

DIRECT PAYMENTS AND WHY THEY ARE IMPORTANT ?

FROM BEING DEPENDENT ON INAPPROPRIATE SERVICES TO BECOMING AN EMPLOYER

INTRODUCTION

Why are direct payments schemes so important? They are important for many reasons many of which I hope to cover in this talk. These kind of schemes have not only transformed the lives of thousands of disabled people in this country but also thousands of disabled people worldwide, especially in the USA, Canada, Australia, South Africa, the Scandinavian countries and many of the developing countries. I know we are mainly concerned here today with the situation in this country, but it is worth bearing in mind this international perspective when we are looking at the importance of these schemes, because when the original pioneers of Independent Living in this country in the early 1980s were planning their schemes they were not alone in their endeavours, because at that same time disabled people worldwide were trying to establish Independent Living lifestyles in their struggles for integration into their own communities and control over their own lives. We in this country were certainly influenced a great deal by the Independent Living developments in the USA and in particular Berkeley, where the first CIL (Centre for Independent Living) was set up to help people with advice and support in Independent Living. We forged many links with our counterparts in the USA and in other countries and these exchanges proved to be invaluable in our initial stages.

Direct payments schemes have liberated disabled people from being passive recipients of inappropriate services to being active citizens and employers leading creative and productive lives. They have enabled disabled people to move out of institutions, given more control and choice over their lives, contributed to a better quality of life with more flexibility and satisfaction and real empowerment. I say real empowerment purposely because empowerment has become a real buzz word recently and as it has been overused, and its real meaning has seriously been undervalued. In this context though it fully represents and reflects the full meaning of the word, because here we are seeing peoples lives change and grow immensely as their confidence and control increases. More significantly these schemes have helped disabled people move away from their lives being dominated by the medical profession and the negative dependency and restrictive practices of the medical model of disability, into the more vibrant, realistic and dynamic mode of the social model reflecting the true values of the world we live in. As far as direct payments are concerned the proof I think is in the pudding and its successful track record clearly demonstrates this and now at last the Minister of State, Virginia Bottomley herself has finally come around and admitted it.

BACKGROUND

I think it is important to put the whole thing into context and reiterate and remind ourselves how and why these schemes started, because not only is it significant in terms of individual disabled people taking control of their own lives, but also disabled people collectively organising themselves in a unified voice to improve their lot in their struggle for their civil and human rights. And that means not only the right to have to have control over basic daily living tasks - such as when to get up, go to bed, go to the toilet, when and what to eat - but also the right to have personal relationships, to be a parent, to have equal access to education, training, employment and leisure activities and the right to participate in the life of the community. The development of the Independent Living Movement is inseparable from that of the disabled peoples' Civil Rights movement. Independent Living is a totally holistic approach to life: personal, social, political and philosophical.

The unique and indisputable feature of Independent Living and direct payment schemes is that they were created, designed, established and developed by disabled people and not by professionals - hence the reason for their success. Disabled people are the experts in this field and always will be. They were created to enable disabled people have more control and choice in their lives, and be involved in all the major decisions about their lives with the ultimate aim of living intrinsically in the community with everybody else and not segregated in institutions. This is where it started. The situation has moved on from here but institutions are still a threat. Independent Living was and still is an equal opportunities issue. It should be for all disabled people who want and choose it. There should be no distinctions regardless of disability, gender, ethnic background, sexual orientation or age.

As I just implied in this country the Independent Living Movement has its roots in that struggle to liberate people from institutions during the 1970s and 1980s. Those early negotiated arrangements by disabled individuals with their respective authorities formed the basis for a workable model for direct payments schemes and through the Independent Living Movements' network a continuity for developing and improving them. As well as this with the development of CILs and other organisations run and controlled by disabled people they provided an ideal infrastructure and framework to help support, inform and advise potential and existing users with their schemes. This is undoubtedly one of the main reasons for their successful record. And on a political level with the development of BCODP (British Council of Disabled People) the national, democratic, representative organisation of disabled people, it provided a unified voice with considerable influence to promote its cause and none better than in its campaign over the last 6 years for direct payments which has now proved its point. BCODP itself has over 100 organisations throughout the country.

