people hire somebody to clean their house or to watch their kids. So why is it so hard for our societies to find ways for the support of disabled people in the community rather than in institutions?

Those questions are for us probably closer around the corner than we might think. The support of elderly people gets also more and more institutionalised. Especially the demographic development in most of our societies with more elderly people needing assistance call for solutions in this area as well. Please let us not make the same mistakes of excluding elderly people who need assistance in daily life in special institutions on the edges of our society. We are already in the middle of this development and imagining that my mother, who turned yesterday 74 and has raised six kids has to move into an institution probably in a double room with a person she hasn't chosen and doesn't want to share the room, honestly scares me.

In a research a colleague and I have done for the Ministry for Social Affairs of the State of Rheinland-Pfalz in Germany about ways to support community living for disabled people we identified two main hindrances for community living.

First I would like to mention the question of systems security, which deals with the structure of the support systems we offer. If a disabled person moves into an institution, things look on the first view quite easy and organised. There is a place to sleep and to live, there will be food provided, there are people who provide care for disabled people, there are other people, so one won't be lonely and the chances that this will be about the same in 20 years are quite good. This all-inclusive-system gives disabled people and especially their parents on the first view security. The question of the quality of life in such institutions usually has to step back in comparison to the life in an inclusive setting in the community because there are on the first view many insecurities:

Will one be able to find an accessible place to live and can one count on having this place for a longer period of time? How about all the help a person needs with the preparation of food, keeping the house-hold in order? Does the person get the personal assistance she or he needs and what happens when they get sick or when one can't find anybody to work for one? Will the funding for the assistance be provided in a proper way? And after all, won't the person who lives in the community be very lonely, because there are no other people with whom she or he can live and interact?

Those are all valid and serious questions, which determine what setting will be chosen – and currently it is very often much easier to chose institutions rather than community living for

disabled people. The challenge of our systems and society is to provide those support systems outside of institutions in a reliable manner and to give disabled people and there parents similar security like in institutions. Therefore the demand for overcoming institutions has to go hand in hand in the development of alternatives for living in the community.

Second I would like to focus on the individual approach how disability and a life of disabled people in the community often is seen and handled. There we stepped into the "independence-trap". Too often disabled people hear the phrase: "You cannot move out of the institution because you are not independent enough in order to live by yourself". Than disabled people have to prove themselves that they are eligible for moving out and all sorts of trainings for them get developed. They have to learn how to cook, they have to learn how to dress themselves, they have to learn how to clean their apartment and many other things to prove that they can make it out there. We see the same tendency in the area of employment. While the assistance in sheltered workshops mainly is a given thing, disabled people who want to work in jobs on the regular labour-market are usually expected that their need for assistance is decreasing and mostly not necessary anymore after awhile. This is a very strange approach because disabled people don't leave their disabilities – their need for support – behind them in the institutions. When they move out or work at an integrated workplace they are still disabled and they still need support. Who has made up that strange rule that living by yourself means being able to everything by yourself. This is a result of the often made mistake in interpreting what independent living means – a real "independence trap".

For us from the disability rights movement independent living doesn't mean at all, being able to do everything independently by ourselves, it rather means for us being able to make independent decisions about our lives. And for people who need assistance to make those decisions or to make those decisions for others to be understood, this assistance must be given. Therefore we in Germany prefer the term "self-determined living" rather than "independent living" because it makes more clear, that it is about determining how we want to live rather than doing everything for ourselves. Taking the approach of self-determined living we move quite quickly away from the current focus on the systems - like institutions - for disabled people to the individual support, disabled people themselves need. If the focus is put on the individual support than it's much easier to conclude that this support can and must be given everywhere and not only in institutions. Disabled people who use personal assistance for example have proven over and over that this approach is much more effective and offers a much higher quality of life.

In order to change our systems and individual approaches towards community living it is necessary

- That political and administrative bodies on all levels send out clear signals that we have to overcome the institutionalisation of disabled people and that we have to develop support systems and individual funding for disabled people to live in the community. Therefore we need a European strategy for community living.

- We need a quick stop of the development of new institutions and absolutely no funding for new institutions anymore – no cent for the segregation of disabled people.

- Existing institutions have to develop concrete timed plans in order to dissolve themselves and to integrate disabled people in the community. We need a clear perspective for ending the institutionalisation of disabled people in Europe.

- In order to prevent the transformation from big institutions to small institutions we need to set clear limits on the size of groups of disabled people living together. Experiences from other countries show that the size of 5 people living together is considered a good limit and is still comparable to family-size conditions. Disabled people need real choices how and with whom they want to live.

- It is also necessary that at the same time we develop the necessary support systems for disabled people living in the community. This starts with barrier-free apartments and infra-structures like transportation and includes reliable services and funding structures for personal assistance, as well as necessary counselling services.

- We have to make sure that those processes don't take place without the people for whom they are designed. Therefore the approach "Nothing about us – without us" must be present and practised in all stages of the development of alternatives. Because disabled people know best how they want to live if one gives them a chance to experience it and to speak up.

- And probably most important, we have to make sure that de-institutionalisation doesn't only take place for people with so-called lighter disabilities. We have to start the process of including disabled people in the community with the people who have the highest need for support. This approach than will probably fit for all the others as well. Living in the community is a civil right for everybody and not a question of the degree of a disability or of the degree of support a person needs.

- Last but not least, we have to make sure that disabled people who currently still live in institutions are becoming visible citizens in our societies.