

More Together Than Ever

Disabled women's experiences of involvement in a self-organised group

Lorraine Gradwell MBE

From women she interviewed: "People don't believe me but I didn't go out for ten years." (page 44)

"I'm completely different now, as a woman, as a person, having rights, being me. I used to be unhappy with how I saw myself, but I see things very differently now". (page 47)

"I won't put up with a lot of things that I might have done before and I'm much clearer about when something's not right and I say '*I'm not having that anymore*'." (page 37)

Published in Great Britain in 2018 by
TBR Consulting

Copyright © Lorraine Gradwell, 1998

The Estate of Lorraine Gradwell asserts the moral right for
her to be identified as the author of this work under the
Copyright, Designs and Patents Act 1988.



This work is licensed under the Creative Commons
Attribution-NonCommercial-ShareAlike License.

Large print – use A4

Medium print – use A5 “booklet” print option

ISBN 9780993526701

Printed by upnorthprint.com

(also available online in PDF format)

TBR Consulting, Manchester M33 7EG, UK



Lorraine Gradwell MBE (1953 – 2017)

Contents

Foreword to the 2018 edition	1
Introduction	2
Words and meanings.....	5
Disabled women.....	6
The disabled people's movement.....	8
The Greater Manchester Coalition of Disabled People	13
Disabled and non-disabled women	15
Subjective reality.....	18
The research process	21
Themes.....	25
Involvement with GMCDP.....	25
Personal relations	30
“I’m not having that anymore”	37
Social relations.....	39
Women’s self-image	42
Confidence and self-image	47
Conclusion.....	49

Bibliography	52
APPENDICES	55
1 -- Research information sheet	55
2 -- Multiple choice questionnaire.....	58
3 -- Research questions	60
4 -- Proposed analysis of the findings	65

Foreword to the 2018 edition

Lorraine, my wife, wrote this piece of research in 1998 as part of her Masters post-graduate course at the University of Leeds course in Disability Studies. Twenty years later it is being published to a wider audience for International Women's Day, 8 March 2018.

Lorraine died in September 2017 and her obituary was in The Guardian newspaper.

This small publication cannot do justice to the fullness of Lorraine's life. A memoir is planned for later this year, and the many tributes to her are also being published.

The important context here is that Lorraine said that becoming involved with GMCDP, along with support from her friends, was what "*kept me sane*" particularly during the early 1980s with a very difficult divorce and two young children. On her home computer, Lorraine named this document file, The Real Thing.

In taking the time to study and to write this research, driving to Leeds every week, working evenings, as well as setting up her second organisation - Breakthrough UK - she was determined to hold the door open to other disabled women to show how to equally benefit from the empowerment that GMCDP had given her.

Tony Baldwinson
February 2018

Introduction

“Self respect arises only out of people who play an active role in solving their own crises and who are not helpless, passive puppet - like recipients of private or public services” (Alinsky, 1972)

The aim of this research is to explore whether or not the active involvement of disabled women in the Greater Manchester Coalition of Disabled People (the Coalition), a campaigning organisation controlled by disabled people, has had a positive or negative impact on their social and personal relations and their self-image and feelings of self-worth, as they view them.

In the context of traditional, stereotypical views of disabled and non-disabled women, this work will seek to establish how disabled women became involved in a campaigning organisation controlled by disabled people - the Coalition - and what impact that involvement has had on their social and personal relations. It will examine what activities constitute “active involvement” for the women and whether the women view the impact of their involvement as positive or negative.

The research will be conducted in a manner which will facilitate the disabled women to influence its development, and to define for themselves what constitutes positive or negative impact. There is an increasing recognition that “Disability cannot be abstracted from the social world which produces it; it does not exist outside the social

structures in which it is located and independent of the meanings given to it.” (Oliver, 1992).

Intellectual debate about disability has, until recently, invariably been based on the “deficit” model, which is based on a belief system that “non-disabled” is the norm and that any deviation - such as in the form of impairment - is necessarily a negative factor in a disabled woman’s life.

The deficit model takes as its norms the realities of daily living for **non**-disabled women, and applies those norms inappropriately to disabled women. There has been little opportunity for disabled women themselves to contribute and to influence the conceptualisation of what it means to be a disabled woman. This research will facilitate the involvement of a particular grouping of disabled women in that debate, and will be conducted by a disabled woman, herself “grounded” in the knowledge and culture which informs the subjective reality of their day to day worlds.

Disabled people experience discrimination and exclusion in society as a whole, but also *within* other, marginalised, groups disabled women experience exclusion. Feminist discourse has not taken account of the daily subjective reality of disabled women, and certainly not of disabled women activists in the disabled people’s movement. This research will be of value both to non-disabled women who wish to be more inclusive in their theorising and to disabled women who wish to further the analysis of the marginalisation of disabled women within both the women’s and the disabled people’s movement.

This work will also contribute to policy debates about the “quality of life” of disabled people, and what constitutes “quality” - too often defined on our behalf by non-disabled people. As Hannaford says about the situation of disabled people, “Deviant from the norm they may be, but deviants of a special kind; deviants by default. Looked upon as helpless and needing help, pitiful and pathetic, they inhabit a twilight world and as such deserve charity, not rights. Charitable institutions “take care” of them and society benevolently “helps”, reminding themselves as they do of the “good” society that they live in.

The disvalued group, without economic or social power are thus relegated to society’s charitable dustbin and must be grateful for the leftovers to be found there.” (Hannaford, 1985, p14).

In this work disabled women will, themselves, consider the impact of particular activities on their personal and social relations and define whether this has been positive or negative.

Further research indicated from this study may be a comparison between the impact that “day services” traditionally offered to disabled women and the daily activities that some disabled women choose for themselves have on their lives. It is imperative, however, that any such study should take account of the subjective reality of the women’s day to day lives.

Words and meanings

A clarification of the term disability is necessary for the purposes of this work. Traditionally terminology relating to disability has been imprecise, with words such as handicap, impairment and disability being used interchangeably.

Early analysts in the disabled people's movement developed the "Social Model of Disability" which reconceptualises the words impairment and disability, as outlined by Jenny Morris:

"Impairment refers to the functional limitation(s) which affect a person's body, whereas *disability* refers to the loss or limitation of opportunities owing to social, physical or attitudinal barriers.

Thus, an inability to walk is an impairment, whereas an inability to enter a building because the entrance is up a flight of steps is a disability. An inability to speak is an impairment, but an inability to communicate because appropriate technical aids are not made available is a disability. An inability to move one's body is an impairment but an inability to get out of bed because appropriate physical help is not available is a disability.

Disability therefore refers to the oppression which people with physical, sensory or intellectual impairments, or those who are mental health system survivors, experience as a result of prejudicial attitudes and discriminatory actions. People are

disabled by society's reaction to *impairment*" (my emphasis) (Morris 1993; page x)

Morris similarly gives an explanation why the term *non-disabled* is used rather than the more commonly used *able-bodied* ...

"the point is that people who do not experience physical, sensory or intellectual impairments are *not disabled* (my emphasis) by the prejudices and discrimination which denies (sic) opportunities to people who do not experience such impairments."
(Morris, 1993, page x).

Throughout this work I will use the terms "impairment" and "disability" as outlined above.

Disabled women

There is not scope within this work to review the literature on women and disability. Moreover, although there are many references to be made in relation to this topic, the discourse available to disabled women active in the disabled people's movement, reflecting on or attempting to analyse the subjective reality of their lives is poor and this indicative study reflects a need for further research.

All women interviewed had physical and / or sensory impairments; the views of women with learning difficulties are therefore not addressed.

Clearly many of the issues within this work are not unique to disabled women - although many in fact are - however, there is not scope to attempt to address a comparative study with either non-disabled women or with disabled men. The agenda belongs to disabled women, active in an organisation controlled by disabled people. Accordingly, the emphasis was on semi-structured interviews followed by a group discussion on themes arising from the individual interviews, identified by the researcher but then selected by the participants themselves.

