The involvement of service users and carers in training within the field of social care and social work has the ability to influence the perceptions, attitudes and ultimately the behaviour of all key participants within the process.

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How to cite:

Barnes, June Margaret (2002) *The involvement of service users and carers in training within the field of social care and social work has the ability to influence the perceptions, attitudes and ultimately the behaviour of all key participants within the process..* thesis, Swansea University.
http://cronfa.swan.ac.uk/Record/cronfa42336

TITLE

THE INVOLVEMENT OF SERVICE USERS AND CARERS IN TRAINING WITHIN THE FIELD OF SOCIAL CARE AND SOCIAL WORK HAS THE ABILITY TO INFLUENCE THE PERCEPTIONS, ATTITUDES AND ULTIMATELY THE BEHAVIOUR OF ALL KEY PARTICIPANTS WITHIN THE PROCESS.

BY JUNE MARGARET BARNES

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This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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This thesis is the result of my own investigation except where otherwise stated.

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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ACKNOWLEDGEMENTS

I would like to thank all of the people who have been involved in any way in the work that forms the basis for this dissertation. These include members of CATCHUP and the service user and carer trainers who worked alongside me in the training of social work students, Mrs Rosita Lewis, former Principal Officer, Physical Disability, Dyfed Social Services Department and the students who participated in this project.

A special word of thanks to Professor Peter Raynor who has been my tutor for the latter part of this work and who has offered a great deal of support and encouragement.

Lastly, but not least, a big thanks to my husband Stephen who has encouraged me to carry on and to complete this dissertation.

This work is dedicated to my parents, Beryl and Ivor Street. My mother was a dedicated carer. She cared for grandmother and then my father, who developed Parkinson's disease soon after he retired. My own knowledge of informal caring was 'academic' until I assumed part-time caring responsibilities for my father when my mother died in 1999. Up until his own death in September 2001 my father taught me a great deal about what it means to become disabled in later life. The experience allowed an 'insider view' of the worlds of both disability and caring.

ABSTRACT

This dissertation is about the involvement of service users and carers in training within the field of social care and social work. It considers some issues within participation before moving on to themes of adult learning and approaches to the social work curriculum.

It is argued that recent approaches to social work education, with a basis in 'reflective learning', potentially offer a rationale and framework for inclusion. The central argument is that participation by service users and carers in the training of social workers has the ability to influence the perceptions, attitudes and ultimately the behaviour of all key participants within the process.

The research design is a qualitative one based on ethical and emancipatory approaches to research in the field of disability. The views of service users, carers and social work students on the training module are collected in the penultimate three chapters.

The concluding chapter is a synthesis of what has been learnt and implications for curriculum development. The main message is that the 'insider experience' brought to training by service users and carers is a valuable tool for teaching social work students. However, outcomes cannot be divorced from processes of teaching and learning and there must be ongoing commitment to anti-oppressive practice and to addressing issues of power. There is much to learn about the way in which the experiential is introduced into the curriculum and related to other parts of the curriculum.

There is a need for collaboration between educators, disabled people, carers and students in devising, delivering, monitoring and updating the social work curriculum. This means engaging with the emerging discourses of disability, caring and education as a pathway to developing more effective ways of teaching students and preparing them for practice with disabled people and carers.

CONTENTS

APPENDICES

PREFACE

In 1992 I was working as Practice Development Worker in the Department of Applied Social Studies at Swansea University. Part of my task was to develop new practice placement opportunities in Dyfed Social Services Department as part of CCETSW's Practice Placement Initiative. Dyfed was embarking on involvement in the 'From Margins to Mainstream' project (Management, 1992). The context of this Joseph Rowntree funded project was the National Health Service and Community Care Act, 1990 and its remit to:

> 'Give people a greater individual say in how they live their lives and the services they need to do so' (DoH, 1989,4)
> and
> 'Be marked by... the involvement, through consultation with service users' (DoH: 1990,3).

The project's aim was to help local Social Services organisations to manage the implied change of culture. The task was to bring users of services from the margins, where there is little involvement in decision making and day to day processes of providing services, into the mainstream. The consultancy role of the Office for Public Management was to stimulate discussion and develop strategies to increase participation at all levels within the local Social Services organisations. A user-led organisation of people with physical disabilities, CATCHUP (Co-operative Action to Change and Hurry Up Progress), was at the forefront of these developments in Dyfed.

CATCHUP offered unique placement opportunities for social work students. Involvement in meetings with the Office for Public Management team gave opportunities to engage with the processes of participation by disabled people and carers. Simultaneously a teaching module on physical disability and caring was evolving in partnership with service users and carers.

The subject of this research, participation in the education of social work students, is important. It is symbolic of a gradual change of culture in personal social services and adult education. The significance of this change of culture lies in an ongoing search for approaches to practice and to teaching which are non-oppressive and effective in terms of their influence on the learning of social work students.

The following narrative gives some insight into my motivation for embarking upon this research.

The role of experience: the experiential context.

> 'The most admirable scholars within the scholarly community ... do not split their work from their lives. They seem to take both too seriously to allow such disassociation, and they want to use each for the enrichment of the other'.
> (C. Wright Mills, 1959 page 195).

The images I hold of disability go back a long way. My parents recall that as a toddler I screamed in terror each time a disabled man passed the garden gate, and they would remove me inside 'out of harm's way'. When I was about 8 years old my best friend suffered a head injury. She was sent away to a 'colony for epileptics'. My friend was unable to walk or talk, needed feeding, nappies changed and I couldn't talk with her any more. The boys in our street made fun and taunted with words such as 'spastic' and I ended up defending her by fighting. These, plus a few other isolated incidents made me diffident about being involved. On the whole, disabled people were different and to be avoided - they were people to feel sorry for.

My first job was as a Child Care Officer. I had no interest in work with disability and reluctantly took over a few cases after the Seebohm reorganisation in 1971. When I moved to work with Barnardos I also worked with some families of children with disabilities, but the work left me feeling de-skilled. How could I support a mother, who had lost two sons with Muscular Dystrophy, through the process of sending her 12-year-old, also with Muscular

Dystrophy, to a residential special school? Disability was a tragedy with seemingly no answers, an intractable problem for me as a young social worker.

The turning point was being faced with the possibility that my own first child would be disabled. My General Practitioner suggested that one way out of my despair might be to work with others in a worse situation. Thus I embarked on the next stage of the journey - work with Huntington's disease patients and their families. Work at a local level led to involvement nationally, and an opportunity to work 'alongside' in an effort to raise awareness. A weekend in London with Marjorie Guthrie, widow of Woodie Guthrie, the American folk song singer and writer who died of Huntington's disease began to open up the possibility of seeing disability in a different way.

My growing interest in disability led me to work with the Spastics' Society - an organisation working for disabled people. There I grappled with issues of institutional living versus care in the community, independence versus dependence, segregation versus integration, medical needs versus social needs. At a practitioner level there was a constant challenge to translate organisational mission statements into every day practice, working with real people in real situations.

It was during this time that I became aware of key actors in the British Council of Organisations of Disabled People such as Ken Davis and Mike Oliver and their then seemingly radical views about the role of established organisations working for people with disabilities. Issues relating to power and the politics of disability began to enter my thinking. This was yet another milestone in the reanalysis of my own position and the beginning of a profound discomfort with the role of social work within the field of disability.

My responsibility for delivering a course on social work and physical disability at Swansea started in 1986. Initially I just presented alternative models of disability and their implications. Then I questioned: 'Who am I to teach about the reality of social and attitudinal barriers to students?' The logical next step was to involve disabled people themselves - the intention was well meaning enough, but the processes and outcomes were extremely dubious both ethically and in their efficacy.

Hence I arrived at a point in my journey where it was time to stop to consult the signposts and to decide about where to go next. I needed a more detailed map and some fellow travellers. I found these in CATCHUP, a group of disabled people and carers, who were also embarking on a new stage in their journey - a journey which was about actively engaging with the processes and decisions which directly, or indirectly affected their lives.

The role of experience was therefore central to the decision to develop strategies for integrating the perspective of service users and carers into the training process, and to simultaneously evaluate progress. Experience had suggested that responses to issues of impairment, disability and disabled people are complex at the level of both the personal and the professional, with the first exerting an influence on the second (French, 1994).

The research hypothesis

The research hypothesis grew out of my involvement with a group of disabled people and carers who joined me in presenting the module on physical disability at Swansea University. The key question is:

> **Does the involvement of service users and carers in training within the field of social care and social work have the ability to influence the perceptions, attitudes and ultimately the behaviour of key participants in the process?**

The process was about working with service users and carers in developing a course module on disability which would start to prepare first year social work students for practice. This meant building on training experience gained by the group in Dyfed, whilst acknowledging the requirements of the course at Swansea University. The research questions clustered around the nature of the involvement of service users and carers. The aim was to learn about the participation of disabled people and carers within a field of activity traditionally reserved for professionals. The term 'change of culture' was used by CCETSW within the context of a project aimed at facilitating 'service users' to participate in social work education (Beresford, 1994). It denotes a move towards a different approach to preparing social work students to practice. This study considers the educational rationale for such a shift of culture and makes some suggestions about considerations for moving forward.

Within the framework of a commitment to an ethical, anti-oppressive base for social work, outcomes cannot be divorced from process. I viewed the process as working alongside, creating dialogue and exchange rather than perpetuating an approach to learning which is about one group learning about another, based on social meanings which are embedded in unequal power relations based on the historical dominance of one group over another (Dominelli, 1998 page 6, Oliver, 1996 pages 43-62). It was important to acknowledge the crucial role, and influence, of power in social work relationships. Issues of marginalisation and oppression at a societal level are mirrored in social work relationships (Dalrymple and Burke, 1995). I believed that working in a way which pays attention to the nature of power within the teaching process would produce learning outcomes that reflect a more reflective and critical approach to power relationships and their implications for practice and a move towards:

> ' progressive approaches which takes the side of people who have been marginalised by structural inequalities such as poverty, sexism and racism and seeks to assist them

> in their desire to reverse the position they are in, that is, to move in emancipatory directions' (Dominelli, 1998, page 5).

It was anticipated that the various sets of data collected in this study would show a degree of paradigm shift on the part of students, some evidence of awareness of what are the 'real' issues for disabled people and their carers. This would be one small step in the direction of a more emancipatory approach to social work with disabled people and their carers.

The time frame of the research

The background work was undertaken in Dyfed in 1991/92. The specific work of data collection and analysis took place between 1993 and 1996. In 1996 I moved from Swansea University and the teaching module was discontinued in the same form after 1997.

The period for writing up the research and its outcomes was from 1996 onwards with an intended submission deadline of December 1997. A short extension was granted in 1997, but this stretched on when a sequence of events, which were beyond my control, made it impossible to complete the work.

This research has taken much longer than initially envisaged. It should, therefore, be acknowledged that there have been developments in each of the key areas covered within this research. A chronology is included in chapter 4 (pages 83 and 84).

Chapter 1

PARTICIPATION IN PUBLIC SERVICES

Introduction

The aim of this chapter is to set the scene by exploring some themes which relate to participation in public services. Participation per se is a large and complex area and for the purpose of this study the main focus is 'consumer participation' within the context of the development of community care.

The development of user and carer involvement in aspects of social care provision has been heralded as 'at the heart of the changes brought about by the National Health Service and Community Care Act, 1990' (Management, 1993). The challenge to involve the consumers of community care services provided the impetus for 'From Margins to Mainstream' which started in 1992. The relationship between the Joseph Rowntree project and this research is explained in the preface.

The initial focus of this chapter is the development of 'participation' in Britain. There will be a brief overview of some of the agendas for participation in public services, by whom these agendas are driven and what this may mean for the process of participation and issues of power.

As the focus of this dissertation is the participation of disabled people and carers in a course of professional social work training a brief history of the Disability Movement is included in this chapter as a foundation for considering some of the specific issues within a specialist discourse.

Finally some models of participation are discussed as a means of highlighting the complexity of transferring participation as a concept into the domain of organisational policy and practice. Two models of participation (Arnstein, 1969 and Burns 1991) are considered in parallel with Barnes' framework on models of disability (Barnes, 1990). The focus of such models is the process of moving towards yielding power and control to people on the basis of citizenship rather than as consumers of public services.

Defining terms

On the surface the idea of 'participation' is a simple one, which has been enshrined within the ideals of democracy for centuries (Richardson, 1983 page 1). Since the 1960s it has accrued new shades of meaning within a widening number of spheres. These meanings, together with the terminology and values which accompany them, will be discussed in order to provide a window through which to view the development of participation.

The concise Oxford dictionary defines participation as 'to have a share in' (Concise Oxford Dictionary, 1964). Within the field of social policy it has been defined by Richardson as:

> 'The introduction of a new set of actors into the various processes, or activities of policy development or delivery, entailing their involvement with others in them' (Richardson, 1983 page 23).

This definition, which can be extended to fields other than social policy, suggests the inclusion of people in a process or field of activity within which they would not be routinely included. Within social welfare 'participation' has become linked with the idea of people who are recipients of services being included with politicians, managers or professionals in a range of activities which influence services. At different stages the impetus for participation has come from politicians, managers, professionals and from people themselves.

But this definition says nothing about the status or role of participants. A lot can be learnt about the basis upon which people participate in public services from looking at the language of participation (Barnes and Wistow, 1991 page 3). At different stages in the history of the Welfare State terminology has changed, reflecting differing and diverse emphases within the overall culture of welfare and of social work practice (political, managerial and professional). At the same time as public interests have been driving the movement towards participation there has been a growing demand for inclusion from civil rights movements and these have brought with them new language. Language and terminology, including the jargonese of professionals, has been viewed as carrying the baggage of oppression (Oliver, 1990, Slee, 1989).

Recipients of personal social services have been variously described as 'clients', 'consumers', 'service users' or 'citizens'. Not one of these terms is neutral; each carries its own political overtones, agendas and implications for the status of recipients of services within the Welfare State and reflects the ever changing nature of social welfare provision (Beresford, 1983). Implications will be considered as part of the historical context within which participation has developed.

Within this study the notion of participants relates to direct recipients of social services, in this case users of a local authority day care and residential service and their informal carers. Whenever the project group are referred to the terms 'service users' and 'carers' are used - the terminology adopted by the Joseph Rowntree 'From Margins to Mainstream' project (Miller, 1993 page 1).

The term 'service user' has a narrow focus, namely: 'a person who is receiving a service' from a Local Authority Social Services Department and who is therefore able to comment upon facets of that service, such as its appropriateness, quality and, ultimately, whether it meets their own assessed needs. It may also be possible for an individual user to appraise the service in relation to the group or community to which s/he belongs, but this raises the issue of representativeness.

'Carer' refers to informal carers, mainly to those whose caring role is born out of a relationship of kinship. The definition of the Carers (Recognition and Services) Act, 1995, includes those who offer a substantial amount of time in caring to sick, elderly or disabled relatives and friends. It excludes anyone who is providing care as part of a contract of employment, including anyone who is receiving payment either in cash or kind.

The emergence of participation in the personal social services

In modern times the provision of comprehensive welfare has been linked to the idea of citizenship (Mishra, 1984). However, the way in which the terms and conditions of being a citizen have been defined in social welfare policy has varied according to political ideology. While the political right have made an unequivocal link between the social rights of citizenship and the fulfilment of a complex set of responsibilities, particularly those related to employment, the political left and centre have argued that citizenship itself should be the sole basis for social rights (Beresford and Croft, 1993 page 4). Within this context it is possible to identify two main approaches to involvement *'consumerist'* and *'democratic'*. Beresford and

Croft argue that while they both have merits it is important to be clear about the difference. Consumerism is essentially about having a voice in services while the democratic approach is about:

> 'how we are treated and regarded more generally and about having greater say and control over the whole of our lives',

and thus: 'the idea of empowerment is central to the democratic approach' (Beresford and Croft, 1993 pages 8 and 9).

The history of participation is beset with ambiguity. The idea of consumer, or citizen, participation took root in the domain of public services in Britain in the 1960s (Richardson, 1983, page 100). By the 1960s important social changes had occurred which impacted on the world of public services; the apparent consensus of the early welfare state was starting to disintegrate (Titmuss, 1963).

For the consumers of public services there was an enhanced awareness of the implications of social services, such as health, education and housing, for opportunities and quality of life. The population in general had benefited from rising educational standards, which led to an increased capacity for involvement by a growing number of users of public services. A more discerning public expected more of services and lay people no longer automatically accepted that the professional knows best; the competence of professionals to make decisions, which affect peoples' lives, was open to scrutiny. The time was ripe for participation. Arblaster perceived an association between rising living standards and education and the 'widespread dislocation between political and social power on the one hand and social and economic status on the other' (Arblaster in Parry,ed.,1972). Within this context, being 'involved' was a perceived means of having a voice and a means of influencing what was happening.

But increasingly participation became a response by politicians, managers and professionals to their own needs and agendas. By the late 1960s the machinery of services had become administratively unwieldy with an ever widening gap between service providers and those they served. The Welfare state was grappling with new problems, which required different approaches. For example, the Government of the day realised that, in spite of the fact that most people lived in decent housing with an acceptable standard of living and a range of services to help at times of crisis, there were many problems associated with urban deprivation (Penn and Alden, 1977 page 1). Part of the strategy to tackle such deprivation was the Community Development Project (Home Office1969), described as:

> 'a modest attempt at action-research into the better understanding and more comprehensive tackling of social need through closer co-ordination of central and local official and unofficial effort, informed and stimulated by citizen initiative and involvement' (Home Office, 1971).

Political neutrality, with a merging of different interests, is indicated. However, the history of citizen involvement in community work has drawn attention to inherent inequalities in service provision and the struggle 'between people in powerless positions against the powerful' (Payne, 1995 pages 165-6 cited on page 160 of Mayo, 1998). It is suggested that this inherent conflict of interests led to the demise of the Community Development projects in the late 1970s (Loney, 1983 cited on page 160 of Mayo, 1998).

In 1968 the Seebohm Committee had advocated greater consumer involvement in Social Service departments. The role of social services was viewed as:

> 'being directed to the well-being of the whole community and not only of social casualties, seeing the community as the basis for authority, resources and effectiveness' (Seebohm, 1968 page147).

There was a recognition that the clients of Social Services often had limited choice about services and control over provision which might affect the quality of their lives over a

considerable period of time. It was envisaged that their involvement would give them a degree of influence on services which were professionally dominated, and close collaboration with community networks was advocated. The Barclay Report reinforced this in 1982.
During the same era medical services based primarily on diagnosis and treatment of illness were complemented by broader strategies of health education, aimed at helping patients to take responsibility for promoting their own health. This trend is typified by the publication in 1976 of a report entitled ' Prevention and Health: Everybody's Business' (DHSS, 1976), the white paper 'Prevention and Health' (DHSS, 1977) and the Court report 'Fit for the Future' (HMSO, 1976).

By 1974 it was obvious that an increase in administrative tiers was placing a distance between policy makers, planners and consumers. Community Health Councils became a means of consultation with the different interest groups in order to gain information and support, even of legitimising decisions (DHSS, 1974).

By the early 1980s the concept of participation in social policy had been adopted in areas as diverse as Social Services, Health, Housing and Education. By 1980 the British Association of Social Workers had entitled a Working Party on Client Participation in Social Work 'Clients are fellow citizens' (Richardson, 1983 page 141). In Health the formation of Patient Participation groups were an attempt by General Practitioners to:

> 'involve patients in taking responsibility for their own health and to avoid the medicalisation of problems by doctors' (Metcalfe, 1982)

Developments in the 1980s and 1990s have been largely located within a 'market' approach to participation (Beresford, 1993). The New Right philosophy of the Conservative governments of the 1980s and 90s emphasised self-reliance and responsibility. The culture changed to that of the 'new managerialism' with its emphasis on concrete and measurable outcomes (Ward, 1998 page 151) within top-down management led agendas. The views of professionals and service users became subsumed in a consumerist philosophy dedicated to the values of entrepreneurialism and business management (Kelly, 1991 page 178) within which the efficient and effective use of scarce financial resources was a key principle. For example the Audit Commission (1985) was charged with looking at the twin principles of economy and efficiency in local authority services and reported on the 'disincentives' to the development of community care as a result of funding policies (Audit Commission Report, 1986). This prompted the setting up of the committee which led to the Griffith's report (1988), the White Paper (DoH, 1989a) and the National Health Service and Community Care Act, 1990. Perhaps the clearest report in terms of consumerism was Wagner (1988) which stressed the need for the users of services to be able to choose between different options and advocated mechanisms for review and complaint.

The implications of the National Health Service and Community Care Act

The principal of user and carer participation of the National Health Service and Community Care Act, 1990 is enshrined within a philosophy of consumerism within a market economy of care (Ellis, 1993). The role of local authorities changed from that of direct provider of non-health care services to being both a provider and purchaser of services within a mixed economy of care, which includes the private and independent sectors. Among the arguments for this change is increased efficiency, encouragement of the development of more innovative ways of providing care and greater 'consumer choice'. However, Braye and Preston-Shoot suggest that this has created a:

> 'two- tier system where those who can pay can choose, while those who need financial assistance must establish need' (Braye and Preston-Shoot, 1995 page 11).

So giving a certain amount of power to people who have the financial ability to purchase their own services while leaving those without purchasing power at the mercy of systems of assessment and care management where professionals assess and define need (Ellis, 1993) and where managers control budgets and access to scarce resources.

Within the market approach the main way in which consumers of services are empowered is through the option of 'exit' – if service users are not satisfied with a service it is supposed that they can remove their custom, thus forcing weaker providers out of the market. Such a mechanism has many potential problems. It does not allow for the fact that within the kind of two tier system described by Braye and Preston Shoot (1995 page 11) those with the least financial means often do not have the option to exit as they are dependent upon residual services. This model does not allow for factors such as the complexities of mixing care, the ethics of care provision (confidentiality), the crisis led situations within which care is frequently provided and the compulsory nature of some care provision (Beresford and Croft, 1993 page 9).

All of the above has posed both dilemmas and challenges for service providers and for professional practice which empowers. The project that was the starting point for this piece of work 'From Margins to Mainstream' had two important principles. Firstly, that the purpose of involvement was to improve the care, and therefore the lives, of people dependent on social services, health and other community care service provision. Thus it is underpinned by concepts such as 'choice' and 'independence' (Ellis, 1993 pages 26-38) Secondly that to achieve lasting change the involvement of service users and carers should inform every stage of community care planning, management and service delivery (Management, 1992).

A central question posed to managers within social services, under the heading 'Sharing Power' by the project team of From Margins to Mainstream was: Are you prepared to welcome users and carers as partners? From the outset this meant looking at not just the nature of partnership relationships but how these could be achieved, how users and carers could be enabled to participate and barriers to participation (Management, 1993).

The questions of 'shared power' and 'partnerships' are not new ones to social work. The implementation of the National Health Service and Community Care Act, 1990 has perhaps thrown such concepts into sharper relief. Some work by Ellis (1993) on 'user and carer' perspectives illustrated the problems of moving from a 'service-led' to a 'needs-led' approach to assessment of people with disabilities and carers within services circumscribed by factors such as ambivalent attitudes towards service providers and competing perspectives on independence and rationing of services. Ellis argues that part of promoting participation is considering how values and power impact on the assessment process, particularly in terms of the way in which they reinforce and create disadvantage. This means recognition of the different interests and agendas of various stakeholders within the assessment process.

But, themes such as 'partnership' and 'empowerment' take on a different aspect when they are related to the structural issues of disadvantage and oppression which are part and parcel of the experiences of many service users and carers (Braye and Preston-Shoot, 1995 page 100). Whilst a reappraisal of the traditional power balance between users and professionals has been taking place within professional circles, service users themselves have been demanding that providers hear and respond to what is wanted rather than impose non-negotiated and often oppressive solutions:

> 'Empowerment happens not just because powerful people give away power, but because oppressed people engage in wresting it from them' (Braye and Preston-Shoot, 1995 page 100 citing Adams, 1990).

Payne argues that:

> 'full-blown empowerment and advocacy perspectives are products of the 1980s and 1990s' (Payne, 1997 page 267)

and that the concepts of empowerment and advocacy have only become central to the activity of social work in Britain in the 1990s. Empowerment is a complex concept that can be related to radical and non-radical approaches to social work – it can be equated with giving more control to service users within processes such as assessment of needs on the one hand while being concerned with radical engagement with the redistribution of power in favour of oppressed groups at a political level (Payne, 1997 chapter 12).

Participation and people with physical disabilities: some key themes

Struggle is central to the whole notion of participation when applied to people with disabilities. This is essentially the fight to achieve basic democratic rights within a social and political context underpinned by concepts of disability and normality which have led to the routine exclusion of those who do not fit in (Rae and Finkelstein, 1990). During the past 30 years the world of disability has been characterised by debate and conflict about basic issues such as:

- how disability is defined and constructed, and by whom;
- needs versus rights: the question of citizenship;
- issues of disabled identity.

The articulation of a clear theoretical viewpoint on disability, its causes and consequences has materialised only slowly. The volume of literature about disability, particularly writing promoting a social explanation of disability has increased (Barnes, 1990,Finkelstein, 1980,Oliver, 1996, Morris, 1991) but the medical understanding of disability is still pervasive in our society and its institutions (Brisenden, 1986, page 176, Barnes, 1991 page 132, Reiser, 1994). A growing number of disabled people have embraced the new thinking, but this is a slow process and there is by no means consensus among people with disabilities about fundamentals such as how disability is defined and interpreted.

The main impetus for a change in the way in which disability is viewed has come from people with disabilities themselves (Finkelstein, 1980 Oliver, 1996 Barnes, 1991, Morris, 1991, Hevey, 1992). In ' Understanding Disability: From Theory to Practice' Oliver describes developments in disability thinking from approximately 1970 onwards. He raises important considerations for the participation of people with disabilities in social policy and related areas. He highlights the tension between organisations for disabled people and bona fide organisations of disabled people, demonstrating some of the problems inherent in moving from theory about participation to participation in action. Oliver argues that the large umbrella organisation that worked for, and on behalf of, disabled people, The Disability Alliance, set up in 1975 was both undemocratic and unrepresentative of disabled people. He contrasts this with a smaller organisation UPIAS (Union of the Physically Impaired Against Segregation) which was created a year earlier as a reaction against this lack of democracy and to work with the concerns of people attempting to leave residential care. Out of UPIAS came 'The Statement of Fundamental Principles', a document which offers an analysis of several issues which are germane to understanding the position of the Disability Movement on the participation of people with disabilities. The issues cluster around definitions of impairment and disability and the underlying reasons for disability and expertise on issues such as poverty and disability income as they relate to people with disabilities.

UPIAS argued that a situation had arisen within which the so called experts on matters such as income for disabled people had missed the point and that it was imperative that disabled people should become their own experts by drawing on their experience of living with a disability.

A confusion about the nature and causes of impairment (the medical or physical condition) and disability lay at the heart of the problem. Not surprisingly UPIAS' 'Fundamental principles' document espouses a social interpretation of disability, viewing disability as something:

> 'imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society' (Oliver, 1996 page 22).

Disability is therefore viewed as a matter of social oppression; the solution a massive social and political restructuring in which people with disabilities are afforded 'rights' rather than 'charity' within the context of 'integration' rather than 'segregation' e.g. in education, employment and public transport. Participation of all disabled people within the context of struggle was seen as crucial. It had the potential outcome of:

> 'disabled people achieving the physical and mental capacities to meet the active demands of employment and other integrated situations' (UPIAS document quoted in Oliver, 1996 page 26).

This contrasted with the narrow approach in which a few became 'expert', excluding the majority from the 'social and ideological developments of our time'. (Oliver 1996 page 26)

The tensions in the relationship between UPIAS and the Disability Alliance are significant for considerations of 'process'. The means by which change is achieved are as important as the ends or outcomes. It might be argued that the vital concern was the economic well being of people with disabilities, stressing ends rather than means. But there were wider issues at stake: issues, which are mirrored in the key themes within the politics of disability and disabled identity. Rights versus charity and integration versus segregation have already been mentioned, but there are other foci such as dependency versus control and competence versus incompetence which are mirrored in the wider debates about participation, empowerment, citizenship and equality (Arnstein, 1969, Barnes, 1990, Burns, 1991, Braye and Preston-Shoot, 1995).

The debate about normalisation (Wolfensberger, 1972, 1984), which is mainly associated with the field of learning disabilities, and the Ordinary Lives Movement (Zola, 1982) should not be overlooked as they provide part of the context for this study. Normalisation has been described as:

> 'the principle by which people with a disability have the right to lead a valued, ordinary life, based on the belief in their value as human beings and citizens' (Ramon, 1991)

Payne (1997) suggests that while the principle of normalisation is about including people with learning disabilities in everyday life and involvement in socially valued roles it also relates to a 'disabled living view' (Morris, 1993) and a 'perspectives' position i.e. a development of an 'oppressed groups' perspective – a perspective 'which seeks to take up and promote disabled people's own perspective on their situation' (Payne, 1997 page 251).

What are the key arguments for participation?

In her analysis of participation by consumers in social policy, Ann Richardson makes the observation about those activities which have been opened up to consumers that:

> 'with a few exceptions these activities would be undertaken anyway without new participants. Most social services would be provided whether or not consumers are actively involved in their delivery.'(Richardson, 1983 page 23)

The above statement conveys the ambivalence, which has dogged the steps of participation in social services and emphasises the need for clarity about why participation is important. Is participation a means to an end or is it an end in itself? What is the nature of effective participation? Who measures effectiveness and against what criteria? Are services, or activities, which are influenced or undertaken by service users in any respect superior to those, which are not, and how is this to be measured?

Advocates of participation begin with an appeal to natural justice. They claim that where recipients of services must bear the consequences of policy decisions there should be mechanisms whereby they can be involved in their formulation (Richardson, 1983 page 52). Weight is added by drawing attention to the increasing complexity of services and the ever widening gap between decision-makers and consumers. The argument itself contains two main elements: firstly that it is a fair way of doing things, and secondly that it creates the potential for 'better' decisions, and better quality service provision (Management, 1992) Hence the argument of From Margins to Mainstream that participation by users and carers is a means to improving the quality of services and the lives of the users of those services. This is particularly relevant to the field of community care which has grown up within a philosophy of services being provided within a climate of 'market economy' with its focus on competition as a partial controller of quality.

Within social work and social care practice the concept of 'partnership' between professionals and service users has come to denote an approach which seeks to minimise the gap between professionals and service users and carers based on an understanding of the complex power relationships which exist in any carer/cared for relationship. By the beginning of the 1990s, when the From Margins to Mainstream project was born, there was a more sophisticated understanding of the factors that lead to service users being disadvantaged and acknowledgement that inequality is compounded by of factors such as culture, race, language, and disability (Braye and Preston -Shoot, 1995 page 98).

A third argument views participation as intrinsically good in terms of its benefits to participants themselves. The act of participating is seen as bringing greater fulfilment and understanding to those involved and is, therefore, viewed as an end in itself. Parry's developmental theories (Parry, 1972 cited in Richardson, 1983 page 54) attribute four potential benefits to the activity of participation:

- political participation as an essential part of the development of human capacities, ensuring dignity and self respect;
- participation leads to the development of educational abilities;
- participation leads to greater self-awareness as those who participate discover their real interests;
- benefits of expression.

People in the Disability Movement, who have fought to counteract the effects of social exclusion and to develop personal and political identity, have endorsed these benefits (Payne, 1997 page 202).

All of the above are consistent with market-led, consumerist agendas within the field of social welfare, which are ‘needs’ rather than ‘rights’ led approaches. The final set of arguments is based within a democratic analysis of involvement on the basis of ‘citizenship’. While there is no real consensus within political circles about the meaning of citizenship it has become equated by Civil Rights groups with equal rights, access and opportunities within the mainstream world and is symbolised by the emergency of the Disability Movement (Oliver, 1996) and with empowerment theory based on social justice (Rees, 1991).

What are the barriers to participation?

Those who oppose, or are sceptical, about participation use both ideological and operational objections. Even the most ardent proponents of participation on ideological grounds may have serious reservations about the processes and agendas of participation (Jewell, 1973, Beresford, 1994, Braye and Preston - Shoot, 1995).

Perhaps conservatism, the tendency to do things as they have always been done, is one of the main roots of resistance. Richardson suggests that traditionally social policy has concerned itself with ends rather than means and that outcomes, e.g. the achievement of a care management approach to the delivery of community care, are more important than the way in which they are achieved (Richardson, 1983 page 3). Added to this there are many assumptions about the recipients of services which may act as a powerful deterrent to change. Consumers of services have been viewed as lacking interest and motivation on the one hand and capacity and expertise on the other. Jordan highlighted a fundamental problem of being a 'client' of social services; a problem which is most apparent within a right wing consumerist approach to welfare, namely:

> 'State intervention only takes place in the event of social inadequacy or moral inferiority'. (Jordan, 1976 page 5)

The corollary is that in order to be a client other rights and obligations of citizenship are suspended. Such ideas are fed by the fact that the groups who are most dependent upon personal social services are not, on the whole, economically independent e.g. children and young people, disabled people and older people. These groups are most likely to be disenfranchised by poverty and by stigma and their many implications and consequences (Barnes, 1991).

Beresford and Croft make the further observation that in its aim to compensate for broad inequalities, the Welfare State has created a 'separate service world' which has led to isolation and restricted rights (Beresford and Croft, 1993 page 4). This has led to systems of categorisation and the development of eligibility criteria based on 'expert' assessment by professionals (Stone cited in Oliver, 1990 page 51). It is not, therefore, surprising that recipients of public services have become dependant and passive and consequently lacking in motivation and the perceived ability to contribute in a positive way to a world which is dominated by professionals. The briefing report of the 'From Margins to Mainstream ' project, published after the first two years of the project noted in its section on 'Problems encountered so far' that:

> 'when things went wrong it was easy to blame users and carers. It was difficult to involve users in strategic decision making because they were often more interested in personal problems than in strategies and overall priorities' (Management, 1992).

Wolfendale has described the nature of professionalism as:

> 'the refining over time of skills of self representation, fighting for one's faction, lobbying and excluding others from outside the profession' (Wolfendale, 1983).

