

SELF-DETERMINED LIVING IN GERMANY

Ottmar Miles-Paul

THE STARTING POINT

In all the countries of the world, and in all social strata, disabled people have the experience of being excluded and disadvantaged. On the one hand, they reap a harvest of many good words and enormous efforts are made to assist them. On the other hand, they experience on a daily basis how decisions affecting them are made without their input and how measures are conceptualized and carried out against their interests.

- Facilities and projects for disabled people are almost always planned and run by non-disabled *experts* without those affected having any serious influence on the basic conditions. In the hiring of employees in institutions, for example, the residents are seldom consulted in any way, although they are the ones who sometimes have to live with the employee for a long time.
- Since societal efforts to promote them are lacking, disabled people are underrepresented in political parties and legislative bodies. As a result, parliamentary debates are usually conducted and decisions made without any input from people who might be affected. Many polling stations, for example, are inaccessible to people in wheelchairs.
- Even in most so-called organizations for the disabled, it is parents, care-givers or well meaning non-disabled people who run things. This frequently results in the lack of an atmosphere in which disabled people can grow and gain influence, not to mention the lack of an atmosphere in which their interests are represented appropriately. Is it surprising, then, that disabled people are so infrequently quoted in the media?
- The picture in the minds of many non-disabled people with whom disabled individuals have to deal on a daily basis, and by which they are seriously affected, tends to be that of needy child-like creatures. Disabled people are mainly seen as suffering, and needing to be cared

for, rather than as fellow citizens with the same rights who are regarded as equals.

Hidden under the cloak of charity and *We only want what's best for you*, a motto which makes any dialog based on equality impossible, we continue to see today a high degree of segregation and a great deal of discrimination in the work being done for disabled people. This is accompanied by ignorance, egotism and helplessness on the part of those who have only the best intentions in regard to the disabled. In accordance with the saying *The way to Hell is paved with good intentions*, disabled people today are still being exposed to the most extreme human rights violations and discriminatory practices without any large-scale public opposition being organized to fight against it. Non-disabled persons who take the side of the disabled often experience repression in the facility where they work or are not hired in the first place.

Above all, Western societies continue to waste enormous amounts of funds and resources on ineffective, and to a certain extent, counter-productive, services for disabled people – a waste that has resulted in the non-participation of precisely those with whom it has to do. According to an assessment of the former advisor on disabilities to the American presidents George Bush and Bill Clinton, Justin Dart, who is also a wheelchair user, the exclusion of and discrimination against disabled people costs American society over \$ 200,000,000 annually. The consequence of this realization was already obvious in the 1970s and 1980s. That is, that disabled people – like almost all other minorities – have to get involved and fight for their own rights. The illusion that others could do it better than themselves was destroyed as early as the big congresses of rehabilitation experts at the beginning of the 1980s. At the conferences it became apparent that, despite their active commitment and expertise in this area, they were only allowed to play a peripheral role and their involvement in the proceedings was secondary to the career advancement activities of the non-disabled participants. Today, under the umbrella of the Disabled People's International, disabled people have founded organizations to advance their cause in more than 110 countries around the world. These organizations are run by disabled people and promote the self advocacy and self determination of the members. These organizations have promoted major initiatives that have resulted in advancements like equal rights laws and the UN Standard Rules of Equal Opportunity for Disabled People which have set new standards for policies affecting disabled people.

BASIC PRINCIPLES OF A SELF DETERMINED LIFE

The concept of self determination for the disabled means not just that people with disabilities must be allowed the possibility of exercising control over their own lives, but also means enabling them to become active on their own behalf, to fulfill social roles and to take the responsibility that arises from such activity. To make sure that this happens, the movement for disabled people has formulated six basic principles. These principles represent the goals that the movement is working towards in addition to rewriting the political program of this new movement.

1. With the demand for comprehensive and legally binding equality and anti-discrimination legislation in regard to disabled people, a decrease in discrimination against the disabled will be secured and equal opportunity in crucial areas will be mandated. These crucial areas include housing, education, employment, access to public buildings and public transportation and to the use of telecommunication facilities.
2. Through striving for the *demedicalization* of disability, the often limitless dominance of the medical profession in this area will be reduced and the taking of responsibility and the access to power of disabled people, to make decisions affecting their lives, will be promoted. Through the development of forms of independent organization of care (disabled people as employers of their care givers) people with disabilities are demanding a long overdue power transition; a transition, that is, from being passive patients to being active consumers and managers of their personal assistance. This leads to the subject of who is able to decide who gives help, when and what help, and how and where it is given. Additionally, through this process of the demedicalization of disability, the often artificial separation of single groups of disabled people, by sorting the disabled into special grades based on severity of disability, will be abolished. This will make solidarity and co-operation that bridges specific disabilities possible among disabled people. Being disabled is not just a question of type and severity of disability but also of the social and power relations that determine their lives.
3. The principle of non-segregation and the greatest possible integration into the life of the community rejects any involuntary separation and institutionalization of the disabled and reinforces the demand for community oriented supportive services so that people with disabilities will be allowed a real range of choices with the greatest possible