This research is centred around the active female members in a specific local organisation; it draws from a small number of potential participants and the specificity of this grouping of women, in a localised setting, renders it unsuitable to being considered as representative of disabled women. Furthermore, as a self-selecting group who wished to share their experiences, there is necessarily an in-built bias in the sample. This study should be viewed as an exploration into similar choices that a particular group of women have made, and the impact that those choices have had on their lives.

The size of the group from which the sample was established is small, no more than twenty to twenty-five “active” women from the Coalition, and therefore “representativeness” is not a feasible criterion. Accordingly, a small sample - three - was chosen to facilitate the participative and qualitative nature of the research, and to create space and opportunity for the participants to influence the themes and content of the

interviews. This work, therefore, must be viewed as providing insights only.

The disabled people's movement

“The disability movement provides the collective context for political identification; it involves processes which challenge views of disabled as incapable, powerless and passive; and it establishes disabled people as experts on disability and disabled people's definitions as the most appropriate approaches to disability rather than the traditional domination of professionals.” (Shakespeare, 1996, p 102).

Traditional views of disabled people have had many influences: the medical, charitable and welfare professions have long dominated our lives, going back in history to the first Elizabethan “Poor Laws” and beyond. This well - established dominance of the “caring” professions over our lives, based increasingly on the development of a concept of need, has led to a view generally held by society that disabled people are dependent, passive, and needing “care”.

The “solutions” to the “problem” of disability have been devised by doctors and consultants, social policy makers and administrators and have consisted of trying to cure disabled people and make them as “normal” as possible, or to ameliorate the situation of disabled people by provision of “special” accommodations within society.

Disabled people are not traditionally viewed as “contributing” citizens, but as “helpless dependants who are incapable of engaging in ordinary social life, let alone productive economic life ...” (Lonsdale, 1990, p59).

In terms of a productive economic life, a prevailing historical view illustrates disabled people progressing from having a “village idiot” role, accepted and recognised by the community in pre-industrialised Britain, moving to the increasing “classification” of disabled people as part of the “deserving poor”, as changes in the organisation of work - and the subsequent exclusion of disabled people because of increasing standardisation of the workplace - began to create a need for welfare provision.

Towards the end of the nineteenth century the mushrooming growth of the welfare society, coupled with the increasing power of the medical professions and the development of charitable organisations, underpinned the creation of a “niche” for the care of disabled people.

This was further expanded with the creation of the welfare state in the middle of this century and the increased credibility given to concepts such as sheltered employment workshops, “care in the community” and other specialised “solutions” to the problem of disability. This process has contributed greatly to the resultant position of disabled people in our society being perceived as dependent, inactive and in need of “care”, with the consequent popular view that to be a disabled person must inevitably be a personal tragedy.

The beginnings of changes, in this country, to these traditional views can be attributed almost exclusively to the growth of the disabled people's movement. On the 20th September 1972 a letter to *The Guardian* from a disabled man - Paul Hunt - calling for "a united struggle by disabled people against all forms of discrimination" (Pagel, 1988) started,

"a chain of events which led first to the formation of the Union of Physically Impaired Against Segregation" (UPIAS) and eventually to a national coalition of groups and organisations (BCODP) controlled by disabled people." (Leach, 1996, p88).

Furthermore, attention is increasingly drawn to the development of a *disability culture* in which disabled people affirm their own value in society and come together to share and develop their own analyses about the influences on their lives. This is in stark contrast to the historical tradition of disabled people being defined and viewed in relation to non-disabled norms by non-disabled society, and being found to be lacking in practically every respect.

Disabled people are increasingly portraying themselves "as a distinct social group, with a complex range of inter-related problems shared in common" (Leaman, 1990), whilst disability is presented as a civil and human rights issue. This is at variance with the traditional medical / charitable / welfare view described earlier, and underpins recent advances towards legislation which recognises the

disadvantage and discrimination that disabled people face on a daily basis.

The Disability Discrimination Act 1995 (DDA) recognises in law that disabled people **do** experience discrimination, whilst at the same time, paradoxically and for the first time in law, permits “justifiable discrimination” against disabled people, thus condoning an attack on their human and civil rights.

The subsequent proliferation - slowly at first but with gathering momentum - of local and national organisations set up and controlled by disabled people, and the associated increases in disabled people’s social activities, is having a major impact both on the development of social policy, on images and representations of disabled people and, fundamentally perhaps more important, on disabled peoples’ own self-images and their concept of their place in society.

As Ken Davis observes,

“There’s certainly a lot of collective action going on, at local as well as other levels. Structures are evolving and programmes are being formulated. Sacrifices are being made and leaders have emerged. Ideological boundaries are sketched in and histories are being written. Links have been established and pledges of solidarity made for the struggles of other oppressed groups”. (Davis, 1993, p285).

That there are increasing levels of activity by disabled people as a whole, and that there are developing links with other oppressed groups is not contested. Nasa Begum, however has argued that,

“The reality of being a disabled woman and having a physical disability (sic) has to a large extent been overlooked by both the disability and feminist movements.” (Begum, 1992; p70);

and Jenny Morris contends that,

“Disability is a women’s issue - in that the majority of disabled people are women - yet the experience of disabled women has been largely absent from feminism’s concerns and, within the disabled people’s movement, has tended to be tacked on as a “special interest”.” (Morris, 1996; intro)

With the emergence of the disabled people’s movement over the last thirty years there has been increasing debate and analysis amongst disabled people themselves on the causes of the marginalisation of disabled people in society and the disadvantage they experience in practically every sphere of life. For disabled women there is an *overlay* of the imperatives that society expects of women as a socially defined group, combined with the messages aimed specifically at disabled people ...

“they have been encouraged to be less assertive and more dependent, and to concentrate their energies and priorities on physical appearance, at times to the detriment of their health and well-being.

“They have often been devalued, and many have internalised negative images of themselves which have constrained their actions. Many have not received the rehabilitation and training necessary to equip them to enter the labour market on equal terms to others.” (Lonsdale; 1990; p156).

As stated elsewhere in this work, generally, feminist discourse has not taken account of the daily subjective reality of disabled women, and certainly not of disabled women activists in the disabled people’s movement. This research, which seeks to explore these women’s views on their own particular situation, will be of value both to non-disabled women who wish to be more inclusive in their theorising and to disabled women who wish to further the analysis of the situation of disabled women within both the women’s and the disabled people’s movement and its impact on their social and personal relations and views of self.

The Greater Manchester Coalition of Disabled People

Throughout the 80s and 90s in this country there has been a growing number of grassroots disabled people’s organisations: the British Council of Disabled People - BCODP - states itself to be the national organisation representing disabled people in the Great Britain: it claims over two hundred thousand disabled people amongst its membership and points to a growing number of new groups being established.

Some of its member groups have been in existence for as long as BCODP itself; the Greater Manchester Coalition of Disabled People (the Coalition) - from whose female members this research is drawn - is one such organisation. Established, controlled and staffed entirely by disabled people, and based firmly on the social model of disability, GMCDP is generally viewed as one of the leading disabled people's organisations in the country.

The aims of the Coalition are:

To promote the independence and integration of disabled people into society.

To identify and challenge the discrimination faced by disabled people in society today.

To encourage and support the self-organisation of disabled people.

(GMCDP Articles and Memorandum of Association. 1986)

Significant GMCDP activities include production of "*Coalition*", a much-respected magazine at the forefront of analysis in the disabled people's movement; ground-breaking work with young disabled people; a highly successful training project and an extensive information service offered to members.

Full membership of the Coalition is open only to self-defining disabled people - that is, no medical or other authority is required to validate "disabled" status - and is drawn mostly from the ten local authority districts of

Greater Manchester, although some of the approximately three hundred members are from elsewhere in the country, as well as a small number of international members.

Disabled and non-disabled women

As we head towards the Millennium, perceptions, and actual roles, of women in society are increasingly changing, as are those of disabled people. However, society generally still has a traditional, stereotypical view of women, that is, non-disabled women. Despite societal trends towards emancipation and equality, women are still often traditionally seen as wives, carers, mothers, and “homemakers”. Furthermore, women are expected to embody traditional notions of “femininity”, for example, softness, gentleness, passivity and deference to men. Driedger & Gray, eds., 1992, Keith, ed. 1994, Morris, ed., 1989, Morris, ed., 1996, amongst others, are useful for writings and analysis on the particular situation of disabled women.