If this is an accurate description of professional culture, it is clear that this is a culture, which will not easily yield its power or perceived expertise. Lipsky on street-level bureaucracy in the United States is even more far reaching in his analysis of the implications of professional control within the provision of public services, documenting the mechanisms used by front line professionals to maintain their own interests and to control service users (Hudson in Barton, ed., 1989). Within such a culture there is a danger that 'participation is just a clever con' by those in authority to legitimise their decisions without decreasing their power (Richardson, 1983 page 5). The key question becomes 'Whose ideas are we hearing?' Beresford and Croft, who are among the key exponents of the potential value of participation in social services, admit that:

> 'Participation is conspicuous for its pitfalls and ambiguities. It can be as powerful a means of preventing peoples' effective involvement as of making it possible'
> (Beresford and Croft, 1986 page 290).

They identify particular risks which stem from the market economy of welfare which characterises community care:

> 'involvement within a consumerist agenda becomes a means of gaining information to preserve market provision, a means of targeting need more efficiently but without any change to decision making or control of services'.
> (Beresford and Croft cited in Braye and Preston-Shoot, 1995 page 50).

The danger is token involvement:

> 'We have a whole group of hand picked users who go to user meetings - hand picked by social services - and then we're told that social services is consulting with users'
> (Bewley and Glendinning, 1994, quoted on page 165 of Oliver, 1996).

Richardson (1983) has also highlighted the risk that ' the participating consumers would be co-opted by the system' thus rendering any distinctive contribution they may have ineffective. This raises issues such as the professionalising of consumers and elitism of a minority. It is a salutary thought that when the consumer voice is legitimised by the system it may lose its cutting edge and be rendered ineffective, thus contributing to a situation of greater social control.

A further objection, or perceived limitation, is that consumers are not representative. It is argued that while groups of consumers may possess common characteristics, they do not form an homogeneous group and that it therefore follows that individuals cannot represent the interests of a wider group; that they are just representing their own situation and interests.

Jewell (1973) suggests that problems of representativeness co-exist with other difficulties, such as elitism, problems of interaction and manipulation by professionals. All of these are problems which relate to process and do not necessarily invalidate the concept of participation.

Some argue that from the point of view of professionals the main agenda was, and still is, the protection of personal and political interests (taking the consumer with them), therefore using participation to their own advantage. A range of barriers to partnership have been identified: 'the power of 'orthodoxy and convention' (Barker and Peck, 1987 quoted by Braye and Preston-Shoot, 1995 page 109) which keeps worker and service user in their respective places. Professional culture is initially reflected at the interpersonal level, often driven by professional insecurity and fear, but then becomes institutionalised through policies and procedures at an organisational level, e.g. assessment and the allocation of resources (Smale et al, 1993, Ellis, 1993).

Models of participation

A number of theoretical frameworks for considering participation have been posited: for this study two are of particular relevance, those of Arnstein (1969) and Barnes (1990). They both present the idea of continua. The focus of Barnes' work is models of residential care rather than participation per se, none the less the notion of participation, or to what extent residents are involved within the care situation forms the basis of his thinking. Concepts such as competence, enabling and empowerment are closely bound up with both frameworks. The following diagram juxtaposes the models of disability (Barnes, 1990) and the hierarchy of participation (Arnstein, 1969):

MODELS OF DISABILITY	HIERARCHY OF PARTICIPATION
Disabled action	**Citizen control** **Delegated power** **Partnership**
Enlightened guardian	**Partnership** **Placation** **Consultation** **Informing**
Horticultural	**Informing** **Therapy**
Warehouse	**Manipulation**

While it is possible to find flaws in Arnstein - indeed the model has been revamped by Burns (1991) on the basis that it is too simplistic - it is important because it is among the first attempts to analyse the process of participation and what this may mean for service users. Where those who run public services profess a commitment to the ideal of participation it is necessary to find some way of judging what is happening. What separates involvement which is tokenistic and which serves professional or service-led, agendas from that which is dedicated to inclusion of service users and carers at every level? Is the nature of participation such that it leads towards ceding professional power and involving service users and carers on a basis of equality?

Burns (1991) suggests that while Arnstein's ladder, which was developed in America, fairly accurately reflected the state of participation in Britain in the 1990s that there were significant differences and that the reality was better represented by a fourteen stage ladder.

Burn's analysis leaves no room for complacency, for him the process of achieving the sort of change of culture required for ultimate citizen control involves an extremely ambitious programme of work. The early stages of the Burn's model approximate to the first six rungs of the Arnstein ladder, but from this point the picture becomes more complex as it describes organisational initiatives which incrementally build towards a position in which bottom-up strategic decision making becomes the norm and where power is ceded to citizens themselves.

Conclusion

Participation is a broad and complex subject, which means different things to different people. It is a challenge to vested interest and power, whether this is the interests and power of professionals, managers or politicians.

A history of participation was included as a means of highlighting some issues, themes and agendas in participation. It was noted that the drive for participation has come from different stakeholders, namely people themselves, politicians, professionals and managers. The process is one that can be used to service agendas based on different political and value positions. It can be analysed from a consumerist or democratic viewpoint on the basis of participants as 'consumers' or 'citizens'. Hence, participation is rarely a neutral activity and it is possible for conflicts of interests to occur.

Disability was the parallel theme to participation in this chapter. The consumer group who took part in this research were members of a wider community of people with disabilities and brief history of the Disability Movement was included as a basis for understanding the particular issues of participation by disabled people and their carers.

Finally models of participation, such as those of Arnstein and Burns, and participation and disability were presented as an aid to developing an understanding of the complicated nature of achieving the change required for meaningful participation by people with disabilities.

Chapter 2

PREPARING SOCIAL WORK STUDENTS FOR PRACTICE: A POSSIBLE RATIONALE FOR PARTICIPATION BY SERVICE USERS AND CARERS

Introduction

The participation of disabled people and carers in a module of teaching on the social work course at Swansea University is the central theme of this dissertation. In this chapter the focus will move from participation per se to participation in education and training.

In 1989 CCETSW published Paper 30 'The Rules and Requirements for the Diploma in Social Work'. This paper provided a framework of knowledge, values and skills which qualifying social workers need to demonstrate before they can be deemed competent to practice. It was an important landmark, but only a beginning.

From the 1960s onwards social work had been vying for a place with other disciplines within a hierarchy of professions such as nurses, teachers and doctors. Social work educators, with lead bodies such as CCETSW, have been faced with the task of defining the body of knowledge required to become a social work practitioner, what skills are needed, and how to relate these dimensions to a professional value base and to ethical considerations. The following statement describes social work:

> 'An accountable professional activity which enables individuals, families and groups to identify personal, social and environmental difficulties adversely affecting them. Social work enables them to manage these difficulties through supportive, rehabilitative, protective or corrective action. Social work promotes social welfare and responds to wider social needs promoting equal opportunities for every age, gender, sexual preference, class, disability, race, culture and creed. Social work has a responsibility to protect the vulnerable and exercise authority under statute' (CCETSW, 1991, page 8).

Social work is therefore faced with the dual imperative of working at the level of the individual, family and group utilising a range of strategies to help, while simultaneously challenging the inequalities within society. While CCETSW provided a framework, partnerships consisting of academic bodies and agencies are expected to translate this into practice. The aim of social work education is to equip students for professional practice. This means considering questions that relate to the whole curriculum - not just what should be taught (curriculum) but how (methodology). Yelloly and Henkel suggest that:

> 'Methods of professional development are significant determinants of professional performance, rather than a consequence of it, and have far reaching implications for the continuing professional development of individual practitioners' (Yelloly, and Henkel, 1995 pages 22 and 23).

The debate about methods of teaching and training and the nature of professional knowledge is ongoing (Thompson, 2000 page 8). There is a perceived tension between the competency based approaches, often promoted by agencies who offer practice experience and methods of teaching social work which afford a key role to research and empirical knowledge. Braye and Preston - Shoot have identified some of the key problems of qualifying competency in social care as:

> 'While these recognise the inter- relatedness of knowledge, attitudes and skills as components of competence, and the influence of the organisational context, they are presented as if unproblematic and mutually consistent and supportive. Staff are left to appreciate and negotiate the sometimes contradictory requirements for practice competence' (Braye and Preston-Shoot, 1996 page 2).

The aim of this chapter is to:

- Consider some main theoretical perspectives on adult learning;
- To look at social work training and some recent thinking on preparing students for practice;
- To link the above to themes in training in the field of disability, and current thinking about the role of disabled people and carers within the process of training professionals.

This will mean entering into the ongoing debate about the nature of social work and what constitutes effective preparation for the practice of social work with people with physical disabilities. Practice must always be at the hub of this debate: what we are preparing students to do, and how? This cannot be divorced from the wider social and political context within which social work operates at the end of the 20th century - at a time which may be viewed as 'transitional' for social work (Clarke, 1993, Rossiter, 1996, Taylor 1996).

The spotlight is on teaching about disability, an area that is traditionally the cinderella both in terms of social work practice itself, and within social work education. (Oliver, 1983 chapter 7). Indeed the area of welfare and disability, with its emphasis on needs rather than rights, is highly contentious from the viewpoint of the Disability Movement. The introduction of the National Health Service and Community Care Act, 1990 has added further concerns about the role and power of social workers in relation to work with people with disabilities (Barnes, 1991 pages 129 - 148).

Some main theoretical perspectives in adult learning

There is consensus within the world of education that teacher, student and the learning environment all play key parts within the learning process. The role and emphasis afforded to each of the constituents varies greatly, according to which thread of learning theory is accepted as most valid.

Within the world of practice teaching of social work students, practice teachers have been subjected to a range of approaches to teaching and learning, with little accompanying guidance about their origins in terms of educational philosophy. For example, tools such as learning styles questionnaires and profiles are commonplace (Honey and Mumford, 1982).

The experiential learning cycle of Kolb (1975) is utilised by many practice teachers as a framework for supervision with students. College based staff may have had even less exposure to theoretical perspectives on adult learning but have still been presented with new trends in course presentation such as Enquiry and Action Learning (Burgess, 1992, McGill and Beaty, 1993) - possibly without the opportunity to make a thorough evaluation of existing approaches.

Theoretical perspectives on adult learning fall into three main groups:

- Behavioural: teacher centred;
- Cognitive: subject centred;
- Humanist: learner centred.

Behavioural theories

Within this tradition the learner receives an external stimulus to which s/he responds - the teacher directs and the learner responds. It is therefore the teacher who controls the process by choosing the stimuli and through a system of feedback influences learning behaviour. Feedback stands on its own and usually follows the learning process. This theoretical perspective provides a basis for both cognitive and humanist theories (Rogers, 1986 page 47). In a behavioural approach learning is incremental and progresses step by step with one stage building upon another. There is an emphasis on learning being measurable in terms of outcomes; it is this theoretical perspective which underpins competence based learning and upon which the structure of qualifications in social work and social care is based (Thompson, 2000 page 120).

Cognitive theories

Cognitive theory moves beyond the idea of learning being about observable behaviour to more abstract concepts such as ‘thinking’, ‘reasoning’ and ‘understanding’. In cognitive theory there is an emphasis on knowledge being constructed through interaction with the environment. Both the process of learning and the materials of learning (subject matter) are of importance:

> 'The material that the teacher - agent orders and the learner seeks to master dominates the process' (Rogers, 1986 page 47).

Learning is viewed as a dynamic process within which the learner is active. Experimentation is a central process. One of the main proponents of this approach was Bruner (cited on page 62 of Armitage et al., 1999) who proposed that learning is achieved through the process of discovery. The learner is given a problem to solve and is allowed to explore the subject from different angles under the guidance of a teacher. Newly acquired knowledge is used as a basis to formulate principles that can be more generally applied to new situations.

Humanist theories

Humanist ideologies are more recent than the other two groups, and humanist learning theory tends to be less coherent than the older more established theories. The primary focus is upon the learner as active, and his or her influence upon the learning process. The urges and drives of the student towards increased autonomy and competence, development, growth and meaning drive the learning process. Within this process the self-setting of goals is of primary importance, as is the social setting within which the learner interacts.

Prior learning and experience is valued within humanistic approaches; learning is viewed as essentially by imitation and identification with others, drawing on both one's own experience and the experience of the wider society (Knowles, 1984). The impetus for learning comes from within the learner and is fed by the whole of life, the cultural and interpersonal relationships that form the social context. The three main tenets could be summed up as:

- Autonomy of the learner;
- The self setting of goals by the learner;
- The role of the teacher is to increase the range of experience available to the learner.

Key theorists within this newer tradition are having considerable impact on the development of social work teaching and it would, therefore, be useful to look briefly at the ideas of some of the main proponents.

The first main group, which includes Rotter (1972), Berne (1970), Carl Rogers (1974), Maslow (1968) and Kolb (1975), draws heavily on personality theories and the idea of a 'locus of control' (Rogers, 1986 page 53) which is within or outside the learner. Learners' personalities are viewed as located on a continuum of introvert/extrovert. At the one extreme introverts may believe that positive reinforcement is not under their control, with tendencies towards fatalism, feelings of inferiority, fear of failure. At the opposite end of the spectrum, extroverts may be more independent, able to resist manipulation and are able to exploit the environment and build on successes (Andrisani and Nestel, 1976 cited in Thompson et al., 1994, page 25).

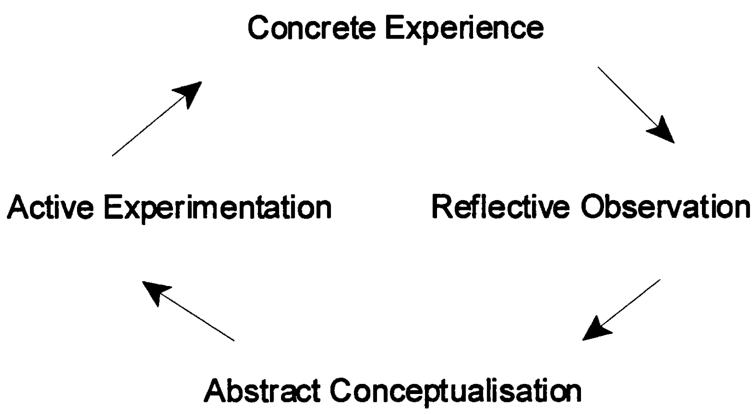
Maslow (1970 pages 56-61) defined a hierarchy of human needs which need to be satisfied before learning can take place, thus a person needs food, shelter, relationships, self-esteem before s/he can truly be involved in self-actualisation, or achievement of potential. In this framework motivation is seen as needs related, with progression to the next level being dependent upon the needs of the level below being satisfied. Maslow's hierarchy does not offer any explanations about motivation within the process of learning itself.

In 1974 Carl Rogers expounded the view that learning is a response to inner drives and compulsions which propel the individual towards autonomy, responsibility and self-determination. Rogers acknowledged that culture plays a part and that the drive towards autonomy, responsibility and self-determination within individuals varies greatly from one society/culture to another. Studies of Asian American families suggest that they place a strong emphasis on academic achievement and that children of these families tend to achieve at higher levels in schools (Stevenson, 1988; Harrison, et al., 1990, Slaughter-Defoe et al., 1990 cited in Bee, 1992, page 519).

McClintock (cited in Rogers, 1986 page 53) considers how the three areas of learning - knowledge, attitudes and practice - vary in different types of learning situations. There is an emphasis on the crucial role of attitudes within the learning process and the relationship of attitudes to knowledge.

A framework, which is used extensively in social work practice teaching, is the experiential learning cycle of Kolb (1984) which emphasises the process by which learning is achieved.

KOLB'S EXPERIENTIAL LEARNING CYCLE



Learning is viewed as a cyclical process that requires abilities to:

- be involved in concrete experiences;
- observe and reflect on these experiences from several different perspectives;
- conceptualise - thus developing theories that can guide future actions;
- test out these new insights and understandings in practice.

Environmental theories are the other most important strand within the humanist framework (Rogers, 1986 pages 54 and 55). They subdivide into human communications theory, social learning theory (Bandura, 1977), total environment (Habermas, 1978) and paradigm transition (Parse, 1987 cited in Thompson, 2000 page 27). One of the more influential of this group of theories is Kelly's 'personal construct theory' (1955). The core of these theories is that the learning environment and its resources and the interaction between the individual and that environment influence learning.

All of the above ideas have become influential to some degree in approaches to social work education (Boud and Knights, 1996) and to the specific world of teaching in disability (Oliver, 1996 and French, 1994). Their significance is in the way that they lead towards a construct of knowledge as mediated between the individual and his/her total environment. Thus knowledge is not viewed as external to the learner - there can be no knowledge that exists independently of the knower (Habermas, 1878). Each learner enters the learning experience with a set of assumptions and views (largely unchallenged) which make up his/her view of the world and of reality based on the early experiences mediated through the social and cultural world within which s/he has been socialised. Michael Foucault (1973) and the post-structuralists have introduced the concept of knowledge being fundamentally influenced by the power relationships within society. The field of sociolinguistics is interested in the relationship between knowledge and language; particularly the imagery embedded within language (Whorf in Carroll, 1956 and Lackhoff, 1975,cited in Siencyn, 1995 pages 9 and 18, Bruner, 1974, Hugmann 1991, page 37).

This lack of certainty has led to what has been described by Rossiter as 'a crisis for social work' as the historical search for a body of 'true' knowledge to underpin the profession has been challenged with the demise of positivism:

> Now, it is impossible to escape post modernism's discovery that our knowledge is deeply dependent on our social location, on the places from which we learned to see. Further, some of those locations are invested with the power to define the world in terms favourable to maintaining existing power relations. Under this condition , social work can no longer claim 'a knowledge base', but must ask instead, how, by whom, and for whom social work knowledge constructs the world'. (Rossiter,1996, pages 142 and 143).

The questions 'how, by whom, and for whom' have become central to the whole debate about social work with people with disabilities and transferable to discussions of training in this area of work.

Problems of preparing students for practice

Within the framework of National Vocational Qualifications developed by CCETSW there is an emphasis on the knowledge, skills and values that underpin good practice. The approach is an incremental approach which functions in terms of competency to perform different tasks which extend from the simple to the complex. The competency approach has been equated with an 'anti-intellectual' stance in social work 'which denies and diminishes the place of theory in practice' (Hardiker and Barker, 1981 on page 48 of Marsh and Triseliotis, 1996).

Social work education as a post-graduate activity within higher education has attempted to swim against the prevailing tide and to maintain, and enhance, a tradition of 'conscious' practice based on a critical and research based model of education. Goddard and Carew argued in an article ‘Social Work: Mechanical or Intellectual’ (1989 cited in Thompson,2000 page 110) that ‘social workers need education rather than training’ and that a challenge for social work educators is to create a perception of social work as a profession ‘at the cutting edge of intellectual activity.’ But, models of teaching and learning which are based essentially upon a theoretic approach within college settings, which is often discipline based and fragmented in nature, and rely on the practice experience within agencies for the task of applying theory to practice situations also have their problems. A limited number of studies suggest that the shift from an 'everyday social approach' to a 'fluent linking of theory with practice' is achieved by only the more competent students while less competent students may only reach a fragmented level of linking theory with practice (Secker, 1993 cited in Marsh and Triseliotis, 1996 page 3). Further studies at post- qualifying stage suggest that social workers make very little use of theoretical content of qualifying courses in their subsequent work (Carew, 1979, Corby, 1982, Gibbs and Cigno 1986). Educationalists and trainers have inevitably perceived a gap between the different approaches to social work training and the unsatisfactory nature of both, and have therefore sought other ways of preparing students and workers for practice (Burgess, 1992, Thompson et.al., 1994 and Thompson,2000, Gould and Taylor,eds., 1996).

New approaches/methods of teaching within social work education

Some of the main ideas, which have recently gained credibility in the field of social work education, relate to 'problem-solving' (Parsloe, 1996 in Gould and Taylor,eds. 1996 page 117), 'reflective learning' (Schon,1983 and 1987) and 'imaginisation' (Gould and Taylor,eds.,1996). These perspectives stem from a desire to bridge the gap between more traditional forms of didactic teaching and the competency based models favoured by many employers. In essence they are humanistically based with a bringing together of several main strands of thinking, namely the autonomy of the learner, the importance of the environment and appropriate support strategies and learning materials (Rogers, 1986 page 48).

In 1992 the course at Swansea began to adopt elements of the approach of Enquiry and Action Learning (Burgess and Jackson, 1990); an approach to social work education which incorporate a problem-solving approach. Enquiry and Action Learning has units which focus on a case or scenario which could realistically be encountered in practice. Students work within small study groups and the role of the staff member within the process is that of facilitator. Lectures on specific topics supplement the group-based learning.

It is an assumption of Enquiry and Action Learning that students arrive on their training with prior learning and experience that can be shared within the group; in this way students themselves become a resource to others. A further guiding principle is that of integration of theory and practice. The starting point is a case/scenario, which is explored from all angles, for example, the legislative framework, social policy, and psychological and medical aspects. Students are expected to choose, or are allocated, aspects of the situation to research and to bring back to the group. They need to be self-motivated, to develop skills in problem-solving, to be active rather than passive within the learning process and to develop independent and critical thought. An additional aspect is the improvement of skills of collaborative working in a group setting. All of this links with the work of Kolb on reflective learning which posits that we learn best when we are personally involved in the learning experience and are committed to aims of learning that we have set ourselves.(Kolb, 1979).

The use of reflective learning has been extended as its potential to bridge the gap between pragmatic and theoretical approaches to social work practice has been recognised:

> 'Reflective learning only has value if its effect is to deepen the complexity of practice; rather than rejecting the sphere of the intellect, the reflective paradigm actually requires an engagement with some of the particularly difficult debates within social theory'.(Gould and Taylor,eds., 1996, page 74).

Gould identifies the potential threat to social work of 'descending into the relativist quagmire', principally the 'abandonment of intellectual rigour'. A crucial part of the reflective process is a consideration of some of the main theoretical explanations.

It is useful to use the comparatively early work of Kolb (1975) as a framework for considering how the process of reflection can be utilised in a way which acknowledges the intrinsic relationship between the domains of the cognitive, subjective and moral within social work education and practice.

Stage 1 of the cycle is concrete experience, e.g. an actual piece of social work practice or case study, which presents a range of issues for practice.

Stage 2 is about reflective observations. This stage offers the opportunity for the learner to describe the situation in a way that is meaningful to him/her; to explore his/her feelings and reactions, assumptions (the subjective)and values (the moral).

Stage 3 is about abstract conceptualisations and generalisations and an opportunity to move from the descriptive and subjective to the theoretical (the cognitive). The focus is on explanations and the theoretical basis for action.

Stage 4 is about active experimentation with, and application of ideas : What will I do next? /what will I do differently?, which leads logically into the next piece of practice.

The evaluative cycle is ongoing and has the potential to be built into the process of every day practice, especially the process of student and professional supervision.

More recent work by Gould has extended the idea of the reflective process with the development of the idea of 'imaginization as praxis' (Gould,1996 pages 63 - 78) with its appreciation of the significance of images as informants of behaviour and practice. Gould is cognisant of the innate dangers of social work systems which develop endless procedures and guidelines as a means of confronting the issues and dilemmas within day to day practice. He argues from the basis of contemporary cognitive science (Lackhoff, 1987 cited in of Gould, 1996 page 64) for a more useful model, based on reflective learning, within which imaginisation (Morgan,1993) is a key process.

The significance of Gould's work is that it releases the potential for exploration of the images which underpin judgements. A five-stage process is suggested as a framework to encourage students to articulate perceptions, views and understandings as a precondition for re-framing action and finding new approaches to practice.

Key concepts in reflective learning which could provide a rationale for including service users and carers in social work education

Some of the specific concepts, upon which reflective learning approach is based, are useful in considering the role and value of involving service users and carers. In discussion of the different theoretical conceptions of knowledge which are gaining ground in social work education, namely those of:

> 'communitarianism, interaction and a concept of rationality which is communicative and practical' (the epistemological framework which informs reflective practice) (Henkel 1995 page 68)

Henkel makes the point that they:

> 'provide an alternative rationale to that of consumerism for involving service users (and students) in these processes' (Henkel,1995 page 69).

In addition, therefore, to the arguments related to the right of the consumer to a voice within a welfare system which is market-controlled and the case for inclusion, based on concerns of social justice, there is a raison d'etre based on the nature of knowledge and of learning. The key questions relate to the development of educational programmes within which the involvement of service users and carers is a key element. These include the training programmes which have originated within the Disability Movement and which hold the principle that training on disability equality should be designed and delivered by disabled people (Swain and Lawrence ,1994, page 92).

One justification for such an assertion can be found within post modernist thinking, as reflected in the following two quotes :

> 'The shift to post modernism, which entails the interrogation of location as it constructs knowledge and careful attention to who can speak for whom, energises the creation of the creation of complex and useful explanations of experiences'.(Rossiter, 1996, page 143)

> ' Post modernist educators grant the wisdom contained in the traditional canons, but insist that people and groups need to transform knowledge in accordance with their own sociological, historical and cultural contexts. For students in classrooms this transformation means curriculum relevant to these contexts, and instruction which incorporates 'difference, plurality and the language of the everyday as central to the production and legitimisation of learning' (Aronowitz and Giroux, 1991 page 187).

Professional learning and imagery

Understanding of the role of imagery and metaphor, as an aspect of the prior learning and experience which participants bring into training situations, is highly relevant to this study. The reasons for this are two-fold. Firstly, it is routine to explore images held by participants on disability awareness and equality courses. Secondly, there is a growing interest in the imagery of social work brought into training by social work students. Any work on preparing students to work with people with disabilities should consider these two themes in parallel.

A study by Harris and Gould in social work considered what sorts of images of social work were brought into social work. It was discovered that many students have limited experience of social workers and often start with the very negative images conveyed by the media and by their previous experience. Students may have experience in fields such as residential care where the role of social workers is often viewed with scepticism (Gould and Harris,1996). They illustrate their argument with the following quote :

> 'There is a growing body of research within professional education that illuminates and extends these discussions of imagery. There is converging evidence that the conceptions which learners bring to their education, through which they attempt to make sense out of confusion, and construct their self-identity as professionals are cognitively represented as 'metaphors, understood as picture preferences or language embedded pictures' (Bullough and Knowles, 1991, page 123).

If the above is valid, one of the key roles of social work education is :

> 'to help students to articulate and review the images that underpin their assumptive world. The premise which underlies this argument is that linguistic and pictorial images are active agents in constructing our experience of ourselves and others' (Gould and Taylor,1996 page 64).

A crucial next stage in the development of learning is to enable students to re-frame the concepts, which not only underpin their world, but which constitute their knowledge base. It is important to ask how social work educators can challenge dominant assumptions and imagery in a way that leads to a changed consciousness.

How is social work with disabled people perceived?

The image of social work with people with disability is not an attractive one. In 1983, Oliver highlighted the inadequacy of training in social work and physical disability. He perceived a persistent tendency (in spite of recommendations of Seebohm,1968 and CCETSW,1974, for the development of a positive social work role), for social work in this area to be lacking in vision of its potential and therefore unattractive to practitioners (Goldberg and Walburton, 1979 page 93).In some instances social work practice is viewed as harmful (Phillips and Glendinning,1981 page 43). The Barclay report stated :

> ' Studies comparing caseloads of social workers of differing seniority' demonstrated that 'unqualified, inexperienced or assistant social workers carry proportionately more cases of physically handicapped and elderly people' (Barclay Report, 1982 1.17 page 11).

Oliver attributed the malaise of social work with people with disabilities to three linked factors. The first of these was the low priority afforded to this group and the consequent lack of career prospects. The second was the difficulty for professionals to perceive any potential in working with this group, which is intrinsically linked with lack of appropriate training as well as inadequate resourcing. It is important to ask why this situation has occurred.

The brief analysis of the history of discrimination against disabled people in Barnes' 'Disabled People in Britain and Discrimination' (1991) illustrates how impairment and people with disability have been subjects of negative imagery and inappropriate treatment throughout the ages. Traditional social work perspectives have embodied a perception of disabled clients as unreliable, helpless and unable to plan. (Satyamurti,1981) It is important to note how this may be linked to trends within service provision:

> 'A Department of Health report recently noted that service developments for disabled people are frequently 'given a lower priority than service developments for other groups of service users' - with budgets heavily loaded in favour of residential and other institutional forms of care. (Barnes 1991, page 126).

There are further links with teaching about disability and social work with people with disabilities. This is an area of social work education with unique features, which may be seen as arising from a combination of factors. Firstly, there is a strong tendency for disability and illness to be linked and therefore to be located within the field of medical science and regarded as the legitimate domain of doctors and therapists. Social work has adopted the medical framework of thinking which views disability as a tragedy, a problem of individuals, a condition which is the target of 'therapy', 'cure' and/ or rehabilitation. (Shakespeare,1993, Coleridge, 1993).

The formulation of the social model within the Disability Movement has led to a grappling with questions about appropriate intervention and a consequent re-framing of questions about the nature and role of social work and care services for, and with, disabled people. This has itself led to further problems about the role of social work, especially given the dilemmas for social workers of the adoption of a Care Management model.

Barnes views services with disabled people as characterised by institutional discrimination, based on false assumptions about the inability of disabled people to have control over their own lives:

> 'the traditional view that disabled people are not able to take control of their own lives has been reiterated and indeed strengthened with the assertion that local authorities should appoint 'case' managers to organise and manage 'care packages' for individual disabled people (HMSO,1989b in Barnes, 1991 page 124).

The very ambiguity of the assessment and care management roles within local authority services is highlighted by the generation of work on what constitutes good and bad practice (Ellis, 1994; Smale et al.,1993).

The British Council of Organisations of Disabled People has called for self-management rather than the proliferation of yet more professionals with control over the lives of disabled people whatever the role of such professionals (Wood, 1990). This does not offer a note of optimism to professional social workers with an interest in this field.

Oliver's 'Social Work with Disabled People' (1983) is still the standard work on Social Work and disability. It has been superseded by his publication 'Understanding Disability : From theory to practice' in which he articulates a discomfort with collective provision within the field of welfare services for people with disabilities being based on the identification of individual need (Oliver, 1996 page 64). The central question is 'why welfare dependency?' Oliver looks at how active citizenship and rights have become translated to passive citizenship and needs. He argues that the core issues are obscured by language; the movement from the language of justice or rights to the language of caring. Caring is a professional activity and justice demands that disabled people are given the right to autonomy - the right to define their own needs and as far as possible to meet them themselves e.g. through adequate education and employment opportunities. Oliver, in common with other writers from the Disability Movement (Barnes, 1991), argues that the way in which welfare services are provided has led to discrimination against disabled people at an institutional level.

Oliver and others (Marsh and Fisher; 1992, Ellis, 1993; French, 1994)argue that a change in professional culture is required if social work is to have an effective role with people with disabilities. This is generally envisaged as a move from the current position where professionals dominate to a climate of empowerment. However, there is no consensus about either the meaning or process of empowerment. Certain formulae, such as working in partnership and listening to users' own definitions of needs within the assessment process, rather than employing stereotyped responses to need, are suggested (Ellis, 1993; Smale et al.,1993). Parsloe and Stevenson (1993) are criticised by Oliver for their critique of changing the culture from problem solving to user and carer empowerment and their assumption that professionals can empower their clients through adopting appropriate practices (Oliver, 1996, page 147) and by changing language e.g. replacing the term 'client' with that of 'consumer'. Oliver argues that the individual and collective empowerment of disabled people can be seen in a number of ways:

- challenge to dominant social perceptions of disability as a personal tragedy and the affirmation of positive images;
- development and articulation of the social model of disability which provided both a critique of the existing individual model and the basis for more appropriate service provision and professional practice;
- the development of a disability culture and the public affirmation of this through the disability arts movement.
- the collective self-confidence of disabled people to engage in their own political activities.(Oliver,1996 page 152).

All of the above can be seen against the background of a wider struggle for citizenship.

Pervasive images and disability

It was stated earlier that it is not possible to divorce the two themes of images of social work, and images of disability and disabled people, when considering development of learning in disability. This is not only because the activity of practice is itself based on dominant images within society but also because it is important to consider what sort of understanding should replace these images.

The recognition that imagery is influential in forming the perceptions upon which action is based, and which itself underpins the status quo vis a vis disability and disabled people has generated efforts to manipulate that imagery and to create a different culture and reality. The 'Ordinary Lives' movement in the U.S.A (Zola,1981),the work of 'Groupement pour l'insertion des Handicapes Physiques', Acquitaine in France (1991), and the Rowntree project on the photographic images of people with disabilities 'The Creatures Time Forgot' (Hevey,1992) are different, but significant examples. The emphasis within each of these examples is to transform the image, thus replacing passive with active, object of charity with contributor to the community, and to display people with disabilities in everyday situations in a way that is at the same time both positive and inclusive. The ultimate aim is not just to change images but to change the responses of disabled and able-bodied people that so often go hand in hand with those images.

It would be naive to fail to recognise some of the possible pitfalls attached to the wish to transform the imagery attached to disability. Salient questions relate to not just how imagery can be transformed in a way that leads to more empowering constructions, but what replaces current imagery and the underlying assumptions.

Some work by Jordan and Smith in 1981 'What the papers do and don't say about disability' leaves no doubt about the damage being done by media portrayals of disabled people. Some work in the same year, The International Year of the Disabled, provides a prime example of how the media attempted to reverse this trend and to portray people with disabilities positively. Zola (1982) noted how the stories featured were often those of 'superhuman heroism and courage'. He describes his reaction as :

> The stories bring up in me and my fellow "crips" the same isolation we feel in the T.V Telethons where money is raised for those poor unfortunates' (Zola,1982, introduction).

His core criticism is that the messages of coping and overcoming are unreal; they do not accurately represent either the 'who' or the 'how' of ordinary living for disabled people. Zola believes that it is possible for disabled people themselves to communicate the experience of disability and to share it with able-bodied people but that:

> 'it is society's denial and resultant distancing which mutes the vocabulary of experience'. (Zola,1982 page 13).

Abberley (1989) argues that there is a problem connected to the wish to see disabled people as 'really normal' - an idea which has its roots in two schools of thought which are diametrically opposed i.e. the thinking which is characterised by the work of Goffman (1961 and 1963) on deviance and stigma, which sees deviance as a product of social values rather than a physical reality, and the work of writers like Sutherland where disability is seen as the common lot of us all, of humanity (Sutherland, 1981).

Both of these lead, in different ways, to a situation where the very real dilemmas and problems attached to being disabled are reduced, which in turn affects responses. Abberley argues that the 'really normal' approach is profoundly mistaken. He believes that what is required is :

- Repeated and detailed documentation of the quantitative and qualitative aspects of difference between the lives of disabled people and non-disabled people.
- Theoretical accounts of how and why this has happened, which are directed towards change (Abberley, 1989 page 56).

