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**Listening to Older Care- givers:
Research into Aspirations for Support**

*Judd Skelton, Michele Moore, Sarah Beazley
Martin Patient & June Maelzer*

**Listening to Older Care-givers:
Research into Aspirations for Support**

Project Report and Proposals for Further Development

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*An earlier version of this report was presented at the Older-Care Givers Conference
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PREFACE

This report has been produced in completion of a project funded by Trafford Social Services and Salford and Trafford Health Authority over a 12-month period. MENCAP is a leading provider of services for people with learning difficulties and their families, and the Sale and Altrincham branch of MENCAP has worked in close collaboration with the funding agencies for some time. The inspiration for this research activity came out of a desire to monitor and evaluate the changing needs and aspirations of families providing long-term care for their sons or daughters with learning difficulties in order to enhance the effectiveness of service providers seeking to support disabled people and their older care-givers in the local area. It is hoped that highlighting the experiences of older care-givers and people with learning difficulties might encourage provider Organisations to critically examine existing practices. The report has potential to influence policy and practice around the UK. The work leading up to this publication has already contributed to information and advisory documents for caregivers, and for local authorities and other service providers, prepared by the British Institute of Learning Disabilities (BILD 1997).

The report describes a series of research interviews and workshop discussions with people connected with the issues described above. In it we try to link issues raised through the interviews with practical ideas which we hope will help to ensure that implications arising from the research do make an impact on the everyday realities of those receiving or involved in the provision of relevant services. As well as looking at what interviewees have had to say, we examine the *process* of carrying out research, particularly focusing on the dynamics of involving disabled people in projects about their lives. An important principle for us is that disabled people should have control over research that concerns them.

We have decided not to avoid challenging and difficult issues but to discuss these as openly as we can, whilst endeavouring at the same time, to recognise the personal commitments and responsibilities which shape the reasons why each individual views things differently. As a group of disability researchers we repeatedly find ourselves needing to take a hard look at our own assumptions and practices in order to clarify and refine our hoped for role as disabled people's allies. When we discuss barriers to maximising the impact that research can make on the lives of disabled people and their families we do include ourselves as part of the problem.

The most pivotal part of the report concerns the findings which illuminate directions for further development and change. It becomes clear that there is a need to build on local successes and also to widen participation of older care-givers and people with learning difficulties in the processes of bringing about social and organisational change. More research will prove invaluable in the process of establishing new initiatives for the support of families in this context. A set of draft proposals for further studies, based on the aspirations of those who have taken part in this project, is included in the report to stimulate ideas about practical ways of evolving new directions. These comprise our own contribution to making sure that this initial piece of preparatory research could make some real difference.

Judd Skelton, Michele Moore, Sarah Beazley, Martin Patient and June Maelzer. Disability Studies Team,
Department of Psychology and Speech Pathology, Manchester Metropolitan University, November, 1997

NOTES ON CONTRIBUTORS

The contributors are all members of the Manchester Metropolitan University Department of Psychology and Disability Studies Team which has emerged as a centre of excellence in the field of Disability Studies and is unique as a provider of psychology and disability studies education in the country. Further information about our activities can be found in Part 5 of the report.

Judd Skelton has been actively involved in disability research for several years, and has achieved particular distinction for his work promoting self-expression and advocacy for people with learning difficulties. Since his involvement as Principal Research Fellow on the project reported here, he has gone on to work with Central and South Manchester MENCAP to support and encourage care-givers and people with learning difficulties in their struggle for control over their future affairs. He has written widely on disability matters, most recently submitting an important paper *'The Relationship Between Self Advocacy and Work for People with Learning Difficulties Living in the Community'* to the international journal *Community, Work and Family*.

Dr Michele Moore runs a postgraduate programme at Manchester Metropolitan University in Psychology and Disability Studies which is currently unique in the United Kingdom. She is an editor for the journal *Disability and Society*, and involved in research on disabled parenting, family life and independent living. She has written extensively, including co-authoring several books with the most recent being one for the Open University Press with other members of the team; Moore, M., Beazley, S. and Maelzer, J. (1998) *Researching Disability Issues*.

Sarah Beazley is a speech and language therapist with Deaf people who carries out freelance clinical and consultancy work. She is a founder member of an organisation providing training in the field of communication. She has written widely on disability issues and about her work on language and communication development. She is currently co-writing a book with other members of the team; Beazley, S., Skelton, J. and Maelzer, J. (1998) *'Learning Disabled People Innovative Options for Living'* Venture Press.

Martin Patient has long experience in the voluntary sector and is known nationally and internationally for his pioneering advocacy of disabled people's rights and opportunities. He has worked tirelessly to encourage and organise the active collaboration of disabled people and service providers in monitoring and evaluation of service delivery and planning. He is currently co-writing a book for Venture Press with other members of the team on issues arising from research with older caregivers of people with learning difficulties; Moore, M., Patient, M. and Skelton, J. (1998) *Enabling Older Caregivers*.

June Maelzer has been awarded an Honorary MSc by Manchester Metropolitan University for her outstanding contribution to widening opportunities for people with impairments. She teaches and writes for a number of disability courses and has held a range of posts, including training officer (AIDS and HIV) for Manchester City Council. She is currently working as a free lance trainer and consultant and is also a highly regarded advocate for disabled people. She is co-author of a forthcoming book with other members of the team; Maelzer, J., Moore, M. and Beazley, S. *Enabling Disabled Parents*. London: David Fulton Publishers.

NOTES ABOUT LANGUAGE

Understanding of what is meant by the term 'disability' has changed over the years, and so too, have definitions of 'people with learning difficulties'. Before going on to examine issues relating to older care-givers and the people with learning difficulties they support, we need to explain the terms we use in this report.

Throughout the text we refer to *social* understandings of disability. We align ourselves with researchers who regard the experience of disability as determined by the social, material and psychological world in which people find themselves and reject individualised and medically based interpretations of disability (Oliver et al 1988; Morris 1989, 1991; Barnes 1990, 1991). Like other writers, our view is that whilst individuals may have impairment, disability is a result of prejudicial actions and discriminatory practices and environments. We wish to stress that people with impairment are disabled by an oppressive society - so, for example, learning difficulty is an impairment but lack of personal support in a day centre creates disability. Thus the general term *disabled people* is used rather than 'people with disabilities'.

We use the specific term *people with learning difficulties* in recognition of the preference of the self advocacy movement. We feel that claiming to take the opinions and thoughts of people with learning difficulties seriously, necessitates listening to, and using their chosen terminology. Reason behind the preference is categorically explained below

"If you put 'people with learning difficulties', then they know that people want to learn and to be taught how to do things" (self advocate quoted in Sutcliffe and Simons 1993 p.23).

We use the term *care-giver* because like Morris (1993), we feel that the definition of a person as a 'carer' is impossible to sustain in everyday life. We believe that there is reciprocity of support, love and help within family life and that the term *care-giver* helps to affirm this. To clarify:

"In the context of the political professional and academic debates on community care, 'care' - whether it refers to people giving paid or unpaid help - does not mean to 'care about' someone in the sense of loving them. Rather it means to 'care for' someone in the sense of taking responsibility for them" (Morris op cit. p.149)

PART ONE - INTRODUCTION

How the report is organised

The report is based on the experiences and views of people with learning difficulties, their older care-givers and providers of relevant services. It provides insights into the perspectives of these three groups, alongside ideas for future policy and practical development generated from our analysis of the views contributed to this project. In addition, we uncover new directions for research and place these within a recognised framework for reflexive disability research which advances human and civil rights (Barnes and Mercer 1997; Moore et al 1998).

The contents of the report are organised as follows. An introductory section gives the background to the work and highlights focal issues. The second section then concentrates on the critical dimensions of meaningful disability research and outlines how the research activities were conducted in the light of these. In the third section, the main findings to come from participants are explored and these suggest several avenues for reflection on current policy and practice. In the fourth section, practice recommendations are discussed and reviewed before moving on to presentation of potential proposals for funding further studies, based on the recommendations of people with direct experience of older care-giver issues. The final section of the report provides an appraisal of the main achievements of this preliminary piece of work and contains suggestions for consolidating future change. We clarify the goals of a follow-up a workshop to enable all those who have been involved in this project to begin the process of evolving a coalition of older care-givers, people with learning difficulties and service providers working together in the pursuit of best practice. All concerned will recognise that much more research needs to be done.

Focal Issues

In the summer of 1997, twelve months after we commenced our research to look at the needs of older care-givers and people with learning difficulties whom they support, a parent of two adult learning disabled sons reminded delegates attending the end of project conference of the most striking messages to emerge. The aspirations of parents of adults with learning difficulties are in many ways not very far removed from those of parents of non-disabled children:

"I guess any mums and dads, very early on alter their sons and daughters are born, have thought 'who's going to look after my child when anything happens to me.

..We wanted to plan, so that when the time was right for our children, they could move out of the family home and set up in their own home" (Riley 1997)

Profound differences creep into the family life of parents with learning disabled children however, when other people make assumptions about the long-term role of the family in care-giving. Parents of disabled people have been pointing out the danger of such conjecture for many years:

"I wish people wouldn't assume that because I love my daughter and want to look after her, I must be all right and able to manage no matter what happens" (cited in Kohner 1992)

It quickly becomes clear that assumptions about the role of family members in providing support for adults with learning difficulties are insufficiently challenged (Dagnan 1997, 1994; Hayden et al 1992). The majority of long-term care given to people with learning difficulties in Britain continues to be provided by family members, and not by professional agencies and support services, yet the voices of families themselves on how they view this state of affairs, are seldom heard (Barr, 1996). The reflections of older care-givers and people with learning difficulties on these matters are largely overlooked and remain noticeably absent from the literature.

This brings us to the second important message to emerge from this research, which is that support services cannot be optimised if the situations of people with learning difficulties and their older care-givers are defined by service providers, policy makers and politicians. There is growing emphasis on user perspectives which, for our purposes, means making sure that people with learning difficulties and their older care-givers have an opportunity to speak for themselves. One of the motivations behind this research has been to amplify provider-led images of older care-givers and people with learning difficulties which typically take centre stage in discussions about support. In this report we are aiming to identify the service aspirations of Trafford-based people with learning difficulties and their older care-givers through their own assessment of their personal situations.

Knowledge about the situation of older care-givers that is already available helps to set the scene.

The complex nature of older-care decisions

As people with learning difficulties and their parents get older, the importance of planning support for the future becomes more and more urgent. It is known that ageing parents experience a great deal of anxiety about the continuation of care, about what will happen, and in particular, about who will take on the role of care-giver when they no longer can (Bigby, 1996). It is also known that older care-givers are often reluctant to dwell on these issues and find it difficult to put in place concrete plans for what they, and the person with learning difficulties they support, want to happen (Whittaker 1991; Mitchell 1997). Given the level of vulnerability which ambivalence about future plans creates for such families, it is of some concern that there has previously been little research which places an emphasis on developing policy and practical ideas for implementing change in this area. A goal for this research then, is that it should encourage new ways of thinking about older care-giver issues, and provide practical targets for action.