Disabled women are the objects of a paradoxical mixture of these two stereotypes: whilst not generally being expected to fulfil the role of parent, lover, mother or homemaker, nevertheless, disabled women are often seen as passive, dependent, needing “care”, and as asexual beings.

Disabled women receive and internalise these “messages” from a disablist and sexist society. As Begum points out

“... there is little doubt that the dual oppression of sexism and handicapism (sic) places disabled women in an extremely marginalised position.” (Begum, 1992, p70).

Disabled women exist and operate in a society whose social organisation does not acknowledge their daily reality; the huge volumes of feminist work examining the position of women in society neither recognises nor validates the cultural and intellectual world of disabled women. As Jenny Morris outlines “ ... the experience of disabled women has been largely absent from feminism’s concerns and, within the disabled people’s movement, has tended to be tacked on as “special interest”. (Morris, 1996, p1).

As Morris further points out, there is little research which attempts to look objectively at the daily reality of the lives of disabled women, from a value base to which disabled women themselves have contributed. Specifically, in relation to feminist research she says that “...disabled women’s subjective reality has found no place in mainstream feminist work.” (Morris, 1992).

Thus many leading female activists in the disabled people’s movement have been critical of the failure of the women’s movement generally to acknowledge the experience and reality of disabled women. The perceptions that disabled women generally have of themselves, their subjective reality, are influenced by the discrepancies between their own experiences of daily living - which are generally not accurately documented nor

validated - and that of the general dominant standpoint of non-disabled women.

A feature of the growth and strength of the disabled people's movement has meant that disability is increasingly presented as a civil / human rights issue - this is at variance with the traditional medical / charitable / welfare view and underpins the recent advances towards legislation, such as the Disability Discrimination Act (DDA) 1995, which recognises the discrimination that disabled people face on a daily basis.

There is also currently a debate about the involvement of disabled women in the groups which constitute the disabled people's movement, with many commentators lamenting the "macho" nature of the movement whilst others cite a dominance of disabled women; for example, as recently as October 1997 three out of four officers (i.e., Chair, Deputy Chair, Treasurer, Secretary) of BCODP, the national organisation, were women.

As Ken Davis notes, throughout the 1980s "progress through organised collective action developed rapidly. The hard fought for unifying influence of the social definition (model) began to bear fruit, as the movement began to coalesce. The decade closed with a widespread acceptance of the radical revision of outlook which had begun in the early 1970s. The social situation of disabled people - the "misfortune" - was now seen as intolerable, not just to themselves as individuals but to disabled people as a social group ... By the arrival of the 1990s, the

movement was already gathering itself to take the next major step forward.” (Davis, 1993, p290).

However, Begum states that “Disabled women have become perennial outsiders, our powerless position has not been seriously addressed by either the disability rights or the women’s movement.” (Begum, 1992, p73).

Therefore, does the process of coming together with other disabled people specifically to address disability as a civil / human rights issue impact upon the social and personal relations of disabled women; and is any resultant impact of a positive or negative nature?

Subjective reality

“Disabled people - men and women - have little opportunity to portray our own experiences within the general culture, or within radical political movements. Our experience is isolated, individualised; the definitions which society places on us centre on judgements of individual capacities and personalities. This lack of a voice, of the representation of our subjective reality, means that it is difficult for non-disabled feminists to incorporate our reality into their research and their theories, unless it is in terms of the way the non-disabled world sees us.” (Morris, 1991, p8).

As stated elsewhere in this proposal, generally, feminist discourse has not taken account of the daily subjective

reality of disabled women, and certainly not of disabled women activists in the disabled people's movement.

For this piece of research the methodology is underpinned by three main approaches, as follows:

1. A recognition of the social model of disability, that is, recognising disability as a societal issue of discrimination in attitudes, access to services and activities, and social policy.
2. The use of a critical social research approach, i.e., to "legitimise" the lives of disabled women and the structures in which they live; through the research process to recognise and validate their own subjective reality.
3. The adoption of a participative, qualitative and emancipatory approach, by and with disabled women - the researcher herself is a disabled woman, active in the disabled people's movement. The research participants were invited, within the framework of a prepared questionnaire, to define their own "start points" and "milestones" / "benchmarks", and to contribute towards the framework of research. Women were invited to make comments and constructive criticisms at many stages of the research.

These three principles have been used to inform the approach in recognition, firstly, of the growing and emerging analysis by disabled people themselves of the causes of their exclusion from society on a day to day level, and the growth of their self - organisation to address

this exclusion, through organisations such as GMCDP. As Finkelstein states,

“In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society” (Finkelstein, 1980, p53).

Secondly, the approach will not adhere to the “deficit” model, which is based on a belief system that “non-disabled” is the norm and that any deviation - such as in the form of impairment - is necessarily a negative factor in a disabled woman’s life. As Hevey explains,

“That disablement (sic) is centrally viewed as personal tragedy and loss within the body, there can be no doubt. This personal tragedy theory of disability is in turn supported by ideologies feeding into it ...” (Hevey, 1992, p13).

Rather this research will seek to enable disabled women to define for themselves the positive and / or negative elements and factors of their **own** lives.

Thirdly, the research is grounded in disabled women’s experience, and as such subjectifies their experiences in terms of elements of their own social organisation and activities. As Smith says of women’s need to develop an appropriate and relevant method of enquiry, “... we began to discover that we lived in a world put together in ways in which we had had very little say.

We found that we had participated unknowingly in a culture and an intellectual life in the making of which we had had little part. We discovered that we had been in various ways silenced, deprived of the authority to speak, and that our experience therefore did not have a voice ...” (Smith, 1990, p1).

So it is with disabled women, who are, and have been, denied access to the cultural and intellectual world of non-disabled women, that there is a need for them to come together to reflect upon their own situations and to recognise and validate the subjective reality of disabled women.

Finally, the methodology is informed not by a positivistic approach, but rather an interpretative one, which “does not conceive of the social world as existing independently of the individual members comprising it, nor does it conceive of the social world as an absolute moral order in which all competent (sic) members of society understand the same social meanings. The social world then is understood as being socially constructed and negotiated by individuals” (Hannaford, 1985, p33).

The research process

The details in these findings are based on series of semi-structured interviews with the three disabled women over a ten week period, concluding with a group discussion involving all three women commenting further on some of

the main themes which emerged from their individual interviews.

This research invited those disabled women active in a leading disabled people's organisation to participate. All female members were contacted by letter with an explanation of the research and an invitation to express interest in participating.

Accompanying information had been sent about the background, aims and objectives, and the process of the research - Appendix 1. It informed women that "the research will be conducted in a way that supports the disabled women to influence its development and to define for themselves what constitutes positive or negative impact".

Twelve women responded to the researcher either by letter, telephone or personal contact; they were asked to complete an initial multiple choice questionnaire (Appendix 2) which was conducted over the telephone. They were asked to indicate the nature and length of their involvement with the Coalition and their age; they were also asked to indicate whether or not they felt that their social or personal relations had changed as a result of involvement in the Coalition; and, if there had been changes, whether or not they felt those changes were - at least partly - related to their involvement with the Coalition. Finally, women were asked if they would be willing to take part in the research itself.

Impairment was not used as a criterion for participation, in line with the methodological approach based on the social model of disability (see above). Furthermore, ethnicity was not used as a criterion as all the active women responding initially were white: this particular issue indicates a potential for further research to explore why black disabled women are currently not actively involved in the Coalition.

Seven women indicated a willingness to take part in the in-depth interviews: given such a small range of “eligible” women, and the methodological approach to the research, the three participants were then chosen by random selection.

The three disabled women selected ranged in age from early thirties to mid-forties and had been involved with the Coalition for between five and eight years; all had physical and/or hidden impairments; they all felt that involvement in the Coalition had had a significant impact on their lives.