Abberley, therefore, advocates a model of teaching about social work and disability which simultaneously asserts and stresses real differences while combating false and oppressive explanations of the origins of difference. Abberley also addresses considerations of the origins of professional knowledge - starting with definitions, which are made by those in power i.e. medical and welfare professionals. This is true at all levels e.g., within the process of assessment. Concepts of normality are developed both as a product and condition of medical and welfare systems.

Post modernism's contribution to the debate : the politics of identity

Disabled identity is a growing theme within writing upon disability (Morris,1989, Oliver, 1996). Peters (1996) points to the relevance of cultural politics within post modernism with its idea of relevance, which is not coded as :'rejection of tradition but as a criterion for determining inclusion'.

Culture is viewed as a terrain of struggle, power and conflict rather than an artefact of social construct. Within the politics of disability identity there is a constant challenge to 'cultural borders' for example, the borders within educational provision as denoted by mainstream and special education. Part of the struggle is the deconstruction of these barriers.

Post modernism offers the possibility of new knowledge based on the views of disabled people as they work towards a critical consciousness of their own identities. Oliver sees this as the ability of disabled people to think critically about their lives ,but acknowledges that not all disabled people possess this critical awareness:

> 'Not all disabled people do of course; some think the only problem is non-disabled people; some think the problems they face are their own fault; some think disabled people should accept the hand-outs they are given and be grateful' (Oliver,1996 page 126).

Peters (1996) sees a decisive role for self-learning, and self-expression among disabled people as a prerequisite for challenging dominant views. The 'insider's viewpoint', i.e. the viewpoint of individual disabled people, is seen as the agent of challenge, with the ultimate aim of deconstructing barriers. Peters is critical of the social constructivist theory within sociology, on the grounds that it is a paradigm which has failed to effect change in attitudes; it is culture bound and based on consensus and has been largely developed by people from outside the Disability Movement. 'Critical pedagogy' is advocated as a more valid alternative. This is defined as:

> 'working towards a critical understanding of the world and one's personal relation to the world' (Peters, 1996 page 223).

Change must start with disabled people and their commitment to change practices within society, e.g. labelling and segregation:

> 'Those of us with disabilities who know what it means to be disabled in the most basic sense of the word through our daily struggles with mobility, physical difference and intellectual challenges, must put forward a disability consciousness which drives creative discourse in the academy' (Peters.1996 page 224).

Disability consciousness is seen as evolving through the dual processes of analysis of cultural borders and of the contradictions created by existing paradigms of disability as deviance. Peters believes that:

> 'If we teach young people with disabilities how to become border crossers at a personal level, the cultural symbols and metaphors prevalent in today's society begin to disintegrate' (Peters, 1996 page 224).

In what he describes as his own 'intellectual journey' Oliver looks at the role of disabled people in what is essentially a journey towards liberation. He has borrowed the concept of the 'organic intellectual' (Gramsci cited in Oliver,1996 page 167) to describe people with disabilities who have developed a critical way of reflecting upon experience and whose work is grounded in personal and collective experience. This is an important concept as it raises, in another guise, the issue of who can speak for whom. Oliver explores the issues of 'allies', noting the contribution of 'positional intellectuals' to movements such as the civil rights movement in America. He suggests that 'organic intellectuals' are less likely to distort the personal and collective experience of people with disabilities, and that the only people who should speak on behalf of disabled people are members of bona fide organisations of disabled people (democratic and accountable organisations) (Oliver, 1996).

Training programmes in disability : what can be learned?

Training in disability is characterised by three basic approaches which, although they may be mixed within programmes, come from particular philosophical or pragmatic standpoints. Most traditional approaches to training in disability originate in medicine and view disability as pathological, individual and tragic (Brechin and Liddiard,1981). The professional role is that of expert. Such an approach has gradually been replaced by different approaches, which can best be described as disability awareness training and disability equality training.

Disability Awareness training has been described as :

> 'programmes of study which are specifically aimed at changing attitudes and behaviour towards disabled people'(Swain and Lawrence in French. ed. 1994 pages 87-103).

The roots of disability awareness training are found in the move from institutional to community care and the perception that the quality of life of people with disabilities, in terms of integration and participation, is negatively affected by the attitudes and behaviour of other people (Florian and Kehat, 1987 page 57 cited by Swain and Lawrence, 1994). Attitudes, and ultimately behaviour, are regarded as having a knowledge component (cognitive), a feelings or emotional aspect and a behavioural aspect. For example a belief that disabled people are ill and that this may be contagious will lead to a feeling of fear and avoidance. The main premise is that changed attitudes will lead to changed behaviour. Most Disability Awareness programmes include a combination of information, (aimed at developing correct knowledge), role play or simulation exercises (to influence the emotional aspect) and contact with disabled people (which targets behaviour).

At first glance raising of awareness of disability would appear to have some credibility and some aspects have limited support. Wright (1980) and McConkey and McCormack (1983) support the positive value of contact with disabled people, especially if the contact is as equals. This is echoed in Wright's 'coping versus succumbing frameworks' (Wright 1980 cited in French,1994). This would seem to link to ideas of positive imagery. Disabled people who are seen as coping challenge the belief that disabled people are tragic and dependent and this can lead to more positive attitudes.

Simulation, e.g. an able-bodied person experiencing being in a wheelchair, has been attacked by French (1992 pages 257 - 266) as potentially counter-productive. The inherent danger is that simulation may suggest to an able-bodied person that they are understanding or experiencing the situation of a person with a disability by being subjected to certain restrictions. However, this is not realistic and could ultimately lead to reductionism and false understanding - the able-bodied person confined to a wheelchair for a day is able to leave behind the restrictions and has none of the ongoing struggle or engagement with the problems which disabled people constantly experience.

The most far-reaching criticism of disability awareness training is its explanation of the aetiology of attitudes and its assumption that changed attitudes will lead to change in behaviour or practice. Attitudes are viewed as responses or reactions to impairment e.g. blindness evokes fear. This does not start to consider why fear may be a response to blindness and furthermore it attributes the response to the impairment, and by implication to the blind person. An alternative approach is Disability Equality Training. The main differences are illustrated below:

Awareness	**Equality**
Impairment	**Disability**
Improving attitudes Towards disabled people	**Changing understanding of disability and changing practices**
Individual tragedy	**Social model part of wider struggle for equal opportunities**
Simulation	**Discussion based**
Led by able-bodied trainers	**Is devised and delivered by disabled people.**

The Disability Equality model of training provides a framework, which is consistent with thinking within the Disability Movement about:

- who should speak on behalf of disabled people: releasing the voice of experience;
- the politics of disability and of disabled identity.

Because the emphasis is on disability rather than impairment it presents the opportunity for the sort of detailed documentation of qualitative difference, and day to day struggles of disabled people from their view point (Abberley, 1989),thus enabling understanding of what are the real issues and concerns. This leads on to consideration of current practice and its implications for people with disabilities. Definitions and language are an integral part of this process.

Because Disability Equality training is located within the social model of disability and viewed as part of the wider struggle of disabled people for equal rights and citizenship it provides a context for exploring theoretical concepts and ideas as a basis for informing practice. Discussion based methods replace simulation as they offer genuine openings for dialogue and exchange of ideas and experience. They denote a change of relationship between the participants with the potential to address power differentials. Finally, Disability Equality training gives ownership of the process to people with disabilities themselves and consequently begins to challenge traditional cultural barriers within education and social work.

Conclusion

This chapter has surveyed some of the main ideas relating to adult learning before moving to review some of recent thinking about social work training in general and teaching about social work and disability in particular. What emerges is the need for social work to grapple consciously with some of the complex issues of practice that empowers people with disabilities. This must include an evaluation of the role of social work; an area which is subject to ongoing debate and where workers have to work within policy and organisational constraints and practices which are themselves disempowering.

The contribution of both recent thinking within social work education and disability equality training has been its recognition of the connection between the personal and the political, the subjective and the theoretical. Themes have been raised such as the need for communication by disabled people of experience, challenging imagery, the politics of disabled identity and the contesting, and ultimate erosion of cultural barriers within a movement towards equality and liberation.

Developing thinking within the field of training in disability, and within mainstream social work education, therefore, presents a fundamentally different set of agendas for participation by service users and carers; these include :

- dialogue and the challenging of traditional concepts of power within education (Gould and Taylor page 154).
- Subjectivity and the emotional world of self (Gould and Taylor,1996 page 153);
- Cognisance of the role of metaphor and imagery in learning (Bullough and Knowles, 1991 page 123);
- ‘Social diversity and what this means for anti-discriminatory practice’ (Best and Kellner (1991) cited in Thompson, 2000 page 72).

Chapter 3

THE DEVELOPMENT OF PARTICIPATION AT A LOCAL LEVEL

Introduction

This chapter offers an account of the context of participation by service users and carers in the teaching of Physical Disability on the Diploma in Social Work at Swansea University. There will be some brief analysis of the inclusion of a group of service users and carers from Dyfed in terms of the themes of participation in chapter 1 and some basic thinking about what this meant for the inclusion of service users and carers in the teaching team at Swansea. The account in this chapter is important because it says something about the starting point of a journey, which at the time was largely unsignposted.

The questions that form the basis for this chapter are:

- Why were service users and carers introduced into what is a professional domain?
- What was the nature of participation?
- How was participation in training facilitated?
- How effective were the early attempts at involving service users and carers?
- How were the lessons applied to the involvement of service users and carers on the Diploma in Social Work at Swansea University?

The material used in this chapter is based largely on documentation collected by Dyfed Social Services in 1992 as an evaluation of their Foundation Training programme for Community Care.

The development of service user and carer participation in Dyfed

The development of participation in Dyfed was part of a more general move to include users in the personal social services (Beresford, 1992, Management, 1992) On the whole the notion that participation is a good thing was prevalent at the beginning of the 1990s. The National Health Service and Community Care Act, 1990 was seen to offer greater opportunities for user involvement in the planning and delivery of services. By 1992 Beresford was able to assert that:

> 'It's no longer a question of "is user involvement a good thing?". Users' organisations demand it. Legislation requires it' (Beresford, 1992 cited on page 59 of Oliver, 1996).

The above is reflected in the history of participation in Dyfed. At a management level there was a move to include service users and carers in services, coupled with a growing demand for inclusion from service users.

The Social Centre for younger people with disabilities was opened at Coleshill in Llanelli in 1986. It was built at a time when the traditional role and philosophy of Day Care (Brechin et al., 1981)and Residential Care (Miller and Gwynne, 1971, Morris, 1989) for people with disabilities, was being challenged (Oliver,1983, Barnes, 1990). Barnes' research into attempts to involve users of Day Centres for the Younger Physically Impaired suggests many barriers to participation (Barnes, 1990). In his analysis he looks at the principal functions of centres for people with physical disabilities by referring to the four models of care identified by Miller and Gwynne (1981 cited in Barnes, 1990 page 34). All four models infer, and encourage, varying degrees of passivity and dependence on the one hand and social exclusion on the other. At best, such provision is viewed by Barnes as an institutional response to the phenomenon of exclusion of people with disabilities from the mainstream of social and economic life and inevitably bound up in a culture of discrimination and stigma.

But Coleshill was a long awaited resource, which was lobbied for by disabled people in Dyfed. Before this younger people with disabilities had often been isolated at home, or using resources geared towards other client groups. People with differing disabilities, life experiences and backgrounds were able to meet on common ground, offering new possibilities for the development of a community of interest (Mayo, 1998 page 162) and for participation.

Coleshill was on the map because of perceived good practice from early in its history. In 1988 Coleshill was nominated by the government as a local 'model activity' for inclusion in the Social Integration network of the European HELIOS (Handicapped in Europe Living in an Open Society) programme. This gave staff and service users opportunities to travel and to link with other projects in Europe in order to exchange ideas and information about practice. The broad themes of the Social Integration network were independent living, care in the community, access and mobility and co-ordination of services.

What was the nature of the participation?

An early feature of Coleshill Social Centre was the encouragement by management of user involvement through the establishment of a user committee. An unpublished paper says of this development:

> "There has been a continual growth in the development of the user group since the opening of the centre and the formation of the 'Client group committee.' While adopting a philosophy of user involvement in the decision making processes which affect the day to day management of the place it was also generally felt that the group lacked the self-confidence to establish itself as a group of people to influence change". (Aitken, 1991)

However, by 1990 the user co-operative CATCHUP (Co-operative Action to Change and Hurry Up Progress) had been formed. The name is symbolic of the early development of political awareness among disabled people in Dyfed. CATCHUP was constituted as a co-operative of disabled people and their supporters, autonomous of the local authority facility. CATCHUP's Management Committee was biased in favour of disabled people. It was composed of ten people with disabilities and five others who were either able-bodied or representatives of organisations working with disabled people. CATCHUP's main focus was an information and advice service run by disabled people for disabled people, with the financial aid of Dyfed County Council and the Welsh Office.

In 1992 Dyfed was chosen from 22 local authorities as one of four case sites for the 'From Margins to Mainstream' project funded by the Rowntree Foundation. The goal during the two years of the project was to enable participant local authorities to:

> ' make user and carer involvement an everyday part of the way its community care services are planned and run' (Management, 1992);

through a programme of consultation, exchange and facilitation, co-ordinated at a national level by the Office for Public Management in London. The benefits of participation were seen both as a 'means to an end' and an 'end in itself'. Hence, participation is advantageous because it potentially leads to more responsive and better services and, at the same time, there are gains for service users and carers of 'being involved' (Management, 1992). The underlying philosophy of the project was the empowerment of users and carers (Miller, 1993 page 10).

The goal of 'From Margins to Mainstream' was improved and more flexible support for service users and carers, not benefits to local authorities. Part of the learning gained during the first year of the project was about organisational resistance to change. A tendency was noted for :

> ‘community care organisations to view user and carer involvement primarily in terms of benefits to the organisations’ (Miller, 1993 page 10)

A further problem was user and carer involvement being seen as a threat by staff. It was noted that staff often feel powerless vis a vis their own managers and that alliances with service users and carers have the potential to empower staff as well as service users and carers.

Transferring participation into the field of training

Documentation from the Coleshill Centre shows that training was on the agenda from early in the Centre's history. As part of the first phase of HELIOS service users were involved in testing an educational package with primary school children. This, and other initiatives aimed at raising awareness of disability, embraced a message :

> If you want to know about disability, ask someone with a disability’ (Aitken,1991)

Such a philosophy had been evolving within the Disability Movement from the 1970s onwards and is characterised by works such as Morris' 'Able Lives: Women's Experience of paralysis' (Morris, 1989) and Oliver’s ‘Understanding Disability From Theory to Practice’ (Oliver, 1996). In the latter Oliver uses his own biography as a basis for theorising about disability and the development of political awareness and involvement.

How were service users and carers enabled to participate?

The earliest involvement in training sessions was embarked upon with little formal training of service users. The rationale was somewhat vague:

> ‘The hope was that even if the group or individuals were bored senseless they might take away with them a subconscious view that those with disabilities do in fact have something to offer (Aitken,1991).

But it was soon realised that service users and carers required preparation in order to maximise their contribution:

> 'We now want to ensure that those who come into contact with the co-operative on a formal basis go away fully aware that people with a disability have a contribution to make'. (Aitken,1991)

In 1991 Dyfed Social Services invested in a three-day course of 'Training for Trainers' for eight service users. Recruitment for the course was based on equal opportunities and aimed at establishing a group with a cross- section of disabilities, ages and life experiences. The male/ female ratio within the group was looked at extensively. The selection process was aimed at identifying those people who were capable of doing the job. Topics included in the training were:

- the purpose and aims of training;
- how to run a training session;
- perspectives on disability and attitudes to disability;
- how to tackle specific subjects such as benefits, disability awareness.

The early experience of involving service users and carers in training

Service users and carers were routinely included in the Foundation training days on Community Care in Dyfed in 1991 and 1992. Their contribution was to offer insight about 'what it is like to be on the receiving end of services'. They were also included in multidisciplinary discussions of case material..

In keeping with standard local authority practice some feedback was collected from participants in the Foundation training. In 1992 the Training Section of Dyfed Social Services Department prepared an evaluation report and I was allowed access to the material on which this was based. A small amount of time was spent reading the material with the aim of establishing emergent themes. The quotes, included in the following section are meant to be illustrative. The material can be grouped as follows:

- How service user and carer involvement was viewed;
- Assessment;
- Planning of services;
- Philosophy and values of community care.

How was the service user and carer contribution viewed?

While a number of attendees alluded to the positive nature of the user carer input, far less offered specific feedback on what they thought this was. An evaluation report prepared by Dyfed Social Services training unit made the following judgement:

> 'Social Service staff who attended appear keen to modify their practice'(unpublished report 1992).

The above assertion is not verifiable. It has not been feasible as part of this study to look at whether this, or subsequent programmes of training which include service user and carer perspectives, are successful in creating significant changes in the behaviour and practice of those who have taken part. This would require using a framework for evaluating human resource initiatives such as that developed by Brinkerhoff (1987, pages 15 and 16).

However, references to the quality and value of the service user and carer contributions do suggest that the intention to make the input of service users and carers more professional (Aitken, 1991) had worked:

> 'Our big success was the consumer, carer slot. They were both excellent. Both very different experiences and approach, but both very powerful messages. They injected a note of realism and energy into the proceedings and were both ideal focuses for the act'.

This, and other comments such as:

> ' Good : A good introduction to the concept of community care. I thought that it was relevant having a carer and disabled person giving their views on community care and expressing needs',

illustrate how the contribution of users and carers was viewed as an important within the context of community care, which is consistent with the Griffiths report and the need for managers to ensure a greater say for users in what help is given to them (Griffiths, 1988).

The evaluation by Dyfed Training Department refers to the low level of response from service users and the ineffectiveness of advertising in attracting service users and carers. Staff had reflected a desire for more inclusion of disabled people within the sessions.

> "I would like more disabled people present".
>
> "I thought the course was very good. I enjoyed the disabled man talking. I would like to see more disabled people taking part".

The one reservation was about how representative service users with a physical disability could be. Many of the professionals worked in the care of elders and found it difficult to relate to the specific experience of younger people with a physical impairment and queried how easily the input could be transferred to their work with elders.

Assessment

The Practitioners' Guide to Care Management and Assessment produced by the Department of Health and Social Services Inspectorate in 1991 makes the following assertion:

> ' Community Care policies challenge all those in the caring services to rethink their approach to arranging and providing care' (Social Services Inspectorate, 1991 page 9).

The emphasis was upon needs-led rather than resource-led assessment and adapting services to individual needs rather than making people fit into existing services' (SSI, 1991).

Guidance at the time and a range of subsequent ongoing publications (Challis and Davies, 1986, Ellis, 1993, Ovretveit,1993, Payne,1995) feature the debate about needs-led rather than service led assessment procedures within community care.

The evaluation material from Dyfed established that staff had been prompted to think about their approach to assessment. The following quote is included because it demonstrates how at least one member of staff had been prompted to think about the complexity of assessment:

> 'The training showed how difficult it is to make an assessment.'

Planning

Involving service users in planning was also a theme:

> ' The people responsible for drawing up plans for the implementation of this act need to listen very carefully to the intended consumers and to the care workers on the ground in all fields and take note of what they say '.

It is significant to register the language and concepts inherent in the same quote, particularly the use of the work 'consumer' with its overtones of community care provision within a 'market' economy of care and the idea of multidisciplinary working. Perhaps the notion of devolved responsibility at a level closest to the service user and carer themselves is also implicit.

The philosophy and values of Community care

Words such as 'control', 'independence' and 'choice' emerged as strong themes in the evaluations. This is not unexpected as such concepts had been the common currency of The All Wales Strategy (Welsh Office, 1991), a 10 year initiative which encouraged Social Service and Health authorities in Wales to develop high quality services for people with learning disabilities. The right to live an ordinary life was a central tenet and frameworks such as the five accomplishments namely:

- Community presence;
- Choice;
- Competence;
- Respect;
- Community participation. (O'Brien and Lyle,1987 in Nocon and Qureshi,1996 page106)

were used to measure progress.

But the Community Care Act highlighted that there was often a shortfall between philosophy and actual practice. Some Social Services Inspectorate documentation of the time says:

> 'The fundamental aim of community care is to promote the independence of individuals so that they are able to live as normal a life as possible' (SSI,1991 page 16).

The following quotes from practitioners in Dyfed denote that they had been challenged to re-evaluate practice based on assumptions about disabled people:

> "It made me think about the need for independence for people who need care".
>
> "Do the professionals sometimes take on too much assuming that the client can't do it for themselves?"
>
> "Good, it made me more aware of what people need in the form of care".

Care needs were redefined as :

- Independence;
- Choice;
- Asking the person what s/he wants;
- Consideration of the user's/carer's perspective.

While the above indicates a shift in thinking it does not offer any clues to how this took place. Another participant suggests the idea of role models, positive images:

> "Thought CATCHUP was an excellent organisation - it showed that users are capable of great input into their own lives".

The final quote identifies the inherent tensions created by notions such as consumerism within the market philosophy of community care:

> "It was interesting to see old values and ideas of 'care' clashing with new ideas and values e.g. self determination of needs clashing with the ideas of 'doing good to people'; 'providing what client perceives as his/her needs clashing with what the supplier perceives as the 'needs' in terms of 'what' and restricted by resources available at present to be drawn upon".

It links with some of the comments made by service users and carers about staff values and highlights the fact that participation challenges both professional and managerial agendas for the provision of care (Braye and Preston-Shoot, 1995 chapter 5).

The experience of participation in Community Care Foundation Training from the point of view of service users and carers

An evaluation session with users and carers was held in November 1992 to look at what had been good, bad or difficult about participation in the Foundation Day training. Comments were made mainly from an individual viewpoint, but some were supported by other group members.

Some practical issues, such as timing and travel, were raised but were subsidiary to considerations of the experience and process of participation, namely delivering a pre-written talk, responding to questions and taking part in small group discussion. Audience response and its impact upon participants was also discussed.

It is not surprising that the most controversial part of the experience was dealing with questions as these were the main way in which service users and carers were able to assess the response and attitudes of their audiences. Some service users and carers found the question and answer session stimulating and creative, an expression of genuine interest by the audience. Others were uncomfortable because of the expectation to respond without preparation and because of the nature of the questions asked, comments made and attitudes portrayed.

Some questions suggested to group members that professionals lacked knowledge e.g. "What kind of care do you like/need?" Others simply viewed such queries as indicative of different levels of knowledge, experience and motivation within the audience itself.

Some group members perceived questions about personal life style as judgmental, e.g. carers had been confronted with issues such as choice of a disabled partner and the advisability of having children.

Patronising attitudes were identified by some of the group, particularly in relation to staff members who appeared to assume that they knew best for the people in their care. This was largely interpreted as resistance to change and service users were also able to speculate on the threats posed to the status quo by the proposed changes :

> “Some people came with fixed ideas, but others are obviously worried about the future : community care is a threat to jobs”.

Assumptions about perceived difference also posed problems. Two service users had been in a situation where a professional had been clearly unhappy about certain expectations being expressed by disabled people:

> 'You want all these things you disabled people - you are different to us'.

Some of the above comments raise some possible issues of culture; not just the culture of care and of social services organisations, but of the external culture within which organisations function.

Work within the Welsh context (Wenger,1991) has demonstrated a link between issues of language and culture and those of care. To look at this closely would require a further study but service users and carers did suggest that responses were more receptive in some geographical areas than others. Experience of some training days had been that there had been some negativity, even hostility. There is a possible association with cultural factors such as attitudes within rural Welsh culture to disability and where traditional views could influence staff perceptions of, for example, disabled people who marry and have children (Jones, 1993, Barnes, 1995).

An example of positive feedback related to how residential care staff had been open to the idea of intimidation of residents who are physically dependent and therefore vulnerable. The service user was able to focus on the issues of dependency within a caring relationship as a means of helping residential care staff to understand the power dynamics within caring relationships.

Overall discussion within the session was more about the costs than the benefits of participation. In spite of this the group judged that benefits outweighed costs and were motivated to be involved further. Service users also thought that the informal contact, the opportunity to meet with professionals over coffee and at lunch and to take part in group discussions had been more useful than the more structured part of the exercise.

How were lessons transferred to the Diploma in Social Work in Swansea?

It was the early work in Dyfed that provided the impetus for inclusion of a group of service users and carers as trainers at Swansea University. The group of trainers was keen to work collaboratively. As a group they had built up a degree of confidence and familiarity with some of the key issues for themselves as users of services and for others as service providers. They were aware of the pitfalls as well as the potential benefits of involvement.

The course at the University in Swansea was the first in Wales to transfer to the new Diploma in Social Work qualification in 1991.The inclusion of service users in the training of student social workers had a low profile. While there had been moral commitment to the involvement of disabled people in teaching on disability based on the belief that this would help students to learn there was no clear rationale for involvement. It is likely that bringing disabled people into an unprepared situation was negative from their viewpoint and that of the students. The emphasis was on sharing the experience of disability, but no real training or support was offered.

In 1992 a mature student requested a voluntary organisation placement in physical disability. It was agreed to place the student with CATCHUP. The student worked alongside service users and carers in the Advice and Information Service. S/he undertook a small evaluative study of the service and linked with a local authority social worker. The learning outcomes from the student's perspective were:

- the opportunity to view disability from the viewpoint of local authority services;
- the opportunity to consider appropriate use of resources;
- the adequacy of service provision;

- good and bad professional practice;
- flaws in social policy;
- disability benefits;
- difficulties surrounding funding and care for independent living;
- issues of discrimination.

In the practice report s/he says:

> "A heightened awareness of these issues must, without doubt, influence professional practice. The social worker must respect the dignity and acknowledge the right of people with disabilities to define and assess their own needs, to provide them with the information which allows them the opportunity to make their own choices and to facilitate the enactment of that choice."

A second placement in 1994 strengthened the role of service users by involving them in every aspect of the placement from contract development to supervision and evaluation of progress. This student report noted:

> "The other important issue which was highlighted by this placement was that of the changing role of social workers. The principles of community care, which stress the need for disabled people to take care of their own lives by being involved in their own care assessments and participating in the wider planning and developing of services, demand that social workers become enablers and facilitators. Therefore, if social workers are to carry out this role in an effective manner it is necessary for them to change their perception of disability. Rather than perceiving disabled people as a problem and concentrating on the disability rather than the person, they must see them as people first. People who have the sort of abilities and capacities that can enable them to overcome difficult obstacles."

In their reports both students stressed the centrality of 'enabling' and 'facilitating' in social work with disabled people. The second makes a clear link between enablement and 'changed perceptions of disability and disabled people. Both placements placed a clear emphasis on the interaction, roles, relationships and power dynamics between the student and the service users who managed and participated in CATCHUP.

Involvement in the teaching module on Physical disability

The service user and carer trainers were first introduced to the teaching on the Diploma in Social Work in 1993, however, the user and carer dimension was not considered in any systematic way until 1994. The method of teaching known as Enquiry and Action Learning (Burgess, 1992) informed the programme and its ideal of partnership between academic institutions and social work agencies was adopted and extended. The planning, delivery and evaluation of the module included a Principal Officer from Dyfed Social Services, members of CATCHUP, a course tutor and a student.

A planning and preparation session took place in February 1994. The agenda was how and what should be taught. During the Spring of 1994 it was decided (on the basis of resources) to include the teaching about physical disability within a module on work with adults entitled 'Ageism and Diversity' This imposed limitations of less formal teaching time and of work with larger groups – a less than ideal situation.

Within the planning group there were some differences in perception between the able-bodied members of the group and the disabled members. The main tensions were about definitions and models of disability. The disabled service users viewed the apparent 'either/or' way in which disability is viewed as a medical or social construction as facile.

The agreed aim of the teaching was the open debate of principles and issues from the viewpoint of the different stakeholders. Students with differing perceptions and levels of experience of physical disability would thus be given the opportunity to formulate questions, listen to different perspectives and examine key principles such as empowerment and control.

The group task centred on case study material, some of which was based on the life experiences of members of the planning group. The group task was introduced in the first session along with an exploration of language, definitions and the legal framework. The student in the planning group proposed that students should not be told that the case examples were based on the actual life experiences of participants. The role of the service users and carers, which was confined to the final session, when students gave a group presentation, was that of a panel of experts.

Rethinking the curriculum

There were a number of influences on the revised module of teaching that was presented in the autumn of 1994. On the basis of feedback from students and trainers on the sessions on Ageism and Diversity it was agreed that more time should be allocated to the subject of physical disability in the curriculum. Allocation of time between formal and informal contact was reconsidered.

The need for smaller groups and opportunities to explore issues with the service users and carers was seen as crucial by all concerned. The function of the group in co-operative learning in EAL has been mentioned in chapter 2 (Burgess, 1992 page 28). Group work theory supports the need for groups to be small in order to facilitate effective group working and interaction (Nelson-Jones, 1991 page 53). Small groups encourage greater interaction between participants. Both students and service users and carers viewed interaction as a key element of the learning process and advocated more systematic involvement by service users and carers in the teaching process.

A workshop at a From Margins to Mainstream Conference at St Clears in June 1994 on service user involvement in the training of student social workers suggested that the role should be:

- To give them an opportunity to ask about the issues confronting disabled people;
- To create an awareness of how they should relate to disabled people;
- To give an awareness of the problems that often confront disabled people in all situations i.e. shops, schools, colleges etc. (Unpublished report, June 1994).

A paper produced by the Office for Public Management in 1994 answered the question 'Why?' should service users and carers be used as staff trainers by pointing to the outcome of "To provide services in a way that users and carers desire" (Management,1994)

The curriculum was also influenced by academic discourse. The work of Oliver on social work with people with disabilities suggests a life stages perspective and the implications for social work intervention. Some stages are viewed as crises for people with disabilities and their families. These crises relate to times of transition, e.g. from childhood to adulthood, within which the individual is interacting with social systems which may be complex, unresponsive or even hostile.(Oliver,1983 page 59). Literature on disabling environments was also relevant (Finklestein and Rae,1991, Barnes 1991 pages 3-7,149).

Within the module itself students were asked to consider the issues of disability from the perspectives of the key actors - the service user, the carer, the wider family e.g. grandparents and siblings, service providers and other public bodies and the social worker. They were asked to appraise the medical perspective and the social perspectives and the various models of practice (Barnes,1990 page 60) and to consider how different theoretical starting points produce different responses to disability and disabled people.

The major challenge for the students was to make the transition from a medical understanding of disability to the social model and then to consider what this might mean for social work practice e.g. policing and controlling versus enabling and supporting (Beresford,1994). Participation was a means to an end: the development of social workers who were aware of the main issues in work with disabled people and their carers and who were able to start to develop strategies for working in a non-oppressive way, based on the agendas of disabled people and carers.

The programme

The teaching programme was entitled: Physical Disability and service user involvement. Its stated aims were :

- To consider social welfare practice in relationship to adults with a physical disability and their carers.
- To consider the effects of 'disablism' within a social model of disability.

  Objectives :
- To consider definitions of disability and impairment and their implications for practice.
- To develop an awareness of key legislation.
- To consider the meaning of disability at different stages i.e. transition to adulthood, young adulthood and middle age.
- To start to develop thinking about appropriate social work practice with adults with physical and sensory disabilities and with carers.

The module was given a total of twelve hours structured teaching and learning time, plus the potential for students to spend more of their own personal time utilising the resource pack and the resources of CATCHUP. Students worked in groups of approximately twelve and were further subdivided into groups of three for the individual tasks within the module.

The most significant change was the way in which service users and carers were involved in the module; which was viewed as a guiding principle of the course. The trainers from CATCHUP agreed to participate more fully in the programme in the role of consultants within the whole module. The issue of representativeness was addressed by using a cross-section of case material, which not only considered life stages, congenital and acquired disability but also incorporated gender and cultural issues.

The CATCHUP group organised the input to the training. It was agreed to change the case material because not all service users and carers were content to be subjected to scrutiny of themselves and their own personal experiences. The first session allowed the opportunity to negotiate boundaries. The teaching outline can be found in Appendix 4.

Conclusion

This chapter has traced the development of participation by a group of service users and carers linked to a local authority based day and residential service. The main focus has been inclusion in staff training in a local authority and how the experience was used as a foundation for work with social work students.

While participation was encouraged by developments at local, national and European levels, it is not entirely clear who provided the main impetus for participation. Managerial encouragement of involvement, e.g. through the development of the user committee, emerges as a major factor, but this needs to be set in the wider political context of the 1980s and early

1990s. The training agenda for the implementation of the National Health Service and Community care Act, 1990 was a key influence and provided the resources to facilitate user and carer involvement in training. But, the politicisation of service users should not be overlooked.

Some themes, which emerged from early feedback from staff in Dyfed and from service users and carers on their early experiences as trainers, have been included. These formed the basis for the curriculum for the module ‘Physical Disability and Service User involvement.’

Chapter 4

RESEARCH METHODOLOGY

Introduction

The research design for this project has been based on a range of methods, and has taken into consideration what is consistent with 'ethical' research practice in the specialist area of disability.

It should be said at the outset that the search for ethical and effective paradigms for research into disability is an ongoing one, and that significant work has been done within the short period since this research was started in 1993. New insights (as well as perspectives which were current at the time when the research was started) will be used as a way to make a critical evaluation of the work which has been done.

It was not initially envisaged that the research period would be so long and an explanation of the chronology would be helpful at this point.

CHRONOLOGY OF THE RESEARCH

Preparation for the research

1992 : Community Care Foundation Training.

November 1992 to February 1993: Student placement with CATCH UP.

Discussions with the CATCHUP committee and Dyfed Social Services of possible research initiative.

November, 1993: Group evaluation of participation in Community Care Foundation Training.

Development, research and evaluation

January - March 1994: Access to evaluation material on Community Care Foundation Training.

March 1994: Planning meeting for Disability module on the Diploma in Social Work at Swansea University.

April/May 1994 : 4 week Enquiry and Action Learning module. Collection of routine evaluation material.

May to August,1994 : student placement with CATCHUP.

August, 1994 : Meeting to review the EAL module with student, researcher, Principal Officer Physical Disability, Dyfed Social Services and a group of service users and carers.

June to September, 1994: Interviews with service users and carers and analysis of responses.

January, 1995: Planning of EAL module with service users and carers. Revision of case material and learning pack.

February, 1995: 4 week EAL module : collection of routine evaluation material.

October, 1995 : 4 week EAL module: Physical Disability and service user involvement

October 1996 : 4 week EAL module : collection of routine evaluation material.