It has long been established that the needs and entitlements both of people with learning difficulties and their care-giving relatives are complex (DHSS 1971; British Association of Social Workers 1985; Todd

and Shearn (in press)). Many ageing parents wish to continue to care for their sons or daughters with learning difficulties for as long as they can and people with learning difficulties often wish to remain in their parental home (Bigby, op cit.). But there is a danger of being over-romantic about this. The long-term support of people with learning difficulties in the family is costly in terms of time, emotionality, thought and relationships. While on one hand people with learning difficulties can, given the support of their families, receive a level of attention and care that is unlikely to be matched elsewhere (Wright et al 1994), it is known that the whole family face many obstacles and barriers when seeking support from relevant statutory agencies (Walker et al 1995). Even so, families which include a person with learning difficulties increasingly find themselves accepting long-term care-giving responsibilities and this is the context in which those who became involved in this research currently find themselves.

We find there is tacit acceptance of a situation in which parents continue to accept long-term responsibility for the care of their learning disabled sons and daughters, even though society legitimises the heightened anxiety and fearfulness experienced by all family members as they grow older (Bayley and Grant 1973; Grant 1986; Orlowska, 1995). Recognition of disability as a civil rights issue has led to growing recognition that disabled people and their parents have a right to an ordinary family life. Yet whilst families may want this, as indicated in our opening remarks, often they feel they would not like their care-giving arrangements to be different (Todd and Shearn 1996). What this suggests, we think, is the contested nature of older care-giver issues. The important point is that older care-givers value ordinary transitions in family life, but are wary of the upheaval this entails.

"I would say to any parent of a child that getting him to leave home at 18 is important. I think at that age they might adapt to the change more easily. It's a time of change for all the family" (Todd and Shearn, op cit., p.395).

In addition, it is important to acknowledge that in the absence of appropriate support, the decisions that older care-givers make regarding the long-term care of the sons and daughters with learning difficulties are not always influenced by choice.

What older care-givers want

There is clearly some urgency for in-depth research to address the preferences that older caregivers have for their care-giving roles. Other writers recognise that a family's response to care-giving responsibilities does not take place in a vacuum (Olsen 1996). Adjustments are determined by the availability of existing support, by other people's expectations of how the family should behave and so on. Age is a variable; care-giving responsibilities mean very different things when they fall to a person of 60 years, as compared with someone of 80. However, age does not necessarily provide a reliable means of assessing the long-term impact of care-giving on a family. Assumptions about the progressive impact of age on the ability to cope with giving care were exploded by many of the older care-givers we met during the course of this research.

Like-wise, the health of an older person is not necessarily a determinant of the extent to which care-giving can be sustained within the family. A major weakness with much of the research about care-giving is its

inability to adequately recognise people with learning difficulties as caregivers (Olsen op cit.; Walmsley 1993; Morris 1993). Further understanding of this issue could create openings for innovative new models of support. Providers need to be able to challenge traditional notions of 'care' and 'dependence' to achieve excellence in service planning and delivery.

Portrayals of the situation of families with older care-givers often deal with problems and paint a picture of oppression and despair. Whilst we do not deny the restrictions that long-term care-giving can place on the life-style, relationships and social activities of all family members, we feel that received knowledge on these matters is often anecdotal and that the aspirations of older care-givers and their sons and daughters must be learned through more than intuition. For this reason, we have set out in this research to challenge uncritical assumptions that are made about what older care-givers want. We feel recycling negative images of older care-givers as victims, who have not only lost their adult independence but now look set to lose the freedoms of the third age, are undermining of families who find themselves in this situation, and promote disempowerment and distress.

We believe that providing knowledge of the things older care-givers and the people with learning difficulties they support value about their living arrangements will equally inform service providers. This is not to deny that an undercurrent of enormous hardship is to be found in the reflections of families. But we have tried, in our approach to this investigation, not to let notions of vulnerability and loss entirely shape our view of what older care-givers want. We regard negative assumptions about older care-givers as dangerous because they create images of hopeless and helpless, eternally dependent and demanding adults with learning difficulties, which we wholeheartedly reject. In addition assumptions about personal tragedy within such families make for crude, naive and inadequate insight into the personal, social and emotional impact of living with disablement.

Support of older care-givers

It seems self-evident that older parents in the role of care-giver to their son or daughter with learning difficulties need a good deal of back up and flexible support (Orlowska 1995; Walker et al 1996). However, previous research has also shown that such support may be hard to come by. There are many potential stressors in the lives of older care givers and the people with learning difficulties they support, such as social isolation and denial of opportunities for an ordinary family life, and support agencies often find themselves able to do little more than manage emergencies and pick up the pieces when things have gone wrong (Heller and Factor 1991; Wright et al 1994). Whilst being an older care-giver is by no means always a negative or daunting experience for the parents of people with learning difficulties, and can have positive implications for the caregiver's general psychological well-being (Hong and Seltzer 1995), the first moves towards avoiding family crises involve listening to those who find themselves facing the day to day reality of providing such support, and challenging complacency about what providing agencies can do to help.

Like our commissioning agencies and many other writers in the field, we think it is unproductive to attribute the difficulties faced by older care-givers to their learning disabled sons and daughters, or vice-versa. We feel that the concerns which parents and people with learning disabilities *share* are central to

new directions for theory, research, policy and practice in this area. What we hope to demonstrate through our analysis of reflections and aspirations of people with learning difficulties and older care-givers, is the critical importance of placing what families have to say for themselves at the front of policy and practice which claims to be about improving their situations. The report seeks to prompt readers to think about their personal role in, and collective responsibility for, evolving support services which take account of this.

The broader picture

Our knowledge of previous research indicates that there are probably as many different accounts of family life where older care-givers support people with learning difficulties as there are family members. We are unlikely to be able to present an unequivocal model of what support systems should look like. We acknowledge the private and public boundaries which will be maintained around the accounts we have collected for this research. Yet to gain fuller insight into older care-givers issues we believe it is vital to listen to families and not make assumptions about the commonalties or differences within and between them.

This brings us on to the broader picture, as framed by current legislation, which contextualises the rhetoric of listening to families and which frames the general rights and entitlements of people with learning difficulties and older care-givers. Recent legislation poses several problems of relevance to this research.

The Carers (Recognition and Services) Act (1995) acknowledges the difficulties which can be faced by care-givers, and provides legislation for the right to an individual assessment of a person's ability to provide care. It is not yet known, however, whether in practice this will bring any real change for the better and the urgent need for funding in order to implement the Act has been raised (Carers Association, 1997). Assessing the needs of care-givers is one thing but subsequent action is another, and the problem whereby good intentions masquerade as positive action - as noted here in relation to the current legislative context - is returned to throughout this report.

The Disability Discrimination Act (1995) is the other main piece of legislation relevant to people with learning difficulties. Yet, in reality, the Act shores up discriminative practices and exclusion and was passed in the face of intense opposition from the disability movement (Campbell and Oliver, 1996). In the same way as we point out the danger of making assumptions about the views of people with learning difficulties and their older care-givers, we signal the need for a cautious interpretation of the extent to which recent legislation is set up to genuinely advance the rights and situations of people involved in older care.

Rhetoric for change, and for improving the situations of people with learning difficulties and their older care-givers, is unlikely to make a difference. It is individual and collective action, aimed at dismantling the obstacles with which older care-givers and the people with learning difficulties they support say they are faced, that will bring about change. That is why in our research endeavours, and in this report, we are committed to placing critical emphasis on processes of bringing about tangible and immediate change. We have few illusions about the impact this work can have. We know that like legislation, research cannot make a difference, but people reading this account can.

Scope of the report

The perspectives of people with learning difficulties, their older care-givers and service providers are interconnected. Our research draws them together to foster the development of a holistic picture of issues surrounding older care-givers and their families. We feel that analysis of, and support for, older care-givers cannot be separated from the perspective of their sons and daughters with learning difficulties. It is worth saying, at this early juncture, that we feel the input of people with learning difficulties has been relatively underplayed in this project because the original interest of commissioning agencies lay with the needs of parents. We have, however, attempted to establish a meaningful focus on the reflections of people with learning difficulties in the families. As has already been said, there is very little previous research which links the aspirations of people in all three focal groups to clear recommendations for improving their situations and our aim is to develop those connections.

So far, we have tried to convey the complexity of issues confronting families and service providers. We move on next to describe how we undertook the research and explain our rationale for eliciting rich, ethnographic data in the form of personal accounts intended to look at the interplay between a family's current situation and future outcomes. There has been an element of 'action research' (McNiff, 1988) in this project which has enabled service providers and service users to share experiences and ideas, and provided an opportunity to foster the development of new policy and practice. We explain how we organised and analysed emergent data and go on to discuss the outcomes of these discussions in relation to Trafford service providers, older care-givers and the people with learning difficulties they support. Through examining the perspectives of providers and families, as revealed by the many hours of interviews conducted for the project, we can begin to see ways forward for other parents, for people with learning difficulties, for policy makers and for professionals.

We have viewed our job as to try and accurately reflect the participants' views, and so use quotations extensively to place emphasis on recurring themes in the voices of those who have shared their experiences with us. In the final section of the report the preoccupations of respondents are reviewed and attention drawn to ideas for innovative responses to the needs of people with learning difficulties and their older care-givers. Recommendations are made for how disabled people, their families and service providers can be supported, empowered and enabled to bring about any immediate changes which fit with the way they see their current and future situations. Thus we are able to finish by presenting practical ideas for improving the situations of people with learning difficulties and their older care-givers in Trafford and to make specific recommendations for direct action and implementation of change.

We set out in this report to widen and stimulate discussion which will encourage the development of policies and practices for older care-givers. Our central argument is that older caregivers and the people with learning difficulties they support must be placed firmly in the driving seat when decisions are made about service provision in their name. Hopefully, the report will be used as a resource which may stimulate readers to reflect on their own assumptions about, and involvement in, the lives of older care-givers and the people with learning difficulties they support. It is worth mentioning that a great deal of interest has been generated by this research nationally.

A major publisher¹ has commissioned two 'Best Practice Guides' from the Manchester Metropolitan Disability studies team which will draw not only the team's wider expertise but also the work described here. These outputs undoubtedly reflect credit upon the service providers who set this research in place.

We have now given some background to the project and briefly examined topical issues facing older care-givers. What follows is a short summary of the research aims, before we turn to an account of the way in which the work proceeded.