Two of the women are in full time employment - one as a policy officer in a local authority, one at the Coalition itself, whilst a third is a sessional trainer and active volunteer and Co-Chair for GMCDP.

The three women were sent an outline of the research questions (Appendix 3) to consider in advance of the interviews, which were conducted in their own homes. The resulting transcript of the sessions was then sent to the women for amendment, comment or any further action.

At all stages women were invited to comment on the research process and content, and to make amendments

or suggested changes. They were offered the option to withdraw from the research at any stage.

The issue of anonymity is worth further explanation here; all women were offered anonymity, at every stage of the research process from initial inquiry to final discussions, although it was accepted, by both the researcher and the participants, that this would be hard to achieve given the small sample range and the identifying characteristics of the situations of some of the women.

However, none of the three women were concerned with anonymity, feeling that the process of being identified was not problematic for them. Only one significant *incident* has been anonymised, at the specific request of the relevant participant.

In the individual interviews all three women identified issues which they felt could be usefully discussed with other disabled women. This led to an offer by the researcher to arrange a discussion, with all three, which was taken up. In preparation for that discussion a preliminary analysis of the emerging main themes from the individual interviews was prepared. These themes were grouped firstly according to those raised by all women, and secondly those raised by two women; they were then fed back to the group discussion and women chose which themes to explore further in the group situation. The resulting views have been fed into the final analysis of the contributions.

A further outcome of the research is that all three women expressed a desire to continue discussion of the issues raised, with the researcher - herself a disabled woman.

Themes

The themes of the interview cover four major areas of enquiry, namely involvement with the Coalition, personal relations, social relations and women's view or image of themselves.

The interviews sought to establish how the involvement with the Coalition occurred and if that involvement had impacted on the range and quality of the women's personal and social relations and their self-image. It further sought to examine whether that impact had been viewed as positive or negative by the women themselves.

In line with the methodological approach the research sought, at all stages, to offer to women the opportunity to introduce new themes or views - this is reflected in the analysis.

Involvement with GMCDP

The route to involvement with the Coalition differed for all three women: one woman became involved through personal contact at work with an existing member, and became an active volunteer at the Coalition until she applied for a job and has worked there since.

Another was “sent” on a GMCDP training course by the manager of the local independent living housing scheme where she lived, because he thought she “had potential”. She felt that participating in the “Training the Trainers” course was “like finding God”, a revelation in as much as people treated her “as though I was a person”.

The third made initial contact with the Coalition herself, seeking further information after reading about the social model of disability and the Union of Physically Impaired Against Disability (UPIAS), an early pioneering disabled people’s organisation, in “The Politics of Disablement” by Mike Oliver (1990). Her reason for making contact was that “I recognised the principles (of the social model) as beliefs that I had but had not been able to articulate”, and described her subsequent initial involvement in the Coalition as “my road to Damascus”.

Levels of involvement in the Coalition vary between the women, though all regard themselves as active. Two women live locally: one was previously a member of the Executive Council - the management committee - and is now an employee, whilst the other has been a volunteer, and is both a sessional trainer and one of the GMCDP Officers. The other woman lives about thirty miles outside the immediate area, but is active in subgroups, lobbying, writing for the “Coalition” magazine and other activities.

Significantly, all three women described a feeling of “being worth something” at the Coalition, in contrast to the common experience that disabled women generally report of being marginalised in society and treated as “other”.

As Jenny Morris elaborates,

“Disabled people have to work continually against destructive forces which see us as powerless, passive and unattractive. It seems that no matter how cheerfully and positively we attempt to go out into the world, we are bound to be confronted by someone whose response to our lack of ordinariness, our difference from the norm, leaves us feeling powerless and angry. Trying to understand the complicated feelings which arise out of our everyday encounters with the world is central to the lives of all disabled people”. (Morris, 1996, p70).

One interviewee explained:

“When you’re in a society where you don’t *feel* you fit, where you feel you’re out of step with the rest of the world it’s not good for your self-esteem. You think “it must be me”, that you don’t fit; but what you need is contact with your peers.”

Typically, when disabled women recount their experiences of trying to interact in a world that is neither welcoming nor built to accommodate them, their subjective reality is often illustrated by tales of difficulty and frustration. As Hannaford outlines,

“We suffer apartheid like our black sisters - “special education”, denied access to things that other women take for granted, i.e. housing, transport, movies, theater (sic), stores and lots of women’s events. We are segregated and incarcerated in institutions (for

our own good of course) and denied our independence; as women have been for centuries. Our sexuality is denied us. Treated like children we are truly hidden from history, our images are nowhere ... (Hannaford, 1985, p127).

In contrast, and independently, all women interviewed used the word “comfortable” to describe their experience of being at the Coalition, expressing a feeling of “belonging” and saying that “it fits” and that whilst many organisations - such as those *for* disabled people - and institutions try to fit disabled people into a non-disabled society, “the Coalition accepts us as we are, on our terms.”

When asked in the group discussion to articulate what they *meant* by “comfortable” one replied,

“When you go out you’re always mentally prepared for a hard time, over access or something, you’re thinking ahead for how to deal with it. But not at the Coalition; I don’t have to pretend to be something I’m not, I can be myself”. Another said “Before the Coalition, all I knew was that I was self-conscious, I didn’t fit, and people stared. That doesn’t happen at the Coalition.”

Another described her initial experience as,

“a safety net. I was encouraged to come in and volunteer - writing up index cards at first. The atmosphere was good and I wanted more - I didn’t

want to go away. I felt protected, I could be myself, the person I'd hidden.”

The participants all felt that their involvement in the Coalition had had a positive impact on their lives, though not all to the same extent. One woman in particular recognised a significant impact on her life since becoming involved in the disabled people's movement, but ascribed it also to the influence of other organisations, such as the trade union *Unison's* disabled members groups and disability arts organisations.

However, all remarked on the feelings of affirmation that they received from the Coalition, as described by one woman,

“It has made me a stronger person, made me feel good about myself. It was not questioned about who I was, I was allowed to be myself and I felt very comfortable. No-one said “we can't take you because you're ... (disabled)”.

The receptive attitude of disabled people at the Coalition was significant in that it differed from the general attitude that society has to disabled people, viewing them as dependent and non-contributing members of society - as one woman explained:

“I don't feel scared of myself anymore, I know that I *can* achieve, that people actually like me, that they're not pitying or condescending; I feel liked for who I am, like a whole person. I used to feel like a jigsaw, things were always out of place although I *knew*, I

always knew it was wrong: now the pieces are in place. The changes have meant that I can live independently and not have to feel that I have to put everything right - I don't just see it (disability) as my problem anymore."

All women reported significant feelings of affirmation and acceptance through involvement in the Coalition, rather than their previous experience in common of the "tragedy" and "deficit" effects of the popular view of disability and what it means to be a disabled person.

Personal relations

FAMILIES: disabled people do not even "fit into their families, but are always the odd one out."

Reflecting on their childhood families, two of the women talked at length about the influence that parents and siblings exerted over themselves as disabled children. They painted a picture of a family which discouraged independence and insisted on "doing for you"; there was a sense that siblings were made to feel "responsible" for the disabled child - had to look out for them - although one woman recognised that "mentally and emotionally I looked out for *them*" and she felt that this relationship had continued into adulthood.

It was considered that families generally feel "judged" by local society if they acknowledge and promote independence for their disabled child, that somehow they

would be viewed as “not caring enough”, and at least one participant said that she found her family “hardest to deal with”.

Shakespeare expands on this issue,

“While women and black people can expect support role models from within the family and community, disabled people are likely to grow up in families where there are not other disabled people, and where there is a parental burden of guilt and shame. This highlights a difference between disability, and race and gender; disability is more like sexuality, in the sense of familial isolation, and the need to come out and reject the burden of difference.”

(Shakespeare, 1996, p105).

Two women identified that the family reaction to their impaired state left them personally with low self-expectations, with a life that was very controlled and for which they were expected to be “grateful”. Conversely, one participant expressed the view that she had never felt over protected by her family but had always been expected to *manage*.