August 1997 : Interviews with 3 students, analysis of tapes and transcripts and comparison with information from other sources.

Submission of dissertation: June, 2000

Ethical commitment and underlying principles

Research into disability related themes is the subject of growing interest, particularly from within The Disability Movement. (Rioux, 1994, Oliver, 1996). The activity of research into disability, as conventionally practised, is viewed with suspicion by a number of academics. Oliver (1996) questions whether the role of research in this field is to interpret or to understand the experience of disability. He concludes that most mainstream research has been interpretative and located within a medical framework and that most research outcomes are the articulations of able-bodied people about disabled people and their experiences.

Davis (1986) has pointed out that the relationship of disabled people to most research is that of passive objects for interviews and observations, designed by researchers with no experience of, or sensitivity to, the day to day reality of disability. This has led, in the opinion of some commentators (Rowan, 1981), to disabled people becoming alienated by, and within, the very process which ultimately affects the quality of their lives. This alienation is underlined by research practices such as lack of prior consultation both on the issues, which require researching, and on how the research should be conducted. As a result Oliver argues that disabled people have come to see research as:

> ‘violation of their experience, irrelevant to their needs and as failing to improve their material circumstances and quality of life' (Oliver,1996 page 141).

The relationship between disabled people and the research community has led not just to disillusionment, but a situation in which research is viewed as part of the oppression of disabled people. The search for new research paradigms has led to considerations of ethical principles that impinge on the nature of what is being researched as well as the manner in which research is conducted.

Zola (1982) has highlighted the problem that 'because prejudices and paradigms run deep' it will take tools and time to develop the voice of people with disabilities. This raises many issues, not least the role of non-disabled people in both research and development and their role in relation to disabled people (Barton, 1994 page 10, Hurst, 1996 pages 123 -143). The core of these issues relate to questions about the right of non-disabled people to be involved in the struggle of disabled people - ultimately are non-disabled people contributing to, or hindering the emancipation of disabled people?

While acknowledging some of the inherent problems of research within this field a collection of articles on new research paradigms in disability published in America (Rioux and Bach,1994) has suggested some guiding principles:

- Critical disability research should question the dimensions that relate to disability ... within a framework of human rights and ethics.
- There is a need to change the relationship between researcher and people with disabilities, and to incorporate the voice of disabled people.
- The recognition that 'because prejudices and paradigms run deep' it will take tools and time to develop the voice of people with disabilities (Zola, 1982)
- Equality is a fundamental basis for a critical perspective.
- There is a need for a framework for thinking about disability which is rooted in a moral and political commitment to equality and a methodological framework which makes explicit its moral and ethical commitments.
- The importance of acknowledgement of the 'discourse of disability' and issues of language and power as they relate to construction of disability.
- Research has a role in developing more enabling constructions of disability and of releasing the voices of people with disabilities.

A research model, which is consistent with the principles of Rioux et al, is that of 'emancipatory research' with its twin principles of empowerment and reciprocity. Oliver suggests that the importance of emancipatory research is :

> 'in establishing a dialogue between research worker and the grass roots people with whom they work, in order to discover and realise the practices and cultural needs of these people. Research here becomes one part of a developmental process including also education and political action'. (Reason, 1988 page 2 quoted in Oliver, 1996 page 141)

Principles

From the outset there has been a commitment to what would then have been perceived as working towards partnership with service users and carers, in a situation where 'expertise' has been viewed as both equal and different.

While the remit and focus of the research changed during the time studied the central theme of 'influence' of service users and carers within the field of professional training has been constant. How this influenced the research design is described on pages 93 and 94. This has demanded grappling with concerns of roles and relationships and the practical meaning of concepts such as 'partnership' and 'equality', which are frequently used naively and without real acknowledgement of the inherent tensions.

Imbalances of power were recognised at the outset. Practices were adopted which aimed to combat these wherever possible e.g. involving service users and carers in planning, offering as much freedom as possible for service users and carers to express their own views within the programme itself and building in opportunities for evaluation. In spite of this, the final responsibility for the programme of teaching itself rested with a professional, who was in turn accountable to work within the guidelines established by CCETSW.

The research model used has essentially been action research by a non-disabled practitioner (the author). A student on placement with CATCHUP from May to July, 1993 helped with some of the data collection. Both were working with members of a bona fide local organisation of disabled people, within which roles and relationships were constantly negotiated and re-negotiated.

The danger identified by Oliver of people with disabilities being 'passive objects' within a process dominated by professional agendas was ever present, in spite of the commitment to user and carer participation inherent within both community care and the ‘From Margins to Mainstream’ project (Management, 1991) which forms the background to the research.

Developing the research project

An increasing amount of research has looked at issues of participation by service users within public services. Researchers have asked: 'Who benefits from participation?' (Wolfendale, 1983); and 'Whose welfare?' (Croft and Beresford, 1986). Interest in participation in education and training is a more recent occurrence (Beresford, 1994, Swain and Lawrence,1994).

At the time when the research proposal was developed in 1992 unique opportunities presented themselves at a local level, both within Dyfed and the Diploma in Social Work at Swansea University. The first progress report of 'From Margins to Mainstream’ said:

> ' There is a growing demand for users and carers who can act as trainers and consultants to community care organisations. The project is aware of both the need and that a number of users and carers are providing training and consultation. If this is to further develop there needs to be a greater understanding of who is involved, the activities being undertaken, the support needs of these users and carers and how they are being met' (Miller, 1993).

Users and carers had in fact been involved in training processes in Dyfed from 1990. Their involvement was on the basis of participation as 'users and carers' within the processes of community care with the lead coming from the local authority Social Services Department. Initially the author of this work was interested in working alongside service user and carer trainers (participatory research) in the development of on going training, developing evaluative tools to gauge outcomes in terms of working practices with staff. Dyfed Social

Services were supportive of some initial work in searching the evaluative material for themes and the researcher also had the opportunity to do some initial work with service users and carers in Dyfed.

The brief of the 'From Margins to Mainstream' project was to promote the process of organisational change within local authorities in order to create a total environment which would be more open to participation, and the influence of service users and carers. The significance of the lead role of local authorities in encouraging participation is something that needs to be open to appraisal in terms of its possible impact upon the process. A salient question is 'On whose terms participation?'.

The individual development plan for Dyfed included 'changing staff attitudes' within the overall community care planning process in order to 'enable participation in planning to be extended to all care groups' (Miller, 1993). Integral to the philosophy of 'From Margins to Mainstream' was the concept of influence; among the focuses of the Margins to Mainstream project was:

> 'Enabling local authorities to change themselves so that users and carers can more easily influence them - rather than enabling users and carers to organise themselves so as to change the local authorities' (Management,1993).

It was this idea of influence which was to become the lynch pin of this research project. Although a number of angles could have been researched, e.g. participation in planning, provision of information or processes of quality assurance the theme of training was eventually isolated. The reasons for this were :

- the explicit function of training in influencing staff development and as a tool for change;
- the specific role and experience of the researcher in relationship to training and to service users and carers;

- the opportunities to extend the involvement of service users and carers to other areas of work, specifically to the development of learning opportunities for Diploma in Social Work students.

While the Joseph Rowntree Foundation's philosophy, as implemented by the Office for Public Management, reflected an interest in developmental processes against a background of 'optimism' about 'user and carer involvement centred community care' :

> 'There is no dispute about the desirability of more user and carer involvement' (Management,1992),

this was not accepted uncritically and this research started with concerns about outcomes in terms of effects on learning and development of the participants within the process. The term 'participants' is intended to include all actors within the process: the disabled people and carers who were trainers as well as students who were trained by them.

The focus had moved from examining the process of participation per se to a consideration of questions related to outcomes of the processes of inclusion and participation in activities that are the traditional domain of trained and expert staff. The process of development and research was itself viewed as part of changing the culture within a framework of anti-oppressive practice; a key consideration within the Diploma in Social Work, as understood by CCETSW. The remit moved from researching the process as it related to human resource development in a local authority to studying the involvement of service users and carers in the module on physical disability on the Diploma in Social Work at the University of Swansea.

The research hypothesis

I wanted to learn about the process of participation by service users and carers within the educational process and to gain clues about whether, and how, inclusion influences what students learn within this process. Part of this is also about the experience from the point of view of the service users and carers : their expectations and aspirations, positive and negative experiences and views of what constitutes success. The following question sums up the area of study:

Does the involvement of service users and carers in training within the field of social care and social work have the ability to influence the perceptions, attitudes and ultimately the behaviour of key participants within the process?

This question stems from the belief that the potential to influence is the capacity to influence constructively and positively i.e., in a way which will lead to securing rights, and to more appropriate professional responses which will benefit disabled people and their carers. It also contains certain beliefs about the process of participation from the point of view of people with disabilities themselves. Participation is viewed as 'struggle'. The word 'struggle' is used to denote grappling with issues related to being a person with a disability at a personal and political level. (Morris,1991, Oliver, 1996, Zola,1982).It is viewed as a process which is likely to be neither painless nor free of conflict for participants.

The participation of service users and carers in the training of professionals is, therefore, viewed as a means to an end rather than an end in itself. There is no place for the 'token disabled person' placed on a platform in order to satisfy the requirements of social policy as implemented at a local level (Oliver, 1996 page 165), or as a way of raising awareness of disability within a programme of disability awareness training (Swain and Lawrence, 1994). The philosophy of participation embraced by this research is located within a 'control model' both in terms of participation (Arnstein,1969) and models of disability (Barnes, 1990). However, it is acknowledged that while this is the goal it may not be the reality for some, or even all, of the disabled people who took part in this research study. The idea of the disabled people and carers as 'organic intellectuals' (Oliver, 1996 page 167) seems an apposite one for this study i.e. a group of people who were trying to grapple with the wider issues which arise from being disabled or a carer out of their own experience. This allows for individuals to be at different stages of awareness and with differing experiences.

The process of participation is not a neutral one and, therefore, the potential for negative outcomes, albeit unintended, must be admitted. As has been illustrated by chapters 1 and 2, possible meanings within participation are diverse and participation itself can be tokenistic, with overtones of practice which manipulates (Oliver, 1996, Arnstein, 1969, Barnes, 1990) or a process which offers control on the basis of citizenship and expertise within a given field.

Research methods

Design

The study itself was essentially an evaluative one, which aimed to examine an ongoing and developing process and its possible outcomes A chronology is given on pages 83 and 84, but not an explanation of the change in the remit and focus of the research and how this influenced the eventual choice of research methodology.

The sphere of interest was in human resource design. The original intention was to engage in a longitudinal evaluation of the outcomes of staff training, which included the participation of service users and carers in Dyfed. It was envisaged that a developmental and evaluative framework such as Brinkerhoff's Human Resource Development (1987)would provide a methodology which would enable researchers to evaluate outcomes in terms of staff performance and benefits, or otherwise, to a Social Services organisation. A description of some foundation work which took place in Dyfed in 1992 can be found in chapter 3. The information gleaned was retained as it offered an insight into some of the ways in which staff thinking had been influenced by the contribution of service users and carers in their training. This was judged to be relevant to the later work with students in training.

When the support envisaged to undertake this piece of work did not materialise, it was expedient to use opportunities presented by the author's role at the University of Swansea. The development of practice placements and the author's responsibility for teaching the College based course on Physical Disability presented an opportunity to study the impact of including service users and carers in a programme of teaching. The key focus was influence. However, whereas the initial intent was to study outcomes linked to organisational goals the eventual study concentrated upon issues of learning and development for service user and carer participants and students.

It was decided to employ qualitative rather than quantitative research methods as this would enable perspectives and themes to emerge during the study rather than having issues clearly defined in advance and then exposed to quantitative analysis. The use of qualitative methods also offered the opportunity for the unique context of the study to be recognised and for the collection of data rich in detail.

The method of triangulation (Dexter,1970 cited in Maxwell, 1996 page 77) was utilised on the basis that the collection of a range of data, which reflect the views and interests of different groups within the development studied, was more likely to yield substantive information about the process and its outcomes. Mason (1996) says of triangulation of method:

> 'In its broadest sense triangulation refers to the use of a combination of methods to explore one set of research questions'(Mason, 1996 page 148).

She suggests that its advantages lie in the way in which researchers are encouraged to research questions from different angles, in a rounded and multifaceted way. While this should enhance the validity of the data by offering the possibility of corroboration this is not unproblematic. Within this study a range of different material was collected in different ways, which introduced the possibility of different, and not always consistent, perspectives.

The material used included primary and secondary data, including review of documentation and reports, evaluative forms that were systematically collected, interviews with service users, carers and students. In addition to the semi-structured interviews the tool of group evaluation was used to obtain feedback at various times during the developmental process.

Considerable attention was paid to the recording of material. Meetings were minuted, some were also audio recorded for blind participants and to ensure accuracy and as an aide memoir. An interview schedule was used with service users and carers, which gave the capacity to review what had been said and to check out answers. The majority of the interviews were also audio recorded, however, it should be noted that a small number of participants were not happy with the conversations being recorded and therefore three exist in written form only.

Research relationships

Relationships within this piece of research were complex and therefore require examination in terms of their possible influence upon the research process.

As is the case with much practitioner research the topic was born out of both the interest and ethical commitment of the researcher, who became a founder member of the CATCHUP co-operative while working as a social worker for a voluntary organisation working in the field of physical disability. Subsequently the relationship changed when the researcher moved into work in further and higher education that offered involvement with local statutory and voluntary organisations and in the teaching of social care and social work students.

The advantages of the above situation may be perceived mainly in terms of the opportunities presented, namely :

- the existence of a network of contacts;
- an existing relationship and degree of credibility within systems;
- ease of access to resources, key individuals and systems;
- opportunities to develop, devise and review a programme of training with service users and carers.

The perceived disadvantages relate to :

- the establishment of clear expectations, roles and relationships : potential role confusion;
- possible 'bias' within the research process;
- establishing a coherent focus.

The way that the research was conducted was considered to be very important. Initial negotiations were with CATCHUP's committee and with Dyfed Social Services (Appendix

1). Early meetings with the committee of CATCHUP were used to discuss the aims of the research and how it would be conducted. When the research remit changed this was also discussed with CATCHUP members as well as officers within Dyfed.

Maxwell (1996 pages 66-69) has identified both the complexity and importance of negotiating, and renegotiating research relationships. During the period of the work with CATCHUP a number of meetings took place with the CATCHUP committee and/or individuals within CATCHUP. Some of these meetings related to the process of developing the involvement in training at the level of providing a placement opportunity within CATCHUP and input to the taught course at Swansea. Other meetings were linked specifically to the research itself. Throughout there was a clear aim to keep channels of communication open and to address issues and concerns as they arose.

Data Collection : sampling.

The aim was to consider as much data as possible at different stages within the development. Decisions about sampling for interviewing and evaluation within this research fits into a 'purposeful' (Patten, 1990,pages 169 ff) 'purposive' (Glaser and Strauss, 1967, Strauss 1987 cited in 1996 page 93) or 'criterion' based framework (Le Comte and Preissle,1993 page 69). In each instance the decisions about what material to use, which people to interview and groups to engage were relevant to the main themes of the research (participation in social work/social care training and education within the context of physical disability and care in the community and the potential influence on participants). It was considered that this would provide a sound basis in terms of interrogating the theoretical position (the hypothesis) and analysing the data. Individuals and groups who were selected for interviewing fitted certain criteria.

The seven service users and three carers who were selected to take part in the structured interviews were not the only ones who had contributed in some way to the training in Dyfed; they did meet the following criteria :

- they were all members of a bona fide organisation of disabled people;
- they were members of a group which was part of the ‘From Margins to Mainstream’ initiative;
- they had all been involved with the foundation training for staff in Dyfed;
- they had agreed to work with social work students at the University of Swansea;
- they could be described as a 'panel' of experts within a local area.

The group was small enough to work with as a group rather than just a collection of interested individuals. They were also based in an accessible location.

Most of the information about student responses was obtained from the use of the routine evaluation form (Appendix 2) filled in by all students for all modules of the course. It was hoped to obtain a hundred percent response from year 1 students on the Diploma. Several factors hindered this goal:

- only the evaluation forms of students who took part in the whole module were used;
- evaluation forms were not used in instances where users and carers were not fully involved;
- a number of students failed to return forms.

Such ordinary events as snow, illness, child minding duties and forgetfulness or failure to co-operate affected the eventual collection of data. Students experienced specific difficulties in February/March 1995 when severe weather and illness meant a low attendance.

In order to achieve a more in-depth picture it was decided to interview a small group of students. It was realised that the small number selected (three in total) would give little more than a flavour of the experience and perceived outcomes of learning.

The criteria used to select the students were:

- participation in the teaching module;
- willingness and time to be interviewed;
- interest and involvement in community care and work with adults.

It was decided to approach the group of six second year students (all female) on the Area of Particular practice in Community Care. Of this group only four had participated fully in the module, and two of them were to undertake community care placements locally.

The third student was selected because he had spent one of his second year placements with CATCH UP in 1994. After qualifying he moved to work in an adult services team working with older people in a care management role. While the interviews with the two second year students were structured (see Appendix 3C), this final interview would be more appositely described as a 'conversation with a purpose' (Burgess, 1984 page 102 cited in Mason, 1996 page 38). This final interview gave a unique opportunity to gain some limited insight into the transference of learning into the post-qualifying period.

Data analysis

A range of data was collected and subjected to analysis to establish common and divergent issues and themes. The analysis was all undertaken by the writer of this study and undertaken without the assistance of any specialist tools of analysis. Each set of data was analysed at the time that it was collected and then all sources were compared and contrasted at a later stage (see chronology on pages 83 and 84).

The material relates to service users and carers as providers of training and to staff and students as recipients of training. For the purpose of analysis, initially each source was treated separately as a block of data in its own right.

The initial piece of work in 1992, predates the M.Phil. submission (See chapter 3).The researcher was offered limited access to the evaluation forms for the Community Care Foundation Training organised by Dyfed Social Services. A perception by the Training Section was that 'staff seemed keen to modify their practice'. The researcher's aim in scrutinising this material was to search for direct references to:

- the contribution of service users and carers to the training sessions,
- clues about how service users and carers were viewed within the process;
- messages communicated by service users and carers;
- any information about areas of practice that staff wanted to modify as a result of the training.

As the context of the training was Community care it was anticipated that themes, which clustered around issues such as assessment and the provision of care, might occur in the feedback.

In order to gain as holistic a picture of the impact of the Community Care Foundation Training as possible the impressions and insights of the service users and carers were obtained through a group evaluation session. This included perceptions of 'audience response' to their contribution. Inconsistencies between the written feedback of the evaluation forms which, when they did refer to user/carer input were positive and the reactions recounted by the disabled people themselves e.g. patronising, negative and reflecting a degree of ignorance about disability, were noted.

Analysis of data obtained from interviewing service users and carers

The interviews with seven service users and three carers were analysed separately. There was a sense in which themes were both imposed and emerged from the data. The questionnaires (Appendices 3) were aimed at finding out information in several broad categories, which clustered around the process and experience of participation within education and training, the perceptions of service users and carers of their message and contribution to training, the target audience and whether and how they thought participation could be extended. The thinking which informed the questions was that of the From Margins to Mainstream project. The material that emerged did not always fit into this framework.

Each interview was numbered e.g. s.u 1 (service user 1) and c.2 (carer 2) and a transcript saved as a word document on a computer. The answers to each question were then merged and subjected to key word searches and other simple forms of quantitative analysis as well as other qualitative analysis, namely reading and interpreting. The frequency with which themes occurred within the data was noted and connections and associations were made. The aim was to establish meanings, particularly in relation to the more abstract concepts such as influence. Notes were then made of how the emergent themes related to the ideas, concepts and themes in participation, disability and education and training that informed this research.

Analysis of sources of data about student response

Several sources of data were collected and analysed in order to seek information on the following areas:

- What was learnt about the process of involving service users and carers in social work education and training?
- How much did student learning coincide with, or diverge from the intended messages of the service users and carers?
- What did the data suggest about student learning in terms of social work knowledge, skills and values?
- What did the evidence suggest about a paradigm shift on the part of students in relation to physical disability and social work with people with disabilities?

The main sources of data were the routine course evaluation forms and the interviews with three students. This data was substantially related to the taught module. A further source was the flip chart material from the presentations given by students. Just one example has been used. Was this congruent with the sort of messages which appeared to come over from the evaluation forms or did it suggest different or contradictory messages?

The taught module was only one aspect of the involvement of service users and carers in the teaching process. During the period when this study took place there were two placements of first year students with CATCH UP, which also provide evidence of student learning and outcomes. This was an area of study that could potentially yield a great deal of data in its own right, but was not the main focus of the research. The student reports on their learning experiences were used to help the researcher to understand what was taking place.

The evaluation forms

A major shortfall of this study is that the evaluation forms that were used with students were not designed to directly evaluate the contribution of the service users and carers to the training. The rationale was that data would be freer from bias if students were simply asked to say what they had learnt without specific reference to the input of service users and carers. With hindsight it would have been more productive to develop special evaluation forms, requesting feedback about the role and perceived outcomes of participation by service users and carers in the teaching process.

This impacted on the nature of the information collected as there was no consistent way of establishing how much the learning outcomes of students were as a result of the involvement of service users and carers. Given that the service user and carer input was not a usual feature of course teaching at Swansea and highly visible within this module it is not surprising that a number of students not only referred to the contribution of service users and carers but also linked this with perceived learning. Other students, while addressing the same questions, made no specific comments or links with service user and carer involvement and one is forced to ask how this should be interpreted. Regrettably the picture obtained is at best a partial one. Suggestions about the probable implications of this will be made in the concluding chapter.

The data from the evaluation forms was analysed thematically, grouping themes which coincided with the key areas of study (as in the analysis of interviews with service users and carers) while concurrently being alert to new or different perceptions or themes. Both process and outcomes were considered.

Interviews with students

The main aim of the interviews with the three students was to find out whether shifts of understanding had taken place in relation to people with disabilities and work in this sphere. The interviews clearly identified the role of service users and carers in the training and asked students to make a link between this phenomenon and their learning. The same basic interview schedule (Appendix 3C) was used with the three students. Supplementary questions, aimed at considering the issues and problems of transferring learning into the world of work were used with student three and the information gained compared with the placement report.

The theoretical approach to learning of EAL embraces the view that prior learning and experience influences how and what students learn (Burgess,1992 pages 9 and 10).Prior experience of disability and disabled people was the theme of the first four questions to the students and subsequent analysis sought to find out what had influenced the thinking and attitudes of the three students before coming on the course. This was followed by questions about the sessions on Physical Disability, the role of service users and carers, how this was perceived and what were the possible effects upon learning and practice. Analysis was aimed at looking at 'before' and 'after'. How had students been influenced in their views of disabled people and carers, including the contribution of this group to their teaching and learning?

Only the final question directly addressed the central issue of this study: empowerment of disabled people and their carers, but all analysis in this study was directed at determining what had been empowering and disempowering as a means of moving forward.

Interpretation of data

Interpretation of data is an important facet of analysing the data. Every effort was made to listen carefully to what was said by service users, carers and students and to report this accurately. It was also crucial to listen to the concepts which formed the basis of what was said and what this conveyed of the influences upon each group and the meanings attached by each group to the experience.

Linguistic issues were taken into consideration. The fields of community care and of disability and social work are littered with jargon and buzz words e.g. consumer, choice, independence, control, normal, which offer some indications of the assumptive world, and culture, of those who use them. However, shared meanings cannot be assumed even when the same words and language are used and it was, therefore, vital to try to determine as much as possible about what sort of understanding existed of key ideas and concepts and whether meanings were shared or different, both within the groups themselves (e.g. service users) and between the different groups.

One example is that of the character of service user and carer participants. Different words were collected in this study : clients, service user, consumers, disabled persons, experts, people with direct experience. How much of a relationship exists between the concepts suggested by terminology and wider ideas? Is the suggestion of 'expertise' elitist? (GIHP Acquitaine 1989-92) Were the service users and carers who were recruited to this activity 'organic intellectuals' (Oliver, 1996); people seeking to control their own lives and the meanings of their experience or were they being manipulated ?(Barnes,1989 Arnstein, 1969).

Were they somewhere else along a continuum e.g. such as that suggested by Arnstein ? (Arnstein, 1969).

Conclusion

The aim of the research was to learn more about the process of participation of service users with a physical disability and their carers in a programme of social work education. The developmental work was undertaken in 'partnership' with service users and carers. The researcher's moral and ethical position was one of emancipatory practice and research. The research was conceived in a climate where involvement on the basis of being a 'consumer' of social services was being advanced.

The reasons why a qualitative research design was used have been explained, together with approaches to data analysis and interpretation of data. The researcher tried to be reflexive about her own role and position within the process as it was difficult to maintain a neutral stance. Whilst a range of material was collected, thus offering potential for variety and richness of data, on reflection the approach adopted is now viewed as limited. The possible implications of the limitations presented by the research design will be taken into consideration in the concluding chapter of this dissertation. The initial approach of Human Resource Design (Brinkerhoff, 1987)would have offered a more defined structure but also had the disadvantage of being linked with organisationally defined outcomes which may not be consistent with the aims and aspirations of consumers of services.

Chapter 5

WHAT HAS BEEN LEARNT ABOUT PARTICIPATION IN TRAINING?

THE VIEWS OF SERVICE USERS.

Introduction

This chapter considers data on the participation of people with disabilities in various aspects of training in the old county of Dyfed and at the University of Swansea during the period 1992 - 1996. The data is presented according to the layout of the questionnaires (See Appendix 3 A) Various types of data was collected in order to elicit information about the involvement of service users and carers in training, and the perspectives of service users. These were:

- recording of a group evaluation session with service users and carers who participated in training in Dyfed (October 1992);
- structured interviews with seven service users;
- notes of planning and evaluation meetings with service users and carers.

The analysis will seek to establish emergent issues and themes as viewed by service users. There will be a parallel consideration of how these relate to the main theoretical perspectives of the research study, namely participation, social work in the context of Community Care and physical disability and the education and training of social work students.

The elapse of time between the collection of data and its final recording means not only that the evaluative material is dated but that developments have taken place in the related fields which are not acknowledged. This does not detract from the value of the perceptions and views of this group of service users on the processes and issues that form the basis of this study.

What sort of people were involved : who participates?

The group itself was a small one, when one considers that the CATCHUP membership numbered 186 ,however, the CATCHUP membership was broader than users and carers. The following table offers a simple profile of the service user group:

Profile of service users (from CATCH UP) involved in training

Age	**Gender**	**Disability**
38 years	Female	Acquired
48 years	Male	Acquired
63 years	Female	Acquired
44 years	Male	Acquired
58 years	Male	Acquired
48 years	Male	Congenital
46 years	Female	Congenital

Five of the group had progressive disabilities. Six were wheelchair users and only one was ambulant, two had additional sensory problems (one was hearing impaired and one blind) and two had significant health problems. Three of the group with acquired disabilities were affected during their childhood or adolescent years. One of the interviewees was in residential care, while the other six were living in their own homes. Four were married with children and living with their families. At the time of interviewing none were in permanent paid employment. The employment backgrounds of the four who had worked included manual labouring, office work, management of a business and work as a lecturer.

How do these dimensions impact on the process of involvement?

The socialisation of people with physical disabilities, within the family and social systems is well documented in research literature and applies to both congenitally disabled people and those who acquire disabilities. (Oliver, 1983, chapter 4, Barnes, 1990, Sutherland, 1981, Oliver, 1996 pages 137-139).

There are some fundamental differences, which are important in terms of likely responses to the experience of disability. Middleton says of children with disabilities:

> 'A disabled child has an assigned role, or, more probably a set of roles in society' (Middleton,1992 page 11)

She describes these roles, which include the happy cripple, the life long child, the punishment role, the scapegoat role and discusses the effects of what are essentially negative roles and a career path in disability which may be difficult for either the child or the family to resist or to break out of (Darling, 1979,Oliver, 1983). One possible result is low self-esteem on the part of the child (French, 1994 page 20, Sutherland, 1981).

Children are often confronted with the added disadvantages that accompany lack of experience of mainstream culture - this is particularly true of children and young people who have a severe and complex level of disability. The education of children with disabilities has been criticised for the way in which it often takes children away from their peer group, may have lower educational standards and fails to counteract the effects of segregation on the development of social skills (Oliver, 1983 page 72, 1996 pages 78 - 94, Barnes, 1991 pages 28 - 61).

People who acquire disability in later life are in a different position to those born with a disability, or who develop a disability early in childhood. Sutherland suggests that they often have more power than children, which makes it easier for them to reject cultural stereotypes of disability and of themselves as people with disabilities and are less likely to conform to roles which are undesirable. Adults who have become disabled are likely to have a more secure personal identity having already established their place in the world. They are therefore more likely to recognise attempts to stereotype and have the confidence to resist them (Sutherland,1981 page 95).Oliver, in his discussion of the hegemony, of disability, talks about the problems of middle range adjustment theories as they apply to disability, particularly to spinal cord injuries acquired in adulthood. The concepts of life events and career as they relate to the experience of disability are viewed as 'a complex relationship between impairment, social restrictions and meaning' (Oliver et al. 1988, page 11 cited in Oliver, 1996 page 138). Thus individual responses to disability, at whatever life stage:

> 'cannot be understood merely as a reaction to trauma or tragedy but have to be located in a framework which takes account of their life histories, their personal circumstances and the meaning their disability has for them; in sum, social adjustment'(Oliver, 1996 page 139).

The seven service users interviewed were users of the day service at Coleshill. Coleshill has both day and residential facilities but only a percentage of residents attend the day centre. The residential home had more younger people with congenital disabilities than the day centre. Many of the younger users of the residential centre had moved from residential special schools to residential care.

Six out of seven of the service users who participated in training had been in mainstream education and had experience of the world of work and/or family life e.g. marriage and children. Interviewees were therefore more typical of the Day Centre user group than of the users of the residential home. This is not an unexpected finding when one looks at studies on disability and dependency (Barton,1989), institutional care (Miller and Gwynne,1976) and the problems of enabling younger congenitally disabled people within day care to participate (Barnes,1990).

Routes to involvement

Training is a highly specialised activity, which may be viewed as 'expert'. Human resource development and education has become a growing industry with a expanding allocation of resources. The points introduced in chapter 2 about current thinking about methods of social work teaching raise issues, which relate to the authenticity and expertise of the contribution of service users and carers. The idea of worldview is germane to post-modernist educational theories and the validity of the concept of expertise based on experience must therefore withstand various tests.

A central question is how did service users and carers become involved and what sort of recruitment, selection processes were used? Jewell (1973) in some comparatively early work on self-management by Day Centre users identifies the problems of professional manipulation. This is echoed in Barnes' study 'Cabbage Syndrome' (1990) and concerns about the tokenism of 'hand picked users' representing disabled people on committees (Oliver1996, page 165). While it is impossible to exclude the influence of significant others upon the viewpoints expressed by service users it is important to ask whose views were being conveyed?

The answers in this section suggest that the initial impetus for involvement was linked to a number of factors. Each group member identified more than one influence on his or her initial involvement in training; they were not asked to prioritise. The coming together of a range of influences is considered to be significant, as it is indicative of an emerging culture of participation within the old county of Dyfed.

Influences on involvement

Committee of CATCHUP	5
Day Services Manager	4
Through involvement with Coleshill	2
Training Officer Community Care /Day services Manager	1
Advert in the Day Centre	1

The biggest single influence leading to involvement was prior involvement in the committee of CATCHUP with five out of seven of the group identifying it as a route to involvement. From its inception CATCHUP had adopted a clear philosophy about the purpose of participation, namely the wish to influence and hasten progress in relation to disabled people.

All users cited additional influences on their decision to become involved, which included responding to an advertisement placed in the Day Centre by the Training Section asking for volunteers to be involved in foundation training for Community Care (one), involvement with Coleshill and the development of CATCHUP (two), being asked to take part in forums which explained 'the normal life experience of a disabled person' (one). The role of the Manager of the Day Centre at Coleshill was mentioned in four of the answers. For one service user involvement started with the guidance of the Day Services Manager:

> 'who believed that disabled people should have a chance to express their views, and should be involved in the planning, development and running of their services'.

It appears that this view was appropriated as s/he had subsequently come to believe that :

> 'in order for disabled people to take control of their own lives they must be involved in the planning and delivery of services at all levels'.

This quote implies that the service user perceived a progressive view of participation as a means by which disabled people would ultimately gain control. It suggests that the culture of participation within the day centre was more than the 'tokenism' criticised by writers such as Oliver, who suggests that the underlying idea that professionals are able to empower clients through 'appropriate practices' and language e.g. 'users and consumers' in place of 'clients' is inherently flawed (Oliver, 1996 page 47).

This is corroborated by the observation of a student on placement with CATCHUP in 1994 :

> 'Due in part to the enlightened attitude of the original manager the day centre from its inception was run with the participation and direct involvement of service users'.

But was this enlightened attitude significant of more than the enlightened guardian approach to people with physical impairments?

A question posed by the early work on patient participation in general practice was: 'Will they be enabled? (Hillier in Pritchard,ed., 1981 page 3). The idea of 'enablement' has connotations of professionals allowing 'patients' into a professional domain with all its attendant risks and opportunities for both professionals and patients. Intrinsic to the operation of participation is the dismantling of barriers to effective communication.

A service user who had expressed an interest in training and was invited by the Day Centre Manger to a meeting with the Training Officer Community Care and encouraged to take part in a meeting on services. This reflects an enabling approach.

Two of the interviewees saw committee membership as a route to later opportunities in training and placed this within the historical context of the development of Coleshill, with one of them making a link with a concern that :' service users would be involved with the development of services'. Information and training were two areas of service development mentioned.

Overall, answers demonstrate that a process of recruitment was happening and that participation within training was just one aspect of a developing culture of participation. An article by the Day Centre Manager refers to:

> 'a continual growth in the development of the user group since the opening of the centre' (Aitken,1991).

Some low-key training had been offered as part of this general development of consumerism. A further selection took place when it was decided to encourage a more 'professional approach' (Aitken,1991). While this refers to offering wider opportunities for training and development to some individuals the article also describes the development as 'unashamedly elitist'. At around this time some members of the group had visited a project in France, Groupement pour l'insertion des handicapes physiques (the group for the inclusion of people with physical disabilities) in Aquitaine (1989-92), which was encouraging more articulate, educated, and often professional people, with disabilities to blaze the trail for disabled people in general.