Research Aims

The aims of this project were:

- to explore the experiences of older care-givers and people with learning difficulties whom they support in Trafford - asking meaningful questions to uncover practical directions for change
- to build on these explorations by linking older care-givers, the people with learning difficulties they support and key service providers, and working together to influence policy and practice - facilitating exchanges of experience and consolidation of best practice
- to develop new practical strategies for overcoming the problems faced by older care-givers and the people with learning difficulties they support - co-ordination and dissemination of innovative new policy and practice.

¹Moore, M. Patient, M. and Skelton, J. forthcoming 1998, *Enabling Older Care-Givers*, Venture Press

Beazley, S. Skelton, J. and Maelzer, J. forthcoming 1998, *Learning Disabled People Innovative Options for Living*, Venture Press

PART TWO : METHODOLOGY

This section of the report provides details about how the research was designed and conducted. Information is given about the selection of families and professionals who took part in the project. Data collection strategies are described. We clarify our procedures and discuss our rationale for extending the processes of enquiry through workshop and other follow-up activities.

Note on ethical considerations

All aspects of this research comply with codes laid down by the Manchester Metropolitan University and the British Psychological Society. Research activities were formulated in accordance with Guidelines for the Development of Disability Research Proposals put forward by Oliver (1992) and as re-examined by Ward (1997). Research practice is carried out with full regard to human rights issues in disability research as discussed in our forthcoming book, Moore, M., Beazley, S. and Maelzer, J. (1998) *Researching Disability Issues*. Milton Keynes : Open University Press.

As agreed with research participants, pseudonyms have been used throughout this report to preserve the anonymity of interviewees and of any individuals or places they mentioned. General job titles rather than specific terms are used wherever possible for the same reason.

Research approach

Qualitative vs Quantitative data

It has been argued elsewhere that only quantitative data "is sufficient to guide the planning of services in Salford and Trafford" (Health Needs Assessment 1996). Indeed, it very quickly becomes clear from our knowledge of other research accounts that the compilation of statistical information is greatly valued by funding agencies (Oliver 1997). However, world-wide discussion on disability related research, and comprehensive argument for a greater respect for disabled people and their families in research which directly concerns them, provides an important backdrop to the qualitative nature of this report (Moore et al 1998; Oliver op cit.; Rioux 1994). The extent to which disabled people and their allies have an opportunity to have their say, to be listened to and to have their views taken seriously within the research process is now regarded as probably *the* most important indicator of the validity of any piece of disability related research. The right to freely contribute to, and fully participate in, the production of research which concerns them is viewed as part and parcel of the right to justice for each individual disabled person and their family, and for disabled people and their allies as a group within society. There is a need to describe and analyse the self-reflections of people living with disablement in their own terms, and for this reason we have opted to resist the structure that a quantitative approach to research imposes upon participants' opportunities for self-expression.

Research that is worth doing

We recognise that disabled people and their representative organisations have reported little experience of quantitative data making any real difference to their lives and consequently regard the collection of such data as a waste of time (Oliver 1992). It is commonly accepted that where researchers remain committed to the collection of quantitative data, the recommendations they end up being able to make reveal little about the reality of disabled people's lives. As a research team, we feel we have an obligation to look to the best interests of older care-givers and the people with learning difficulties they support, and that without prioritising their viewpoints and concerns we have little hope of conducting worthwhile research.

Like other investigators (Barnes and Mercer 1997) we can find our reluctance to produce large scale statistical information is at odds with the approach preferred by those who commission research. Statistical data would be far less disturbing than the personal reflections we present, many of which cry out for immediate action. But we do not attempt to protect the sensitivities of the reader behind numbers and statistical summaries. We have tried to project older care-givers' and learning disabled peoples' own images of themselves using their own words as far as possible, to make visible the ways in which they view their situation, and to give voice to their ideas about what service providers do well, or conversely, might do differently. Thus, the report highlights the importance of enabling older care-givers and people with learning difficulties to define their own issues. It requires the reader to accept that older care-givers and the people with learning difficulties they support are knowledgeable, that the deep reflections of a small number of people are more valuable than cursory indications about the many, and to look afresh at older care-giver issues, from families own starting points.

How we carried out the work

As has already been made clear, we acknowledge the traditional tension between qualitative and quantitative approaches to research. We have explained our reasons for preferring a qualitative methodology and this reflects our personal and social stance to the research topic. It is worth pointing out that qualitative research is exactly the same as quantitative research in terms of having the means to ensure rigour (Sheared, 1997). Readers can be reassured of the rigour of this research precisely *because* we make no attempt to deny our own commitments. We are seeking to report *interpretations* of what Trafford older care-givers and the people with learning difficulties they support have told us, in order to encourage challenge and debate, and make no claims for the data beyond its potential for rich and stimulating interpretation.

Research participants

Selection of older care-givers and people with learning difficulties

Access to families who might like to participate in the research was controlled by Trafford Social Services for reasons of within-service confidentiality and, due to on-going parallel research activity, in order to regulate the number of projects with which any particular family was currently involved. This meant that the research team could not instigate any particular sampling strategy or approach families directly. Instead a system was set up whereby invitations to take part, together with relevant background information and details of how to contact the research team, were provided for Trafford Social Services, who undertook to send these on to relevant families. The merits of this system were that the research team did not have any information about families choosing not to take part, and we are grateful to Trafford Social Services for their acceptance of the right of those families who did wish to become involved not to be known to them.

The original aim was to interview between twelve and fifteen families. In the time period available, fifty-three invitations were provided to be sent out by relevant Social Services officers and eleven families volunteered to be interviewed. It is necessary to point out that having to hand on, this part of the process placed the research team in a position of some uncertainty. Conducting recruitment by proxy meant we could not have complete knowledge of how the project was presented and to whom. Later on, when the project became known about locally, several families contacted us to express concern that they had not been invited to take part. Despite these difficulties however, we accepted that the target population would be defined by Trafford Social Services, though it must be acknowledged that the eventual mechanism for recruiting participants did not enable everyone who would have liked to take part to be included, and the reasons for this were outside of our control.

Characteristics of older care-givers and people with learning difficulties taking part

Twenty-eight members of eleven families from across the borough agreed to take part in the study. People with learning difficulties participated in interviews for all but three of the families. Inevitably, interviews were not an appropriate medium for accessing the views of all of the prospective participants with learning difficulties and so focused group explorations were set up as an adjunct to the conventional interviews. (Specific information about the nature of research procedures is given later on).

Most of those who agreed to be interviewed were parents providing older-care and their son or daughter with learning difficulties, but a few siblings also joined in. In all except one family, the focal person with learning difficulties lived in their parental home. Those interviewed lived in different parts of the catchment area and in a range of social and material circumstances. People from black and ethnic minority communities were included in the study.

Participation of service providers

We intended that participation of service providers would be determined by older care-givers and people with learning difficulties who were invited to nominate a service provider whose reflections they thought might be valuable for the research. In the event, only five service providers were nominated, as many of the families felt they had so little contact with professionals that they were unable to nominate a relevant person. This reaction is typified by the following remarks:

Interviewer: maybe later on in this interview you can suggest someone who is important to you, like a service provider who [you] found to be good

Respondent: ... well I've not found one yet, you know. They come and they go, you get a different name every time you ring up.

Indeed, the five service providers who were eventually nominated were all named by more than one family which provides strong testimony to the perceived personal salience and efficacy of these individuals. Of the five service providers nominated, three agreed to take part, providing some insight into social work, community nursing and voluntary sector perspectives on older care-giver issues. We sought to widen participation by service providers through issuing a questionnaire to a further sixteen people who we knew from our wider experience of local services to be fulfilling key provider roles.

Representativeness of participants

We do not claim that the research reports the views of representative groups of older care-givers, people with learning difficulties or service providers. Despite this, we believe that the material collected highlights sufficiently wide-ranging issues for it to be applicable to a great many older care-givers, people with learning difficulties and providing agencies. Readers may question whether our sample of participants enable us to present 'the real picture', but we will argue again, as in other of our publications (Beazley and Moore, 1995) that this does not actually matter. Whether the accounts we present are regarded as 'reliable' or 'valid' simply depends on personal beliefs about objectivity anyway. We have set out to *illustrate* the perspectives of a small sample of older care-givers, people with learning difficulties and their service providers in a way which we hope adds a helpful vitality to the development of relevant policy and practice. The most important of our aims is to prompt readers to challenge their own way of looking at the older care situation.

Research procedures

Accessing the views of older care-givers and people with learning difficulties

As has been described, families were invited to take part in the study via a letter. It was explained that anything the families did choose to share with the researchers would be treated confidentially. Assurances

were given that names of participants would not be given to anyone else or included in any written reports and that we would ask no-one else for information about the family. We made every effort to assure families that their confidentiality would be treated with the utmost respect. Once a family agreed to be interviewed, all participants were reminded that everything discussed would be confidential and permission sought to tape-record the meeting. Each family was offered a copy of their transcript and return of the original tape-recording. We felt it was important to remind participants again of the safeguards for confidentiality at the end of the interview, in case they needed further reassurance following the disclosure of personal material.

We chose to use a semi-structured face to face style of interviewing which focused initially on the past experiences of older care-givers and their learning disabled son or daughter. We then went on to focus on the present situation and aspirations for the future, in respect of long-term arrangements for support of the person with learning difficulties. One of our priorities for the style of interviewing was that it should not recycle or perpetuate negative images of people with learning difficulties and their entitlements (Oliver 1993) and consequently as well as finding out what makes life difficult, we were determined also to explore the positive elements of older-care provision within the family and to try and tease out reports of excellence in service provision as well as descriptions of the problems encountered. This is why we asked participating families if they could nominate a service provider who had made an important contribution to their situation. Other than this, our approach was to leave families to shape the content and course of the interview, as it was felt that they would know best what the relevant issues are and how they wanted to talk about them (Beazley and Moore 1995).

A copy of the interview schedule was sent to each participating family prior to the first meeting so that they could familiarise themselves with our expectations and have a chance to think about what they might want, or not want, to say. Prospective participants were also given the chance to change their minds about being involved once they had seen the schedule, but everyone was happy to go ahead.

All participating families chose to be interviewed at their home, and we feel this did help to reduce some of the power imbalance created by the trappings of professionalism which could arise if families were interviewed, for example, at the university. Interview sessions were relaxed, led by the family and lasting between 45 minutes, and 3 hours. Thus although the range of respondents may be fairly small, the data is wide-ranging, in-depth and extensive.