She reflected that perhaps that had been helpful, and that had it been otherwise she may have ended up attending a day centre. However, she did feel that she would *welcome* the occasional help from her family who live nearby, and wished that they did understand that she sometimes needed help, but they always expected her to be independent.

This remark brought the observation that “you’re either *over-protected*, and therefore can’t do as you want - or they don’t recognise what you need and so you still don’t get what you want.”

All women felt that their relationships with parents and / or siblings had been influenced by their involvement with the Coalition; most attributed this to their families’ reactions to changes in themselves. This was expressed most strongly by one woman –

“I’ve disassociated myself from my all brothers and sisters, except for my brother, with whom I’ve always been close. They all depended on me, but I gradually got to a point where I had to sort *me* out. They don’t like the “new me”, they say “what do you need this Coalition for?” they can’t cope with it and see it as competition.”

Another woman commented that her siblings, who have always been “overpowering” in their determination to “look after” her, are now more wary of intruding in her life, and “often act as if they are walking on broken glass around me, so I must be changing.”

Since becoming involved in the Coalition the nature of close friendships had changed quite markedly for all women, although all had retained at least one longstanding previous, non-disabled, friendship. Two women spoke of these longstanding friends as people they could freely discuss things with, “a ‘big picture person’, a thinker, she was the only good person in my life

at one point”, and “our relationship has not changed or been influenced because we discuss things.”

However, all women now counted the majority of their friends as disabled people; for one woman it was significant that most of her friends now were,

“disabled people, most of them radical activists. I *have* been aware that it was changing and there has been almost a complete change over the last three or four years. I *did* have non-disabled friends, and I gained quite a lot from those relationships, but most have faded away. I have many new friends, many through GMCDP or Unison or the (disability) arts movement.”

Another woman particularly valued the,

“support mechanisms and friendships. People respond to you, they notice things.”

One woman observed that

“I feel that seven years (of friendships) at the Coalition balances out the previous thirty years; I have friends I can just ring up and feel comfy, I hope they can do the same.”

The issue of peer support was clearly important to the interviewees, whereas prior to their involvement in the Coalition peer involvement had not been a feature in their lives; indeed one woman was at pains **not** to be

associated with other disabled people, feeling that there was a stigma attached to such socialising.

Lois Keith offers an explanation why it is so important for disabled people to get together,

“to talk, to write and to listen to what others have to say. The disabled people’s movement and the growing disabled people’s culture recognise our need to examine our common heritage and shared experiences and the ways in which these oppress us. Trying to understand what is going on in these encounters, analysing our reactions, is not just an act of self-preservation, it is also important in understanding the power relationships which exist in the relationships between disabled and non-disabled people.” (Keith, 1996; p83).

Of the friendship that they felt they had received from disabled women in particular there was a recognition that, whilst not all disabled women are necessarily supportive, however there is “a common denominator with other disabled women, most of us know where we’re coming from and there are a lot of bonds.

Also, the way you’re treated as well; there’s a lot of deep rooted stuff - non disabled women don’t have a clue. I went to a party once and a (non-disabled) friend said to my partner,

“She can’t speak properly, she’s blind as a bat; how do you put up with her?” You don’t get this with disabled women. Disabled women push you on

more, they bring out your potential, things you may have suppressed in the past.”

It was recognised that,

“some disabled women have been an influence, but not all; there are some disabled women who are not supportive - especially those women who are part of our organisations because it suits them to be a part - there’s a non-disabled woman in there!”

For all woman there were particular individuals who had been significant to them in their development, with several women cited by more than one participant as being especially supportive or being seen as a role model.

As one woman explained in relation to a particular friendship,

“she has been very influential; it’s good for all of us to have that kind of relationship, to know that there are things you just don’t have to explain.”

All women were satisfied with their current social lives and the range and level of friendships that they had developed; one felt that she is now “a more interesting person, I feel I can talk now but I had nothing to say before. I come across as more positive now, I have something to say.”

When they first became involved in the Coalition two women had been previously divorced and one had a marriage that was not going well. One woman is now

remarried to a disabled man who has been prominent in the Coalition; the fact that she has a hidden impairment whereas her husband has a quite obvious impairment often leads people to assume that she is his non-disabled carer;

“my family often view him as the disabled person in this relationship but myself as ‘someone who has a lot wrong with her’.”

Neither of the other two women, one of whom has divorced since joining the Coalition, is in a steady relationship; both express a preference for their lives to remain that way, for the present at least. One woman felt that,

“it’s very different for disabled women than disabled men, it’s harder to have a partner. The differences between what women look for in a partner and what men look for have a significant impact on disabled women, given the issues of body image and traditional female roles - which disabled women are not generally seen as being able to fulfil.”

Of the events leading to her divorce, one woman said that,

“While my marriage was breaking down my (now) ex-husband blamed the Coalition for “putting ideas in my head, because I wasn’t capable of my own ideas”. He was quite abusive, he would ring the Coalition and threaten to kill me. He said that we would still be happy if there was no Coalition. The trouble was, I’d started arguing, standing up to him.”

All women, then, felt that their involvement in the Coalition had an impact on their personal relations, including partners, families and close friends, though this impact was occasionally seen as negative by participants and often by their families. In commenting on relationships and the inevitable power dynamic, Lois Keith identified this issue,

“Unfortunately the world doesn’t really seem to like disabled people taking strength from being together, at least not in public. The common view of being kind and charitable to us is that the public is willing to tolerate us one at a time, but feels deeply uncomfortable when there are too many of us together.” (Keith, 1996, p 83).

“I’m not having that anymore”

Women felt that, since becoming involved in the Coalition they have become more confident, “happier” with themselves and more valuing of their own needs; one remarked that,

“In terms of relationships I have a lot more self-esteem and my confidence has improved. I won’t put up with a lot of things that I might have done before and I’m much clearer about when something’s not right and I say ‘I’m not having that any more’.”

However, the positive influences that women felt the Coalition had had on their lives also produced some

effects that were viewed as negative by the participants, and that the changes in themselves led them into conflict with their families; one woman regretted the fact that she felt that she,

“was in a battle again, I had to fight people I loved and cared for. My mum is still quite patronising but she’s backed off because I stand up to her now. My friends view the changes in me positively, but not my family. I don’t think they’ll ever get over the changes in me.”

Longstanding friendships were also affected by the changes occurring through involvement in the Coalition –

“there is a down side; my existing friend has always been a bit disablist and racist, she wants to know what’s “wrong” with disabled people. When she first met my partner she said” don’t you think you’d better get someone else, someone with legs?”. We lost something on that night, I was very angry with her, also upset. I phoned and we chatted, we see less of each other, it’s been three years now.”

It was doubly cruel to have to hear such comment from one considered a friend; Jenny Morris illustrates this attitude,

“It is not only physical limitations that restrict us to our homes and those whom we know. It is the knowledge that each entry into the public world will be dominated by stares, by condescension, by pity and by hostility.” (Morris, 1991, p 25).

Social relations

“It’s a long shot chance of me meeting another disabled person locally.”

Many disabled people, whilst ostensibly living in a local community, have little opportunity for personal involvement in local activities in an independent manner because of the inaccessible nature of the majority of buildings and activities.

Housing choices are limited by cost and availability, amongst other factors; for disabled women, who are less likely than disabled men to be working, and who may have the additional limitations of childcare responsibilities, the potential for isolation in the home is even greater. Add to this an inaccessible public transport system and infrastructure and the prospect of isolation is great.

One woman interviewed made the point that, as a disabled person, “sometimes you’re “placed” in a community, for example in sheltered housing, isolating you from the general community anyway. Disabled people also get “pushed out” in different ways, some can’t get a mortgage so their housing choices are restricted. Then there are those who need support workers, potentially limiting choices even further.”

Two of the women contributing lived in purpose built housing, whilst another is an owner-occupier of a bungalow. None felt that they had any level of significant involvement in their local communities. Their immediate

responses to the enquiry were “none”, “non-existent”, and “probably very little”.