Preparation

Among the recommendations of CCETSW's paper 32.2 'Changing the culture: Involving service users in social work education' (Beresford, 1994) is the provision of training at levels which vary from self-confidence and assertiveness training to specific 'training as trainers'. Question 3 was aimed at establishing the nature of the commitment of the local authority to the preparation of service users and to gauge how service users evaluated the training and /or support offered to them.

Five service users took part in a three-day training course at the Ferryside Centre in June 1991, financed by Dyfed Social Services Department. The course concentrated on offering basic skills in presentation, how to approach an audience, content and planning of an educational session.

The feedback from service users about the content and usefulness of this course was mixed. The training had taken place almost three years before the interviews. Two service users admitted that they could not clearly remember the sessions. This does mean that the feedback obtained was neither as full nor as accurate as had been hoped. Positive aspects noted were :

- the emphasis on skills of presentation, which included the use of training equipment such as flip charts, video and Overhead Projector;
- the way in which the course looked at 'expectations' of recipients of the training;
- help with self-expression, and how to approach a group;
- the emphasis on consideration of 'case material' from different professional perspectives.

Criticisms of the course included :

- the lack of hand out material;
- that the training was 'too basic'.

According to one service user preparation for the Community Care Foundation days started approximately five to six months after the above training sessions and was on a group basis because the arrangement was to work in pairs. The theme was: 'What it feels like to be a recipient of services?' and the Day Centre Manager facilitated the writing of scripts, however, in his/her view :'The best bits were those which were "ad-libbed", and the only background information was on :

- The constitution of the audience;
- the programme.

This appears to link with other experiences of service users, who perceived that they had been involved in training sessions without a great deal of background knowledge of the training itself, its context and aims and objectives. This raises questions of how participation by service users is understood and the role and function of service users within the activity. The exchange of information is a crucial factor in any transaction, particularly one that aims at the ideal of partnership. Croft and Beresford (1993) suggest that information is one of the eight key elements which contribute to making user involvement for services and organisations a reality (cited on page 137 of Dalrymple and Burke, 1995). However, it should be said in mitigation that, in spite of much guidance which was current at the time, there was a great deal of confusion within local authorities about the implications of implementing the legislation.

Two service users had been encouraged to join an accredited 'Training for trainers' course which was 'part of an initiative to encourage people with disabilities to participate in public speaking'. One service user was critical of part of this course, which had been difficult because of the complexity of language. Offering of an extra day in which opportunities had been given for the planning and presentation of a training session was a response to these difficulties. Another service user was waiting for an initial three days run by a London based organisation.

The CCETSW work on involving service users in social work education identifies language as a barrier and advocates abandoning social work jargon and evolving a 'shared language' which is simple and clear; the language of the lay person rather than the professional (Beresford, 1994 page 48). An additional point relates to sensitivity to language and culture as this study has been located within the Welsh context and within a service user and carer group which was bilingual (Williams in Williams et al.,eds. 1994 page 191).

The extent of involvement in training

All the service user interviewees embarked upon training through the Community Care Foundation training days. By 1994 there was evidence of widening opportunities. The question about ongoing involvement in training was answered from different perspectives. Two service users answered in terms of :

- involvement in the ongoing training of CATCHUP volunteers as a form of work preparation;
- through involvement in local task groups.

The focus of the first answer was training other people with disabilities to enable them to participate in the running of the information service. Task group participation was seen to raise professional awareness of the capabilities of people with disabilities through the process of working in partnership:

> "Although I am disabled I have a brain and am capable of expressing ideas".

For some of the group involvement had broadened out from inclusion in forums, which included a service user perspective, to fuller participation in disability equality training. One service user had led the Open University courses 'Disability Changing Practice ' (1990) and 'Identity, Sexuality and Relationships'(1991). Another was involved in Disability Awareness training in local primary and secondary schools.

The training of social and health care professionals had become a special focus for service user trainers. Three of the group had given input on the Diploma in Social Work at Swansea; one had also contributed to the Diploma in Social Work at Cardiff University. A move away from the somewhat narrow context of social care and health is reflected in work with the Citizens Advice Bureau , Welsh Water ,Welsh libraries and by participation in the Open University's Tutor and Counsellor Training.

How much commitment was there to future involvement?

Three service users did not envisage future involvement because of deteriorating health . Four were open to opportunities either on a local level (e.g. through task groups) or to wider opportunities offered by local authorities and other bodies. Chapter 3 gives feedback from the group evaluation of the involvement in the Community Care Foundation training held in October 1992. The problems of negative or even prejudiced responses identified in the group evaluation were not expressed as concerns in the individual interviews.

The briefing paper for 'From Margins to Mainstream' published in 1992 noted in 'Problems encountered so far' that :

> 'Staff attitudes and professional worries can slow down change.... Staff may have paternalistic attitudes, or may underestimate the ability of users and carers to contribute' (Management, 1992).

However, evidence suggests that such negatives did not act as a deterrent and notions of the positive value of participation maintained that motivation.

The concept of influence

While all the service users were serious in their desire to influence others, and confidant about their ability to do so, there was no consensus about either the concept of influence or the means of influencing. However, the wish to change peoples' perceptions, understanding and attitudes provided the impetus for involvement:

> "... If you don't believe that what you are going to do is going to influence people then there is little point in taking part in training activities ..."

But the same person equated the word influence with 'persuasion'; a hard word with overtones of coercion. S/he suggested that their role was to:

> "change people's attitudes by making them more aware of disabled people's situations."

Two other service users shared the view that they had the potential to influence thinking:

> "... It can put a lot into peoples' minds that they hadn't thought about ..."

While his/her colleague was able to say that:

> "... In my case, some of the insights I have revealed about living in a residential home have definitely influenced at least one person's outlook ...".

Abberley (1989) could be seen to support this view of the role of training by suggesting that social work students need to be informed of the qualitative and quantitative differences of life as a person with a disability, but within the context of understanding conceptual models of disability and provision for people with disabilities.

Another theme was participation as a means to influence professionals to reconsider stereotypical and negative views of disabled people through challenging beliefs.

> "... positive opportunity to influence professionals, e.g. nurses, doctors, health visitors ..."

S/he had experienced stereotypical responses to disabled people. In one instance the belief that :

> "... most disabled people are lacking in educational background and are poor ..."

His/her experience was neither one of educational deprivation nor poverty and s/he was keen to underline the individuality of life opportunities and backgrounds of disabled people.

The above raises the question of representativeness. Such a response fails to acknowledge the accuracy of the view of the professional in terms of the experience of many people with congenital disabilities vis a vis educational opportunity (Barnes, 1991 chapters 3) and the economic disadvantage (Craig, 1992 cited on page 84 of Means and Smith, 1994 and Barnes, 1991 chapter 5) endured by the majority of people with disabilities.

Negative stereotyping occurred as a theme in the service users/carer evaluation of their input into the course at Swansea University (August 1994) It was noted that students tended "to see physical disabilities as a problem" and that:

> "the presence of disabled people in the training sessions had enabled this imbalanced view to be redressed".

The tool for changing negative perceptions was seen as the group's ability:

> "to demonstrate that disabled people have capacities and abilities, essentially that they are people first, and that with the right support are able to surmount most obstacles".

A service user who said:

> "... Yes, I had hoped that professional bodies would realise that disabled people are capable of taking control of their own lives ..." further reinforced this.

The targets of influence

While service providers were the main targets of influence other groups were mentioned; namely the general public, children, middle-aged people, other people with disabilities, and people whose work brings them into contact with disabled people, e.g. housing officials.

There was a perception that:

> "... The younger generation are better informed, they have a greater awareness because some of their peers in school are likely to be disabled ..."

This statement appears to be based on a premise that the presence of disabled children within mainstream education settings creates awareness among their peers: an idea which is not unproblematic as it does not recognise the complexity of the ongoing debate about integration v segregation and inclusion v exclusion in education (Oliver, 1996 chapter 6).

It was not an unexpected finding that social care and health professionals were viewed as the most important group by all interviewees, as this was the main group targeted by 'From Margins to Mainstream'. However, little consensus emerged about who were the most significant people within the overall category of 'professionals'. Terminology used to refer to professionals varied and included 'direct carers', 'front line workers' and 'people at the top'.

Table of professionals whom service users aim to influence

Health Visitors	**1**
Social Workers	**2**
Care Managers	**1**
Doctors (G.Ps)	**2**
District Nurses	**1**
Care Staff	**1**

The term 'direct carers' was used by one service user to denote:

> "... Those people in the Health and Social Services who are working directly with people with disabilities. Not the people at the top but those at the lower levels. Hopefully they would then carry their awareness with them and it would filter up through to the higher levels of their agencies ..."

But two others questioned this bottom-up approach to influence and potential change

And thought that the most significant targets of influence were :"the people at the top"

as they potentially have a cascade influence upon staff at lower organisational levels:

> "... They are the ones who probably most affect attitudes and ways of doing things. However, the people who I think it is most important to influence are those who are caring for us, or who have direct contact with us, like social workers and care staff ..."

A fellow service user thought that "management" needs to be influenced but that a bottom-up approach is potentially more effective.

One interviewee talked about 'front line workers' as:

> "... the others who tend to be at the 'hard end' and have to visit to decide what the person is looking for, help that is needed and who have to try to help in a non-patronising way ..."

while another thought that a particularly good group to influence would be students or professionals who are new to their work:

> "... Ideally the people so influenced are students, or those who are new to the work, who haven't got fixed in their ways and think that they know it all. This awareness would then be part of their thinking and they would carry it with them wherever they went and pass it on to the others ..."

The above data suggests that relevance of professionals was judged in terms of likely impact upon the lives of people with disabilities; a factor which varied according to individual experience of 'helping' professionals.

Within the answers Health and Social Service personnel were given equal recognition, but there was little consensus in the answers and none of the answers reflected a clear understanding of the multidisciplinary nature of work within care in the community and the issues for service providers. This is not surprising when one considers the difficulties and lack of consensus in community care at both a policy (Hoggett, 1992 cited on page 83 of Means and Smith, 1994) and operational level and the difficulties of integrating and sharing power, with service users (Walker,1988).

What did service users hope to influence?

This question gave service users the opportunity to build on their earlier answers to questions about influence. Responses cluster around two main themes:

- beliefs and images;
- the way in which significant others behave towards people with disabilities.

Only one service user used the phrase 'images of disability' and s/he connected it with the Disability Equality training pack 'Disability: Changing Practice', which links beliefs with models of practice (Open University,1990). Other answers identified a range of beliefs and attitudes that service users wanted to challenge as a means of changing practice. Terms such as 'anti-oppressive' and 'power' do not feature in the answers but the dimension of power in relationships is implicit. The underlying attitudes and images viewed as significant were:

- a tendency to see the disability rather than the person;
- the assumption that to be disabled is inevitably a negative experience;
- fear of disability/people with disabilities;
- the belief that disabled people are unable to control their own lives;
- the belief that people with disabilities may not be able to speak for themselves.

These dimensions were thought to have an impact upon different processes of interaction within care practice. Service users perceived that what happens at an interpersonal level also finds expression in institutional and societal cultures. A further consideration was the internalised oppression of individual disabled people.

The two main issues for social care and social work practice emerged as effective communication and control; inter-related themes that can be analysed in terms of empowering practice. The first quote is endorsed by some earlier research into residential and nursing home care, which demonstrates the low priority given to the maintenance and development of social skills and self-confidence (Brisenden, 1985 page 2).

> "... I want to show that we are not just numbers, that we don't want to be put in pigeonholes. We can speak for ourselves, and even those who have difficulty with communication can understand what is being said to them if care staff or social workers take the time and patience to listen or to find an interpreter. What they have to say is important. Therefore I would try to influence care staff and social workers to have the patience to listen to us no matter how difficult that may sometimes be".

Was this service user equating lack of voice with lack of identity for disabled people, especially those who are in residential care settings where the most severely disabled people tend to be largely unheard ? (Allott and Robb, 1998, SSI 1993).

The same service user viewed advocacy as a role for fellow residents with good communication skills, who would be in a position to understand and empathise through shared experience and day to day contact within the residential setting.

Several service users wanted to challenge the idea of service users as dependent and unable to control their own lives:

> " Also making people aware that disabled people have the ability to control their lives and situations they happen to be in".

This service user also talked of the connection between the personal and the political .Being seen as competent and in control leads to the fulfilment of the duties of citizenship with its resultant benefits (Doyal, 1993) but acknowledgement of the basic rights of disabled people as citizens is a pre-requisite. The introduction to the case for a new law says :

> 'We begin with the assumption that there are two main goals for a modern welfare system. The first is to promote greater equality - meaning not uniformity, but equal

> life chances. the second is to give people greater autonomy and more control over their own lives, within an acknowledged framework of social and economic interdependence. These goals exist to ensure that, as far as possible, everyone is able to participate in society, to enjoy its fruits and to realise their own potential'(Coote,1992).

Another service user identified environmental barriers as preventing control and participation by disabled people, and added that social planners and architects need to be influenced – a theme echoed by the Disability Movement(Barnes, 1991 page 228, Finkelstein, 1980).

Both the themes of effective communication and the right of disabled people to be in control of their own lives dovetail into the wish to influence professional practice. Good professional practice was associated with 'effective communication', 'partnership with people with disabilities' and 'the promotion of better quality of life':

> "How the professionals are going to perform their duties and make the quality of life better for disabled people"
>
> "... If you are a social worker or occupational therapist don't go away and do nothing. The service user still has the problem ".

The word partnership was interpreted as:

> "The way in which professionals involve the service user in what they are doing"
> "Professionals should do the job - if there are problems e.g. lack of resources they should explain".

But s/he realised that staff performance can be affected by conditions of employment and questioned how staff who are underpaid and given low status can be committed to quality services (Lee Tre-week, 1998 page 230). S/he thus started to identify the complexity of professional practice which 'empowers'. This service user's thinking about the way in which able-bodied helpers and carers may caught up in the politics of oppression, is reflected in the comments of Stevenson and Parsloe:

> 'Changing one's attitude is difficult and not entirely a matter of will. It is more likely to be achieved if the whole climate of the organisation changes and workers can see examples, at all levels, of managers espousing the empowerment, not just of users and carers, but of staff too' (Stevenson and Parsloe,1993 page 10).

Oliver questions assumptions that 'professionals through the development of appropriate practices can empower their clients' (Oliver,1996 page 147), arguing that empowerment is a collective process ' on which the powerless embark as part of the struggle to resist the oppression of others'.

A consideration of particular relevance to discussions about partnership is just how far professionals are willing to allow incursion into areas of perceived weakness (Hillier,1981 page 4, Braye and Preston - Shoot,1995 page 103). Perhaps the greatest barrier on the part of professionals is admission to lack of knowledge or inability to find solutions to problems: a difficulty perceived by the two service users quoted earlier who had been concerned about professionals who either do nothing or fail to explain their own difficulties as workers.

'Competence' is a key consideration for management and training structures within organisations. The idea of competent staff is closely intertwined with that of the competent organisation (Braye and Preston Shoot,1995 page 69); which, in this context cannot be divorced from issues of quality services.

> 'Workers will experience difficulty empowering and valuing others when they do not feel powerful and valued (Read and Wallcraft, 1992 cited in Braye and Preston - Shoot, 1995 page 69).

A final response was couched in terms of impact on peers with disabilities, namely:

> " To emphasise the role of empowerment".
> " To break down the barriers of fear which sometimes prevent people with disabilities questioning the services they receive".
> " Also disability doesn't have to be a negative experience, it can be positive ".

It is possible to see this response in terms of the structuring of disabled identity. Disabled people are at in different places in their journey towards personal and political awareness.

The three points are all significant for considering some common reactions of people with disabilities to their situation (French, 1994 pages 47 - 58). The idea of 'internalised oppression' is encapsulated in the words 'fear' and 'negative', and by implication being 'disempowered' in relation to public service providers.

Messages and contributions

Questions 9 and 10 of the questionnaire were aimed at eliciting the main messages and what service users considered to be their contribution to training.

What sort of message were service users aiming to convey through training?

Only six of the seven service users chose to answer this question. One of the interviewees did not think that there was anything to add to the previous answers. Five answers suggest an awareness of issues of equality on the basis of citizenship (Braye and Preston- Shoot, 1995 page 83, Bynoe, Oliver and Barnes,1991) and concerns about the inequality of opportunity for people with disabilities as a result of barriers e.g. physical access (Barnes, 1991 chapter 7) and discrimination within society (Oliver, 1996 pages 155 and 156).

Messages about equality were expressed in different ways, ranging from simply: "That we are equal to everyone else", to the more complex:

> "People with disabilities are a microcosm of society, but they need help to function within everyday life" e.g. because of environmental issues."

The second statement reflects a social, rights based model of disability and a belief that if people with disabilities were offered a barrier free environment they would be able to function alongside their able-bodied counterparts as participants within society (Barnes, 1992 chapter 7).

Difference and its inherent tension in terms of the construction of identity was a theme which service users shared with disabled writers. It was raised in the group evaluations of October, 1992 and August, 1994, and is reflected in the following quotes:

> "Don't be patronising. People with disabilities don't want to be treated differently."
>
> "I am trying to get people to see me as an able-bodied person rather than a disabled person. I'm me, not my disability. I am trying to get people to change their own perception of disability."

Another service user suggested the need to "demystify" disability by encouraging participants in training to think about the commonality of disability -emphasising the 'us' rather than the 'them'. Such an approach has been criticised by Abberley (1989).who analyses the 'really normal' approaches of writers such as Goffman (1963) and Sutherland (1981) which have been readily espoused by disabled people. He says that what unites these two very different approaches is a belief that disabled people are 'really' normal and that the supposed abnormality of disabled people is the result of some kind of 'mistake'. It follows that if we can enable people to see disability and disabled people differently, to change their attitudes, that they would realise that disabled people are really the same as them after all. Abberley concludes that this is a harmful approach as it minimises the difficulties experienced by disabled people and that it not only be replaced by the teaching about the nature of experience of disabled people cited earlier in this chapter but also:

> ‘ We need a theory and practice which sees the fundamental problem of disabled people as one of oppression’(Abberley,1989 page 56).

The final two messages are about good practice within community care:

> "That people (users and carers) have their own needs and opinions and should not be grouped together. For them (professionals) to listen and take the advice of those with experience."
>
> "Ask the individual service user what his/her needs are?
> e.g. Assessment”.

The point has been made that the voice of experience of people with disabilities is frequently negated by professionally dominated assessment and care management procedures. There is a great deal of rhetoric about 'needs-led assessment' within Community care, but this has been criticised from a number of different angles. Doyal in his discussion of 'Human Need and Community Care' argues for:

> ‘ the advantage of linking basic need satisfaction to the rights that the duties of good citizenship entail’,

but recognises the inescapable implications for the commitment of adequate financial resources and recourse to legal systems to enforce rights (Doyal, 1993 page 282). Oliver and Barnes contend that:

> 'professionalised service provision in a needs based system of welfare has amplified existing forms of discrimination and created new ones' which include 'professional assessments and practices based upon invasions of privacy, and a language of paternalism which can only enhance discriminatory attitudes' (Oliver and Barnes,1991 page 14).

Contribution to training

Service users had differing understandings of their contribution and role within training. The first quote contains a belief that social role is significant in predicting response:

> "being a trainer automatically challenges peoples' attitudes towards people with disabilities".

However, caution is needed; it is rather unsophisticated to assume that change is contingent on just experimenting with roles. The role of 'trainer' is more prestigious than that of a 'disabled person' per se, but credibility is also vested in the way in which the role is performed. It has been suggested that the whole idea of 'contact with disabled people as part of course design' is essentially flawed (Swain and Lawrence, 1994), but even those who uphold its virtues (Wright,1980 pages 11 and 12) recognise that how people are portrayed is crucial to whether attitudes and beliefs are challenged and changed. The service user and carer evaluation of the Community Care training days suggested patronising attitudes and expressions of views about service users being different by staff. This raises the question of how prepared they were to listen to the views of service users, even when service users were offered a different role and status.

Another response was linked with the service user's earlier response about being seen as an able-bodied person rather than a disabled person, i.e. a person in one's own right, rather than e.g. an object of pity, a person in a wheelchair. The respondent is expressing a further point about the focus being the activity and the role itself i.e. trainer and facilitator rather than simply a wheelchair user , albeit a wheelchair user in an unexpected role.

> "Nothing special - just a normal trainer/facilitator who happens to be in a wheelchair".

The contribution of the experience of being disabled was the main rationale of involvement in training from the viewpoint of the agency. While this was on the agenda of all participants individual perspectives were different. For one person " being disabled' was the main contribution, coupled with :

> "a light hearted approach and easy going attitude. A willingness to answer as well as to ask questions. A 'good listener' and can generally see both sides of the argument".
>
> "Being able to explain my personal problems i.e. the problems encountered which relate to my disability."

Thus, the ability to enter into a dialogue characterised by openness and exchange of views was very important; also the fact that being disabled is not all doom and gloom. This was reflected in this service user's approach to work with students -in a group evaluation of the training at Swansea s/he had expressed surprise at the predominantly negative assumptions displayed by the students within the sessions.

Two service users thought that their contribution was as recipients of services. The first focused on issues of assessment and provision of services, including some of the stressful aspects of being at the mercy of professional systems and procedures, while the second was able to contribute insight into being a user of residential care services. Implicit in both answers was the idea that professional awareness would be raised by the sharing of their experience and that this would lead to improved practice.

> " A lot of professionals are involved in the provision of services, but they do not always see the outcome for the person with the disability."

This service user was keen to focus on the disempowering nature of assessment processes, which are the passport or barrier to a range of benefits and services which affect the quality of life for people with disabilities:

> "The assessment process is particularly important, but also potentially difficult for people with disabilities who have to go through a range of professional assessments'.
>
> 'Assessment usually highlights the things the person cannot do and the result is a negative self image."

The invasion of personal privacy and assault on self-esteem meant that s/he usually takes 3/4 days to get over an assessment. Medical assessments for disability benefits, and which emphasise incapacity, were viewed as particularly difficult. Such assessments were viewed as encouraging dependency:

> " People may become reliant on services - fearing their withdrawal. Fearful of complaining. For a lot of people it is easier to become dependent on others than to struggle to achieve independence".
>
> "It is only rarely that a person gets a self assessment. If a person is capable of self assessment s/he should be allowed to carry it out."

This service user's ideal was a tripartite assessment incorporating the views of the user, carer and professional :

> " This should underpin the package of care".
> " There will always be the need for professional people but it depends on the role."

The above view highlights the importance of the roles and interactions between professionals and other participants in the assessment process. Ellis makes the point that most service users and carers seek independence and only accept professional help reluctantly. Furthermore there is a struggle to maintain normality and protect privacy. There is often a tension between the expectations and perceptions of service users and carers and those of professionals and this can result in assessments which fail to address people's own priorities (Ellis,1993).

The following offers a different perspective, that of offering a realistic insight to professionals into the lives of disabled people who use services, such as residential care, with the aim of enabling them to be more knowledgeable in their interactions with service users:

> "As a user of services - from transport to being in a residential home - I can talk about both the negative and positive experiences of disabled people like myself. I can hopefully pass on this knowledge to people like yourself (a social work student) and give them an understanding that will enable them possibly in the future to counsel someone who may be frightened and apprehensive about going into a residential home".

Representativeness

Did participants view themselves as representative of other people with disabilities, and if so how were they representative? A perennial argument against the involvement of consumers is that they are not representative (Jewell,1973, Croft 1993, Richardson 1983). Beresford describes the problem:

> 'Representativeness is a contentious issue. Many people in disability and service user organisations feel that their representativeness is challenged by service providers to invalidate what they say, or to exclude them. They argue that there is a double standard whereby the representativeness of professionals and policy makers isn't challenged in the same way. The same questions they say are less likely to be asked of more traditional and more powerful organisations'(Beresford,1994 pages 80-83).

The opinion of the student on placement with CATCHUP in 1994 was that it was probable that the participants in CATCHUP's activities were:

> 'no more or less characteristic of the general population in terms of peoples' willingness to get involved. In any setting, whether you're dealing with people with disabilities or people who are non-disabled I think there are always people who are prepared to participate and to get involved and those who aren't'.

The answers in this section fell into three groups – yes; yes, but only to an extent; and no.

Only one service user thought "Yes it's definitely possible"; while just one other was equally definite that to be representative is not possible:

> " No, you can't, you are giving a one off personal experience and stating your own personal views";

However, the same service user reasoned that:

> " However, you can broaden out your input and give perspectives on other disabilities, but with the proviso that this may not give an accurate account of how these other people will see things ".

Five respondents thought that they were representative, but only to an extent - answers were qualified in different ways. The main area of reservation hinged around the uniqueness of individuals. There was also some tendency to think in terms of medical rather than social dimensions of disability:

> "This is quite difficult because everyone is an individual."
>
> "Every disability is different- there can be a lack of understanding by one person with a disability of the problems of another person with a different kind of disability."
>
> " I can't pretend to know what it's like for somebody who might have Multiple Sclerosis or Muscular Dystrophy. I cannot say how they feel and exactly what they experience."

But the uniqueness of individuals and differences, which arise from different sorts of disabilities and circumstances, was only one aspect. The other side of the coin was shared experience:

> " On the other hand I do know what it's like to be in a wheelchair. I do know what it's like to be blind so I'm in a much better position than an able-bodied person to make people aware of what it is like to be disabled from both a negative and positive point of view."

and the insights gained from moving within the world of disability:

> " Yes, maybe not as fully as someone who has a different disability, but where you associate with people you gain some knowledge."

Similar views had been expressed in relation to communication within a residential home and the way in which disabled people could be advocates for others with communication difficulties.

Specific means of achieving a degree of representative within the training process are suggested. The first of these is by being a role model within the training role and providing a positive image on behalf of other people with disabilities, while maintaining an individual perspective :

> "In some ways I do represent disabled people when I am training but I always make it clear that I'm not representative and I try not to be dogmatic".

A further proposal was that trainers could establish guidelines for professionals:

> " I can speak about my own disability. I use guidelines e.g. to be patient and listen."
>
> " By trying to establish general principles - things that professionals need to take into account. Helping to develop a general awareness of what is happening to people with disabilities, what sort of indicators to be aware of and how to see and put yourself in that other person's position."

Being able to put oneself in another person's position is a growing theme within literature on social work education and training:

> 'The ability to shift perspective, to stand in the shoes of people needing social care services, to appreciate how they might experience this encounter, is an important part of preparing to approach people who use, or may wish to use services' (Braye and Preston - Shoot, 1995 page 131).

Spreading involvement

A question on extending involvement was included as an acknowledgement of the aim of the 'From Margins to Mainstream' project to spread change and broaden the level and range of participation. Answers reflected a continuum of opinion from pessimistic to pragmatic and optimistic.

Two responses were about perceived barriers. The first indicates a commonly held belief about participation in general; i.e. people are apathetic if they have no cause to fight. The antithesis is that having a cause mobilises people to action - an idea that finds its expression elsewhere in concepts such as crusadership and moral entrepreneurship (Darling 1979, Oliver, 1996 page 156). It is interesting to revisit the historical and social context of the study and to note that service users who were middle aged or older had been part of the fight for improved services. The Disability Movement in this country has largely emerged since the International Year of Disabled People in 1981 and Coleshill opened in the mid 1980s.

The perception conveyed by the next quote should be seen against the background of the progress achieved by people with disabilities in Dyfed. It must have seemed that younger disabled people had more advantages and that they had gained opportunities and services without working for them:

> “People are not interested; they are apathetic. Younger people don't have to fight."

This contains little understanding of the wider issues of social inclusion, which motivate organisations of disabled people. It is rather based on a service-based, dependency culture where needs take supremacy over rights (Morris, 1998 pages 166 –167 in Allott and Robb, 1998). It also raises the question of whether the socialisation of younger people with disabilities in the education system leads to an internalisation of oppression and passivity (Oliver, 1996 page 70).

The cost of involvement in terms of personal resources and energy was an issue for one service user:

> " There is no easy answer to this. If you take unpaid carers, they are often stretched to breaking point as it is and any spare time they may have they don't want to spend involved with committees. No I don't have an answer."

Some recruitment strategies were identified:

> " By trying to recruit more volunteers from among service users, to be involved in the task of raising awareness among professionals."

> " It might be a good idea to start by extending into the Coleshill Centre and asking other people (that is people from outside the immediate CATCHUP circle) if they would like to attend seminars, conferences or training sessions (when someone in the CATCHUP circle is not available)."

The idea that people are attracted and motivated by success is implicit in the following answer: "By learning of the success of others in training."

Extending training opportunities could potentially attract recruits and enhance confidence:

> " By being trained themselves. There is more obvious need for people from rural areas - there are issues about services in rural areas which are not being voiced, there are more problems in grouping together etc."

> " By getting together a group of people who would like to come to a training session - people who are shy, or may not be as vocal - give them a days fun session and at the end explain what will be involved if they want to go further."

But involvement in training was not viewed as viable for all service users and an advocacy scheme was suggested:

> " To develop a system of representation for those people who are less able/unable to express their own needs."

Lastly recruitment could be helped by information about practical support such as transport and financial support. The point was made that service users should be treated in the same way as professionals.

Future involvement

A consensus emerged that service users hoped for future involvement to be routine and planned and at' all levels' within statutory, voluntary and private sector services. Joint training of social services and health service staff and of student social workers was mentioned as a priority. One benefit of involvement in an ongoing programme of training was 'the opportunity for the kind of question and answer session which I have found most effective" - a point which is suggestive of the development of dialogue between professionals and service users. The basis for participation was their expertise as disabled people – in the context of disability training it was proposed that 'we are the professionals'.

But widening circles of influence were also inferred in answers that suggested that it should be arranged for :

> " a disabled person to be available at every major meeting - arranged on an area basis. It would be preferable to have two people working together on an area basis."

And the possibility of future influence upon policies on the employment of disabled people:

> " I would also like to see the lack of employment opportunities raised in the authority and I believe that service users could help in developing this awareness."

The potential for the future inclusion of more marginalised groups, such as people with learning and communication difficulties, was also expressed.

Support for future involvement.

The 'From Margins to Mainstream' project ensured that the support requirements of service users and carers were considered from the outset. There was regular consultation about the effectiveness of support. Support ranged from transport through to financial incentives and help with caring arrangements.

Two service users did not want further support. One considered support unnecessary and the other intended to retire because of deteriorating health. The other interviewees referred to training and financial support.

> " Further training - I would especially like to undertake training on how to work with users with learning disabilities ".

S/he noted that people with learning difficulties tend to be "excluded - they are often not given the time, space or adequate support to express their views."

Training to communicate the message to a wider audience was important to one service user:

> " We need more help to get the message across, not just to care staff, social workers etc. but bank managers, shop keepers and other people in the community we have to deal with."

Two service users mentioned financial support; one mentioned the problem of benefit regulations.

Success in training

The 'From Margin to Mainstream' case planning form for Dyfed recorded existing benefits to service users and carers of involvement in training as ‘gaining confidence and improvement of communication skills’. The potential benefits and outcomes of the project were ‘promotion of a better understanding of impairment and disability’ and ‘to play a positive role in influencing the attitudes and actions of staff and others’ (Lewis, 1992, unpublished document).

In the light of the above, the final question of the interview asked the service user group to evaluate their own success. Service users measured success in two ways – external response and personal satisfaction. The level of interaction within the sessions, particularly informal contact, was seen as significant:

> " I think that it was very useful - there were plenty of questions and answers, opportunities to talk informally with professionals e.g. in the lunch break."

This was combined with indicators of enjoyment and usefulness within the sessions.

> " In evaluation to date most people appear to have offered positive feedback, although some complained that it was too basic."

> "Very successful. The feedback is that inputs are enjoyed and that it does have an impact. This is demonstrated by an increase in approaches to CATCHUP."

> " I think they have gone away from a training session with a better understanding. Although I must say I prefer informal sessions in which people can ask questions and discussion take place, rather than a formal lecture type structure."

More individual measures e.g. a feeling of personal satisfaction, were based on the service user's evaluation that the message had been listened to and understood.

> " After a routine training session it gives me satisfaction to have put across a message and to feel that those who have been involved have listened and understood."

Three other service users were less convinced: one felt unable to respond, another said that s/he was unable to answer because of "lack of feedback" while the third judged that the success was:

> " Probably negligible, because most of the people we have been talking to already have some idea of our problems. In a sense we have been preaching to the partly converted. We should be talking, for instance to hospital doctors who treat us like machines to be repaired and who have no idea what it is like for us to manage outside the hospital environment. Others we need to talk to are employers, people in shops, banks and other public amenities who have little or no awareness of the experiences of disabled people."

Conclusions

This chapter is important as a collection of views of a group of service users on a complex process. Some key themes have suggested themselves.

Participation didn't just happen. It was encouraged by a culture that embraced the philosophy of 'involvement' - albeit on the basis of 'consumerism' and possibly within a managerial-led agenda. The organisational dimension impacted upon processes of selection, access to preparation and training and opportunities for ongoing involvement and the development of skills.

The organisational expectation that service users should contribute ‘what it felt like to be a user of services’ was a narrow remit. Perhaps this was reflected in the approaches to preparation (enabling) which appear to have concentrated on the skills of delivery within a disability awareness model. Whilst it is significant that ‘shared experience’ was being seen as a possible tool for change the thinking which informed such an approach was not clear.

There is evidence to suggest that, although personal experience as users of services was the starting point, service users aspired to being involved as more than ‘consumers’. The occurrence of themes like ‘equality’, ’control’, ‘ability’, ‘partnership’ and the wish to change attitudes and negative stereotyping by professionals and others (including fear, prejudice and misinformation) indicate a movement towards a rights based understanding of participation as citizens.

Service users had the confidence to believe that they could influence professionals and that this would feed into practice. Views of the concept of influence and of whom and what should be influenced varied as did the messages and perceived contribution of service users.

The main themes cluster around the belief that professional attitude and practice may be influenced by:

- creating greater understanding of disabled peoples’ situations (insider knowledge);
- stereotypical and negative views being challenged by meeting people like themselves who are positive role models;

- insight being offered into what is seen as appropriate and inappropriate professional intervention;
- empowering other disabled people to address issues of oppression in their own lives.

Chapter 6

THE VIEWS OF CARERS

Introduction

In 1994 Twigg and Atkin published 'Carers Perceived: policy and practice in informal care'. This book was a landmark in the development of awareness of issues concerning informal caring. It begins with the assertion that 'Carers are no longer the Cinderella's of social policy' and highlights the way in which carers, and their situations, have become increasingly visible within the public arena and the politics of care. It points out that there had been a general lack of coherent and strategic thinking in relation to caring and that this was echoed in the scarcity of theorising on the relationship between carers and services within academic literature (Twigg and Atkin, 1994, page 1).

