Personal responsibility as precondition for personal and social change

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> *I'm afraid I have nothing new to say on this topic, no new insights, no new research results. What I am saying is common sense, rather obvious and self-evident. Please consider my comments as a kind of reminder for myself and other people.*

According to one of my favorite definitions, Independent Living is a civil rights movement working for personal and political power for persons with disabilities. The definition is short and to the point. It focuses on the two levels we are working on, the level of the individual and the level of society. For our topic - personal responsibility and change – the definition might serve as a helpful starting point.

What is personal power? I'd venture to suggest that it means having, as an individual, control over one's everyday life and life projects to the degree this is possible, having influence in one's family and society, to be somebody who other persons can count on, to be listened to and to be respected.

How is personal power acquired? To me the key question is whether I feel responsible for my life or whether deep down I believe that somebody else, my parents, school teachers, social workers, politicians or other people are ultimately responsible for how I am living my life. If I do not see myself in the driver's seat holding the steering wheel in my hands, how can I change directions in my life?

As long as I see the power over my circumstances in somebody else's hands, I will be convinced that what I think, feel and do does not really make a difference. Most likely, I will allow other people to speak and make decisions on my behalf. Such a position has its advantages. We don't need to take responsibility for our actions, we can blame other people or plain bad luck when things go wrong. It is convenient to have excuses. If somebody else is responsible for my problems, there is nothing I can do, no use in even trying. With such a fatalistic attitude I make myself very dependent on other persons and give them a lot of personal power at my expense. I might have dreams of what my life could be, I might dream about achievements, recognitions, friendships and relationships. But if any of that should come true, it would be by coincidence. Most of my dreams will just remain dreams.

I am not sure whether the issue of control is a purely Western or a universal concept. Is it also true in your culture that we are torn between, on the one hand, taking responsibility for our shortcomings and, on the other hand, blaming somebody else, circumstances or predestination and fate?

When we realize that we all can take more responsibility for ourselves, for example, our health, our education, our relationships to others, we will have the means to change our situation. This realization in itself is already a strong empowerment. When we represent ourselves not allowing other people to speak for us, we can train ourselves and with time get better. When we take responsibility for our mistakes, we can learn from them and hopefully improve. And, we can also take credit for our successes. Each small step forward will confirm us in our direction and encourage us to take more steps.

These observations apply of course to all people, with and without disabilities. But as persons with disabilities it can be more difficult for us to feel in control. We often meet the attitude that disabled people need to be protected, since we are seen as dependent on other people, such as the helping professions, unable to take care of ourselves. When meeting such expectations early in life we can easily internalize them and make them to our own prejudices against ourselves. Then it might be difficult to realistically assess our abilities, to know how much we can do for ourselves and where we should seek advice and assistance from others, in particular, professionals. It seems to me that the more we rely on other persons, the less we trust and train our own abilities. As a result of overprotection we not only lose personal power, we are also prevented from taking risks, from making mistakes and learning from them. There is a lot to be said about the importance of taking risks.

Somebody might react and say, why should disabled people have to be constantly in charge of their lives, defend their interests, be on guard and never allow themselves to relax when other people don’t seem to live like this all the time either? But what are the alternatives? If I don’t check whether my assistants charged my ventilator batteries last night, who does? Since I’m the one who gets no air when my ventilator runs out of electricity, it is in my own interest to be careful and to check.

Here, it helps to have disabled friends who can support us in acquiring such an attitude. We all need role models from whom we can learn, who share the fruits of their experiences as disabled persons with us, whom we can identify with because they are or have been in the same situation, because they know and feel what we are talking about. We call this peer support. It is the Independent Living movement’s foremost pedagogical instrument.

Can we get personal power by claiming our rights? As disabled people we often talk about rights, the right to accessible public transportation, for example, which is currently a hot issue in Sweden. According to the United Nations Convention on the Rights of Persons with Disabilities and the Swedish Government, people with disabilities in Sweden have that right. But a piece of paper about your right to accessible busses does not automatically mean that there is an accessible bus at the corner. The problem with rights is that, in a democratic system, the majority of the population has to believe that disabled people indeed have such rights. In trying to convince the majority it might help our cause when we can point out that we need the realization of a particular right for meeting our obligations as individuals, as family members, as citizens. Accessible transportation, for example, will better enable us to get education, training and work, will help us in raising a family and in contributing to society in many other ways. The better the balance between the rights we claim and the duties we are willing to take on, the more our rights will be respected.

In my view, personal power comes naturally from taking on responsibilities. When our daughter was a child, she liked pizza. As parents we let her have pizza as often as she wanted - if she baked the pizza herself. In that way, she had the personal power of deciding what the family would eat for dinner. We all, whether children or adults, with or without disabilities, can increase our influence within family and society when we take part in the decision making and take on functions.

Gaining political power works the same way. As a group, we can acquire influence and power, when we are prepared to join and work in organizations that work for our equal opportunities and full citizenship.

Let us first look at the organizations that are supposed to work for these goals. Do our organizations truly represent us, are they run and controlled mainly by disabled individuals? If not, risks are that our organizations portray us in public primarily as recipients of care and not as equal citizens. Self-representation is not only necessary in our personal lives, we also have to have self-presentation in our organizations. As soon as we allow non-disabled people to speak on our behalf, the public gets confirmed in the preconceived notion that people with disabilities are incapable of defending their own interests and need non-disabled people who will do it for them. Such organizations cannot be expected to be successful in gaining political power and using it towards our goals.

The organizations we see in our countries are still primarily organizations FOR and not OF disabled people. Often they divide us into medical diagnoses, because traditionally they have promoted medical care and research, raised money for us in the streets and in public campaigns, played on and encouraged the public's pity for us. Again, these are not the organizations that will succeed in convincing society that disability is a natural part of human life, that we can make meaningful contributions to our family, neighborhoods and society.

Only with strong organizations we can be respected by our governments and can be effective partners in designing and implementing the policies we need for living and working, equal to others in the community. Our organizations will be as strong as we as their members make them. We have the type of organizations we deserve and each of us is responsible. So, again, as in our individual lives each of us should ask, how can I take more responsibility. Without responsibility, no influence. Without duties, no rights. There are no shortcuts.