Even with children still of school age and attending the local schools, one woman explained,

“the boys are at the local school, though I’m not really involved, it’s not very accessible. This links to the feeling of being “out of step”, although people tried to be nice to me I always felt different, never felt part of what was going on. I never joined the PTA for example. I would chat to the other mums at the gate but I didn’t really make friends. It was probably about me as much as anything, I didn’t feel I wanted to join in - but I don’t remember getting any invitations either.”

Another felt that she had tried to be involved with local disabled people but was disappointed that,

“other than day centres there’s little choice.....seems that local disabled people just want to be “looked after”. Some of them had experience of the Coalition but they hadn’t changed. I didn’t like the fact that other disabled people could be oppressive, they thought more about the money than the issues. They have “their little places” (i.e., day centres); they want nothing more than care and services.”

Interaction with neighbours was also minimal, though one woman did feel she had a good relationship with a neighbour, “although I don’t feel I return that much I do try to reciprocate.”, whilst another, living in an estate of

purpose built housing, observed that “some of my neighbours just want to be “looked after”, but I’m not sure that it’s really a choice.”

For all women involvement in local institutions such as schools, churches, community centres was virtually non-existent; one had recently joined the local Labour Party and recognised that as the “new girl” she was in danger of being nominated to every local committee, but did feel that this might be a path to more involvement in the local community.

One woman felt that the only local person she really spoke to was the black proprietor of the local shop, feeling that the fact that they probably had issues to do with discrimination in common led them to exchange views and develop a relationship. She felt that the potentially patronising nature of some local activities,

“would go against my beliefs, like fundraising, doling out hampers to disabled people. I’d maybe get involved in something like Neighbourhood Watch, or stuff around parents, but preferably disabled parents.”

One woman said that, because of the large amount of time she spent on Coalition activities she didn’t feel she had time for local involvement. All three women described a growing preference for spending more time with other like-minded disabled people, with one also recognising that the peer contact and support available through

involvement in the Coalition has increased her confidence and ability to “operate” in a non-disabled world.

“I’ve needed a few years to develop my own confidence, my knowledge, being a part of the Coalition has been quite significant in that. I feel ready to join in non-disabled activities, and feel confident as a disabled person to raise disabled people’s issues in that kind of arena because it really is tough, you need a good grounding - you need to know that there are disabled people around in an organisation such as the Coalition who can back you up.”

Overall women reported very little activity or contact with others in their local community. All women had children who might have been regarded as a “pathway” or “lever” into local relationships and / or networks, but the combination of environmental and attitudinal discrimination had contributed strongly to women’s non-involvement.

Women’s self-image

“I remember going round the house singing “The Ugly Duckling” because that was how I felt.”

Disabled women are the recipients of the “messages” that society gives out to all women, with the added imposition of society’s view of how “tragic” it is to be a disabled person. Messages about the “body beautiful”, underpinned

by the media's constant promotion of a slender and attractive female form as the ultimate, are overlaid with the notion that to have an impairment is a personal disaster which renders the individual pitiable and pathetic. Families, friends, partners, neighbours - all the people with whom we have any kind of social or personal interaction contribute to the "drip feed" of factors which influence our self-image. Disabled women experience the two oppressions of disability and sexism and their consequent view of themselves is inevitably compromised:

"His accusation confronted me. He had called me ugly. There was more to beauty than wearing make-up and stockings, or the right clothes. I was ugly, and not because my legs were too skinny, my bust undeveloped, or my face too plain. I was ugly because I was a disabled person. I was ugly and I would get uglier as my disability progressed."(Hall; 1992, p134).

One woman felt this particularly,

"I could never sit in a room full of women and feel comfortable ... I used to feel threatened by other women, I never felt a part of my sisters' world, the 'body beautiful'."

The experience of childhood for disabled children can be demeaning and isolating; one woman described herself as "very pathetic, non-existent; my mother saw me as a burden, a cross to bear ... I saw myself in a totally negative way."

Another woman said that,

“I had a good mum and I loved her, my parents were overprotective though, and indulgent, I got away with lots of things and didn’t always feel like a good daughter because I gave my mum a lot of hassles. There were always lots of things “wrong” with me, I was a “demic”, the local reject, the runt of the litter. I felt I had a lot “wrong” with me. My mum came to my first job interview with me and told them all the things that I *couldn’t* do.”

As described earlier, disabled women have often grown up in an environment which has ensured that they develop a low level of expectation for their adult years and negative feelings of self-worth. One woman described herself previously as “very passive, quiet, I didn’t mix, didn’t go out. People don’t believe me but I didn’t go out for ten years.”

Relationships with partners were not always positive experiences for these women, one of whom described,

“a destructive relationship; he would tell me that I wasn’t much of a woman, that ‘all my bits weren’t right’, he’d say ‘there’s enough wrong with you’.”

For another woman, her (ex) husband took over from her parents in being the protective carer,

“After I got married my husband took over and ‘cared’ for me, and I became passive. I think disabled people are ‘conditioned’, they have to do as they’re told and

be 'cared for' - they have to be grateful. My husband was a carer, not my lover; he was a 'hero'. But I only got married to have a father for my baby and to get social services off my back; if they'd given me the support I'd needed I wouldn't have married and I only stayed married to keep the kids. He would never let me look after the kids - he liked the £200 a week and the car outside, that's what he was upset at losing."

The feminist principle that the "personal is political" is reflected in many of the relationships which intrude on the lives of disabled women. Relationships with professionals was one theme which arose during the group discussion, and specifically in reference to issues around childbearing. There was a strong view that professionals, and social workers especially, were not necessarily helpful in their interventions. For example,

"The Social Services (SSD) got involved when I got pregnant, they said that my baby was 'at risk'. They ground me down and I had a nervous breakdown; my baby was kept in hospital for six weeks; the doctor, midwife, health visitor, someone visited every day. I was on my own, it seemed like I was fighting the world - fighting the professionals, fighting those close to me: I was desperate at the time and couldn't cope.

"The SSD ruined my life: they kept my baby in hospital for six weeks, they said she had a chest infection, but I found out later - much later, through my solicitor when I was getting divorced - that it was because they thought I couldn't cope. They got me all

upset, then they put me on Ativan and barbiturates. They engineered it so that it looked as if I couldn't cope, as if I wasn't looking after her. They would call early to take her to nursery, we would still be in bed and they would say 'don't worry, we'll sort her out at nursery', then they would record that she was still in night clothes and her nappy was dirty."

Reported attacks on the self-confidence and personal autonomy of disabled women, and their consequent impact on self-image and feelings of self-value are legion. Among this small group one or more women had experience of being offered abortions and / or sterilisation for no medical reason, rather than they were disabled women; were warned that they "might have a baby like you"; were told they'd been "stupid" to get pregnant; were pressured into amniocentesis and were warned not to get pregnant again or they would be "admitted" for the whole nine months of any future pregnancy.

Although not an issue related directly to the aims of this research, the women involved felt strongly that such damaging intrusions into the personal lives of disabled people were commonplace and had potentially devastating negative impact on their lives and feelings of self-value. All the women feel that now, having experienced a supportive rather than a destructive environment, they would challenge such professional attitudes and know where to look for support and information.

Confidence and self-image

“You get your pride back, once found, you’ll never lose your pride.”

All women felt that involvement in the Coalition had proved to have a positive impact on their self-image and, perhaps more significantly, feelings of self-worth. One woman remarked,

“I think I’m more respected, taken seriously. I’m happier with myself, I value my own needs more - though probably not as much as I should! I get views from other people, positive views of myself that surprise me, people listen and turn their attention to me and I’m taken aback.”

Another woman said that she felt,

“totally different now because of my involvement in the Coalition. Recently I was having a ‘heavy’ debate with someone, I said I **do** understand, yes I **am** a disabled person, I realised that I was talking to someone who had the same experiences and I realised there was **nothing wrong** with me.

“I feel naturally contented now and comfy with people, I feel good about myself, not like an imposition or something that shouldn’t be around; I’m completely different now, as a woman, as a person, having rights, being me. I used to be unhappy with how I saw myself, but I see things very differently now.”