SELF ASSESSMENT

One of the primary and philosophical premises of Independent Living is self-assessment. This is based on the notion that the individual best knows their own needs, are the experts in this and experience it directly and if necessary together with

their disabled peers are best at arriving at an accurate and more appropriate assessment and appraisal of the situation. Obviously in order for the scheme to be accepted by the social services it then needs to be agreed in partnership by the care manager or social services representative so that it can then be put through the system. I do not use partnership too lightly here either because there have been cases where professionals have taken the lead and it has often led to schemes going wrong. We believe that if the assessment is right from the start there should not be any problems. It is of our belief in Hampshire that the early Independent Living advocates were in fact the first care managers on the scene, a long time before community care got going.

SELF ORGANISATION AND DECISION MAKING

Independent Living is all about taking control of ones life and developing more choices and options. This happens because the individual assumes responsibility in all the decisions that affect ones life. This is encapsulated in the term some authorities use to define IL practitioners ie. SOCS(Self Operated Care Schemes). The main notion here being the aspect of self-operated and self-directed. In other words all direction, organisation, supervision, training etc. resides with the disabled person and all the decision making processes that go along with this. It was once said that IL is about identifying choices, and being able to come up with alternative solutions when needed, and sometimes this requires the ability to be able to think fast and be well organised, especially in the case of an emergency situation arising this is paramount. It is the self development that occurs in this process which is what real empowerment is about. Also the skills that are developed can ultimately help disabled people into real and gainful employment.

QUALITY OF LIFE AND FLEXIBILITY

This is one of the main findings of the research done by Morris and Kestenbaum and more recently Zarb in "Cashing in on Independence" on behalf of BCOOP. One of the main features of IL is undoubtedly the high quality of life and satisfaction which is experienced and gained by disabled people. Improvement in the quality of ones life not only means more personal, social and vocational satisfaction but also usually means peoples health and general well-being tends to be better. It has other spin offs like a more positive approach to life generally and good personal and social relationships which can be helpful in ones attitude and relationship to ones assistants. However people are people with an impairment or not and we should not expect DP to be more saintly than others, so they will have the occasional inter-personal and communicational difficulties and problems like everyone else, and will deal with them accordingly.

BEING AN EMPLOYER

This is the area where we have seen the biggest changes. What a contrast on the one hand disabled people, either being in institutions or dependent on fragmented unsatisfactory local services in a very passive role to being a responsible employer and having to take on all the many tasks and responsibilities that go along with this, which is like running a small business. As well as keeping abreast with all the administrative and financial aspects like keeping records, doing the PAYE schemes, getting adequate insurance cover, drawing up job descriptions and contracts and conditions of employment - there are also the practical aspects like advertising, interviewing, employing, training and supervising and directing etc. Some people have these qualities naturally but others need to develop these skills and this is where the disabled peoples' movement is valuable in providing this type of training, advocacy and support. Some organisations have refined this knowledge, expertise and training to a fine art. This is an area where the support factor is crucial and with many people it can be an on-going process and where the role of advocates and administrators can be an integral feature of some peoples schemes. This peer support was absolutely crucial when we first got our schemes going. We would often help each other out in both advice and practice.

EMPOWERMENT.

Already in what I have said I have outlined a number of areas where disabled people have directly become empowered by living independently eg. taking control of their lives, creating choices, being decisive and assertive, articulating their needs, being an employer, and being an advocate just to mention a few. As well as these more individual qualities there is also empowerment in terms of raising ones awareness and becoming committed to a cause and the politicisation that goes along with this process. This is certainly the case with Independent Living advocates and activists who are not only running their own schemes but are committed to the objectives of the Independent Living Movement which is inextricably tied up with the campaign for equal rights, which as you know is again gaining momentum.

IN CONCLUSION

I think there is more than enough positive experience and evidence to support the whole direct payments issue and campaign and personally I do not see any problems. The usual ones of accountability, abuse, exploitation of workers, irresponsibility, inability to cope, risk factors and so on will continue to prevail but as I said earlier the proof is in the many success stories and the numbers that have achieved it, both quality and quantity and at the end of the day it is still only up to those who choose to do it and that is how it should stay. I look forward to the day when a conference like this is not necessary and direct payments are the norm.

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