The involvement of people with learning difficulties as informants in research is a relatively new phenomena. However, interviews are increasingly seen as a useful method for accessing their views (Atkinson and Williams 1990; Booth and Booth 1994; Walmsley 1996), especially interviews which are conducted over more than one meeting (McVilly 1995). Thus we built in an option for families to spread the interview over several meetings if they wished and three families took us up on this. In addition, a series of workshops providing opportunities for focused group explorations was set up.

The marrying of interviews and workshops provided the means for all participants, and particularly those with learning difficulties who may have little previous experience of making their personal views known, to contribute to the research as fully as possible. A day of workshop activity was convened to bring people with learning difficulties, their older care-givers and service providers together, with the aim of further

progressing matters arising from the individual interviews and firming up collective ideas about the implementation of change.

Accessing the views of service providers

A greater degree of structure was built into the interview schedule for service providers in order to focus their reflections on those issues which had been raised by the families. A provisional schedule was reviewed by one of the participating families before being finalised in order to ensure that they felt it covered issues of sufficient relevance to the family agenda. Again, as is standard good practice for this type of research interview, the schedule was then made available to participating service providers in advance, for their convenience and perusal. All service providers chose to be interviewed either at their place of work or at the university.

As the number of service providers nominated for inclusion by the families was small we decided, as mentioned earlier, to supplement the input of providing agencies by circulating a questionnaire to a further sixteen people. The questionnaire for service providers covered the ground which was to have been the focus of interviews, had more people been willing to take part in a face to face discussion. Only three questionnaires were returned.

Service providers were also invited to contribute to the research by participating in focused group explorations at the day of workshops. Six service providers attended the workshops representing social work, the charity business, advocacy development, supported employment development and a local user-support group.

Stimulating implementation of change through workshop activity

As previously indicated, a one-day programme of workshop activity was organised to bring all of the research participants together. The aim was to facilitate the sharing of ideas about ways of improving support of people with learning difficulties and their older care-givers, and to set in place concrete plans for making sure that changes would begin to happen. One week before the workshop day we held a drop-in day to enable families to come and familiarise themselves with the chosen venue and ask any questions they might have about the workshop. The drop-in day was intended to reinforce the message that the workshops would be for families and to alleviate any apprehensions before-hand. It proved an extremely useful strategy for establishing the confidence of families for working together with service providers and, we feel, was in large part the key to success of the workshops later on.

The initial part of the workshop programme was intended to clarify those priorities of people with learning difficulties, their older care-givers and service providers, which had started to emerge through the interviews. Participants worked in role-defined groups so they were able to focus specifically on the issues

which were important to them. These role-based workshops were then followed by a feedback slot at which a representative of each group could relay what they had been discussing to the other groups.

To get the discussion off to a lively start the first workshops looked at some of the things that the interviews revealed had made service providers and families angry. We then moved on to consider ideas for overcoming some of the difficulties which were being recognised and for dismantling barriers which participants perceived to be impeding service delivery. The final part of the programme involved each individual older care-giver and service provider drawing up a practical plan of immediate action which they could realistically take to bring about some sort of tangible improvement in their situation over the next three months.

Participants with learning difficulties were facilitated in their group explorations by the involvement of representatives of a well-known self advocacy organisation. Discussion focused around three main themes, 'things we are good at' - with the potential to elicit skills for ordinary living; 'things we don't like' - having potential to elicit life-style preferences, and 'what we would like to do with our lives,' - having potential to identify areas for possible change. Action plans were not formulated by participants with learning difficulties, instead their contributions were summarised in a picture-based report of their explorations which were widely circulated following the day.

It was agreed that the efficacy of the action plans, and their potential for bringing about improvements to the situation of people with learning difficulties and their older care-givers, would be evaluated at the forthcoming end of project conference which was then just over three months ahead.

Notes were taken to document workshop proceedings by a facilitator from each of the three groups and also by members of the research team. This enabled a substantial amount of material from the day to be recorded.

Summary

In conducting this research, there were four main sources of data collection : in-depth interviews with older care-givers and the person with learning difficulties they support; in depth interviews with nominated service providers; questionnaires sent to a wider group of service providers; and focused group explorations designed to integrate and consolidate the reflections of all of the major stakeholders in this project. All of the interview material was fully transcribed, supplemented by the additional sources of written data, and then read and re-read three times by members of the research team with experience in recognising key themes. We organised the material according to the principles of thematic analysis which we believe provides the appraisal technique of choice for the type of data obtained, enabling as it does, the most critical and significant aspects of the data gathered to be rendered visible (Smith 1995). The analysis is presented in the following section. Responses strongly suggest that a larger scale evaluation would provide not only confirmation of the value of current initiatives and experience but also generate many indications of further ways forward.

PART THREE - RESEARCH FINDINGS

How the findings are organised

During the course of this study older care-givers, people with learning difficulties and service providers expressed their views on a wide range of subjects - often sensitive ones. Our aim is to reflect their viewpoints and examine the arguments being developed as the respondents talked.

The technical thematic analysis shows the data to fall into a number of principal areas. Aspirations for future support reveal imaginative plans as well as expectations, coloured by reserve, based on years of experience. Resource issues are important. Though respondents were not unrealistic, families and service providers alike could be fiercely critical when judging the efficiency with which they perceive support is delivered. Respondents were able to identify barriers to support aspiration, to expose the origins of disempowerment that stem from isolation and exclusion and to contradict and challenge the rhetoric of service philosophy and support which they encountered. Years of ongoing meditation on preferences for the future illuminate the necessity for flexibility of service provision and all respondents raised searching questions about ways of improving services for older care-givers and the people with learning difficulties they support.

Not all of the respondents talked about each of the above-mentioned topics, and everyone attached a different priority to the issues they discussed. All of this means that the quotations included in this report have often been extracted from lengthy, embroiled conversations which makes it impossible for the real strength of their meaning to fully emerge. Selecting passages for this text has not been easy but we have done our best to show what we have judged to be the principle areas of reflection. Providing testimony to this is the inclusion of contradictory and minority views intended to indicate that our representation of the data is not skewed. Our over-riding aim is to prompt readers to make their own sense of what respondents have had to say.

The findings reflect many differences relating to culture, family structure, family dynamics, community, environment, different interests and belief systems as would be expected. However, there were also many common threads, mostly from the experience families have shared of numerous changes over their many years of care-giving. These include changes in attitudes, in educational philosophies, in the nature of available support for people with learning difficulties; changes in policies, in labels that they have been given and more general changes in society towards family life, health, retirements, the rights of older people and so on.

Older care-givers and people with learning difficulties had a vast amount of experience that they wanted to tell us about, by no means all complaints and upsets. There were issues that were of anxiety to families, and they recognise that there are many barriers in their day to day lives which need to be removed. But their contributions were also full of practical suggestions, positive experiences and ideas for identifying ways forward so that they can get the support that is appropriate for themselves and their families. The depth and breadth of experience that older care-givers and adults with learning difficulties can draw upon means that their wisdom is built on years of observing and learning and there are many lessons to be learned from

acceptance of this. The input of service providers illuminates the issues further and is bound to provide stimulus for other professionals.

The structure of this part of the report follows the subjects which most preoccupied older care-givers and their sons and daughters. What struck us most forcefully was the way in which families blot out their own ideas of what best practice might look like by expressing what they would ideally want in terms of dreams. What they think they might get is more of a prosaic actuality. Thus, the nature and complexity of the perspectives of service users and providers is difficult to explore. Having said this, we turn now to the major themes within our data, raising potential areas for further consideration along the way.

Aspirations for future support

I would like one thing to be on my grave stone when I'm dead. I would like it to be that I had a dream for my sons; that their life is as ordinary as can be, because there's a lot of value in an ordinary life. [my dream is] for Steven and Richard - known as people who have a severe learning disability and Richard, my youngest, has just about every label it is possible to have, - when the time is right, to move into their own home, that they have been included in choosing and live with people who want to live with them.

The father speaking above gives a poignant reminder of priorities which currently abound in all the major pieces of current policy and legislation relating to disabled people's lives, such as an ordinary life, a home of one's own, personal freedom and choices. Often, however, the priorities seem only half-remembered by providing agencies, leading this parent to feel he is talking about a dream. Time and time again, we found that when older care-givers do have a clear vision of exactly the kind of provision they would like for the people with learning difficulties they support, they construe their preferences in this way. They draw a line between their aspirations - which they present as idealistic - and the reality they expect for the adult life of their son or daughter. Yet the 'dreams' consist of nothing more than the preservation of basic human rights and rather ordinary aspirations which any parent might hold for their adult children:

that would be a dream, to have a big bungalow say with three or five bedrooms.. they must have their own bedroom, they must have their own individuality .. I have it all planned really, and a garden, patio doors leading into a garden where they could sit, with trees for shade or with hammocks

Only one additional requirement marks out the aspirations parents have for their adult children who have learning difficulties:

caring staff, staff who understand.

24 hour support by a staff team or a team of enablers.

The need for 24 hour staffing is common-place, and catered for by existing providing agencies, but older care-givers we spoke to seem uncertain about their son or daughters' entitlements:

They [need to] have somebody going in in the evening. Now I don't know whether a carer stays in overnight or what they do if anything happens in the night, but that's the sort of thing we want for Sandra. She doesn't like being by herself

[ideally] it will be staffed by, you know, fully trained people and they will have night people there as well because John needs 24 hour care. It should be a home from home.

Another primary aspiration of older care-givers is for their son or daughter to be treated with the same regard as in the parental home:

It is important that the values that they are surrounded by are ordinary family values. Respect .. and seen as people first, so they are included in any decisions that are made.. as if they still lived with us.

But long-standing experience of lack of control over support services and personal assistance for their learning disabled son or daughter has convinced parents that their chances of securing such back-up belong in the world of dreams. In the absence of confidence in support that outside agencies will provide, the aspirations of many parents are reduced to simply being able to remain involved in the provision of care themselves for as long as they can, even if their son or daughter is to live separately from them:

I would like to take a good part in it. I would want to be able to walk in and help with the washing up. Help with seeing Michael off to the centre, you know as long as I could you see. Or just go and sit with him in the garden if I got too old, you know, just to be able to go and sit in the garden.

Looking into the future can be a daunting task, not least where people do not feel in control of, or aware of, possible options for themselves and their son or daughter. Many of the families we spoke to, seemed uncertain about specifying what support they would like, possibly because experience has taught them to expect very little and to manage on their own. Yet, as the quotations presented so far suggest, most of the older care-givers we met were supporting their son or daughter with learning difficulties in the context of loving and protective family relationships and were quite clear about what areas of concern lay ahead. What they needed, was for their concerns to be acknowledged by others.

Acknowledging the aspirations of older care-givers

Discussing prospects for future support is undoubtedly difficult and emotionally charged, but parents did not want to shy away from it during the interviews. Many said they found contemplating future support an upsetting and worrying business. Hesitation is typical:

you know if anything happened us... no, I don't like it.. I suppose you do have to think of these things.