One view was that

“disabled women have such a lot to juggle and balance - I feel I’ve got a nice balance at the moment. I’m still in awe of it all, I can’t believe that I’m actually living my own life, that I left. I thought I was giving up a lot of the time, but I wasn’t.

“On my deepest, darkest days I think of the worst times and think, ‘yeah, you’ve done a lot’. I like my life as it is and I would like to achieve more; I set goals now - achievable and manageable - not too high, but getting bigger now. Things are changing all the time; life revolves and keeps revolving. I’m not at a standstill and nothing surprises me. I believe I can achieve a lot more.”

Another felt that getting involved with the Coalition was

“one of the best things that ever happened to me; I’ve often wondered what *is* it about GMCDP? ... It’s the organisation that I feel the best part of.”

And for another,

“your whole world changes ... it changes your whole life and there’s no turning back. I don’t feel I’ve got across exactly the nature of change, though it has turned my life around.”

Conclusion

Although “self-selecting”, and not a representative sample, nevertheless the responses of this particular grouping of disabled women provide insights into attitudes and practices towards disabled people both of society in general, and service provision and professionals in particular.

Two “different worlds” were described by the women - disabled and non-disabled worlds - with marked contrasts between how these worlds respectively impacted upon the interviewees and their self-confidence and feelings of self-value. Even as children, two participants told how they were made to feel “less” than siblings, alienated from family and friends and all reported specific feelings of distance from non-disabled women.

However, all women experienced empowering feelings of being “worth something” at GMCDP: undoubtedly there was a process of politicisation at work, not least via the exposure to role models and peer support.

That this process was not available to them in the wider community is significant. Disabled people do not generally have access to affirming and validating activities and structures; rather they are constantly reminded that they are less than normal and excluded from mainstream society, whilst “special” provision further segregates and marginalises.

Also significant is the fact that all women also spoke of how they felt “recharged” by involvement with the

Coalition, to the extent that they felt able “to operate in a non-disabled world” and be better prepared to face the often hostile and barrier - laden environments that they had to negotiate in their day-to-day lives.

“I can be myself, be accepted on my terms.” expressed the feelings of validation that were experienced, demonstrating the need that disabled women have to be accepted as they are, as intrinsically whole and not in need of change, or “cure”.

Further research indicated from this study may be a comparison between the “day services” traditionally offered to disabled women and the daily activities that some disabled women choose for themselves, such as involvement in self organised groups like the Coalition, and the variance in the impact that these differing activities have on women’s’ lives.

Mike Oliver has argued that,

“most social research has failed to acknowledge or even be aware of recent attempts by disabled people to reformulate and devise more appropriate definitions of disability. Hence this research has failed to incorporate important issues into its epistemology and methodology resulting in severe criticisms of its findings, usefulness and relevance, and hence has contributed to the oppression of disabled people.” (Oliver, 1993).

If we accept disability as social creation, and if disabled women feel more able to speak their truth to other

disabled women, then the social relations of research production must take this into account.

The research methodology used here enabled this particular grouping of women to express views and recount experiences that they reported they would not have shared with a non-disabled researcher. Also, the discourse available to disabled women active in the disabled people's movement, reflecting on or attempting to analyse the subjective reality of their lives is poor and this indicative study reflects a need for further research.

Debate about research into disability continues to develop, whilst disabled people themselves often remain absent subjects. There is disagreement about the existence, and the desirability even, of independent research,

“I am not a disinterested observer, but a participant in the processes I describe. I recognise that this could lead to criticism in sociological terms, because I might be perceived to be too close to processes which I seek to analyse.

“However, independent research is indeed ultimately a fiction, and my own engagement gives me insights which can be useful in the research and enable me to get closer to the people and experiences which I try to analyse.” (Shakespeare, 1996).

Lorraine Gradwell,
April 1998.

Bibliography

Alinsky, Saul D, (1972); **Rules for Radicals**; New York, Random Books, (from an unsourced handout)

Begum, Nasa, (1992), Disabled Women and the Feminist Agenda, **Feminist Review**, No 40, pp70 - 84.

Davis, Ken, (1993) On the Movement, in Swain, Finkelstein, French & Oliver,; **Disabling Barriers, Enabling Environments**: London, Newbury Park, New Delhi; Sage; p284

Driedger, Diane and Gray, Susan, (eds.)(1992); **Imprinting Our Image**; Canada; gynergy books;

Finkelstein, Victor; (1980), **Attitudes and Disabled People**: New York; World Rehabilitation Fund (reprinted by RADAR); p53

GMCDP Memorandum and Articles of Association 1987; Greater Manchester Coalition of Disabled People.

Hall, Lesley; (1992); Beauty Quests - A Double Disservice, in Driedger, Diane and Gray, Susan, **Imprinting Our Image**; Canada; gynergy books; (p134)

Hannaford, Susan; (1985); **Living Outside Inside: A Disabled Woman's Experience; Towards a Social and Political Perspective**: Berkeley, California; Canterbury Press.

Hevey, David (1992); **The Creatures Time Forgot: Photography and Disability Imagery**: London and New York; Routledge.

Keith, Lois, ed. (1994); **Mustn't Grumble**", London, The Women's Press.

Keith, Lois; (1996); Encounters with Strangers, in Morris, Jenny; **Encounters with Strangers**; London, The Women's Press, p 83.

Leach, Bernard, (1996); Disabled People and the Equal Opportunities Movement, in Hales, Gerald, **Beyond Disability - Towards an Enabling Society**; London, Newbury Park, New Delhi; Sage. (p88)

Leaman, Dick; 1990, The Commodity of Care, in Stanton, Ian (ed.) COALITION Magazine, Manchester, GMCDP Publications.

Lonsdale, Susan (1990), **Women and Disability, The Experience of Physical Disability Among Women**; Houndmills, Basingstoke, Hampshire and London; The Macmillan Press

Morris, Jenny, ed., (1989); **Able Lives, Women's Experience of Paralysis**, London, The Women's Press.

Morris, Jenny (1991); **Pride Against Prejudice**: London; The Women's Press.

Morris, Jenny, (1992), Personal and Political: a feminist perspective on researching physical disability; **Disability, Handicap & Society**, Volume 7, Number2, page157.

Morris, Jenny; (1993); **Independent Lives - Community Care and Disabled People**; Houndmills, Basingstoke, Hampshire and London; The Macmillan Press

Morris, Jenny, (1996), **Encounters with Strangers, Feminism and Disability**, London, The Women's Press.

Oliver, Michael, 1990, **The Politics of Disablement**, London and Hampshire, Macmillan Education Ltd.

Oliver, Michael, (1992), Changing the Social Relations of Research Production? **Disability, Handicap & Society**, Volume 7, Number2, page 101.

Oliver, Michael, 1993; Re-defining Disability: a Challenge to Research, in, **Disabling Barriers, Enabling Environments**; London, Newbury Park, New Delhi; Sage; p67.

Pagel, Martin (1988); **On Our Own Behalf**; Manchester, Greater Manchester Coalition of Disabled People.

Shakespeare, Tom; (1996); Disability, Identity and Difference, in Barnes and Mercer; **Exploring the Divide, Illness and Disability**; Leeds; The Disability Press; (p105)

Shakespeare, Tom; (1996); Rules of Engagement; doing disability research, in, **Disability and Society**: Volume 11, No. 1, p 117.

Smith, Dorothy E, (1990), **Texts, Facts, and Femininity, Exploring the Relations of Ruling**, London and New York, Routledge.

APPENDICES

1 -- Research information sheet

DISABLED WOMEN IN GMCDP

This research is on the active involvement of disabled women in GMCDP, and the effect that they feel that involvement has had on their lives.

The following background information was sent to you in the summer, you may no longer have it and so I am sending you another copy:

the background to the proposed research,

the objectives, and,

a brief description of how I hope to carry out the research.