degree of self determination. In this way, a life with equal rights, lived in freely chosen surroundings, is made possible for disabled people.

4. With the demand for the greatest possible control of disabled people over their own organizations, the movement for self-determined living for the disabled calls for something which in other social movements, for example in the women's movement, has long been a matter of consensus and which is also becoming standard in the area of disability. That is, that those directly affected have control over the leadership of their organizations, represent the organizations in public and themselves determine the political goals and policies of these organizations.
5. It is necessary to insure in the future that the work with the disabled, which is now part of a welfare industry worth billions of German marks, is really focused on the interests of those whom it is primarily intended to serve – namely on those of the disabled and not on the interests and constraints of the professional organizations. To accomplish this, the greatest possible degree of control over services for the disabled by the disabled themselves is demanded.
6. With the principle of peer counseling, and peer support as the key to the empowerment of disabled people, the members of the movement for self-determined living thus commit themselves to mutual support, advice and to promoting each other. This commitment will enable more and more disabled people to travel the rocky road to self-determination and, in addition, make it possible for them to take on the responsibility in our society that goes along with it. Correspondingly, the future priority of the promotion of advisory services is called for so that the principle of peer counseling – the advising of disabled people by disabled people – can be fulfilled. This will allow the empowerment of disabled people to proceed on a large scale basis.

PERSPECTIVES AND CHALLENGES

Kalle Konkolla, the world president of Disabled Peoples' International, who is from Finland, usually asserts the following when there is more complaining going on about problems than efforts being made to solve them: "We don't have problems. We just have challenges!" This statement is true for the movement for the disabled and, thus, for all professional work with disabled people. While the disabled movement has, on the one hand, set up an extensive network of facilities, especially in the

Western countries, these facilities, on the other hand, have contributed significantly to the segregation and dependency of disabled people, due to institutional structures and constraints. As a result, we must now, more than ever before, accomplish a radical change to the empowerment of people with disabilities and to their open participation in society. This means an enormous transformation in their role for many disabled people, one that must lead them beyond the care that formerly prevented them from becoming experimenters and active agents in their own affairs. This will not happen from one day to the next, requires positive role models for those affected by disability and, above all, a deliberate effort to promote disabled people, without putting them in a subordinate role. The good, but also the difficult, thing about this process is that it must mainly be accomplished by disabled people themselves since emancipation cannot be ordained or dictated.

The society and its institutions are presented with the following challenges if people with disabilities are to be supported in their emancipation.

- The facilities devoted to professional work with the disabled, and those people employed in this field, must develop and carry out plans that support the organizations for disabled people, which chronically suffer from lack of funding and personnel, and do so without relegating these organizations to a subordinate status. On the one hand, this is a big challenge for both sides. On the other hand, it also offers a variety of unsuspected possibilities for the disabled individuals who are supposed to be what it is ultimately all about. Because the knowledge in this area that has been gained over the last twenty years clearly indicates that the best education or training, without an accompanying high level of self confidence on the part of those affected, often leads nowhere.
- The involvement of disabled people in the political decision-making process must be deliberately promoted. The central preconditions for this are the making accessible of all public events to people characterized by the widest range of disabilities, the motivating of disabled people to take part in political processes and naturally also the readiness of the political parties to share power and to choose disabled persons as candidates for elective offices.
- Last but not least, our attitude above all will be crucial in determining how far we develop from being a *well meaning* society to one that actually does well in respect to the disabled. To find out if we, with our ideas and plans, are on the right path, it will always be indispensable to sit down with those primarily affected, take their opinions

seriously into consideration and support the implementation of these. It is irrelevant how quickly or slowly we move in this direction; the time when the disabled accept, without opposition, practices that are against their interests, is coming to an end.

The slogan *Nothing About Us Without Us* is not just one proposition among many but, more and more, is becoming the standard program statement of a civil rights movement whose members are fighting for their rights. The general public must fight with them so that *in reality, nothing which affects disabled people takes place without their active participation.*