Another admitted:

I thought 'well I must do something and sort John's future out,' but I was a bit of an ostrich.

But the reasons for discomfort are not simple. Reluctance to talk about the future does appear to confirm the widespread impression that parents want to put off significant decisions about the adult lives of their son or daughter. This is not wholly explained though, by perceived reluctance to face up to one's own mortality. Important questions are also raised about what else parents might be fearful of thinking about, especially if this turns out to be perceived inadequacies in service planning and delivery. This was so for the family above who went on to explain:

I didn't want him to have to go into a home. And my husband was very, very, very much against him going into a home.

There seems to be a critical, albeit difficult, role for service providers as enablers of planning processes. Fear of the unknown plays a large part in refusal to acknowledge what might be about to happen next. In this sense service providers are just as vulnerable as service users. However, the data suggest that acknowledging the concerns of older care-givers is likely to provide an important start in reducing uncertainty. If families can hold on to the expectation that providing agencies will at least acknowledge their dreams and respect their nightmares, then they might begin to be less reluctant to think about some of

the things they ordinarily dread bringing to the front of their minds. All of this reaffirms the need for service providers firstly to listen carefully to the reflections of older care-givers and secondly, to ponder their own role in delayed decision making. In some cases, repeated discussions will be necessary, as not all of the possibilities will be explored at once, and families may change their minds and circumstances alter. It will therefore be important that service providers continue talking to families, even if their plans are idealistic, uncertain and for the future.

This sort of recommendation typically threatens to widen the gulf between families and service-providers. The latter understandably feel relatively impotent cast in the role of dream makers. But if the rhetoric of listening to parents is treated as more than rhetoric, then service providers can see the power with which they are invested. The families we spoke to dream of an ordinary home for the adult they support, perhaps a garden. Patios and hammocks are mentioned, as the flight of fantasy really takes off, and to be able to help with the washing up. One mother told us delightedly:

from what I've heard, you know, I am going to be able to do what I like with his bedroom.

None of these aspirations are really the stuff of dreams. They are rather basic aspirations, acknowledgement of which, in itself, imposes no mill-stone around the necks of purchasers. We would urge any reader in any provider role to think long and hard about what they can do to at least acknowledge, and thus respect, the aspirations of families. A sense of being genuinely listened to seems to be the foremost requirement of all of the families who took part in this study.

Evidence from our snap-shot of older care-giver dreams shows the magnitude of what they want in terms of long-term support is not beyond what they might reasonably expect, at least, to talk about.

Uncovering the aspirations of older care-givers

Part of the reason why the views of older care-giver seem often to go unheeded can be found in myths surrounding their wherewithal for engaging with uncomfortable planning decisions. As we embarked on this research, the weight of anecdotal evidence that the aspirations of older care-givers are difficult to elucidate because parents don't want to think about impending death, seemed hard to refute. There is a common belief that talking to older care-givers demands considerable reserve. We felt, perhaps not unlike providers in the field, that when talking with older care-givers we had to tread on egg shells. Many of them, after all, are within a short number of years of dying. But our data suggests that taboos surrounding talk about death in fact function to generate poor listening and can prevent the aspirations of older care-givers being realised. The view peddled by some writers, that parents delay making decisions about the adult lives of their son or daughter (McGrath and Grant 1993), was disputed by many of the people we spoke to.

Two things are important. First, several parents talked explicitly about their worries for their son or daughter when they die. They wanted to make sure that this research account stressed the significance of approaching the end of their lives faced with ongoing uncertainty about what the future holds for their adult

children with learning difficulties. Second, families are aware of, and refute, the view that they are reluctant to plan for the future because they do not want to face up to the certainty of their own death, or of something incapacitating happening to them. A number of older care-givers we spoke to made the point that all the time they feel they are coping they consider it unnecessary to sort out alternative arrangements. On the other hand, most parents said they wanted to see their son or daughter settled before they reach crisis point.

Again, careful listening is imperative because the process of coming to recognise increasing difficulty in providing care is an imprecise affair. The need for families to be encouraged to engage in planning for the future is coupled with a very indeterminate notion of when this should happen. But this lack of clarity is not invariably produced by the evasions of old age. Rather what looks like delayed decision making on the part of a parent, may actually be the product of delayed listening on the part of professionals:

These carers, every day they are one day older and one of these days there is going to be three or four of them who are going to fold up in an instant because they clearly cannot go on forever. I mean the analogy... if you sit in a bath and you increase the temperature by one degree every three hours, when do you jump out saying 'that's scalding' it is probably hot. ... There is always that feeling that well, you are going to cope.

Raising expectations

Our data reveals a sense in which families feel their needs and expectations are destined to remain unheeded by service providers. At this point, older care-givers look to themselves for solutions. Several families talked about the preparations they had made for sorting out their personal affairs, including advance planning of, and payment for, funerals. It is not simple to put such arrangements securely in place:

Knowing how to make a will .. insurance policies .. a lot of people won't insure our children. I have to do it through MENCAP and insure [my son] through them, because his funeral will cost just as much as for anybody else.

Other families, through anxiety about perceived lack of future support, found themselves swamped by worry for the prospects of their son or daughter without them, and comments about 'hoping their son or daughter goes first' were not isolated. The following quote illustrates the nature of such fears unequivocally

I've heard a lot of women say this, 'I'm not really afraid to die but I don't want to while my son or my handicapped daughter is still alive'. And a lot of them say that they are thinking of taking them with them when they go. You know, overdosing them.

Such feelings demonstrate the overwhelming nature of some of the issues facing older caregivers. The acute fact facing service providers here, is that people with learning difficulties 're under threat for their very existence if older care-givers and their sons or daughters cannot expect, and be given, more tangible support in their struggle for control over their future affairs.

There is evidence to support suggestions made elsewhere that euthanasia will increasingly be forced on elderly disabled people in Britain (Rock 1996). The call for service providers to do every possible thing they can to prevent this abuse of human rights must not go unheard. Who can say when the fear created by lack of certainty about long-term provision will prompt the damning reality that 'a lot of' parents are said to be contemplating? Some older care-givers are already seeking to muster support for what they see as the inevitable course of events:

You've got to accept the situation, you've got to make sure that you put pressure on your MPs and so on, and make sure that you elect people who are in favour of euthanasia, that's an absolute certainty.

There is an urgent need identified here to raise expectations for older care-givers and people with learning difficulties. We believe that the whole community, and not just service providers can no longer shy away from questions about euthanasia. It is imperative for professional readers to think about the individual and can take in immediate response to these issues.

Yet it is easy to understand why families have feelings of profound insecurity about the future for a son or daughter who has continued to live in the parental home. Over the years many parents have faced constant battles and have had to cope with the toll of alienation from professionals that is often exacted in response to dogged determination (Beazley and Moore 1995). As parents become older, their care-giving role remains central and other factors, such as personal health, or the move to retirement, may remain peripheral. Some older care-givers told us that this role keeps them young, but even so, were conscious of the possible problems that could creep up. We identified complacency in the response of at least one professional however, who tried to assure us:

Older care-givers have more time free as they will usually be retired.

Many families have been thinking forward for many years, and trying to match their ideals for support with what might be possible. A view frequently expressed, was that detailed planning for their son or daughter's future support, instigated at a time chosen by families, would bring peace of mind all round.

Providing peace of mind

Many respondents talked about wanting 'peace of mind', the format for this being sometimes clear, sometimes not, and different for different families:

We want to know *at this stage* what's going to happen to him when we pop off you see. He could settle down in a flat or in a house with two or three other people and that, I'm sure.. but how would anybody go about it supposing we pop off and Daniel has to do this job ? He wouldn't know the first thing about who to apply to.

These anxieties bring into question the value and effectiveness of existing individual planning practices, and we return to this issue later on in this report. Many parents were tormented by the feeling that despite a dim certainty that some sort of planning and support would eventually come into play, no comprehensive arrangements would be made while they were still alive. Anxiety stemming from lack of meaningful knowledge about future options was widespread amongst the families we interviewed, and came across as one of the major sources of stress and distress:

It would also be a great comfort to the family themselves to know that she's [going to be] experiencing independence, but at the same time she's in good hands and they don't have to worry.

Peace of mind is mostly associated with believing that service providers will be faithful to their obligations of care:

when [our daughter] gets upset the first thing she says is that she wants to buy herself a house. We know that she can't look after herself, but we would like to have that facility where there is a person there.. and you know, she can have the freedom, but as well she can have some kind of care as well, somebody caring.

Families need to know that a secure system of on-going support will safeguard the future of their son or daughter:

I would like a social worker to visit pretty often. You know, to come and see whether the heating was all right or not. He'll be able to cook a bit for his self.. If he'd got a visitor you know, 2 or 3 times a week, just to see that everything was all right with him

The nature of such on-going support is clearly of great interest especially as families knew of incidents where people with learning difficulties had been rendered vulnerable when trying to live independently:

Luke Jones, he was the first one that I knew about like, and he had his flat door on fire didn't he ?
Now there's only one door on them flats. He had a chip pan fire you know.

Assurances about the quality of support that will be made available to people with learning difficulties entering new life-styles need to be backed up by clear preparatory action. If one family can endorse the support that their son or daughter receives to another family contemplating change, then the path of new arrangements is clearly much smoother.

Managing transitions

A powerful message picked up by the researchers is that transition beyond the parental home is, more often than not, seen as an ideal scenario by older care-givers and their son or daughter with learning difficulties. At the workshops, participants with learning difficulties put forward the view that they would eventually like to move away from their parent's home. There was widespread agreement that everybody needs to, and deserves to, leave their parental home at some time in their lives

They've got their own life to lead and that's the end of it.

Gradual transition from the parental home to a home of one's own for the person with learning difficulties was seen to offer advantages for both them, and for their older care-givers. Parents wanted their son or daughter to be settling in to their new home while they were still able and around to support them through the transition, but were not necessarily eager to hurry any changes

What I want for the future for him is a home he can get to know as his second home but not to be in it permanently to begin with. I don't want to lose him you see until the time comes.

Prospective loss of involvement in the life of the person with learning difficulties was what parents most feared. Many were afraid that they would be excluded from planning and organising day-to-day activities if

their son or daughter no longer lived with them, and that they would lose contact. The need to maintain close ties and to continue giving support came across very strongly:

I hope to be included in my sons' lives as long as I'm alive.

At least one parent believed that service providers could usurp the rights of a family and seize control over a person with learning difficulties:

[if service providers think I can't cope] they'll take him off me and no way will I have him. You see once you let go of them and let them go, you have nothing whatsoever to do with them. You can go and visit, but you're not his guardian any more. They are his guardian. They can move him wherever they want and I can't do a thing about it.