BACKGROUND: Until recently research on matters which may be of importance or interest to disabled women has been carried out almost exclusively by non-disabled women. It has also been recognised that there is little research which attempts to look objectively at the daily reality of the lives of disabled women, from a 'value base' which disabled women themselves have established. This means that our activities and actions are 'judged' not on our terms but on the terms of non-disabled women. This proposed research will be based firmly on the 'value base' of the participants themselves, disabled women.

The aim of the research will be to establish why disabled women have become involved in a campaigning organisation controlled by disabled people (GMCDP), and what impact that involvement has had on their social and personal relations. It will define what 'active involvement' means, and will ask the women whether they view the impact of their involvement in GMCDP as positive or negative, or indeed both.

The research will be conducted in a way that supports the disabled women to influence its development, and to define for themselves what constitutes positive or negative impact. In short, the research will develop in a way which the participants themselves decide, facilitated by the researcher.

Objectives of the research:

to examine whether disabled women feel that involvement in GMCDP has had a significant impact on their lives,

to explore whether that impact has been positive or negative

to establish whether disabled women find positive role models, particularly other disabled women, in organisations controlled by disabled people,

to find out whether there is a value to disabled women of social and community action with peers, this value to be defined by disabled women themselves,

to find out if, from the point of view of disabled women, peer contact has an influence on their social and personal relations.

HOW the research will be carried out: The original letter was the first stage of the process. I am now inviting those women who are full members of the Coalition who contacted me to complete a short questionnaire to help me pick a small number of women to interview. The nature of the research is such that I will interview no more than three or four women. The purpose of the questionnaire is to provide a basis to select as broad a range of women as possible to take part in the research.

The results of the research will be written up for my dissertation, which is my final piece of work for my degree. All work will remain confidential, unless the participants wish it to be otherwise, and anonymity will be preserved.

My thanks for your involvement,
Best wishes,
Lorraine Gradwell.

2 – Multiple choice questionnaire

The purpose of the questionnaire was to generate sufficient data from which to sample a varied cross-section of disabled women involved in the organisation and to invite women to express an interest in contributing further to the research by being considered for eligibility for the interviews.

Areas of enquiry, therefore, included the following questions and information:

1. Length of your involvement in GMCDP. e.g. number of years.
2. Nature of your involvement in GMCDP - specifically, one of
 - a. member of Executive Council
 - b. member of a subgroup, or
 - c. staff who has been one of a) or b) above.
3. Your age range,
 - a. 16 - 25 26 - 35 36 - 45 46 - 55 56+
4. Whether your -
 - a. personal relations
 - b. social relations
 - c. views and images of themselves have changed, because of your involvement in GMCDP?
5. If yes, do you feel that this is, at least partly, related to your involvement in the organisation?

Aim of the research

Has the active involvement of disabled women in the Greater Manchester Coalition of Disabled People

(GMCDP), a campaigning organisation controlled by disabled people, had a positive / negative impact on their social and personal relations, as they view them?

This research will seek to establish why disabled women have become involved in a campaigning organisation controlled by disabled people (GMCDP) and what impact that involvement has had on their social and personal relations. It will look at what activities constitute “active involvement” and whether the women view the impact of their involvement as positive or negative.

3 – Research questions

The interview themes cover four major areas of enquiry:

- a) involvement with GMCDP,
- b) personal relations,
- c) social relations
- d) view or image of self;

There will be an opportunity for you to introduce your own themes during the interview. This is in line with the methodological approach of the research, which aims at a participative method of enquiry. (offer further explanation)

Involvement in GMCDP

How did your involvement begin?

Has it has changed,

How?

Why?

With what effect?

Personal relations

What was your family situation / circumstances before becoming active?

What is your family situation / circumstance now?

What, if anything, has changed since becoming involved with GMCDP?

How are the changes viewed;

positively,

negatively,

mixture,

neither?

Has involvement in GMCDP influenced those changes?

How much?

In what way?

Has the influence of other disabled women been a factor?

How much?

In what way?

What / who were your friends and acquaintances before becoming active in GMCDP?

What /who are your friends / acquaintances now?

What, if anything, has changed since becoming involved with GMCDP?

How are the changes viewed;

positively,
negatively,
mixture,
neither?

Has involvement in GMCDP influenced those changes?

How much?

In what way?

Has the influence of other disabled women been a factor?

How much?

In what way?

Social relations

How would you describe your involvement / activity in your local (geographical) community?

How would you describe your involvement / activity in local (geographical) politics / organisations, e.g. school, church, community centre, etc.

What would you say is your vision of yourself as a member of local community (geographical) - NB: the aim of this is to demonstrate the validity of the role of disabled women as citizens, as defined by themselves

What, if anything, has changed since becoming involved in GMCDP, in relation to:

your involvement / activity in your local (geographical) community?

your involvement / activity in local (geographical) politics / organisations, e.g. school, church, community centre, etc,

your vision of yourself as a member of local community (geographical).

View of self

How did you view yourself before you became involved in GMCDP, in various roles as a woman- e.g.

daughter
sister
mother
partner
friend
employee
other?

How do you view yourself now in various roles as a woman - e.g.

daughter
sister
mother

partner
friend
employee
other?

What, if anything, has changed since becoming involved in GMCDP in the way you view yourself as -

daughter
sister
mother
partner
friend
employee
other?

The final part of the interviews will be concerned with the participants' additional contributions -

Is there anything you would like to add in relation to:

- a) your involvement with GMCDP,
- b) your personal relations,
- c) your social relations
- d) your view or image of yourself;

Is there anything further you would like to add which is not covered by the above categories?

Would you wish to be anonymous?

4 -- Proposed analysis of the findings

Women will be offered the chance to comment on the transcript of their interview.

The analysis will seek similar themes, differences and commonalities in the responses; to identify and isolate patterns and to consider whether there is a causal relationship between involvement in GMCDP and the women's views on their social and personal relationships and their self-image.

Analysis will seek patterns, differences and commonalities for:

All questionnaire and interview themes, including any new ones introduced by the women;

Positive and negative responses;

Self-image;

"Roles" played socially and personally - wife / partner / carer / parent, etc;

Comparison of domestic situations - e.g. living with parents, children, alone;

Comparison of ages;

Length and level of involvement / activity in GMCDP.

The subjective views of individuals will be used to ascertain whether or not there have been changes to their personal and social relations, and to determine whether

the changes are viewed as being positive or negative, or indeed a mixture. This relies on individual participants' **versions** of events and is in line with the chosen methodological approach which seeks to validate disabled women's own experiences and subjective reality, rather than make comparisons based on norms derived from the life experiences of non-disabled women.

Women will also be offered the chance to meet together to discuss the research and the findings: this will be according to the following:

analysis of the four central themes:

themes introduced by the disabled women;

that is, if, during the course of the interviews individual participants raise issues or contribute new themes which are appropriate to the aims and the methodology of the research, and which would contribute to the data set, other participants will be invited to a supplementary interview to discuss these matters;

items of great similarity and/or contradictions;

that is, if a consistent theme - or a wide contradiction - emerges which merits further enquiry, in line with the research methodology, participants will be invited to a supplementary interview to discuss these matters, which will be included in the overall analysis.

Women will also be asked for their comments, and further suggestions on proposed dissemination.

In line with the participative approach of this research the participants views and suggestions concerning dissemination of the findings will be sought. The view of the organisation of which the women are members will also be ascertained. More generally, the research findings will be of relevance to those involved in public policy making, and in service design and delivery, since it will potentially challenge current perceptions and norms about what constitutes appropriate activities for disabled women.

The findings of this research would be of specific interest to:

disabled people and their own organisations,
women, women's organisations and publications,
"professional" organisations and people in the
"disability" field,
academics and researchers in the "disability" field.

Therefore, dissemination will be aimed at:

British Council of Disabled People (BCODP)
networks, including "Coalition",
The "disability press", e.g., "Disability Now", DAIL
magazine, etc,
"Disability & Society" periodical,

“Feminist Review” periodical,

Guardian “Society”,

The internet - Disability Bulletin Boards and
Newsgroups, and Women’s Newsgroups.



Lorraine Gradwell MBE (right)
with her mother Inga Mahoney,
at the University of Leeds graduation event