The first thing to note is that the number of carers involved in training initiatives for community care in Dyfed was fewer than that of service users. The eventual number interviewed was only three, all of whom were spouses of service users - three of the group of service users were single and a further spouse had not participated in the training initiative within Dyfed. It is however pertinent to raise questions about the fact that carers overall were afforded a lower profile than service users: this will be considered in relation to the profile of carers.

The structure of the interview used was similar to that used with service users (See Appendix 3B), but changed slightly in order to incorporate some slight differences e.g. length of caring and relationship to the person cared for.

What sorts of people were involved: who participates?

The following table gives information about the three carers who were involved in the foundation training for Community care in Dyfed.

Gender	**age**	**Period of caring**	**Relationship**	**Impairment of person cared for**
Female	48 (37)	11 years	Wife	stroke/ communication difficulties
Female	56 (30)	26 years	Wife	hereditary impairment
Male	53 (35)	18 years	Husband	congenital impairment

Figures in brackets (37) denote age when the carer assumed caring responsibilities. Relationship refers to the relationship to the person cared for.

The dimensions of gender, age, period of caring, the nature of the caring relationship and the impairment of the 'cared for' person were viewed as significant. In this very small sample two were female carers while the third was male. They were all in the relationship of spouse to the cared for person and all assumed caring responsibilities at a young age, while they were also in caring roles as parents. The differences in terms of the physical impairments of the partner in each of the three situations have also been noted. The three situations include:

- a family with a progressive hereditary disability with all its implications for the next generation;
- a caring situation arising from a congenital disability where there was some awareness of the disability prior to marriage;
- a suddenly acquired disability arising from an acute medical incident.

Although statistically there are more female carers in the population than male, research has shown that the incidence of male carers is greater than might be expected (Baldwin and Twigg, 1991). Approximately three-quarters of male carers care for a dependant partner or spouse (Arber and Gilbert, 1993 page 137, Parker and Lawton 1990a, 1990b; Parker, 1992 cited on page 3 of Twigg and Atkin, 1995).

It has been noted, in relation to female carers, that most carers are beyond child rearing age and that it is usual for their child-care responsibilities to have ended (Ungerson, 1993 page 146).

During the 1980s it was realised that demographic changes, particularly the anticipated growth in the population of elders, and of patterns of caring, would increase both the potential for informal caring and the demands on informal carers. This would present challenges to health and social services in terms of providing co-ordinated and integrated systems of care (Challis and Davies, 1986 pages 1 - 7).

Thus it is atypical for carers to also be parents and to be in the dual role of carer and parent has particular difficulties (Ungerson, 1987): an issue that will be considered later in this chapter.

Becoming involved

As in the case of service users, the development of participation by carers was founded upon their relationship with the Coleshill Day Centre. The Day Centre Manager and committee membership of CATCHUP were identified as catalysts. The specific factors, which fostered interest among service users, are discussed in chapter 5 and are common to carers.

The main motivation was to influence professional practice. The impending implementation of the National Health Service and Community Care Act, 1990 was seen to offer new opportunities and all three carers viewed the training of staff as an important challenge. There were common themes, but differences in emphasis, which relate to the different situations of the individuals interviewed. These will be developed later in this chapter.

One of the carers wanted to influence professional practice because of his/her perception that 'no-one knew how to help them'. The context was his/her partner becoming severely disabled as a result of a stroke This is a theme which highlights issues about the nature of the experience of carers when they are forced to interact with professionals within the acute medical sector.

Research indicates that once a person enters a hospital and becomes the responsibility of a hospital consultant it is likely that care and treatment will be narrowly focused upon the patient. Hospital consultants are less likely than other professional groups to consider the needs of carers and, other than in exceptional circumstances, carers and their needs remain in the background as part of the taken for granted resources within the community and may even become invisible (Twigg and Atkin pages 71 and 72). It is acknowledged that the period of hospital discharge is likely to be extremely stressful (Care Plan, 1997 Vol. 4 page 29) for carers, not least because of the potential problems of professional response. It is suggested that although professionals differ in terms of their training and roles within community care that professional response to carers and their situations is commonly dominated more by their assumptive worlds than by what has been learnt through formal training (Twigg and Atkin, 1994 page 27). Problems, which have been identified, relate to:

- narrow instrumental roles;
- the way in which medical professionals see the carer;
- professional expectations of caring relationships e.g. assumptions based on gender and the type of relationship;
- different levels of knowledge of available resources and services;
- the discretionary aspects of professional involvement with carers;
- differences in local policy.

The above will be considered in vis a vis what carers said about perceptions of specific groups of professional workers later in the chapter.

Preparation

Only two of the carers interviewed identified specific preparation. One described the preparation as 'informal'. The other said that:

> " A chap came to the day centre - we were under the impression that he would be showing us how to use flip charts etc., this wasn't the case, but he was quite informative. Information was given about who we were going to speak to and locations."

The third carer suggested that the only preparation had been through contact with the world of disabled people and carers and personal experience. This picture contrasts with that of service users who had accessed more opportunities for formal training as trainers. The article by the Day Centre Manager (Aitken, 1991) refers to the inclusion of carers in this training, but it may be significant that at the time the whole profile of service users as trainers was being highlighted without a comparable movement among carers. There are several possible explanations, namely:

- the remit of Coleshill and CATCH UP was primarily to work with, and to empower, service users;

A corollary to this is that the role and status of carers was less well defined. At the start of this study the only legislation which gave any rights to carers was section 8 of Disabled Persons (Services, Consultation and Representation Act) 1986,which required Social Services to 'have regard' to the ability of the carer to continue to provide care for an adult with a disability who was being assessed. While the White Paper Caring for People acknowledged the strong role of informal care (DoH, 1989), the National Health Service and Community Care Act, 1990 did not in fact mention the rights of carers (apart from the right to be consulted, via representative voluntary organisations).

- the limited resources of carers in terms of time and energy.

Day centre provision is traditionally associated with offering respite and it was perhaps assumed that carers might not wish to be involved in formal initiatives within the centre.

The extent of involvement in training

The degree of involvement varied from two Foundation days, to occasional training to extensive involvement. At the time of interviewing none of the carers were involved in any training, however, there were negotiations with hospital managers to hold sessions about the position of informal carers with medical staff. When compared with the response of service users it emerged that more service users than carers were involved and that the extent of their involvement in training was greater. This suggests more investment of time and interest and a wider range of opportunities for service users. Perhaps this is not surprising in the light of the ambiguity of the situation that carers occupy in relation to service providers (Bibbing, 1998 page 179).

The concept of influence

Professional attitudes to carers and their effect on practice were seen as important. It was the view of the carers that professionals need to take account of the difficulties for carers and families as well as for the person with the disability. However, whether they had been able to influence was doubtful from the point of view of one carer:

> " I had initially hoped that the final outcome of training would have had some influence, but it would not appear to have had any effect on the professional and official bodies"

When one considers some of the feedback by carers in the group evaluation (October 1992) and the problems of some professionals in understanding the position of carers the expression of scepticism is not unexpected.

Literature on informal caring provides ample evidence that the nature of the relationship between the person being cared for and the carer is frequently the subject of ignorance and misunderstanding. This can arise from 'myths and stereotypes' of caring e.g. within the Asian community, (Gunaratnam, 1993), orthodoxy within welfare policy and provision as it relates to expectations of female carers (Graham, 1993) or the silence about male carers which results in under estimation of the problems of being a man and a carer (Arber and Gilbert, 1993).

The Carers (Recognition and Services) Act 1995 has identified three main categories of informal carers: adult carers, parent carers and child carers. Although the group of carers in the group studied was small, and the primary carer in each instance is an adult carer the presence of children and young people in each of the families during the period when they had commenced their caring role is significant. Each of the carers interviewed had become carers during their thirties, an optimal time in terms of child rearing and a period when the economic, social and emotional impact of disability upon the family units would have been profound.

How did carers view their influence, whom did they wish to influence and what was their message?

Carer 1 focused on the 'system' and identified targets of influence as, not only professionals who interact with carers, but:

> "Official bodies and groups who might have some idea how to meet the requirements of disabled people and their carers".

S/he wished to influence the system and viewed the message as:

> " Caring is a full time occupation for most carers, for which their contribution to society is completely ignored, or at least taken for granted (the system). Recognition by government must be obtained".

Since 1994, when these interviews took place the Carers Recognition Act, 1995, has been implemented. This has offered some of the official recognition asked for by this carer but, for reasons outlined elsewhere in this chapter, carers are still in a relatively weak position.

Carer 2 viewed professionals in general as the target group, but was particularly keen to influence social workers:

> " Social workers, doctors, health visitors etc. but especially social workers".

Social workers were seen as having:

> "no idea what is entailed in being a carer. They appear to expect that because someone has been coping in the past, they will continue to cope no matter the circumstances ".

This carer wished through training activities:

> "To change attitudes, make people aware of the problems confronted by carers and disabled people".

The message for training related to the way in which carers are identified in relationship to the disabled person. The danger of professionals acknowledging the needs of the disabled person while ignoring the carer and the rest of the family group was pinpointed by the carer who wished to:

> " Make social workers aware that it is not just disabled people who need help but also their carers, and especially where there are children in the household the rest of the family. What do children think and feel about the situation? They might need help and counselling and help to overcome the difficulties that the situation places on them. It is important for social workers to understand that, particularly where disability strikes a member of an established family, ongoing counselling and practical advice about benefits, support groups and other available services would be invaluable in helping them overcome their initial difficulties ".

S/he suggested that if her young family had this kind of help when her partner became disabled 26 years ago it would have made life much easier. In this instance there were also issues about dealing with a hereditary disability.

The emphasis upon young carers and their special needs in terms of support was adopted by the Carers National Association, who refer in their literature to Child Care and Community Care legislation. Section 17 of The Children Act, 1989, 'emphasises a child centred approach, encourages collaboration and multidisciplinary planning' in the delivery of services to 'children in need' (Carers National Association, April 1996). Young carers are viewed as ‘children in need’ as their own needs are often subsumed by those for whom they provide care (Bilsborrow, 1992 cited on page 176 of Allott and Robb, 1998).

Continuity of help and support does not fit well with the model of care management and assessment adopted by social service departments. It is the nature of many services that they respond to a crisis, or appeal for help, put in services and then withdraw. Some contact is offered through the review system, but often this relates more to the ongoing monitoring of practical services, and is dominated by considerations of efficiency and cost effectiveness, rather than the mental or emotional well being of the carer or the family. Research has shown that carers tend to be diffident about seeking help, but that when they do so their expectations are of continuity and of a proactive, rather than reactive, response by professionals. (Hunter et al., 1988 cited in Twigg and Atkin, page 142).

Carer 3's answer drew out implications for professional practice of her/his family's experience. The answer gave a snapshot of a whole process, starting with hospital admission and continuing through the period of hospitalisation to hospital discharge and beyond; a time characterised by extreme trauma and upheaval. There was greater emphasis given to the role of social services than of health; the social worker being notable because:

> " The hospital social worker was very busy, possibly inexperienced, and didn't have the knowledge of the problems faced at home ".

S/he was advised to contact the area social worker on their return home. The area social worker was very helpful, but: " Because I was seen to be 'coping' closed the case". In this carer's opinion:" Cases need to be reviewed and time offered". S/he summed up the implication for practice as:

> " The nature of the early contact - the nature and quality of counselling - someone for us ".

The role of paramedical services in hospital discharge arrangements was also important. Issues around hospital discharge were viewed as extremely difficult and problems exacerbated by professional responses. This carer thought that there was difficulty in being allowed to care for her partner at home because of perceived risk and difficulty in obtaining essential aids. Professionals were assessing risk and gate-keeping resources, and there was a perceived conflict between what the carer viewed as the natural role in caring for a spouse at home and the response in relationship to aids necessary for hospital discharge:

"I want him home, let me have hoist to go home".

Research demonstrates that discharge from hospital and equipment provision is extremely problematic:

> 'The health service ombudsman has investigated many times the arrangements, or lack of them, made when people are discharged from hospital. This is not surprising, given the long standing problems afflicting hospital discharge practices (Marks, 1994). Indeed, advice from the Department of Health and professional organisations elsewhere refers to the need for timely and appropriate provision of equipment and adaptations when people leave hospital (DoH, 1994)'(Mandelstam, 1997 page 205).

Hospital discharge has been associated with stress and difficulty for many carers as they face radically changed circumstances in all aspects of their lives (Parker, 1993 cited on page 72 of Twigg and Atkin, 1994). The nature of these difficulties range from the interpersonal, family difficulties changed financial circumstances to social isolation.

It appeared that the importance of the husband and wife relationship was being overlooked, as were the difficulties within the home situation e.g. related to dependent children. The same carer suggested the importance of a regular review process, an acknowledgement that circumstances can change - a view that concurred with that of Carer 2.

When asked 'What do you think is the main message of involvement for you?' Carer 3 replied: " The danger of lost identity as a carer". S/he had already given clues about to what this signified in previous answers e.g. other roles such as spouse becoming secondary to the role of 'carer', lack of understanding and acknowledgement of what sustained caring involves and a parallel deficiency in services which focus on the carer. She went on to explain:

> " If someone is coping initially it does not mean that this is always going to be the case. The carer can be under great strain emotionally and physically and this will affect the quality of his/her caring ".
> " There is a need for someone with whom the carer can talk through what s/he is trying to achieve ".

Understanding the experience of informal carers within the overall context of Community Care is becoming an increasing focus of interest within the academic community. The Carers Recognition Act 1995 has offered a firmer policy base, but still leaves many issues for practice. Resourcing is piecemeal and the assessment of a carer's needs is usually triggered by assessment of the service user. The needs of carers may be in conflict with those of the people for whom they care and resources are often targeted at those 'on the brink' of collapse (Twigg and Atkin, 1994 page 149).

The most coherent and comprehensive articulation of the issues surrounding community care is still that which is found within feminist thinking, which offers insight into normative social expectations of female carers based on concepts of obligation, responsibility and duty (Finch and Mason, 1993 page 96, Graham, 1993 page 124). Among the most important aspects highlighted is the impact of long term caring arrangements upon the quality of life of women:

> 'To feminists community care is a means of reinforcing women's oppression. It traps women within the private domain of the family home and leaves the carers struggling with the emotions of love and duty' (Begum, 1990, page 18).

A further perspective is that of ethnicity and culture and the implications for social work and social care. Coleshill is based in Llanelli with its industrial heritage but operates within Carmarthenshire, an area with a high number of rural communities. It is an area, which according to the 1981 census had between 55% and 70% of Welsh speakers in its population (Williams et al. eds., 1994). This has not been considered as part of this study, but the observation should be made that within such an area traditional cultural norms and expectations are tenacious (Aaron et al. eds.1994). In spite of social changes, it would be fruitful to consider the role of language and culture on patterns and expectations of caring:

> 'The needs of carers who prefer to speak Welsh should be considered by authorities, particularly to enable them to participate fully in any assessment and to give effect to

> the principle of equality between Welsh and English enshrined in the Welsh Language Act 1993, as far as is appropriate and reasonably practicable' (W0C 16/96 cited in Roberts et. al. eds., 1998 page 80).

The contribution of carers to the activity of training

The answers within this section reflect different perspectives, which flowed from different experiences of caring. The first suggested a theme which is central to community care and literature on caring, namely that of the individuality of carers and caring situations:

> " To remind them that every carer is an individual " and the need for professionals to tailor intervention to the specific circumstances of the carer:" any front line worker fits person to a package rather than the other way around".

This is a theme which constantly occurs in the ongoing debate about needs-led versus resource driven assessment and care management within Community Care (Smale et al.1993, Ellis, 1993). Within this process one carer 1 judged that:

> "People need people who are informed" and the "chance to look at 'what if' - with carers".

The concept of 'what if' indicates the need for planning within situations of uncertainty such as changes in the health of the person for whom s/he is caring, changes in the circumstances, health of members of the family or of his or her own health. The carer may have to face a situation where s/he is no longer able, or willing to care and must handle the transition to residential or nursing care. In the case of progressive disabilities many carers will have to cope with the death of the person for whom they are caring and for families where there is a genetic disability carers may be concurrently dealing with the manifestation of the disability in more than one generation.

This carer also sought acknowledgement that it is not possible for carers to dwell on things for too long, indicating the pressure and stress that can arise from continuous caring situations. Stress and the concept of 'burden' in caring relationships is a theme which has been explored a great deal (Baldwin, 1985, Parker, 1993 cited on page 4 of Twigg and Atkin, 1994) but about which there is little consensus (Zarit, 1989), mainly because individual perceptions by carers of the position within which they may find themselves may vary substantially from one situation to another. It is also a contentious notion for people with disabilities, emphasising as it does the 'negative' connotations of the caring/cared for relationship with the disabled person being construed as a burden. A dilemma for professional assessment is that 'solutions' such as 'day care' or 'respite care' may fail to acknowledge the wishes, or even needs, of the service user. A constant question for professionals must be 'Who is the user in this situation?' Issues of commonality and conflict of needs and views are complex but inescapable for professionals who wish to practice in a way which empowers (Braye and Preston-Shoot, 1995 page 127).

The importance of professionals recognising and working with 'our own relationship' i.e. the marital relationship was isolated. The interview reflected the difficulties for the marital relationship when a partner suddenly becomes severely disabled. Professionals are inclined to see caring as an extension of the marital relationship. Blaxter (1980 page 219) suggests that disability may lead to three types of problems in marriage: difficulties of a personal or sexual nature, problems of practical resources and, as a result of the linking of the first two, problems of role expectations within the marriage. Oliver (1983) points out the need for social workers to be cognisant of all three when undertaking an assessment.

Influencing other carers to express views was the aim of one carer and was coupled with concern that social workers may not take the carer and his/her needs into consideration. There was the dual aim of giving carers a voice and raising the awareness and response by social workers:

> " To encourage other carers to get involved in putting their views across"

> " To encourage social workers not to ignore the carers - it does happen. To encourage them to understand how the carers are feeling "

The contribution of experience and the associated knowledge was central to the final answer in this section.

> "Imparting knowledge gained through experience and contact with disabled people".

Representativeness

Each of the three carers had developed strategies for dealing with the tension of being individual and yet belonging to a group with shared characteristics or problems.

- By offering basic guidelines e.g." Starts from the knock on the door - person who really cares/someone who is comfortable with you. Knowledge is important - ask questions".
- By attempting to elicit the views of the wider group, however " It is a problem because different carers have got different problems'.

One carer tried to canvas the views of other carers before attending meetings or training sessions, or to report back what has been said and elicit their thoughts. However, many of the carers who attended the local Carers meetings were so relieved to get out for a break that they just want a social chat and were reluctant to talk business. This links with the earlier point that carers do not always want to 'dwell on' caring. This experience of establishing carers' groups is underlined by research that has shown that most carers value groups for the social contact and may even resent the intrusion of information or business (McLachlan et al. 1985). The most successful groups are those with a social or recreational focus (Twigg et al.1990).

Listening and understanding the situation of other carers was also the strategy of the third carer:

> “By listening to, and understanding the problems of other carers. There is a certain empathy between carers even when their individual needs may differ ".

Spreading involvement

While there was consensus that more involvement by carers is desirable, there was also clear acknowledgement of the barriers and problems of involvement.

A strategic approach to spreading involvement was advocated by one of the carers. Inclusion of service users and carers on planning committees to look at inter-agency policies and in groups dealing with issues for carers and disabled people was suggested. The dissemination of information was central to the strategy as was the ideal of multiplying examples of good practice to other locations.

As in the case of service users lack of motivation or interest to be involved was cited as a barrier - what a service user had described as apathy, was viewed by a carer as complacency:

> "There is a lot of complacency to overcome. In Coleshill, when the idea was first proposed, a lot of people thought it was a good idea, but very few wanted to get involved. So there is no easy answer to that question".

But successful outcomes was viewed as a spur to involvement:

> "Through them seeing that pressure by users/carers is beginning to be productive".

Some factors identified by service users did not arise in the interviews with carers e.g. transport, remuneration and support with alternative care arrangements.

Future involvement

A view that involvement in training had been limited and the wish for more regular and systematic opportunities was shared with some service users:

> " So far the extent to which users and carers have been used in training has been single one day sessions in each division of Dyfed with Home Care staff and the other half with social workers and care assessors. This is not enough, these sessions should be established on a regular basis, with all day sessions for the same group of people,

> which would give a lunchtime opportunity for informal discussion to take place. In a way informal discussion is just as important as formal seminars, because it enables people to ask questions and for the users/carers to think of things they might have overlooked in the more formal setting"

Transference into practice was the test of effectiveness of the contribution to training:

> "By them taking notice of our needs. Too often we are told what we need; it would be nice to be asked and then to be acted on in a positive manner".

Support for further involvement in training

Two carers did not see the relevance of this question as they were not involved at the time of interviews while the third did not see the need for further training or support at that time.

Success in training

As in the case of service users, the measures of success used by carers were related to internal factors, such as enhanced confidence, or to external indicators such as the level of approval exhibited by individuals or audiences within sessions. Involvement had made one of the group ' more self-confident and sure of her/himself', while increasing awareness of ' some of the problems and difficulties experienced by Social Services Staff'. At the same time s/he had thought that:

> "After the sessions, although they have not been long enough or regular enough, many of the participants appear to have had a better awareness of the position of users and carers".

It was this need to create 'better awareness' of carers' situations that appears to have provided and sustained the impetus to participate.

Lack of feedback was seen as a problem by the third interviewee:

> "This is difficult to assess as there has been very little feedback. I would hope however that any influence has been positive".

Conclusions

While the content of this chapter is important it is limited by the fact that it is based on the views of a very small and atypical group of carers. The interviews took place before the implementation of the Carers (Recognition and Services Act), 1995 and are indicative of the struggle of carers to be heard and for their contribution, needs and rights to be acknowledged. The process of involvement itself suggests a low profile for carers.

The three interviews demonstrate a high level of solidarity between the carers and the cared for. There appears to have been little questioning of the role of family as the traditional caring unit (Finch,1989). None the less the answers reflect the ambiguity of caring relationships and the tension between needs and rights in caring. The emergent themes reflect this ambiguity and the framework on caring developed by Twigg and Atkin (1991, pages 12-15) is a useful tool of analysis. It appears that carers were viewed (and perhaps viewed themselves) as 'resources' but wished to be acknowledged as at least 'co-workers' (with the acknowledgement of their role in supporting the disabled person) and ultimately as 'co-clients' (being seen as having needs in their own right).

The theme of lost identity and of invisibility emerged in several different ways. At a political level it denoted being denied recognition and one's contribution to society being taken for granted. In engagement with 'caring systems' such as hospitals and social services carers perceived that the focus was the 'cared for', namely the person with the disability, rendering the carer 'invisible'. Within the domain of family and social networks the role of 'carer' transcended other roles, e.g. wife and mother.

‘Burden’ was a further theme. At no point did the carers describe the disabled person as a ‘burden’. They did, however, reflect the strain of being involved in a substantial, long term caring relationship with inadequate or inappropriate support. The impact of caring upon the wider family, particularly children, was an important point.

That ‘no-one knew how to help them’ was a powerful message, which appeared to reflect lack of imagination and of knowledge on the part of professionals about the situation of the carers. The three carers in the study were asking for understanding, for professionals to listen to their point of view, to be able to enter into the world of themselves and their wider families. Part of this understanding by professionals was acknowledgement of the changing, and sometimes unpredictable nature of caring, and its effect upon relationships, especially when the caring relationship is a long term one.

What also emerges is a picture of what the three carers saw as important qualities for social workers and their roles. Social workers were seen as ‘someone for us’, people who are ‘informed’ ,who are willing to lay aside assumptions and listen and who care. The role of social work was seen as both preventative and supportive. Being there ar the beginning and offering counselling especially in areas of relationships, offering information and advice on areas such as benefits, support groups and other available services was important but carers also reflected the need for ongoing contact and support (on a regular review basis) from social workers.

Chapter 7

THE VIEWS OF STUDENTS

Introduction

The aim of this chapter is to consider the possible impact of involving service users and carers in the training of social work students. Its focus is the views of students about the module on physical disability within which service users and carers were members of the teaching team. There is some reflection upon learning opportunities provided by placements with the user-led organisation CATCHUP as a way of considering the wider aspects of involvement.

A variety of materials are used in order to give as comprehensive a picture as possible of how students evaluated the involvement of service users and carers in a scheme of professional training. These include:

- evaluation material from 1994 – 1995;
- a self-report by a student on placement with CATCHUP;
- student presentation material from the course of teaching in October/November 1995;
- insights gained from interviews with three students.

The aim of analysing student comments was three-fold:

- to determine how students viewed service user and carer involvement in the learning process;
- to establish common and divergent themes within the material itself and to see how these connect with broader themes within the worlds of academia and practice;

- to consider the links between service user and carer hopes and objectives and learning outcomes, within the context of the overall aims and objectives of the course itself.

Student feedback is used as a means of gauging views on the process of teaching and learning outcomes in the key areas of knowledge, values and skills. Each section of the chapter starts with a brief review of what emerged from service users and carers and then looks at how student views relate to these key themes.

Insights gained from interviews with two students who undertook the module in 1995/96 are used to supplement the material from evaluation forms. The third interview with a former student who was on a practice placement with CATCH UP in 1994 is treated as a separate section at the end of the chapter (please see pages 98 and 103 for the reasons for this). Something should be said about the three students selected for interview before moving to the main sections of the chapter.

The student interviewees

Student A was a single woman graduate, with a background in voluntary work. Her career included direct care of older people, research into caring and housing rights work. Her main contact with physical disability was through caring for older relatives within the family, a childhood friendship with a disabled child and work with older people in nursing homes.

Student B was married woman and a mother. Her background was as a nursery nurse, work with voluntary and statutory organisations and with children with physical disabilities as a play therapist in a hospital.

Student C was a married man with a recent academic background in sociology. Prior to this had run his own business and worked in the printing trade. Before joining the social work course at Swansea he had no direct contact with people with physical disabilities.

Course evaluation

The views of Diploma in Social Work students at Swansea were collected over a three-year period using the routine evaluation forms used for all courses (Appendix 2). Chapter 3 documents how the nature of the training input varied during the three years, as evaluation from service users and carers and students fed into changes in course structure and content.

The numbers of evaluation forms returned by students are as follows :

Course	**Number**
May 1994 (Ageism and Diversity)	35
February/March 1995 (Service user involvement and Physical Disability)	23
October/November 1995 (Service User involvement and Physical Disability)	32

Note: the number of students on year 1 of the course was approximately 50, of these 12 were following the Probation option.

It will be noted that while less than three-quarters of evaluation forms were returned in May 1994 and October 1995 the number dropped to approximately half in February/March 1995.

No question on the routine evaluation forms addressed the involvement of service users and carers in the training, and information gathered on all dimensions of involvement by service users and carers was freely offered by students.

The data relies heavily on student evaluation and it is, therefore, expedient to consider the reliability of student views. An assumption has been made that it is good practice to obtain feedback on the quality of teaching input on a social work course. Routine evaluation is consistent with the practice recommended by CCETSW as part of ongoing monitoring of Diploma in Social Work courses.

The format of the questionnaire used on the Social Work course at Swansea is consistent with the advice contained in 'What's the use of lectures?' (Bligh,1971). Ratings on particular scales, preferably ranging from 1-6 and, therefore, reflecting a continuum of opinion is considered to be more reliable than relying on non-verbal or verbal feedback. Anonymity is also likely to lead to more honest feedback.

The subjective nature of all feedback is assumed by Bligh who proposes that different emphases within evaluation correlate with personalities and with domains of interest:

> 'Arts and social science students had strong preferences for lecturers who 'provide the framework for independent study', 'indicate where further information can be found', 'talk freely around a few notes' and who 'leave room for students to exercise their imaginations' (Bligh 1971 page 139).

Feedback is only valuable as a gauge of student learning, and it is, therefore, equally possible to learn from negative as positive feedback. In this study the use of evaluation forms has been complemented by the interviews with individual students.

The honesty of students has been assumed. Marris (1965, page 134) suggests that students are the best judge of lectures as they are the only people who have to listen to them. It should, however, it should be conceded that there is a possibility of positive bias given the specific nature of the interaction in this context.

Quality of input

Students were asked to grade course content, structure and presentation based on a sliding scale from poor to excellent. Judgements on quality of input were made in relation to the whole module, which included the teaching contribution of staff, an external speaker from Dyfed Social Services as well as that of service users and carers. The learning experience was also influenced by the provision of course material, including a resource pack (see Appendix 5) and case material used within the sessions. The aim of each week-long course was to provide an integrated learning experience and the utilisation of different methods and materials formed part of a total experience. While the framework and teaching materials for the course remained constant during the four weeks the nature of each of the courses was unique, reflecting the character of the different groups of students and the contribution of different service users and carers.

What did the student evaluation forms suggest about the process and method of teaching and its effectiveness?

Spring 1994

	A	**B**	**C**	**D**
Content	23	9	4	-
Structure	11	15	7	2
Presentation	20	11	3	1

Spring 1995

	A	B	C	D
Content	7	16	-	-
Structure	5	18	-	-
Presentation	6	17	-	-

Autumn 1995

	A	B	C	D
Content	15	17	-	-
Structure	11	14	6	-
Presentation	11	19	1	-

A = Excellent, B = Good, C = Satisfactory, D = Poor.

Whereas the 1994 evaluations vary in their ratings between poor and excellent there is much less differential in both sets of 1995 evaluations with no evaluations giving satisfactory or poor scores. It is believed that there is a clear link between issues of quality and the process and method of teaching.

Evaluations did not concentrate exclusively on the user/carer input and student comments reflect the positive and negative features of the whole module. Proceeding from the premise that the context and total experience are an essential consideration in learning outcomes (Rogers,1986, Burgess, 1992) all indicators of effectiveness of the process will be considered. Chapter 3 presents a descriptive account of the development of the programme and the differences between the teaching structure in 1994 and 1995.

There were far more contrasts in how students evaluated the course in 1994 than in those gathered from the two modules in 1995. Out of 35 evaluations 18 specifically mention the inadequacy of time and of these 13 couple this with the need for smaller groups or the problems of being physically cramped. A further three just allude to the problem of group size. Both of these considerations are linked in a number of instances with statements about:

- The importance of the subject and the need for far more in-depth exploration of issues;
- The way in which the size of the group limited the interaction with the people with disabilities.

The second point about interaction with people with disabilities raises some interesting considerations. The level of 'interaction' within teaching sessions can be construed as indicating the extent to which students are engaging with the subject and 'motivation' to learn(Armitage, et.al., 1999 pages 83 and 84). 'Enthusiasm' on the part of students has been cited by proponents of EAL (Burgess, 1992).The association between learning and group functioning is discussed elsewhere in this chapter.

There is less feedback on group process in the two sets of 1995 evaluations. This can be related to the restructuring of the module which allowed students to work in smaller groups, the doubling of time devoted to the module and a more extensive role for service users and carers.

Comments on group dynamics and how these impinged on learning only appear in the evaluations of the first two sessions held in the autumn of 1995. At this stage the two groups of students were not only completely new to the course but were also being initiated into a different approach to teaching.

Positive factors referred to are :

- other group member's experiences;
- working **with** disabled people;
- working together as a group e.g. in finding information;
- the benefit and support of group work;
- working in a team;

The only negative was viewed as :

> “The structure and teaching model is very dependent on the commitment of individuals to participate fully - sometimes individuals can be quite destructive to fully realising the group's potential”.

The structure and teaching model were based on co-operative learning based on group work. The experience of this approach in Bristol indicated a variation between groups, some of which seemed to 'gel' easily and maintained their motivation in the absence of staff, while others were less effective (Burgess, 1992). In this instance a further variable was introduced, namely the presence of service users and carers. This will be considered further later.

Student views of service user and carer involvement in the process

The interviews with service users and carers had emphasised the limitations of professional knowledge of disability and had identified the need to challenge stereotypical and misinformed opinions about disability, disabled people and the position of carers. The training role had been seen as a potential agent of change :

- through providing a positive role model;
- by sharing experience, i.e. the problems associated with being disabled and by offering a realistic insight into the lives of disabled people and carers;
- through interaction with professionals and students, listening, responding to questions.

It is, therefore, vital to enquire to what extent the student evaluation forms and interviews with a small number of students support service user and carer expectations. Evidence that students viewed the involvement of service users and carers as among the most valuable aspects of the learning process is considerable. This remained the case when there was criticism of how this aspect was incorporated into the teaching programme. While this is reflected in the three sets of evaluation material it is more prominent in the two sets of information from 1995 students when the user and carer contribution was more substantial and more specifically structured.

Throughout this chapter the views of the two 1995 students who were interviewed during their final term will be used to supplement the information collected from the forms. The interview with a third student, who was on practice placement with CATCHUP, is used to consider transfer of learning to post-qualifying practice.

Providing a positive role model

The presence of disabled people and carers in the teaching programmes attracted a great deal of comment from students, which although mainly positive was not unconditionally so. The programme was not set up to ensure that service user and carer participants adhered to certain viewpoints and there was an inherent risk that participants would not be 'politically correct' or toe the party line in the views they expressed. The case material offered the opportunity to consider disability within a wide social context and to think about issues linked with race and culture, sexual orientation, hence offering the potential for students to explore concepts such as 'triple jeopardy' (Norman,1986). This meant that there were aspects of experience within the case material that were outside the experience of the trainers.

The question of the credibility of the service user and carer contribution is central to the idea of positive images. Although none of the students used the terminology 'positive images' or 'role' these ideas were intimated in other ways. The inspiration of a positive perspective is expressed in the following:

> "Huge range of issues facing disabled people and their families;
> Thought about these issues and tried to imagine being in the described situations;
> Also learned a lot about positives as well as negatives".

The second of the above comments is arresting in terms of the theory on imaginisation as an aspect of reflective learning (Gould,1996). For social workers who wish to empower service users and carers:

> 'The ability to shift perspective, to stand in the shoes of people needing social care services, to appreciate how they might experience this encounter, is an important part of preparing to approach people who use, or may wish to use, services' (Braye and Preston-Shoot,1996 page131).

Overall, the same student judged that this had been:

> "An excellent method for exploring the issues around disability - ranging from practical to ethical considerations".

