

Compromise And Corruption Moving Ahead on The Road To Citizenship

**A Presentation at the International Conference on
“Self-Determination and Individualised Funding”.
Seattle. 29-31 July 2000
John Evans, UK**

Self Determination, Citizenship and Rights

Independent Living started with the wish for disabled people to achieve self-determination and control over their lives. It was about moving out of institutions and into the community and graduating from university. It was a community-based approach, which endeavored to provide disabled people with equal citizenship. Its motto was to ensure that despite the impairment of the individual and the restrictions which result from limited mobility etc., that a disabled person should still have equal access, facilities and opportunities to function equally in the world. Independent Living was all about challenging these restrictions.

Part of the process of an individual achieving self-determination was the introduction of Direct Payment schemes. A Direct Payment scheme is a means to an end, and the end is Independent Living. The Direct Payment scheme buys in the support that one needs in order to achieve this. This is the ideal, as long as the scheme enables the person to do this, and it ensures that Independent Living is the goal. Unfortunately what restricts this and the individuals needs led assessment is the system.

The system sometimes operates in a way forcing compromise upon the individual. It is the way that the service provider can maintain control. Independent Living practice enables disabled people to challenge the system, hence the power struggle. The only difficulty is when the allocation of resources is restricted, it can impede the Direct Payments scheme through not allowing enough funding for the individual for the whole amount of time required in their assessment. This can often have a negative and restrictive effect on the person.

Compromises

Whether we like it or not, we have to live with compromises. It is a question of trying to get as much as one can out of the situation. When it is down to negotiation and compromise, it can go both ways. The basis of Independent Living is self-assessment in that the individual assesses their needs because they know what they want.

This is in complete contrast to the professional who will assess the situation from the point of view of ignorance and the level of resources available. As we live in a social policy situation where rationing is part of the reality we have to fight to safeguard our needs. Whatever happens, we must be sure we do not lose touch with what Independent Living stands for. We can compromise with the level of resources, but we cannot compromise with the goals of Independent Living. It is a question of affirming our rights and citizenship. This is our ideal on the path to self-determination.

The important thing for the Independent Living movement is that it is united in its struggle to maintain its principles and rights to self-determination. This is why it is important to build partnership between users and the service providers in order to work together constructively to further develop Direct Payments. There are many threats to us, as well as those of compromise and corruption. Others are severe charging policies as well as abuse from within the system.

Abuse of the System

Abuse of the system occurs mainly as far as we are concerned from the way it is organised. A particular concern to disabled people and cause of abuse, comes from agencies providing support and assistance to individuals running their own Direct Payment schemes. This can happen in a number of different ways, e.g. allocation of inappropriate staff, untrained staff, where the individual has no control. There can also be abuse by the workers who do not carry out their tasks effectively, they can exert mental and physical abuse, as well as not being reliable, punctual or responsible.

There can also be abuse from a system by individuals not being allowed the amount of time they require. This comes from the care managers bad interpretation of the situation, and abuse of their power.

I am aware that I have focused on the abuse of the system as opposed to abuse by the individual. I have done this purposely because it is usually this kind of abuse, which is referred to most. It is almost as if government authorities are paranoid about individuals abusing the system and keeping the money for themselves. I find this insulting, because in my 18 years of experience of running my own schemes and advising others about theirs, I have never come across any of this kind of abuse where the individual spends the money on something also rather than their support. It is really a crazy idea because if we do not spend money on the support we need, then we don't get out of bed, go to the toilet, eat, drink and stay healthy, because without this support we are pretty worthless.

I know each government authority has a public responsibility to be financially accountable, because the money used for Direct Payment schemes is public money. It is just a shame that so much energy, time and frustration is used up on it. It would be far better spent on improving the quality of services and thinking about new ways and solutions for developing Direct Payments.

In my experience disabled people are only too happy to be responsible and accountable. The last thing we want is for things to go wrong and for there to be problems because it is our lives and our livelihood. In fact I find that disabled people are very creative with their Direct Payments money, and make sure they get the most out of each pound spent, and are constantly looking at ways for improving their schemes.

Needs Led Assessment and Service Led Assessment

Independent Living is based on self-assessment. This is the foundation and starting point. We have to ensure that we constantly promote the needs led approach, and challenge any service led approach which threatens it. This is our ideal, and the fact that we are seeking and living control and choice over our lives demands it.

If Independent Living schemes are going to continue to develop in a positive way, it has to be done in a way that accepts the notion of needs led assessment, otherwise the philosophy will be corrupted. The future depends on a good working partnership between the pioneers of Independent Living and the existing service providers. By working together to try and fully realise the full potential for Independent Living it can also help firmly secure the future for Independent Living without threats and corruption. In order for this to be fully accepted and safe it needs to be done within the existing legislation framework. The solution for this is in civil rights legislation, which includes and incorporates Independent Living.

Independent Living and Human Rights

The disability movement in the UK and in many other countries, is committed in its intention to help fully bring out civil rights legislation, which includes Independent Living. We know this is a goal that will not be easy to achieve, but one that is absolutely necessary in order to safeguard the future for Direct Payments. Disabled people cannot be as satisfied until this occurs and cannot be complacent. Until Independent Living is legislated in law, disabled people will always feel that there is a threat of ending up in institutions at the end of their life.

In the UK Independent Living started by people moving out of institutions into the community and this is how we want it to remain, so that disabled people can live in their homes for as long as they want, regardless of their impairment.

Whilst there is always the threat that resource led approach stating that there is not enough money in the system to provide for Direct Payments, could lead to an either restricting or ending Direct Payments schemes, disabled people cannot rest or relax. This is why trying to achieve legislation with Independent Living enshrined in it as a right is one of the most important objectives facing disabled people in the new millennium.

Disabled people have always been imaginative in designing solutions to their difficult situations, and this particular one of getting strong Independent Living legislation is a further development in this

unfolding process. We must be able to protect ourselves and this is the way that we see we can do it. This is one of the major challenges facing the Independent Living movement in the coming years.

John Evans,
July 2000