Ambivalence from professionals towards the persistence of such beliefs reinforces vulnerability. We are not suggesting that professionals intentionally perpetuate such fears, but some of the parents we spoke to voiced unfounded apprehension about the prospect of eventual exclusion from their son or daughters life. This raises many questions about what service providers can do to resist and dismantle the tyranny of such myths.

Most care-givers did not want to hand the care of their son or daughter over to providing agencies wholesale, but described ways in which they envisaged the burden of care might be more equitably managed:

It would be lovely if he could stay there for a few days a week and just perhaps come home at weekends.

Parents clearly wanted to enjoy time with their family whilst defining some greater independence from each other. Solutions for how this could be achieved were offered including ones which allowed the parents themselves to change living accommodation rather than their sons or daughters.

Reversing transitions

Another option which parents talked about was moving themselves out of the family home, so that their son or daughter could stay put and realise their right to an independent life. They did not see support as a one way affair in which professionals are required to take the lion's share of responsibility for the long-term care of their sons or daughters. Many parents placed the onus of responsibility on themselves and introduced a discourse of families supporting providers:

My future plans for [my son] are to leave the house for him to still live in, with a possible two others like himself to share. With 24 hour support. We would sell to the Housing Association or similar, and we would rent a property nearby. This would be perfect for my son. And the only way I could give him up. The house is well adapted for him and would suit anyone who shared with him. A dream, may be, but who knows! I would still be able to visit him, maybe take tea with him. I could always have him for weekends and take him on holiday. I would do the respite care instead of social services. I would still have strong contacts with my son.

But once again, a family's own plans are presumed to be 'a dream.' This particular dream is not an uncommon one. A second family talked through some of the practical, relatively minor, steps which they envisage providing agencies would have to take to make it come true

They could say 'well Dan can stay here. What we'll do is, we'll do this, we'll do that, we'll knock this down and we'll bring somebody else in, and we'll then feed in the necessary staffing'.

It is worth pointing out that the families' notions of long-term provision are not strikingly different from that which professionals will already have in mind. The provision of aids and adaptations, 'the necessary staffing,' will all be on the agenda of purchasers and providers. The main demand these families seem to making, is for the relevant agencies to enable parents to provide housing if they so wish to do. This specific subgroup of parents are not asking support agencies to provide accommodation for their son or daughter. All they want is a guarantee of an appropriate level of personal assistance to enable their relative with learning difficulties to have an acceptable standard of living in their familiar home.

From the older care-givers perspective, the idea outlined above, potentially relieves providing agencies of a substantial part of the resource burden associated with their long-term obligations of care. In the minds of those who discussed this scenario with us, resistance to their plan seemed difficult to comprehend. But we did find the fundamental principles underlying the parents' preferences are recognised by some service providers

Your own home is a safe environment where your past present and future can be recognised, enjoyed and planned for. Many people I meet in community homes have, or can express, very little about their pasts.

The advantages, for all the family, of the person with learning difficulties being able to remain living in familiar surroundings were convincingly portrayed by one parent:

It was very noticeable to me that the only time John was really happy was when he came back into the house through this front door. They told me when the mini-bus came round the corner he would start shouting. When they got him off the bus and wheeled him up, you could watch his face and I was really pleased because he was so happy to be home.

The notion of 'home' is warmly conjured up here but it can have different meanings for different people of course. A sense of 'home' often includes the people around you, not just the bricks and mortar. In childhood, siblings might have played an important role in the concept of home and family and several older care-givers talked about their role in these later years not without some evident heart-searching.

Challenging assumptions about the family

For some older care-givers, concerns about how their son or daughter would live in the future were eased by the willingness of other family members to offer help and support. Siblings of the person with learning difficulties sometimes agreed to take on care-giving responsibilities but this prospect generated as many vexing questions as it might help to resolve. Most older care-givers we spoke to felt that accepting the involvement of others might impose unacceptable obligations on those others, and they were mindful too, that they would not wish other people to be faced with some of the trials and tribulations that they had themselves faced over the years. Of particular note, was a desire to protect siblings from long-term care-giving responsibilities. Anxiety is compounded if, in addition to not knowing what role other family members might play in the future, there is equally no certain knowledge of how statutory agencies might intervene:

I try to talk my daughter Out of it but she says that she would look after Shaun. But not on the same level I look after him. In other words, she would want him to be away so many days and then she would have him at home. But she said she would never want him to be fully residential, so I don't know what is in the future, what arrangements social services are making for the future, I don't know.

Not all families have offers of support from relatives, and others might not know whether they can rely on the involvement of those around them or not. The following remarks show the importance of avoiding assumptions about locating support within the family:

My husband died about twenty years ago now and I didn't think I need worry because I had such a large family and I thought perhaps each would take it in turns to have [my son], but I was wrong and they don't want him.

And even to talk about 'the family' is almost to assume a shared understanding of what families are like, whereas participants in this research experienced an elaborate complexity of family realities. A mother providing care in the context of a reconstituted family with multiple commitments could anticipate support:

Frank is my second husband, we've been married eighteen months .. he's tickled pink with Michael, you know he's very good with him, he's excellent with him and we never have a dull moment with him despite my son not being able to talk.

All of the data presented so far highlights the importance of recognising and seeking individual accounts, and of not assuming there is a typical account of family life when older care-givers provide long-term support for their son or daughter with learning difficulties. Whilst family members may share critical experiences, their interpretation of these and their view of their particular roles, responsibilities and aspirations will differ. These points are illustrated further by the way in which families make sense of barriers to their support aspirations, and their insights can be usefully contrasted with provider perspectives. Our research shows, to start with, that families may feel support from providing agencies cannot be assumed:

why do service providers, especially local authority providers, speak a different language?

The following discussion will consider how the participants view the origins and significance of difficulties in older-care giving. In doing this, we are sometimes able to juxtapose user views with provider images of what is involved in the provision of services for older caregivers and the people with learning difficulties they support. Readers are encouraged to consider why these insights are important for improving current provision.

Resource issues

Disempowerment and resource constraints

Older care-givers who took part in this study were conscious of the resource constraints that surround support services, notably, the lack of resources:

I suppose in every council they all have problems spinning the money out. It's only like the Government, they have got so much money and each department wants their cut. ... You know the defence, saying 'I want so much you can't cut mine down' and everybody is fighting to get a bigger piece of the cake and that's what it must be like in local councils.

There was a feeling that those in control of funding are hard pushed to make limited resources stretch

I mean you take the aged, the aged say that there should be more done for the aged. You talk to the disabled, they feel that more should be done for them. You talk to the out of work people, they feel more should be done for them and so it goes on

Given these constraints, some families think the needs of older care-givers and their families are likely to be underestimated

Unfortunately improvements [to the situation of older care-givers and people with learning difficulties] will come from one of two ways. One is for me to win the lottery or secondly for the local authority to realise there is time bomb waiting.. But of course they don't see our time bomb as really being a problem. They see other time bombs like the education provision or the pavements are collapsing or they need some more roads done or they need some more libraries. There is big demands on resources and social services is a very big eater up of money.

Most families were aware of resources limitations and expressed a genuine sadness that some services they valued in the past had since been withdrawn:

Everything that was a pleasure to [our sons and daughters with learning difficulties] seems to have been taken away from them, because [providing agencies] say they can't afford it.. they have no finances.

Accepting that there is pressure on resources led many families to lose sight of their real aspirations for support and to resign themselves to the notion that any sort of assistance, however minor or ill-adapted to their needs is something to be grateful for. This 'fact of life' syndrome clearly constitutes a source of disempowerment for families. Older care-givers find themselves without liberty to criticise the way services are run and with little motivation to assert their rights to services which, the 1996 Carers (recognition and

Services) Act states, they are entitled. In the following quotation parents articulate some of these concerns. They had been explaining that they feel the day centre which their daughter attends is insufficiently stimulating and tasks engaged in during time spent there are of little relevance for acquiring skills for ordinary day-to-day living. They felt unable to complain however, for fear of jeopardising their daughter's place at the day centre, which would have many draw-backs:

They told us that most of the government is closing, and we doesn't know if she will be kept in that day centre or not, whether she will get a place. While the government isn't doing anything we can't do anything. I mean these are all the things that [make] you think 'something is better than nothing,' at least she's got a place there. If they tell us tomorrow there is no place for her .. we can't do anything.

Older care-givers we spoke to were mindful of and usually sympathetic to, the situation faced by services. They recognised that the resource situation is largely unalterable. But there seemed to be a more disturbing acceptance that they would be a casualty of any cut-backs, rather than any insistence that services respond to the tensions with creativity and commitment to the needs of older care-givers and the people with learning difficulties they support.

Participation on resource issues

As would be expected, service providers also mentioned the huge problems stemming from resource pressures and openly acknowledged the difficulty prioritising the budgets they are given to work with:

we get allocated a set amount of money ... and we've got to decide you know and sort of assess everybody which is difficult when your whole case load predominantly is sort of high eligibility.

You can only re-prioritise so far, so I'm wondering what the solution is going to be for this.... You can only stretch so far and then it just becomes impossible to stretch any further without increased resources from somewhere. But at the end of the day, I don't see where that increase in resources is coming from.

The way in which the above two service providers put the resource problem suggests that they view service users *en masse* and position themselves as relatively immune to, and unmoved by, the day to day predicaments of individual families. To be fair then, it might be predicted that not all families will be

sympathetic to the issue of resource limitations and we picked up on the feeling that resources are not being utilised in the best way. In the eyes of older care-givers and people with learning difficulties, responsibility for resource allocation lies in the personal motivation of purchasers and providers to be moved by the urgency of their struggles. Some older care-givers were angered by what they saw as a contradiction when people in post to support people with learning difficulties and their families were not sufficiently motivated to find ways forward:

I want to feel that they are doing what they should be doing... because the money *is* there to be paid for these people and they *should* be working to do this job, not to just sit around their office and say 'well sorry mate we can't do it' and fob you off.

One service provider acknowledged the enormous debt which providers owe to families providing care and touched vaguely on the issue of parental participation in resource management:

Parents and people who choose to care for someone are the most dedicated people I have met. What better service provision could there be? These people should be given the respect, support and finances that they need.

From our interviews it has become apparent that older care-givers and the people with learning difficulties they support are not adequately consulted about resource issues. Many believe there is wastage of resources because services are not tailored to their specific needs. The role of families in decision making about resource issues is one which evidently needs to be addressed. Respondents were realistic about the range of solutions to their problems available to professionals, but were understandably dissatisfied when resource limitations were used to justify treatment of them and their family as 'cases' rather than individuals faced with a range of pressing and practical problems.