Other evaluations suggest that the presence of service users and carers transformed the experience from what might have been just an interesting academic exercise to a more realistic learning experience, with the potential for creating links between theory and practice:

> " It was good to have a disabled person and a carer in the sessions to ground us in reality while discussing theories and ideal situations ".

The above is typical of a number of statements in the 1995 evaluations which utilise the words 'real', 'reality' and 'practical' to denote the way in which the presence of disabled trainers and carers rendered the experience more authentic.

The two student interviewees supported the above view and introduced additional perspectives. Student A reflected that s/he had radically changed her view of disability and people with disabilities as a result of the teaching on the social model of disability in the social policy teaching. She recorded her reaction to the service user input:

> " I remember being quite surprised by some of the things s/he said - in that they didn't fit with my picture that I'd newly established of the social construction of disability. S/he very much described her/his disability in old fashioned physical terms ".

The session with service users had moderated her views:

> " I'd gone from one viewpoint to the other extreme - and had forgotten that maybe a lot of people didn't necessarily have this view of themselves or their circumstances ".

Student B reflected that:

> " I had a lot more insight into disability. I realised how positive people with disabilities can be - I don't automatically think like that ".

She viewed the service user and carer input as valuable because:

> " They were the people with the knowledge and expertise. They knew more than I do about benefits, things like how to get around, shops for example. Across the board they have to learn things as they go along ".

By sharing experience and offering a realistic insight into the lives of disabled people and their carers

Enlightening professionals, and others, about the reality of life with impairment, or as a carer, had been a goal of service users and carers. Evaluations confirm that students had gained a greater insight into those factors which affect everyday living, while simultaneously emphasising the complexity, and inter-relatedness of issues. These quotes from evaluation forms show that some students were starting to consider the situations of disabled people and carers from their viewpoint.

> “ Deeper knowledge of carers and clients' views / real problems and issues and resources “.
> “Excellent information from CATCHUP. Gave an insight into real situations and resources available. also had excellent handbooks on benefits etc.“.
>
> ” Attitudes towards disabled people and attitudes surrounding the caring role; practical difficulties of being disabled. It was very helpful to speak/listen to the experiences of a disabled person and a carer ”.
>
> “ Looking at disability in its social context was excellent - trying to understand perspective of disabled person - how everyday life affects people “.

Student A gave a wider perspective:

> “ I thought it was quite useful in terms of actual local services because they did have quite a lot of knowledge and that was useful - you know just the practical, where you go, who you talk to, how it works - you know good things and bad things to do and good and bad people you know in this system ... that kind of specialised knowledge that you can only get from someone who has already been through that system “.

Student B described the service user and carer contribution as 'more in touch'.

Attention was drawn in some student evaluations to the underlying question of representativeness. Some students appeared to generalise while others used phrases such as 'personal views' to denote the restricted nature of individual views.

Through interaction

Co-working with service users and carers was mostly construed positively :

> “ Useful and interesting to involve users to give voice to their experiences and share information”.
> “Interesting talking to people with physical disabilities first hand ”.

The 1994 module on Diversity included service users and carers in the final session only, as a 'panel of experts' commenting upon the presentations of the students on case material which was based upon their own life histories. Interaction was more limited than with the next two intakes of students, nevertheless the evaluation material uncovers a number of interesting points about the nature and potential value, and pitfalls, of interaction with people with disabilities within the sessions.

The utilisation of people themselves as both case models and commentators was viewed both positively and negatively. For one student:" Listening to people who were the case models was powerful".

Another appreciated the value of an honest appraisal, but recognised the need to be aware of the image that may be portrayed and the reality behind it. However, comments were not unequivocally affirmative - a student who viewed the inclusion of service users as "the most ethical and efficient way of learning" was critical of the way in which the interaction was set up:

> " We should have had more explanation and time over the case studies, because I don't like learning by default (i.e. it set up a situation where wrong answers were the tool for learning)".

The student presentations in the final session exposed their assumptions about impairment and its implications for the lives of the subjects of the case studies: students hypothesised about needs and ways of addressing them before hearing the feedback about how it was from the point of view of the people themselves. The conjecture by this student that the service user and carers were right and the students wrong when views diverged does not reflect what usually happens in professional assessment where it is more likely that professional views will dominate (Smale et al., 1993, Ellis, 1993). The 'power' dynamics of the final session with a reversal of the usual roles may be significant. S/he believed that to be forewarned would have changed the situation, and also makes the very important point that there should have been smaller groups in order to facilitate the interaction. A number of other students referred to their own erroneous assumptions/misconceptions and how the session made them face up to the problem of approaching people without taking stock of the baggage which they brought with them in terms of their feelings and reactions to disability:

> "How we tend to react to diversity, own feelings need to be looked at;"

and again the wish to look at the issues at more depth in a smaller group is expressed. There was a further perception that one of the main barriers to understanding can be the tendency to relate to the disability rather than the person.

Several students commented on the way in which open and frank discussion with people with disabilities had helped to deconstruct this particular obstacle to understanding, a few adding that more informal discussion e.g. over coffee would have been even more valuable.

But there were pitfalls for students. Some evaluations and interviews suggested that it led to a certain amount of circumspection by the students in expressing thoughts and views, perhaps arising from a lack of ease in the presence of people who are usually in the role of service user. This may be compared with the caution exercised by professionals who find themselves in situations such as case conferences where professional assumptions, knowledge and judgement may be open to scrutiny and potential criticism and where professionals must squarely face the question of whether they are working 'with or for users?' (Dalrymple and Burke,1995 page 143).

The two students interviewees reinforced the above. They both believed that the contribution of disabled people and carers was very effective, but thought that some aspects of interaction were not simple. Student B had been conscious of a lack of ease with disabled people, probably stemming from lack of experience and contact in every day life, while student A said:

> " I was a little bit worried - a little bit intimidated to ask questions initially ... just the whole politics of it, them being service users and us being social work students asking these awful questions, coming across as patronising, ignorant ".

However, what could be viewed as negative and inhibiting also had a positive side:

> " I had more need to be sensitive and I think actually it made me more thoughtful in the questions I asked which I don't think is a bad thing ".

In common with some service users this student valued the interaction outside the formal structure of the session itself.

Learning outcomes : knowledge, values and skills

CCETSW's guidance on social work training refers to the knowledge, skills and values which underpin competent practice (Paper, 30). Chapter 2 discusses some contemporary educational theory and the factors that influence learning outcomes for students. Chapter 4 acknowledges the limitations of this study - the real test of influence is practice outcomes. The various evaluations with students fall short of this ideal - they mainly express the impact of the training, particularly the contribution of service users and carers, upon the knowledge and values of social work practice. To a lesser extent they refer to skills such as communication. All of these areas feed into issues of effective practice.

Knowledge

The theoretical base was the starting point and reading material, including the resource pack, was aimed at helping the students to examine the fundamental differences between medical and social understandings of disability and the implications for social work practice. There was also a brief theoretical input, some teaching on legislation and exercises that helped students to explore their prior experience and how they defined disability.

In the autumn of 1995 Social Policy teaching, which strongly reinforced the social construction of disability, ran concurrently with the Physical Disability and Service User Involvement module. Hence some students arrived in the sessions well informed about the theoretical issues that inform social policy.

In the interviews service users and carers communicated a wish to influence the attitudes and beliefs of professionals as a first step towards improving practice. A link was made between underlying negative beliefs and the way in which professionals approach people with disabilities in tasks such as assessment. Professionals were viewed as :

- seeing the disability rather than the person;
- viewing disability as an inevitably negative experience;
- being fearful of disability and of people with disabilities;
- believing that disabled people may not be able to speak for themselves.

Carers had expressed the beliefs that "no-one knew how to help them"; that professionals lacked awareness of the needs of carers and were thus unable to help effectively in situations of crisis such as hospital discharge. The medical and social constructions of disability were not specifically mentioned by either service users or carers, but were implicit in the way in which they outline key issues e.g. of equality, barriers to functioning within society, dependence versus independence.

What do student evaluations say?

A review of the material suggests that the knowledge of students of disability had been affected by the:

- altering or modifying of existing views and beliefs: unlearning or relearning;

- strengthening of existing knowledge;
- acquisition of new information, perspectives, knowledge;

The following evaluation of the effect of the module on one student's learning is suggestive of a paradigm shift. What also makes it interesting is the apparent connection between moving from a medical to social understanding and being less afraid of disability as a field of work.

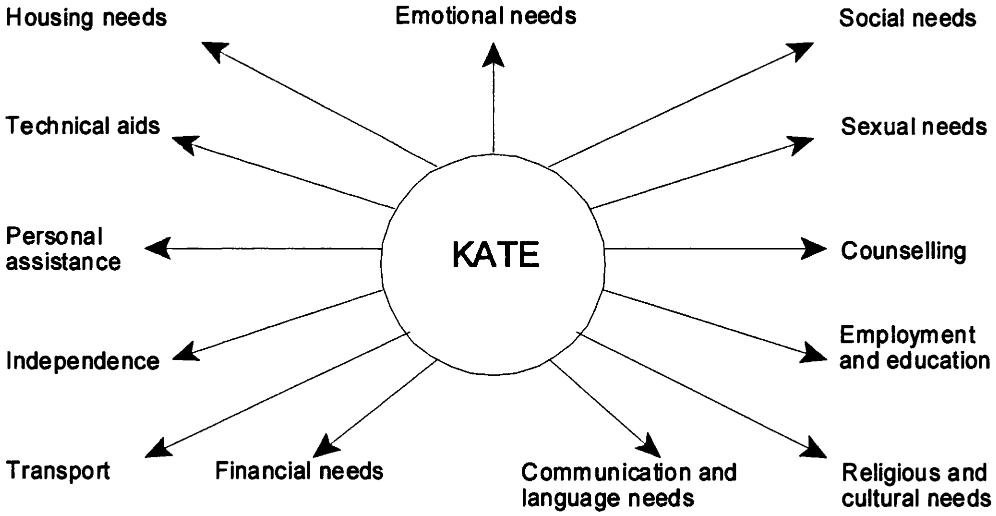
> " It changed my view of physical disability from a sort of wishy-washy - but basically 'medical model' to an awareness/understanding of the social model of disability" and "finally it made me much less afraid of disability as a field ".

Fear as a facet of social attitudes towards people with disabilities is well-documented (Middleton, 1992 pages 42-43, Barnes, 1991 page 12) and almost certainly impinges on the ambivalence of professionals about working in this field. What is not clear is the aetiology of that fear or how to counteract it (French, 1994).

A comparison with the sphere of race would suggest that combating racial prejudice is a complex matter and that relying on teaching about multiculturalism is flawed as it suggests that teaching about other cultures will dispel the prejudice and intolerance through creating a new knowledge base which will lead to tolerance and understanding (Donald and Rattansi, 1992 page 25). The missing element is the political understanding of the cause of racism within society. Oliver (1983, 1990, 1996 pages 43 - 62) and others (Barnes, 1991, page 23, Davis 1986) strongly endorse the view that this is also true of thinking about disability and current intervention, but as outlined in chapter 2 there are different ways in which this is viewed within the disabled community. The opinion of Abberley (1987) that learning must, in part at least, be based upon understanding the real qualitative and quantitative differences faced by people with disabilities in everyday living is epitomised by the following student comments on what was learnt:

> " Awareness of real difficulties disabled people encounter in life ".
> " How disabilities affect every day life ".

Student presentations at the end of each module revealed how students had considered a breadth of issues which influence the quality of life for people with disabilities and their carers during various life stages. They also demonstrated how students were obliged to face up to the tension between concentrating on the medical, with its overtones of adjustment and loss, and focusing on the social aspects of disability. The following diagram was used as the starting point of one group for their presentation on the issues for a 19 year old girl with a severe disability:



Their colleagues within the same EAL group identified, and defined the following issues for carers:

- Finance
- Living in a rural area;
- Emotional support;
- Possible emotional issues;
- Practical support;

- Assumptions of others;
- The future.

Spheres of knowledge cited by student evaluation forms ranged from the practical through to the emotional and ethical, linked with the following themes:

- benefits and their complexity;
- resources and their limitations;
- assessments and their implications;
- legal aspects;
- the role of social workers.

Social work values

The view was expressed in the interviews and group evaluation sessions with service users and carers that changed attitudes would lead to changed behaviour. This assumption is open to challenge from within the academic and disabled communities (French, 1994). While in some instances modification or alteration of behaviour may ensue this is not always the case. Those who seek to evaluate programmes of training in disability need to be cognisant of the complex relationship between attitudes, knowledge and beliefs and professional performance (Swain and Lawrence, 1994 pages 88 - 101).

Service users had experienced a number of attitudes that they perceived as problematic which would almost certainly indicate poor practice :

- people being patronising;
- condescension;
- insensitivity;

- prejudice.

They believed that the manifestation of such attitudes belied a number of problems, which originate in the realms of the cognitive, the emotional and the behavioural. The assumptive world of the professional was the starting point.

Service users surmised that negative attitudes and behaviour e.g. hostility, were rooted in beliefs or ideas which were themselves problematic. Stereotypical assumptions, such as the belief that disabled people cannot control their own lives or speak for themselves, were seen to play a major role. Combined with the cognitive was the feeling or emotional element, for example the fear of people with disabilities. A tendency was also noted for people to see the disability (the impairment) rather than the person. This was seen to result in a breakdown in basic communication which may become exaggerated with some groups e.g. those who have speech and language impairments or who are badly disfigured.

Attitudes therefore have cognitive and emotional aspects, which may affect behaviour. An aspect of behaviour which has received growing attention within social work education and practice has been language as a conveyor of attitudes and beliefs (Dalrymple and Burke, 1995 pages 42- 46).

One of the service users believed that :

> “ being a trainer automatically challenges people's attitudes towards disability “.

S/he perceived that role was important : the group session in 1995 suggested that during the early experiences of participating in Community care training event responses had been mixed with not everyone accepting the changed role.

Carers

In common with service users carers also discerned professional attitudes which were unhelpful to them. These mainly clustered around the nature of the informal caring relationship and official expectations of what they should and shouldn't do.

The invisible and unstated nature of caring is a strong theme - caring was generally seen as not attracting a great deal of professional time, attention or expertise. The exception was when there were problems associated with risk e.g. in handling: a situation, which may be of much more importance to professionals than to carers themselves. Carers were appealing for acknowledgement and recognition of their individual situations and problems for themselves and their families (including children) coupled with appropriate help. They isolated the following beliefs and attitudes, which they had encountered among professionals:

- because someone has coped in the past they will go on coping;
- unwillingness to allow carers to take risks;
- fitting the person to a package rather than the other way around;
- difficulty in working with relationships e.g. between partners.

What do student evaluations say?

The student evaluations, interviews and reports reveal a consciousness on the part of some students that their own attitudes needed to be reviewed, both in relation to disabled service users and carers and social work with this group. For one student the group work had stimulated a: " Total rethink about disabled people and the language we use" .For another it had raised :

> “ the issue of empowering disabled people so that they are the people informing able-bodied people rather than vice versa “.

A number of students admitted that they had been led to review assumptions based on ignorance or prejudice as a direct result of participating in the module. The aim of the module was to enable students to be more informed about disability and the lives of disabled people as a basis for future practice. This meant reviewing dimensions such as beliefs, opinions and language and did not wholly depend upon the dimension of participation to fulfil this aim. However, it is important to isolate the contribution of service users and carers as a special and unique aspect of the module and to question its possible effect within the overall teaching process.

A number of student comments offer indicators of what may have been taking place :

- the querying of assumptions and views in the light of the perspectives offered by service users and carers;
- the introduction of a degree of caution about views expressed in the presence of service users and carers, particularly the use of language;
- the constructive use of service users and carers as consultants to augment the teaching process.

A few students referred to conformity to equal opportunities and/or anti - discriminatory practice, while others mentioned empowerment. The in-depth interviews with the two students reinforce the fact that there was a raised awareness of issues of language.

Social work skills

The development of personal and social skills, including those that relate to team membership and working is strongly advocated by proponents of group methods of teaching and learning

(Burgess, 1992 page 17,Vanstone and Raynor, 1984). Within this module there were the additional dimensions of communication with service users, including those with sensory impairment. More light is shed upon this aspect of development by the interviews and placement reports where benefits of, and barriers to, effective interaction are highlighted.

From training to practice

The student placement report of 1994 and the subsequent interview offer a perspective on transfer from training to practice. The student's report is a reflection on learning experiences within the placement. The placement was a split one with part of the time spent working alongside service users and carers (as a colleague) and the remainder working as a carer in a voluntary residential home for younger people with physical disabilities. The contrast between the two environments and roles was stark, but within both there was a commitment to the principle of involvement albeit at different stages of development.

Enablement of service user/carer participation consistently emerges as the theme of the practice report. There is constant recognition of the tension between a theoretical approach to participation, which might be seen as idealistic and the practical challenges of implementation. Throughout, the student was contending with the question of what enabled and what inhibited participation at all levels. He was able to isolate specific examples of good and bad practice. For example in a planning meeting:

> " Business was conducted in a language and style which epitomised the professional committee approach ".

He warned that if modifications were not made it could render the whole process of user/carer representation counterproductive and eventually result in service users and carers perceiving their involvement as mere tokenism and pointless. In contrast:

> “ The meeting, which was chaired by a carer, was conducted in a comfortable and comprehensible manner “.

The encouragement of people to express their own ideas and opinions was central to an empowering model of participation.

What the student described as the issue of “enhanced dependency versus enhanced opportunity “ was a parallel theme within the placement. He described his learning experience as having given him “a faint insight into the lives of disabled people “ through working with disabled people and their carers in a wide range of situations and roles. He was concerned to avoid generalisations and his reflections and analysis exhibit his realisation of the complex relationship between the total environment within which disabled people find themselves and their own individual characteristics.

The interview

The aim of the interview was to enquire to what extent the focus of enablement and empowerment had been transferred to the post-qualifying period. The interview discloses the student's standpoint on disability, and what he believes to have been the key influences before, during and after his training.

Phase 1 : Before training

Before social work training student C had conceptualised disability in terms of dependency, an image informed by what he saw of disabled people in the community. He had reasoned of wheelchair-users that if they needed to be pushed by someone else that there was inevitability about other aspects of dependency. The image was modified in the case of blind people, whom he perceived to be more independent and, therefore, likely to be able to cope in the community.

Phase 2 : During Training

Student C viewed experience within placement as significant because it enabled him to consider influences on disability and dependency and motivation to participate, within two different settings. This was by no means simple and he acknowledged the danger of being naive and the pitfall of generalising. From his work with service users he learnt that residential care could be restrictive and create dependency for one person while liberating and offering enhanced opportunities to another. The student report, and the interview, displays a clear acknowledgement of the complex relationship that exists between the individual and his or her environment.

The student sums up the quintessential difference for him of being a student on placement in an agency run by users and his social services placements (with the same user group):

> " It was vastly different. You were gaining two completely different perceptions, working with people who are using services, and particularly people who are involved ...people who are putting pressure on people who are shaping services as well, you are getting a viewpoint of their needs. You are seeing social services from a completely different viewpoint.
>
> I think that generally one of the major problems with social services is that they are by their very nature hierarchical organisations and generally they are very authoritarian. As a consequence I think that because of the culture within social services departments the response to peoples' needs tends to be quite paternalistic ".

He expands on the above considerably by drawing out the major cultural differences and the inhibitors within social services to participation.

The process of placement offered varied opportunities for seeing participation at first hand - an important element for the student was being exposed to situations where he was working alongside and where he and service users were in different roles in diverse settings. The student roles included being a direct carer undertaking a range of personal care tasks, facilitator, researcher, apprentice, co-worker. Service users were variously in the role of cared-for , manager, teacher, co-worker and assessor. The student was permitted a rare opportunity to enter into the world of service users and as a result began to perceive situations from their viewpoint and to think about concepts such as 'limitations' in an alternative way - e.g. elements of absurdity in the planning of a conference at which the delegates were blind:

> " I thought considering it was a conference for blind people, they had a buffet lunch - you were actually making the person who is blind dependent on someone else ".

The experience had prompted him to look at "things which I had never thought about before". He had been able to look at ways to overcome difficulties and how" people can be enabled to take more control of their own lives " through access to the sort of facilities and opportunities which release people's capabilities rather than emphasise handicaps. Working in two different settings in totally different roles and relationships had accentuated the whole issue of the dependency of disabled people on the one hand and their potential on the other. He commented of his work with the organisation of disabled people:

> " I felt that I was working alongside them, that really they were helping me more than I was helping them, so really for me it was a junior partnership ".

within which he agreed that the service users were the 'experts'.

Phase 3 : Post training.

After obtaining the Diploma in Social Work, student C moved into Social Services as a Care Manager working with older people, a setting in which disability is a key issue. The final part of the interview was aimed at establishing whether, and how much, he thought his placement with an organisation of disabled people had impacted upon him as a worker. His answer to the question: 'Would you say that the experience with CATCHUP and working with service users and carers in that situation has influenced the way in which you have subsequently practised ?' was 'Yes and no'.

The answer reveals the tension between personal constructs that influence and determine practice and the wider culture within which practice occurs. Hence the experience as a student in training introduced ideals for practice which have been only partly realisable. Barriers identified were :

- the organisational culture within social services which tends to be paternalistic and to foster dependency;
- the way in which services are based on dominant ways of thinking within society;
- the sheer volume of work which makes it difficult to be creative and to break out of time honoured ways of doing things and to fulfil ideals such as 'working in partnership'.

Working with the status quo was an ongoing struggle, but in spite of what often amounted to a sense of deja vu, he and his colleagues spend time discussing potentially more enabling models of practice. Hence, there was commitment to continuous professional development.

Conclusions

The material presented in this chapter suggests a mostly positive attitude by students towards the EAL module presented at Swansea University between 1994 and 1996. This does not mean that there were no issues about either the process or the content of the teaching. Evaluation underlines the continuing need to search for more effective ways of teaching social work students.

It is significant that an area of social work practice, which generally has low status, was considered to require a greater allocation of time in the curriculum by some students.

Students were keen to have more interaction with people with disabilities and carers, both on a formal and informal basis. The contact with CATCHUP and with individual disabled people and carers gave authenticity to the learning experience through offering a more realistic insight into the lives and needs of service users. Reflection on interaction e.g. use of language appears to have led to greater self-awareness on the part of some students. However, there were issues around interaction with service users within the learning experience which need to be considered further.

Some students were open to the idea of the expertise of service users. For some this was confined to the domain of 'personal experience' while others made links with the world of disability e.g. service users being more expert on issues such as the day to day struggles of people with disabilities e.g. navigating the complexity of the benefits system. Thus making a connection between the personal and the political.

The college based teaching module and the placements with CATCHUP were located within a social model of disability and aimed at helping students to question the assumptions that they brought to the course. Only one example of student presentation material has been introduced in this chapter and this does infer that at the end of the module the students were reflecting on the wide range of issues that impact upon the lives of disabled people and carers.

The three interviews with students illustrate that each arrived on the course with very different life experiences, views of, and assumptions about disability and disabled people. It is a deficit of the research design that this background data was not available in terms of the student groups as a whole. There is some limited evidence from the routine evaluation forms that some students had utilised the learning experience to question assumptions and frameworks (including images and metaphors) which informed their thinking about disability and to move forward. The interviews with the two second year Area of Particular Practice in Community Care students suggested a 'paradigm shift', but in one instance this was linked with social policy teaching, which had been based on a social understanding of disability.

The final interview recorded in this chapter was an attempt to gauge the impact of working alongside service users and carers and how this had weathered the transition to becoming a professional social worker employed by a Social Services organisation. The material suggests that the experience had facilitated engagement with the 'complexity' of practice issues vis a vis disability and social care provision, including the complex nature of the relationship between individuals and their environment. Issues such as disability and dependency had been re-framed. The main value had been the reversal of the usual perspective: the opportunity to see social services from the viewpoint of the user of services rather than the provider. Working alongside service users had demanded flexibility and imagination and while on placement he had moved towards a 'control' model. In the post-qualifying period there was evidence of an inherent tension between personal constructs and organisational restraints upon practice.

The implications of the above will be considered further in the concluding chapter.

Chapter 8

Introduction

> 'Service users are beginning to play a role in social work education (Beresford and Croft, 1990, Beresford and Harding,1993) which is potentially highly significant and may be one of the most important challenges ahead for educators' (Gould and Taylor, 1996 page 159).

The final chapter of this dissertation will cover the following areas:

- a review of the research project itself;
- a critical discussion of the research design and process;
- the learning gained from this study;
- a rethinking of the course;
- conclusions.

Throughout this chapter there will be an attempt to engage with some of the key issues which the inclusion of service users and carers presents for education and the emerging discourses within education.

A brief review of the research project

It was a search to understand the significance of the role of service users and their carers in the training of social work and social care staff that was the starting point for this research. The key question was:

'Does the involvement of service users and carers in training within the field of social care and social work have the ability to influence the perceptions, attitudes and ultimately the behaviour of key participants in the process ?'

The work has been challenging. In spite of an underpinning commitment to anti-oppressive practice, I am aware that both in social work practice and education we are struggling with what this means for day to day practice with groups of people who are marginalised (Shardlow in Dominelli et al., pages 23-33, Dalrymple and Burke, 1995). Dominelli in her analysis of what anti-oppressive practice meant in the bleak climate of the end of the 1990s notes that there is a need for collaboration between academics and practitioners to discuss models of good practice as a way of moving forward. This will mean being involved in a change of organisational culture with a flattening of unequal, hierarchical relationships to allow more democratic and creative responses to the development of better and more relevant services to those who need them. This has profound implications for relationships with people who are traditionally the users of services:

> 'Service users also have to be brought on board as equal participants in the enterprise. Anti-Oppressive practice, therefore relies on teamwork in the best sense of the word and is hard work (Dominelli, 1998 pages 18 and 19).

The above quote echoes what this study was all about, namely trying to achieve teamwork between professional social work educators and a group of service users and carers. The ideal of working on the basis of equality was ever present. What has been learnt is that encouraging meaningful participation as opposed to token involvement takes time, energy and commitment on the part of educators and service users and carers. It means being imaginative and willing to take the risk of moving away from the safety of time honoured ways of approaching training.

This chapter marks the last, but not end, stage in the reflective learning cycle outlined in chapter 2 (Kolb, 1979). It is a cycle which has occurred and recurred several times during this project. It is not the end stage because it is hoped that the learning gained from this study can be used to inform the next stage of a journey towards the teamwork that Dominelli envisages as central to anti-oppressive practice. This means further inclusion of disabled people and carers in education and training. I have learned a great deal through undertaking this work, about opportunities and also barriers. It has taken much longer than intended and there are many unanswered questions as well as new questions. Some assumptions which were made at the beginning have been found to be flawed and new perspectives have been gained, while others have been tested and have been proved (albeit tentatively) to have some validity. If I had the opportunity to start this research again I would alter the research design. The teaching approach and course content need to be constantly revised and updated in the light of new developments in the field of education, social work, disability and caring.

Stage 1 of the learning cycle was the concrete experience of participation, of working alongside a group of service users and carers in the development and delivery of student placements and a small teaching programme on Physical Disability in the Diploma in Social Work course at Swansea University.

Stage 2 was that of reflective observation about what was taking place and its meanings and significance for participants: what were their thoughts and feelings about participation? What did it mean to them?

Stage 3 was about abstract conceptualisation. There was a desire to understand more about why participation by service users and carers is important, and why their inclusion in social work education and training may be significant. What are described by Thompson (2000 page 6) as 'pre-existing concepts' needed to be tested and theoretical understanding extended .

The background for this study was found in the first two chapters. Chapter 1 highlighted some issues in participation in general before moving to look at the struggle for the inclusion of disabled people as a marginalised group. This was related to models of disability and of participation before progressing to a consideration of some themes in social work education and training in chapter 2.

With hindsight it is realised that the hypothesis was based on a basically 'consumerist' approach (Management, 1992) to participation. It was also formulated in terms which are consistent with behavioural and competency based models of social work education and evaluative frameworks such as human resource design (Brinkerhoff, 1987). The search for a different rationale for participation has resulted in a growing understanding of 'emancipatory approaches' and their implications for social work practice with disabled people and carers (Oliver, 1996, Dominelli, pages 3 and 4, Thompson in Dominelli et al., 1998 pages 319 and 320). A large part of the learning has been gained from considering recent approaches to social work education and training, based on post modern (Taylor, 1996) and latterly sociocultural approaches (Northedge, 2001).

Stage 4 is the final stage of the cycle, namely active experimentation; the basis for action.. This is a synthesis of what has been learned in the first three stages and a basis for beginning to consider how the process might be taken forward in the future. This chapter will include a critical review of :

- The research design;
- What has been learnt from this study ? How did the study change or confirm the views of the researcher?
- What issues need to be addressed for participation in education to move forward? How might such a teaching programme be organised in the future?

The research design

This will be reviewed in terms of underpinning values and methodology and approach, selection of the research subject, collection of data, data analysis and evaluation.

The value base

I realised at the outset that there was a need for the research design to be grounded in 'ethical practice' consistent with concepts such as 'emancipatory practice' and for there to be a very clear underlying commitment to the values of participation (Rioux and Bach,eds.,1994).

The process in this study included consultation and negotiation and at times moved over into the sphere of 'partnership' . It was not always clear within whose agendas we were working. Sadly, at best, it probably reflected an 'enlightened guardian' approach to the service user and carer trainers (Barnes, 1990).

The discourse on 'Methodological Paradigms that Shape Disability Research' have moved on since I started this research (Campbell Brown, 2001 pages 145-168). Looking back it is possible to reflect on the process and were I to undertake a similar piece of research now I would be interested in blending a qualitative research methodology with the strategy of 'Participatory Action Research' (Campbell Brown, 2001 page 160), with its goal to:

> 'increase the relevance of research by placing the individuals being studied at the center of the decision making process and ultimately to empower people' (Tewey,1997 page 1)

Such an approach is wholly consistent with working towards a 'control model' of participation (Arnstein, 1969, Barnes,1991) based on a social understanding of disability (Oliver,1996 page 32 – 42) and an anti-oppressive stance vis-a-vis work with disabled people and their carers.

Selection of the research subject

The research subject and the related question were selected very early in the process. While the core concept – namely that of influence through the process of participation – remained constant the field of study itself changed. Difficulty in engaging with the significance of this change has had far reaching consequences for the research. Essentially the goal posts moved but the direction of the research did not.

The locus of the research moved to participation in the training of year 1 social work students as the service user and carer trainer group extended their activities. The target group changed from staff in a local authority working in the field of community care to first year Diploma in Social Work students. The research question was formulated in terms of what might be seen as broad organisational outcomes i.e. the behaviour of participants (staff performance) and what is measurable in terms of staff performance.

While it could be argued that the behaviour of participants in terms of practice is the ultimate goal of a programme of professional training, this was far beyond the scope of this study and required greater resources than were available. Selection of a narrower field e.g. the influence of the inclusion of service users and carers on the way that first level social work students perceive disability and caring might have been more productive.

Data collection

The chronology on pages 83 and 84 illustrates that the initial data was linked with the participation by service users and carers in training for community care in Dyfed. This provided an interesting historical perspective and gave some themes for comparison with later material but the fact that the interviews (and one meeting) with service users and carers were linked with this earlier experience has proved problematic. It was possible to capture something about views on the processes of participation and some of the group's thoughts about influence, messages, aspirations and needs but formal feedback and evaluation on the experience of involvement in the teaching module at Swansea University was limited.

A general comment is that the scope of the study was large and unwieldy and suffered from lack of focus. Although data was collected from a range of sources with the aim of exploring the subject from various angles, the amount of data eventually yielded was in fact quite small and some of the sample (e.g. carers) was atypical. In retrospect it is realised that the study would have benefited from a far more rigorous approach to what data was being sought and why.

Similar limitations apply to the data gathered from students. Much of Chapter 7 is about the views of students on the learning experience, but this information is restricted as a result of lack of acknowledgement in the evaluation of the taught module of the contribution of service users and carers to the teaching process. Although the anonymity of the forms might have led to more honest feedback (Bligh,1971) it also means that there is no data on participants.

Some evaluation forms imply that by the end of the module there had been some reframing of thinking about disability and caring. Some links had been made between the input of disabled people and carers and student learning. However, the lack of an accurate profile of the students and their own starting points combined with a lack of specific questions about the participation of disabled people and carers means that there is no consistent and accurate way of identifying the perceived contribution of service users and carers to the teaching programme, or the possible effect on the beliefs, attitudes and thinking of the students.

Only the three interviews with students make connections between pre-existing views, perceived learning and the participation of service users and carers. The sample was very small and biased in favour of students with a stated interest in the field of disability. Only the third of these interviews, the one with the former student who had been on placement with the user led organisation, ventured into the area of transfer of learning into practice.

The reports for the two student placements with CATCHUP offered some supplementary information but this relates primarily to the wider experience of working alongside service users and carers in practice – a different situation which would have opened up wider aspects had it been researched in its own right.

Analysis and evaluation of data

A variety of data was collected which gave the potential for themes to be examined from a number of angles utilising the tool of triangulation. Analysis proceeded according to themes that had been selected, and which are most evident in the questionnaires, which were used with service users and carers. There was some exploration of emergent themes within the material, but I realise that I was mainly looking for themes that I, as the researcher, thought were of importance. Looking back I can see how I thought that there was a connection between attitudes to disabled people, images of disabled people and the way that disabled people are treated, hence the exploration of themes such as positive and negative images of disability. This may have lead to significant 'other' perspectives being lost or at least subsumed by what I thought was important.

What has been learned from this study?

The module was compulsory for year 1 students on the Diploma in Social Work at Swansea. I viewed knowledge of the world of impairment and disability as a step towards helping students to meet the requirement to develop anti-discriminatory practice in the field of disability (Stevens, 1991 pages 7, 17 and 25, CCETSW Paper 30, 1991 paragraphs 1.19 and 2.2.3). I believed that the participation of disabled service users and carers in professional training was an important aspect of working in a way that is non-discriminatory, but I was very unsure about the nature of the contribution (What and why?); the potential influence upon learning (how did direct input by service and users impact on learning?): and how that contribution could be best utilised as part of curriculum design.

Some key themes, which relate to process and outcome, have emerged from this study and these will be listed in this section of the dissertation. I suggest that these are of importance to thinking about approaches to inclusion in education and training. I have tried to differentiate between those themes which are reasonably firm and ones which are more tentative.

- Although the research question was worded in terms of outcomes, much of the learning of this study was about processes, the processes that encourage or conversely inhibit participation by disabled people and their carers in training.