An important issue concerns the willingness of service providers to position themselves as working *with* families and not for them, but relinquishing power is still seen by some professionals as a contentious issue:

Maybe you know there should be more control or shared management of teams and social workers and whatever by parents. You know, a co-operative of some sort where parents feel .. I mean maybe that is a dangerous thing to suggest, that we put carers in charge of the resources.

Recognising the power of, and differences in, personal philosophies about improving services for older care-givers and the people with learning difficulties they support, is vitally important. Improved support is unlikely to emerge if control of resources is managed in such a way that service providers limit the scope of what families can do. Paying lip-service to the involvement of older care-givers and disabled people in deciding what they get from support services, quickly exposes professionals as resistant to the challenges

families might present to their systems. The comments reported above show a provider wishing to dictate the level of influence which older care-givers and people with learning difficulties can exert over their own lives. There is a strong case for training to support professional development in the context of negotiating fundamental changes to long-standing practices which might now be viewed as oppressive.

The participation of older care-givers and people with learning difficulties in resource issues appears to be desirable for families and providers alike, and the data suggest this is an area which merits further development, both on processes of participation, and in relation to subsequent outcomes.

Inclusion in the community

Isolation and the construction of silence

At the workshops it emerged that many families felt isolated in their local communities. There was perceived isolation as recipients of support from service providers, as well as in relation to other families, and from the neighbourhood at large. Like Gething (1997), we found that isolation and disability combine to create loneliness and render families unable to convert their own problems into shared issues. Many families recalled that in the past, families provided mutual support and would help each other whenever the need arose. They felt that such a spirit of benevolence was seldom found in contemporary life:

everybody pulled together then ... but they don't do today, they are not like that now, the society's changed hasn't it?

In days gone by, coffee mornings and family support groups had enabled older care-givers to get together and feel part of a wider group but such meetings were no longer organised by service providers. Increasingly, the older care-givers who spoke to us were identifying disadvantage they experience when organisation of services renders them less visible. Many questions are raised about the need for greater attention to local support networks:

Interviewer : So you don't get together with the parents at all, the other parents now?

Respondent : No, no-one at all.

Isolation of people with learning difficulties and their older care-givers reinforces public ignorance about their dilemmas and recycles prejudice and disabling attitudes. The bulk of families found empathy very hard to come by:

I had one man pass me in the street and walked on and he stopped and he turned round and just literally stared at John. He didn't say a word to me at all, and then he just walked off again, and I found it very hurtful.

Not all families reported direct experience of narrow-mindedness and discrimination, but an acute sense of being outsiders was common-place:

in general they are friendly towards us but it is true that no contact is made with Jason.

Families described their isolation as an accepted part of their life, and realised that it left them unable to expose the commonality of their problems. While people with learning difficulties and their older care-givers remain isolated they cannot lobby effectively for better support. It goes without saying that there are lessons requiring individual action for everyone here. Policy initiatives such as the 1989 White Paper '*Caring for people: community care in the next decade and beyond*' (DoH 1989) aimed at encouraging inclusion of people with learning difficulties in the community, seems to have made little real difference. We are again reminded that the power of enabling policy is negligible if the question of individual action remains unaddressed.

Family responsibilities for inclusion

Parents know that family life offers warmth, security and continuity, but realise there are limitations for adult sons and daughters living at home with their parents. Many older care-givers were conscious that while the opportunities they could provide for their son or daughter were culturally appropriate in the context of their family life, they were not always appropriate to their age:

[he needs] young people to look after him, so he's brought up in a younger environment than what he has here I'd like to see him have a younger environment really.

Many parents confessed the age difference between themselves and their son or daughters to be a barrier to a mutually acceptable socially life. While care-givers were often at a loss as to how to engineer same-age contacts, they frequently said that their son or daughter would benefit from the company of people their own age:

I mean [finding friends for our daughter] it's all right, but they would have to be much younger than us wouldn't they?

Opportunities for the person with learning difficulties to develop independence varied enormously between families, and parents realised the long-term implications:

I think possibly looking back on it, I maybe babied John a bit too much. I just automatically.. with spooning the food in without thinking and holding the cup for him to drink from. So possibly I didn't let him do a lot for himself I think they've got to be encouraged to do things on their own.

Sometimes parents described professionals as setting back the bid for greater independence too:

[the care worker] was a lovely girl, but she made too much fuss of Michael and we don't fuss him. We just treat him normal, 'come on, hurry up', you know, this kind of thing.

Numerous comments suggest a role for service providers in mediating changes in the relationship between parents and their son or daughter as the desire for greater independence increases. In the following example, the sibling of a person with learning difficulties explains that families cannot comfortably manage this transition without outside support:

She needs to experience some independence to give her that confidence. With being around parents who know her situation, she's not able to obtain that confidence.

Similarly, parents recognise that their role in providing opportunities for personal and social development is awkward:

He'll say 'go away mum' and then he is left with [the visitors]. If I do go in he doesn't like it. He says 'you go out mum' because he wants to be one-to-one. And he wants to have his own thing going .. make a friend with him and chat with him.

Others expressed outright anger that an adequate range of activities depended more on older caregivers than on service providers. Frustrations are evident in the next two quotations which reveal service providers having high expectations of family members but failing to apply those same expectations to themselves:

Could we take him shopping? Could we take him on the bus? Could we take him round the library? Not what they would do at all. And they were doing nothing at all you see, it was only one way traffic. . . I want to feel that they are doing what they should be doing.

Well they plan this individual programme that they're going to do with her, but more often than not it's mother that ends up with more jobs.

Like parents who spoke to Todd and Shearn (1996), those in our study frequently talked about the difficulties they experience trying to fit everything they need to do into the time available. With precious little time to themselves, older care-givers understandably wished that providing agencies might assist with setting up social contact and leisure opportunities which their son or daughter could pursue independently of the family. Our findings are very similar to those reported by other writers for people with learning difficulties living with their parents Dagnan and Drewett 1992; Dagnan, 1997). Most people with learning difficulties who live with their parents rarely go into the community alone (op cit.) and this pattern of isolation was experienced by families living in Trafford. Facilities to occupy people with learning difficulties are largely confined to week days and office hours, so that during weekends there is very little on offer:

They need to organise some facilities where [people with learning difficulties) can go at weekends. Now that my parents are ageing, they can't take her out every weekend and that's what she likes to do. She wants to go out somewhere.. she gets very upset and frustrated if she has to stay at home.

Activities outside of the home are most likely to offer people with learning difficulties the chance of age appropriate experiences and to relieve their parents of the stress associated with continually finding things for the family to do together, but we heard many accounts of inadequate access to such opportunities:

We just go our own way now, Tara and me ... you don't really have much happiness in my position because there's not many places where you see I can really go without Tara.

Most of the friendships valued by the people with learning difficulties we spoke to, had originated through involvement at day centres or colleges and few reported contacts outside of these horizons:

Interviewer : Do you see anyone outside of there?

Respondent: Outside? No.

Michael's no friends. I mean they can't meet some friends and go off for the day. They never have friends. When they have birthday parties I have to send a cake into the centre and they just have it there.

It seems that when a person with learning difficulties is not at college or at a day centre there is nothing for them to do, and so for many families, weekends are a time of profound isolation. The sister of one of the people with learning difficulties we met described the loneliness and distress associated with such times:

Sometimes we go out visiting families but that's very rarely. Saturdays he normally goes shopping with his brother just to keep himself occupied, otherwise there's not a lot he can do at weekends and he gets very bored and upset and he upsets his parents.

And isolation can be associated with cultural expectations:

The thing is because with Asian families, they're very sort of enclosed. I mean they take it as their own responsibility.

Clearly, the comments of older care-givers are an essential part of building up appropriate services for them, alongside services for their adult children. The barriers such families face are great and there are many disabling consequences tied up with isolation and exclusion. A recurring point of discussion was that people with learning difficulties wanted to get out more. Older care-givers have stated that they need the help of service providers here. For service providers to be able to put in place what people with learning difficulties want, they need to listen to these accounts and to think about changing.

Provider responsibilities for inclusion

At the workshops many people with learning difficulties made the point that they found their lives boring. This was echoed by a number of parents, both during the workshop and individual interviews, who indicated that they would like their son or daughter to have a wider range of daytime activities and a greater variety of experiences. Several suggestions were put forward of things the participants with learning difficulties would like to do, including working, perhaps in a shop, going out more and going on holiday. However, much greater flexibility of service delivery is required to facilitate these activities.

The right to lead a fulfilling life seemed to be an afterthought for many of the people with learning difficulties involved in this study. This is not meant to be reinforced by the structure of this discussion though we accept that the structure does reflect the priority that is commonly attached to quality issues in the lives of people with learning difficulties (Banfalvy 1996). Many care-givers wished to remind us of the significance of quality in disabled people's lives:

Respondent One: She's been making hats for the last two years

Respondent Two : That's not stimulating the brain, it's making it lazy more, I mean it's like factory work. I mean they do it because they have to do it to pass the time [but] she can't carry on like this, she needs something stimulating.

There are practical consequences of neglecting opportunities for purposeful activity:

Michael is waking up at three o'clock in the morning and half past five in the morning and not going to sleep again because he's not being stimulated during the day. There's nobody doing anything with him. He's just going in [to the day centre] and sitting down on a chair all day.

Some parents said they were satisfied with leisure opportunities provided for their son or daughter but their remarks were qualified:

I'm very happy with them. They take him swimming from time to time, they take him to the pub, they take him round the shops.

There were many instances where parents explained that any help with occupying their son or daughter had to be gratefully received because the family was unable to expand opportunities.

Of course, it is counter-productive for parents, and undermining of people with learning difficulties, if activities on offer make no reference to the likes and dislikes of those they are supposed to interest:

I get a report saying Shaun did not want to take part in the beauty session. Well I don't think he does really.

Some descriptions revealed unsatisfactory experiences which threatened relations between families and service providers

If she goes to cookery they bring buns home and things like that. And I sent a note last year saying would it not be possible to teach them how to make themselves a snack? I got a snooty letter back saying it wasn't in the curriculum.

A problematic area raised by service providers was the issue of parents being resistant to change, and it was pointed out that sometimes older care-givers may prevent their son or daughter from participating in

activities which they might enjoy and derive benefit from. The value of self-advocacy was being questioned by one parent:

We have a client who has joined a self advocacy group, whose Mum is quite protective and orders him about basically in his life. And one night she came in from being out all day working and was very tired and said to him 'oh just pass that over please' which was a footstool and he said 'well you know where it is' and he would never have done that. She was unhappy that the advocacy service was teaching her son, because she felt that she was losing control of him.