It is possible by looking at some of the themes raised by service users and carers to identify what was thought to be significant for them in terms of participation in the specialist area of training. This is mainly about preparation, but also spills over into involvement in the teaching process. The diagram that follows is based on my own interpretation of what potentially empowers and disempowers. It reflects what was said by service users and carers during interviews, the group evaluation of the experience in Dyfed and the work that was done with service users and carers in preparing and evaluating the course at Swansea. It is also draws upon the material provided by students placement reports.

Preparation which is empowering	**Disempowering**
Clear information	Lack of information
Clear expectations of role and responsibilities	Unclear expectations/ uncertainty
Positive role	Token involvement
Language which is culturally and linguistically suitable	Inappropriate language complex, jargon
Preparation which enables participants to cope with all expectations/roles	Partial preparation
Presentation of own material	Script reading
Preparation and training which recognises and builds upon existing abilities, skills and aspirations	Lack of recognition of abilities, skills and aspirations
Clear boundaries which are negotiated e.g. to safeguard confidentiality	Unclear boundaries

The above table can be analysed in terms of some of the conditions that facilitate active participation. It is significant that much of the emphasis is not upon training the individual but upon an enabling environment which includes dimensions such as access to information and a social and emotional environment which is conducive to being able to cope with expectations. Experiencing oneself as 'competent' and 'valued' (validation of one's contribution) is central.

- One of the clear messages of this study was that service users and carers were concerned to redress the imbalance of power between themselves and professionals.

The disabled trainers wished to be treated as 'equals' and for their voice to be taken seriously. Carers also wanted to be heard. Both groups described what had been largely unresponsive or inappropriate responses to their situations from health and social welfare systems and reflected a wish to change the nature of their interaction with professionals. The training/educational involvement was viewed as a potential vehicle for this change to occur.

Themes which emerged from service users as important aspects of inclusion in training were being on an equal footing rather than being 'patronised', stressing the 'us' of interaction in place of the 'us and them' which had been the experience of some in professional/service user relationships e.g. in assessment. The importance of the 'informal', situations of 'two way exchange' and the role of the lighter, more fun aspects of interaction within training were emphasised.

For the carers in the study being listened to (the reverse of being invisible and unheard) was linked with enhanced confidence, and the experience of working with professionals was perceived by one carer as leading to greater self awareness as well as to more understanding of the perspective of others. There were signs, however, that there had been potential for service users and carers to be exposed to negative attitudes and exposure to prejudice in a way which is disempowering.

- There is insufficient evidence to generalise about how at ease or otherwise students felt working alongside service users and carers.

As a group facilitator it was my observation that some students were initially uncomfortable about discussing case material with service users and carers. This is not unexpected as there would have been differing levels of experience of disability and of disabled people within the groups and one is able to assume the existence of factors such as prejudice and stereotyping (Armitage et al., page 33). The value of 'working with' service users and carers was expressed by students. There is a small amount of evidence to suggest that some students worried about being 'patronising' and were uncertain about issues such as appropriate language and that this had an effect upon the freedom of the students e.g. to ask questions within the group learning situation.

- Within this study 'experience' was a recurring theme. The experiential (the subjective) was viewed as a tool for teaching and for learning.

Any perceived authority (expertise) within the teaching situation was attributed to having a first hand knowledge of what it means to live as a disabled person or as a carer and the experience of interacting with others in a similar position. Being a user of services allowed an 'insider' evaluation of the approach of professionals to processes such as assessment and to comment on what they saw as important in terms of their own needs.

This was not 'positional' expertise derived from professional or academic status which is the norm for teaching in higher education but expertise based on experiences – so participation within the discourse communities of disability and of caring was likely to be at different levels, reflecting diverse experiences and different stages of understanding and awareness.
It is, therefore, too simplistic to expect a uniform response or message from service users or carers.

Both service users and carers in this study wanted to contribute their own unique experiences; and for their experience to be listened to. Different messages emerged from the experiences of service users and carers. Possible ways to impose uniformity e.g. by encouraging the use of scripts were not favoured by service users; they potentially smack of tokenism, manipulation and managerial control (Oliver, 1996 page 165).

Service users reflected the desire for negative stereotypes to be challenged and to be treated on an equal basis, for abilities, including the ability to be in control of their own lives, to be recognised.

There was a very definite emphasis within the material from service users on the positive as an antidote to the negative, but this could be a potential barrier to authenticity and 'telling it as it is' if it leads service users who are disabled into a situation where they need to appear positive, over-comers within their own stories of tragedy or victims of ignorance and prejudice (BCODP Hearts and Minds Campaign, 1999).

The three carers identified that their experiences had been marked by lost identity and invisibility; the burden of being in a long term caring relationship; the inability of significant others to help them. It was this experience that provided the motivation and impetus to participate in training.

For some students the sharing by service users and carers of their personal experience of being disabled or a carer coupled with the knowledge gained from working with the wider issues of disability and caring e.g. through the involvement with CATCH UP, added 'realness' and 'authenticity'. The knowledge gained was identified in terms of insight into the everyday reality of life as a disabled person or as a carer. In learning terms it made the learning experience 'relevant', a factor that is closely associated with motivation to learn (Thompson, 2000, page 124).

- The service user contribution per se does not necessarily connect with wider social understandings of disability.

While there was some evidence of a paradigm shift on the part of students , e.g. from a basically medical understanding to a social model this was not necessarily as a result of the service user/carer perspective. One student suggested that the main understanding of the implications of 'social ' understanding was derived from social policy teaching and that the service user perspective appeared to be located in a 'medical' understanding. The feedback from the disabled trainers on their 'messages' was indicative of a social understanding of disability but was not verbalised in these precise terms.

- There was very little consensus on 'representativeness' within the context of training.

This is a concept which has been used (mainly by the opponents of participation) as a basis for judging whether or not participation by service users is justifiable (Richardson, 1972). It is also a concept that has gained currency in terms of 'who speaks for whom?' within the Disability Movement (Oliver, 1996 page 165). Where representativeness was seen as relevant it was on the basis of moving within the worlds of disability and/or caring.

- Part of the learning of this project is about the need to engage with uncertainty and unpredictability within the learning environment.

The data also suggests that engaging with the experiential meant facing uncertainty. This could be a potential barrier both to effective and ongoing involvement by service users and carers and to the learning of students if it is not worked with appropriately within the context of group learning.

- Imagery and metaphor and their importance to the way in which significant others responded to disabled people and carers emerged as important themes.

Some evidence was found in all the sources of data examined that powerful images of disabled people, e.g. as dependant were at work among the recipients of training in Dyfed and later at Swansea University. It was not unexpected that feedback from service users and carers in group sessions highlighted the existence of stereotypical views and prejudice towards people with disabilities and carers. Neither was it an unexpected finding that disabled service users were surprised that in the sessions on disability students had largely seen disability as a problem. It is expedient to ask whether this was linked to prior understanding or to the way in which the teaching material had been set up?

A notion that came to the surface during this study was that by changing the imagery or the language perceptions and attitudes would be changed. There was some limited evidence from staff feedback in Dyfed, the course evaluations and interviews with students at Swansea that meeting disabled people who were in 'control of their lives' did prompt some rethinking and re- framing of ideas about disability and caring, but it is not possible to say to what extent this was the case.

There was a small amount of evidence from student evaluations that work in this field was regarded more seriously and that some students may even have been thinking about this as a career option. This is an area that is deserving of further research.

- It was not possible to say how this re-framing of concepts such as disability and dependency might have transferred into the way in which students would approach practice with disabled people.

The only insight about transference into practice was from the interview with a qualified worker who had spent a four month placement with the user-led organisation. This suggested that although the student had espoused a 'control' model while on placement putting this into practice within the context of local authority services for older people was severely affected by the restraints of work in a social services organisation.

- A review of the data suggests that at every stage there was recognition of difference but that there was difficulty in knowing how to address this within the group process.

For example, 'You disabled people are different to us' (reported statement of staff member in Dyfed). Students at Swansea feared being patronising (an attitude based on perceived difference). The data from the interviews with service users suggests that there were strong tendencies, even incentives, to deny rather than to work with difference and that these were working at different levels.

The denial of difference can be seen in the wish for service users to be seen as the same as everyone else – 'just an ordinary trainer who just happens to be disabled'. But where did this originate? The wish to merge, to fit in links with the philosophy of 'normalisation' which had characterised the All Wales Strategy on Mental Handicap (Welsh Office 1983). It may also have been encouraged by the efforts of management to professionalise the contribution of service users and carers. One of the dangers identified in chapter 1 and reinforced by disabled writers is being 'co-opted by the system' (Braye and Preston Shoot page 109, Oliver,1996 page165) and consequent personal messages and issues being blunted.

Students revealed how at the beginning of the module on Physical Disability their feelings were mixed - some students were willing to admit that they brought feelings of fear, discomfort, ignorance and worries about being patronising into the learning situation. There were concerns about how to respond appropriately and sensitively to perceived difference. Language was an issue, as was 'political correctness', for example students considering themselves to be more aware than some service users of theoretical constructs of disability. This coincides with what Oliver says about the very different levels of awareness of people with disabilities (Oliver, 1996, page 102).

There is a great deal of overlap between the above points. I realise that they do not form a conclusive list, but for me they have emerged as offering a foundation for rethinking my approach to participation in training.

Rethinking the course on the basis of this study

The educational model employed as a framework for this teaching module was Enquiry and Action Learning; an approach to course design and delivery which departs from more traditional academic approaches to the delivery of the knowledge, skills and values which form the requirements for qualifying social workers (CCETSW, 1991). The module on physical disability at Swansea was constructed around case studies, teaching input (on the law), small group work, self-directed learning utilising the resource pack and group presentations by students. The feature that made it different was the participation of service users and carers. The participation of service users and carers was not confined to college based learning but extended to practice placement provision , an area which lends itself to further investigation in its own right.

In order for participation by service users and carers to become a routine part of social work education it is necessary for educators to be convinced not just of the justice of inclusion but also of its efficacy. This means returning to the basics, namely the aims of inclusion, the process (method) of inclusion, the curriculum and the contribution of service users within it and evaluation of learning.

The aims of participation by service users and carers in education

At the beginning of this study I attempted to look at some agendas for participation and for participation in social work education. It is possible for participation to serve different agendas and to operate at different levels (Arnstein,1969, Burns,1991 Barnes, 1990). On the basis of what I have learnt from this study I would suggest that the following form an agenda for a programme of social work education in which service users and carers are enabled to participate in a meaningful way:

- To start to redress the unequal relationship between service users and carers and professionals;
- To help students to review the images that they hold of disability and caring (embedded in language and culture);
- To enable students to start to understand the lived in reality of being disabled or a carer;
- To enable students to make links between the everyday situation of the individual service user, carer, family and group and the wider issues of discrimination and oppression;
- To create a pathway into the specialist discourses of disability and caring;
- To help students to be both reflective and critical about the role of social work with disabled people and carers.

The above is a basis for helping students to generate more realistic, imaginative and creative responses to social work **with** disabled people and carers.

But how can meaningful participation in education be facilitated?

If the above aims are used as a framework it is possible to start to rethink what may be needed in terms of facilitation.

For me, meaningful participation, as opposed to tokenism, denotes the kind of participation which flows from the creation of a partnership between service users and carers and staff in colleges and agencies who are responsible for the delivery and design of training programmes. It means working with the agendas of service users and carers themselves and offering the kind of assistance that they need to enter the specialist field of educating others. It means helping them to be honest about their own experiences at different levels, the level of the personal, the social, and the political.

Some extremely useful work has been done in the field of facilitating inclusion, e.g. the guidelines found on pages 5 and 6 of 'Changing the culture: Involving service users in social work education' paper 32.2 by Peter Beresford, which also embraces the need for 'partnership' within the teaching and learning environment within the over all context of anti-discriminatory practice (Beresford, 1994). The practical aspects covered by Beresford are about creating a level playing field between professionals and service users. They include providing an accessible environment, appropriate training at varying levels and payment – aspects which were, to an extent, adopted in the work in the work at Swansea.The earlier table offers suggestions about what may be features of an enabling environment and begins to engage with some of the wider issues of facilitation.

It is also worth mentioning that students valued the small group environment within Enquiry and Action Learning. Service users and carers expressed a dislike for formal lecture type situations and wished for more informal contact to be built into the learning programme.

- **Curriculum and the contribution of service users and carers**

The design and content of the curriculum has important implications for the processes of participation and of inclusion within education. Although the work at Swansea involved collaboration with service users and carers and a student, in retrospect much of the control over the curriculum and who was responsible for which aspects of it, lay with the 'professionals'. This immediately mirrored the usual relationships within social work with the pitfall that participation would be tokenistic rather than genuinely based on the agendas of service users and carers themselves.

I have concluded that the main contribution of service users and carers to the curriculum is personal experience. But, I have also learnt that there are many issues around the way in which personal experience is constructed and integrated within an overall programme of learning. The challenge is to:

- maximise the control of service users and carers over their own contribution within the teaching process and within the teaching process as a whole;
- to help service users and carers to be authentic and to own difference in their contribution;
- to create pathways from the experiential to the theoretical;
- to challenge the experience of students in order to help them to reassess their experience and the assumptions(including the images and metaphors) on which they are operating;
- to help students to begin to think about the issues for social work practice and patterns of service delivery.

But such aims cannot be divorced from the issue of power in social work education and in social work itself. There needs to be a recognition of, and willingness to work with barriers within the learning situation.

This study has identified several barriers to 'authenticity' – i.e. telling it as it is and presenting Dominelli's 'lived in reality' to professionals (or students who are in the process of becoming qualified). For the disabled trainers these were the pressures to be seen as 'the same as' (denial of difference), to overcome negative stereotypes by presenting a positive image, e.g. 'coping' as opposed to 'succumbing.' But being real may mean admitting to problems such as struggling against debilitating pain – a message which may not equate in the minds of students with social rather than medical models of disability. The reality for carers was quite different, professionals expected carers to cope, part of their 'invisibility' was linked to being an unacknowledged resource. A danger for a teaching module, which incorporates user and carer perspectives, is that this will be replicated unless potentially uncomfortable issues such as the dilemmas presented by competing rights and needs are brought into the open.

The unpredictability within the learning environment was a further barrier. Service users, carers and students will all be at different levels in terms of their understanding and knowledge of the fields of disability and caring and they were entering a specialist learning environment. Presenting the personal can lead to intrusiveness, lack of understanding , being patronised and even judged ,leaving service users and carers vulnerable. I was aware of the danger identified by Beresford that in some approaches traditional relationships of client/worker are merely reinforced within the training situation – service user participants become 'case studies', 'objects of interest' (Beresford, 1994 page 33), with all the overtones of manipulation and token involvement.

Rossiter (1996) notes the propensity on the part of social work educators not simply to control what, but how, students learn. Social work education has been dominated by pedagogical forms that connote 'doing it right' and suggest prescriptions for dealing with problems based on dominant ideology and 'corporate agendas'. If social work is to move towards working with user led rather than professional led agendas there is a need to start to grapple with what service users are saying within the educational programme. But this inevitably leads to the question of how to include the voice of service users and carers within social work training.

Much can be learnt from more recent approaches to social work education, of which Enquiry and Action Learning is only one. I intend to review some concepts which are meaningful to me as I reflect on my experiences of doing the research and that may be useful in terms of considering the way forward. They are not intended to be prescriptive, rather ideas which may provide a basis for considering what may be the more 'imaginative ways of teaching' which involves service users advocated by Beresford (Beresford, 1994 page 79). Such possible concepts include 'dialogue' (Haraway, 1988 cited in Rossiter, 1996),'reflexive learning' (Moffatt,1996), 'imaginisation' (Gould, 1996), approaches located within the genre of 'reflective learning' (Taylor, 1996) and socio-cultural approaches to education (Northedge, 2001). What each of these approaches to education has in common is that they provide ways of exploring a variety of perspectives and contain the possibility of actively engaging with diversity.

The idea of creating 'dialogue' within the learning environment, enabling the expression of different perspectives is an important one for this study. It moves away from traditional ideas of expertise within a teaching situation and the hierarchical relationships that accompany it. Rossiter argues that the challenge for social work education is to realise that the sort of prescriptiveness that goes with corporate agendas and dominant ideology no longer exists and that this has profound implications for what takes place in the classroom. . She draws on the work of Haraway, (1988) and of understanding the concept of 'knowing' as 'developing through dialogue between multiple perspectives developed from different locations'. While Rossiter's work relates to freeing the voices of students from minority groups, allowing different perspectives and meanings to emerge within the classroom, it is a concept with potential for both including and valuing the contribution of service users and carers.

Moffatt (1996 pages 47ff.) argues a case for reflective practice based on the work of Davis (1995) and Dore (1994) that 'people grow in connectedness with others through relationship' and 'knowledge is constituted through interpersonal connection rather than being developed in isolation'. This offers possibilities for teaching and practising in a 'reflexive' manner, through students becoming aware of their own responses, their own role within the interaction and how this impacts upon the way that the service user tells his or her own story. This work has usually centred on video or audio material and opens up the possibility of the subjective being linked with exploration of interpersonal dimensions such as hierarchy, difference and power within relationships.

The tools of 'imaginisation' can help learners to review the images with which they are operating (Harris, 1994 page 40, Gould, 1994 page 68) and which are powerful informants of practice. Imaginisation is the structured process by which groups and individuals are helped to articulate the images that inform their behaviour, and practice the adaptation of these images as a means of 'reframing'action and finding new approaches to practice (Morgan, 1993). The work of Gould relates to the images which students hold of social work and their influence upon the way in which they see themselves as practitioners and contains the idea of images which are dysfunctional and the basis for poor practice and those which are creative and the basis for 'assertive and empowering practice' (Gould, 1996 page 69). As one of the themes of this study has been that of metaphor and imagery and the way in which this informs orientation towards work with disability and attitudes and practice with disabled people it would be interesting to look at how this approach could be adapted to work in this field.

The above three approaches with their basis in reflective learning offer possible frameworks for exploring the experiential and the more subjective aspects of learning, but, the curriculum also needs to make connections ' an engagement with some of the particularly difficult debates within social work' (Gould and Taylor,1996 page 74).

As I look back and reflect on the experience at Swansea I realise that my expectation was that service users and carers offer an authentic insight into what disability and caring meant to them. I was also aware that this implies far more than presenting an individual perspective – the challenge for practitioners is to respond to 'issues and questions which are identified by oppressed groups themselves.' In this sense the issue of representativeness becomes an important one (Oliver, 1996 page 12). Dominelli argues that:

> 'Being rooted in peoples' lived in reality ensures that anti-oppressive practice responds to the issues and questions which are identified by oppressed groups themselves' (Dominelli, 1998 page 7).

Hence the challenge for social work practice that is anti-oppressive is to be able to work with people at an individual and personal level while actively engaging with the wider social and economic issues that impact on the lives of disabled people and carers. Within teaching programmes it is important to create a bridge from the 'lived in reality' of individuals to the wider issues identified by oppressed groups. I think that it is important to recognise that neither people with disabilities nor carers form homogeneous groups and can agree with Beresford (1994) that it is important to involve the views of a range of disabled people in teaching programmes and to engage with the wider issues of diversity.

Creating links within the curriculum

This was one small module within an overall two-year curriculum. Although the research concentrated on this module per se there are definite signs that the learning of students about impairment and disability was influenced by other parts of the curriculum – e.g. the social policy input which heavily emphasised the social model of disability and its implications. The work on Enquiry and Action Learning was contextualised within an overall anti-discriminatory framework with an interweaving of different components within the curriculum (Burgess, 1992 pages 79-86) – e.g. workshops on anti-racism. If some parts of the curriculum are free standing it is important to know how they relate to modules such as the one on physical disability and caring.

Some recent work by Andrew Northedge based on socio-cultural approaches to education could perhaps offer a way to help students to cross the boundaries between the everyday discourses of service users and carers, the discourses of care practice with disabled people and carers and academic perspectives on disability and caring. Northedge's work relates to diversity within student populations and originates in his experience of designing and delivering first level social care courses for the Open University where course entrants come from diverse educational, social and cultural backgrounds. Northledge argues that new approaches to course design and delivery are required as neither the 'more traditional "knowledge delivery" model, nor more recent "student centred" models of teaching adequately address the challenge of diversity' (Northedge, 2001,page 1). He suggests that :

> 'If education is to meet the challenge of diversity we must recognise that teaching is not primarily "delivering knowledge." Rather it is constructing appropriate discursive environments which allow students to participate at a variety of levels. It is also supporting and assessing them in ways that recognise the legitimacy of progress at different levels''(Northedge, 2001 page 11).

Thus curriculum design is about constructing appropriate discursive environments within which knowledge can be shared between people who come from different backgrounds and who have different levels of understanding of a subject. The role of the teacher is to design a curriculum (learning opportunities) which offer pathways into knowledge communities (such as social work) and to create bridges between different sorts and levels of discourse within that community. It means recognising that the aim of education is to enable students to become critical and analytical, to become active participants within a knowledge community and to be aware of the ongoing debates within that community. Such a curriculum includes a range of carefully designed materials to help students to participate at different levels:

> 'students 'hear' short bursts of discourse at various levels, ranging from domestic and media discourses, through discourses of care practice, to the discourses of research and theory' (Northedge, 2001 page 11).

To my knowledge the above work has not been considered in relation to participation by service users and carers in education. It is the notion of discursive environment which I would like to explore in relation to curriculum development in which the participation of service users and carers is routine. The Open University course combines distance learning material with some seminars. Unlike the Diploma in Social Work course at Swansea (which is at postgraduate level) it targets an academically diverse group of students. Written and audio-recorded case studies are used as a way into learning and as a way of creating links between the different discursive worlds that operate in relation to health and social care. The point is made by Northedge that the 'story line' which is the peg upon which everything else hangs, needs to be strong (2001, page 8) and well delivered if it is to lead to a flow of meaning within the classroom. The role of the teacher is to plan and guide excursions from familiar to specialist discourse, by:

> 'generating an initial flow of meaning from everyday discourse and then, while sustaining that flow of meaning, gradually shifting to a framing within the specialist discourse, the students are able to experience the making of meaning within the specialist discourse'.

(Northedge, 2001 page 5).

Such an approach offers a firmer role to the teacher and is very different to the earlier ones described which are more consistent with self-guided learning and the role of teacher as facilitator.

- **Research and evaluation, including assessment of learning, needs to be developed as an integral part of programmes and systematically applied.**

While there was some attempt to evaluate the module of teaching (more in placements) there were lost opportunities because no consistent, appropriate model of evaluation was in place. Armitage (1999, page 193) defines the role of evaluation as 'gaining information about course effectiveness'. Assessment, a parallel process, in education relates to individual student performance in terms of learning outcomes.

There are various models of evaluation in use in education but they are not equally applicable to different approaches to learning and learning outcomes. It is important that any attempt to evaluate is based on a clear understanding of the philosophy and principles of the course itself.

Armitage et al. (1999 page 197) in their work on 'Teaching and Training in Post-Compulsory Education' suggest that 'Qualitative Evaluation' offers a more complex approach to measuring course effectiveness than more traditional scientific approaches. Several features of qualitative evaluation lend themselves to a study of a course within which different interests, methods of exploring a subject area, are built into course design. These are:

- views the course as a human, social activity, not as a scientific experiment;
- interested in a host of content and process issues but especially the course intentions and organisation, the experience of the course in practice and the range of outcomes, including the unintended;
- also interested in the perspectives of everyone involved, not just the course designer(s);
- uses methods such as observation, interviews and questionnaires as well as assessment and other data;
- reports more language based than statistical (Armitage et al., 1999 page 197)

The introduction of such an approach would be beneficial as a supplement to more measurement- based approaches. It is a flexible design, which has the advantages of being able to accommodate the views of staff, students, service users and carers on the core issues of process, content and learning. It has the potential to work with the sort of themes and issues outlined earlier. The 'experience of the course in practice' allows for scrutiny of areas such as the way in which roles and relationships are constructed within the teaching programme and allows for reflexivity within the process – e.g. what sort of experience was the group learning experience from the point of view of all participants? The range of methods lends itself to working with diverse groups of people within the process of teaching and learning and would provide an excellent starting point for collaborative work on the most appropriate ways to design and evaluate a course with service users and carers. Finally, but not least it is consistent with the idea of 'Participatory Action Research' (Scott Campbell Brown, 2001 page 160).

Assessment

There was no coherent approach to assessment of this module. The only method of establishing learning outcomes was the group presentations held in the final session of the week's study. Feedback from students suggests that this is not a good method of trying to establish individual learning outcomes as the group method of learning is one in which it is possible for some students to be active and others passive. The feedback from service users and carers was that the thoroughness and thoughtfulness of the student presentation material impressed them.

The introduction of a small formative assignment involving a critical analysis of group presentation material would provide a useful tool for helping students to reflect on the experience and to make some links with theoretical perspectives.

So what may be the challenges for inclusion of service users and carers in social work education and training?

The work described in this dissertation was entered into in a genuine spirit of partnership with a group of service users and carers who were committed to the ideals of inclusion and were willing to give of their time, energy and abilities. There have been many limitations and as a result of circumstances the module at Swansea did not continue in this form after 1997.

I have concluded that the main challenge for social work education is to discover effective methods of inclusion, which genuinely work with the agendas of service users and carers within an overall curriculum. This means working with disabled people and carers at every stage of the planning, design, delivery and evaluation of an educational programme. It implies learning for all participants.

This study has looked at one approach based broadly on the model of Enquiry and Action Learning (Burgess, 1992) Since then the model of 'reflective learning' (Kolb, 1979) has been used as a basis for developing the discourse within social work education and developing different approaches as a response to the 'far reaching changes' which are faced by social work educators and practitioners in the 21st century. (Taylor, 1996, chapter 12). Some of these have been considered in this chapter as possible ways of thinking about the inclusion of the service user and carer perspective in the curriculum.

There is much to be learnt from the developing discourses within disability. The recently published 'Handbook of Disability Studies' is introduced by the statement 'Disability is an enigma that we experience but do not necessarily understand' (Albrecht,Seelman and Bury,eds., 2001 page 1). This volume represents a critical, but not definitive, consideration of the emerging field of disability studies and illustrates the extreme complexity of disability as a field of study. In a critique of the nature of the relationship between disabled people and caring professionals Swain and French (2001 pages 734-751) conclude that there has been very little shift in power from professionals to disabled people. They conclude with that there is a need for professionals to :

> 'recognise clients' experiential knowledge as a foundation for learning, with professionals expert knowledge at the service of the client' (Williams,1993 page 12 cited on page 750 of Swain and French,2001).

Concurrently discourses on caring have moved on. In 1995 the Carers (Recognition and Services) Act was implemented and in 2001 'The Carers and Disabled Children Act'. The report of Carers UK 'It could Be You' (2001) predicts that the structural potential for becoming a carer is increasing dramatically with 60% more carers needed by 2037. Evidence suggests that at best responses to carers are piecemeal and at worst non-existent (Help the

Aged, 2001) and that an increasing number of carers will be unable or unwilling to sustain the caring role.

All of the above demands a radical reappraisal of the way in which social work services are designed and delivered and presents a huge challenge to social work educators.

Conclusions

In my preface I outlined the experiential context which was my starting point for the work which informs this dissertation. Using the analogy of a journey I suggested that I had moved from understanding disability as a tragedy with no seeming solutions towards a social understanding. My personal experiences and imagery of disabled people informed the first; the second was based on meeting people who helped me to question my assumptions and to re-frame my thinking about disability. This has led to an ongoing engagement with these issues as a basis for practice.

I have learnt a lot from the service users and carers with whom I worked in this study. I have been prompted to revisit my own values and ways of approaching my practice and teaching. Perhaps the most important learning stemmed from the message of the stark reality of interacting with professionals and systems which on the whole neither heard nor understood their needs or aspirations. This is constantly reinforced by writers within the Disability Movement who have documented the extremely problematic nature of the way that relationships between disabled people and health and social care professionals have been constructed leading to a situation of institutional discrimination, in which professionals often become part of the problem rather than the solution (French and Swain, 2001 pages 734-751).

Given the time lapse between the collection of data and bringing this dissertation to fruition it is possible that the situation has moved on somewhat, but the continuing engagement within the academic community (Thompson, 1998 page 319, Beresford, 2001 pages 494-512), Disability Movement (BCODP,1999) and the Carers National Association (2001) suggests that exclusion and marginalisation is still the normal experience of the majority of disabled people and carers in Britain in spite of advances in legislation, commitment to service user involvement and growing knowledge of issues of how organisations can become more user friendly.

All of this presents tremendous challenges for public services and for social work practice with disabled service users and carers. The service users and carers in this study aspired to their voices being routinely included in training, including social work education. I hope that this study has been one small step towards considering what are some of the issues for that inclusion.

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Deputy Director

Eich Cyf/Your Ref:
Fy Nghyf/My Ref: MH/KJD

Gofynner am/Please ask for:
Training Section
Ext 4434/4433

27th November, 1992

Mrs June Barnes,
Practice Development Worker,
Centre for Applied Social Studies,
University College,
Swansea.
SA2 8PP

Dear Mrs Barnes,

Re : Postgraduate Research at Swansea University

Thank you for your letter which I have discussed with Mrs Margaret Harries. The Department would wish to support you in this research and would obviously like to have a copy of your findings, when complete. I shall ask Mrs Harries to keep me informed from time to time.

Best wishes,

Yours sincerely,

John Wreford

J. Wreford,
Deputy Director

Appendix 2

Course monitoring and evaluation form

Teaching sessions on ....

Name...**Date**.....................

The Swansea Dip SW programme is concerned to ensure that the teaching it provides is of a high quality and meets the learning needs of the students. It would be helpful, therefore if you could comment on the following:

a) What did you learn from the session/s?

(i)

(ii)

(iii)

Circle A B C or D (A = Excellent, B = Good, C = Satisfactory, D = Poor)

b)	Content of sessions	A B C D
c)	Structure of sessions	A B C D
d)	Presentation of sessions	A B C D

e) Any other comments (including conformity to E.O and anti-discriminatory practice)

Please continue overleaf.

Interview with Service Users (3A)

1. Can you tell me how you first became involved in training?

2. a) What is your age?
b) Gender?
c) Disability?

Were you born with a disability or did you become disabled during childhood, or have you become disabled as an adult?

Have you ever been employed? If so, in what capacity?

3. What preparation or training were you offered before you became involved in training?

4. To what extent have you been involved in training activities?

5. Are you taking part in any training related activities at present?

6. Do you see your involvement in training in terms of influence?

If so :

7. Who are the key people whom you aim to influence?

8. *What do you aim to influence through your involvement in training?*

9. What message are you trying to get over in your training?

10. What do you see as your particular contribution to training as a service user?

11. What is your particular contribution to Community Care training?

12. How can you be representative of people with disabilities when you are involved in training?

13. How do you think more service users and carers could be encouraged to be involved in training?

14. How would you like to see the Local Authority using your own contribution, and the contribution of other service users and carers in the future?

15. Do you need further support in order to develop your interest and involvement in training?

16. How successful to you think your involvement in training has been to date?

Interview with carers (3B)

1. *Can you tell me how you first became involved in training?*

2. What is your
a) Age
b) Gender

3. Are you caring for a :

a) Partner
b) Child
c) Other relative
d) Non-relative

4. For how long have you been a carer?

5. What preparation or training were you offered before you became involved in training?

6. To what extent have you been involved in training activities?

7. Are you taking part in any training related activities at present?

8. Do you see your involvement in training in terms of influence?
If so :

9. Who are the key people whom you aim to influence?

10. *What do you aim to influence through your involvement in training?*

11. What message are you trying to get over in your training?

12. What do you see as your particular contribution to training as a service user?

13. What is your particular contribution to Community Care?

14. How can you be representative of people with disabilities when you are involved in training?

15. How do you think more service users and carers could be encouraged to be involved in training?

16. How would you like to see the Local Authority using your own contribution, and the contribution of other service users and carers in the future?

17. Do you need further support in order to develop your interest and involvement in training?

18. How successful to you think your involvement in training has been to date?

Questions for interviews with students who participated in training sessions (3C)

1. Briefly what was your background before coming on the Diploma in Social Work?

2. What have been your main contacts with the world of physical disability

3. What do you think was your main view of disability/people with disabilities before coming on the Diploma?

4. What do you view as the most important influences upon the way in which you view people with a physical disability?

5. What do you remember about the sessions on physical disability last year?

6. Do you think they altered your perception of disability /is yes How?

7. How did you view the role of service users/carers in the training?

8. To what extent you think their contribution was effective ?

Marginally?
Fairly
Very

9. Do you think that service users / carers have a role in the training of students and professionals?

If so what do you think it is?

10. What may be some of the problems of involvement?

11. How do you think that service users and carers can be empowered to participate?

12. Any other comments.

Appendix 4 A

Course outline : Physical Disability and Service user involvement

Aims:

- To consider social welfare practice in relation to people with a physical disability and their carers;
- To consider the effects of 'disabalism', within a social model of disability.

Objectives:

- To consider definitions of impairment and disability and their possible implications for practice;
- To develop an awareness of key legislation that impacts on the lives of disabled people and their carers;
- To think about the meanings of disability at different stages during adulthood:
  Transition to adulthood;
  Young adulthood;
  Middle adulthood.

It is intended to briefly consider issues around congenital and acquired disability.

- To start to develop thinking about appropriate social work practice in relation to adults with a physical/sensory disability and their carers.

The teaching of this module will be in partnership with service users and carers from Dyfed and will integrate a service user /carer perspective.

b) Teaching Plan

Session 1 (3 hours) : Introduction to definitions of disability, the language of disability and models of disability (1 hour 15 minutes)

Coffee break

Introduction of case material and group learning task : discussion of key issues with service users and carers (1 hour and 30 minutes)

Sessions 2 and 3 (6 hours total) self-guided group learning based on the task.

Session 4 (3 hours) Group presentations and feedback from service users and carers.

Appendix 5

Contents of Enquiry and Action Learning pack: Physical Disability and Service User involvement

Learning objectives.

2. Definitions of Disability and Impairment.

3. Case scenarios.

4. Summaries of Legislation that affects disabled people and carers.

5. Policy documents from local authorities : e.g. Corporate Action Plans on Community Care.

6. CCETSW : Current Disability Issues and Social work

7. Articles on Disability

8. Articles on Caring

9. A reading list

10. List of contacts (service users and carers) who were available to discuss issues, either on the telephone or in person

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