The meanings attached to self-advocacy by care-givers as well as by people with learning difficulties are known to profoundly influence the impact of self-advocacy on family life (Mitchell 1997). It is to be expected that the impact of self-advocacy will be complicated and affect older care-givers in many different ways. It would seem important to ensure that professionals are well equipped to support families struggling with notions they may well perceive to be relatively new and untried. Self-advocacy is unlikely to offer anyone beneficial opportunities for self-empowerment if the process of teaching it fails to take into account the impact of developing self-advocacy on the range of significant others in a newly empowered person's life.

Acknowledgement of the sexual rights of a learning disabled son or daughter was another area which one service provider considered to be difficult for some parents:

Sometimes [there is) a denial of the fact that their children might have sexual feelings, which can lead to problems through naiveté' or lack of understanding the boundaries of what is acceptable in society, because no-one has ever explained.

Again, many different understandings and assumptions surround the expectations people have for individuals with learning difficulties and it is not in the least surprising that older care-givers will hold traditional and possibly restrictive views of what sexual rights are appropriate for their son or daughter. There is likely to be discomfort between all three parties, parents, people with learning difficulties and professionals, when sexual rights are talked about. It seems helpful to place emphasis on creating solutions here, by seeking further information about what families want, enabling all three parties to examine and re-examine their opinions and using educational forums as the vehicle for bringing about change. Service providers may recognise that parental responses to these matters are constantly shifting and much depends on professional support. Greater social acceptance of the sexual rights of people with learning difficulties appears to have changed the parameters of care-giving for some families. The importance of receiving help from outside the family seems crucial in maintaining comfortable arrangements within adult households.

We have seen so far that a myriad of difficulties make older care-givers aware that in order for continued care of their son or daughter to be viable in the family home, it is vital that they have support from

professional sources. In other cases, where the person with learning difficulties does not carry on living with their parents, it is clear that mutual dependence does not simply disappear, and all members of the family need support in realising their aspirations for the liberation of independent living. The next part of this discussion looks at the barriers families report in receiving the help that they need and at the various steps towards dismantling those barriers that have been taken as part of the process of this research.

Removing barriers to support aspirations

One of the clearest messages to come out of the workshops was that families and service providers perceived a wide gulf between themselves. All of the participants wanted something to be done about dismantling a range of barriers which they felt obstructed relationships between older care-givers, people with learning difficulties and providing agencies. We begin by looking at some of the obstacles which people had encountered.

Real contact

Many comments described lack of meaningful contact between families and social services:

I don't know whether other parents have said to you that there seems to be a lack of communication between the staff and the parents... it seems as though lack of communication is a big division.

You will find quite a few saying the same thing about it - there is no contact with the other side of the fence.

I mean this is it' lack of contact between you, it's just name only.

Service providers were also mindful of the need for more effective links with families. They acknowledged that considerable room for improvement exists in the way in which social services and families work together:

I think the main areas for improvement should be in service provision to work more closely and to keep working, I suppose, with parents. ... The biggest thing I think is to try and continue to give

people a voice who actually have the services and I think we've got a big difficulty with striking a balance between the carers views and people who receive services.

The key thing is that you actually know the person, so when you come to do assessments and things you actually know the carers, you know the situation at home and it makes it easy to sort of give an overview and sort of try to prioritise.

In the above quotations, service providers reveal an expectation of diversity and difference both within, and between families, which will help to guard against generalisations about their circumstances and needs. Certainly, families agree that more consistent contact with service providers would reduce misunderstandings:

Come and sit and listen to families first. Find out about [my son], spend a bit of time with him, before starting to tell me what I need.

One interviewee described how misunderstandings quickly become seen as the family's fault' which is both undermining and distressing:

I met a lady last week who has a son [who is] in a wheelchair permanently. And she wanted a fortnight's holidays from the 10th to the 24th.... And they wrote back and said 'you can have the 10th but you'll have to come back home the middle weekend and take him out on the Friday and put him back on the Monday'. She said 'well I'm going to Ireland, how can I come all the way back from Ireland, take him out Friday, put him in Monday and then go back?' .. The girl on the phone, bearing in mind she's never met Mrs M. and Mrs M. had never met her or her child, said 'oh you want your son to stay on his own all weekend then do you?' ...[Mrs M.] got a little bit upset about it and she went to her local councillor about it. .. To be spoken to by a young girl from social services who doesn't know you and suggests that ... and yet when the councillor wrote to the director of social services, they denied ever saying it and made Mrs M. out to be liar.

Feelings of powerlessness are very clear in this account. It was common for care-givers in this study to feel they could not complain, or get anything done about their complaints if they did so. Such frustrations obviously create barriers between families and service providers and indicate the need for a climate which is both conducive, and responsive, to user feed-back:

Instead of sitting in an office behind a big pile of paper, which they shouldn't have to do, [service providers] should get out and meet the family.

Distance between the various stakeholders is also created if service providers give the impression that they do not prioritise, or respect a family's own agenda. In the following example, a father is explaining that a social worker was due to visit the family at 10.30 a.m. to discuss future housing for his sons

We were sat here waiting like and all of a sudden ten o'clock the phone goes. I answered the phone and it was her like. She couldn't come, she'd got something more important. I said 'well as far as I'm concerned there is nothing more important than what we want to know'.

We invariably found that those service providers who gave inadequate responses created anger, disappointment and disempowerment of older care-givers and the people with learning difficulties they support. This is stark contrast with support that is efficient and comprehensive:

I was delighted with the new arrangements for respite care. Every three months I was being asked by phone for my dates for short respite care for the next three months. they also confirmed by telephone and by letter. There has been a big improvement since twelve months ago.

A proactive approach is valued by the above parent, but others had found professionals less forthcoming:

You don't see them. I had to ring them [and say) 'I haven't got a social worker you know', they don't rush themselves at all

As each family goes through a range of interactions and outcomes, with many different service personnel over the years, they are understandably cautious about the usefulness of individual professionals. Let downs quickly create scepticism and increase the likelihood of that other provider-user relationships will be characterised by distrust and tension:

There's not many social workers I do like. I study them and I know right away whether I like them or not.

Unfortunately the power of the self-fulfilling prophecy can be so great that families are put off making contact with relevant professional agencies, they become dismissive of service providers and prefer to go it alone:

Interviewer : And you don't have a social worker or anything like that?

Respondent : No

Interviewer : Would you like one?

Respondent : No. Not while I can manage

This paints a picture of the stress some families find themselves under when they say they do not want help but recognise that this situation is possible only for as long as they can cope, an indefinable period in itself. Many of the older care-givers knew that things need to alter and we look next at what families would like to be different.

Tangible continuity

Many families present at the workshops missed not having a key service provider with whom they could build up a relationship over time, and whom they might feel genuinely understood their circumstances and their needs. Where a key worker is allocated, or has been in the past' families valued this greatly. The necessity for a key service provider, was borne out by the low number of families able to single out a professional who consistently supported and enabled them. Consistent support, that can be accessed with relative ease, need not be particularly elaborate to prove invaluable

Respondent: I am in contact with Elaine and she is on the end of a phone so I can ring her up

Interviewer :So she's quite a supportive person, you find her someone good to talk to?

Respondent Yes, she is.

Here, we are reminded that the involvement of professionals at a relatively unintensified level can make an important difference to support of a family. Knowing there is someone to talk to, or someone who will know who else you can talk to, is seen as supportive and liberating, in contrast with not knowing who can help:

He was replaced by a young woman. I think her name was Rowan, she didn't last very long. And after that came a young chap called Jim, but again 'he didn't stay very long. Now that must be at least two years [ago] maybe longer than that' and

up to now there isn't a replacement at all for them at the moment. So you ask anybody on the community team [and they say] 'we don't know who they are'.

Any system of communication which relies on intermediaries seemed to be problematic:

I want to speak to someone in authority who can show an interest. It's no good getting someone who is just a clerk in the day time They'll say 'yes, we'll see to that' and that's the end of it you see, because all they do is write a report and the report is forgotten about for ever.

Again, the problem of not being able to receive support at the time when it is needed is identified:

They come and they go, you get a different name every time you ring up, the last time I rang up for this Jane Wood. 'Oh I'm sorry she's left'. I said 'who do I speak to?' 'Oh can I take the message?' And you're speaking again to someone you don't know again.

As a result of finding professionals often lack knowledge about a family, service users come to question the use of involving them:

you're dealing with people who you've never set eyes on .. who have never set eyes on [my son] .. saying you know, 'well can't Michael do this ? And can't Michael do that?' And I'm saying 'I wouldn't be asking for this if Michael could do it'.

Again, families were realistic They recognised that many professionals do not enjoy conditions of service that encourage them to stay in any one position for long. Older care-givers understood that frequent staff turnover made it difficult to build up long-term relationships. They did not imagine that a quick solution to this problem was available, but wished to emphasise the degree of difficulty which this brings:

I think part of the trouble is their staff changes, they are moving on all the time to better themselves which is quite reasonable, but it means that there is never anybody there that you know.

While the above explanations are plausible, they provide little solace to families who need their questions answered and problems resolved. Expedient contingency plans for ensuring continuity in one guise or another require a closer look.

The importance of having support from sources outside the family was discussed by most of the families. But help is only liberating if families are assured that the person offering support knows their son or daughter well:

I think they are kind of juggling their workers around ... I haven't met this latest one, but I'm now on my third agency and each time I'm hoping that this is going to be it and I'm going to actually get somebody who will be able to cope with Shaun and bath him and that I will be able to just relax.

Part of the 'hoping' that things will be all right relates very closely to not being certain of what options are available nor how such choices may change with new policies, different management or fewer resources. Access to information on a regular basis seems to be key to helping families plan and prepare.

Knowing what is available

One of the distinguishing things about the older care-givers we interviewed is their resignation to 'making do and getting through'. Other researchers suggest that parents of people with learning difficulties learn a great deal over the years to confirm that very little support is likely to come their way (Todd and Shearn 1996). Often it is not the case that a lack of formal support is available; rather a lack of information about possibilities is common-place. This can be construed as part of the general array of obstacles that stand in the way of getting support

Lack of information may stem from the specific problem of not having a key service provider with responsibility for ensuring access to information. Since information is a critical determinant of personal empowerment, barriers to obtaining it have crucial implications for both service providers and service users. There are disturbing implications if service users feel that information is regulated or used selectively. Low levels of information, or patchy information can have dangerous consequences. If service providers lack information about a particular family, for example, their input may be ill-advised or unreliable. Respondents recognise the difficulties this creates for themselves, for their son or daughter with learning difficulties and for professionals too:

I like social workers to stay in the job longer and they get used to you and you can get used to them, but they don't stay in the job. They are always leaving, chopping and changing, that's what worries me over Tom in years to come. You know, all this that they've got wrote down, and the people that are there now, who will be there when Tom needs them?

If families lack information about service providers, than the extent to which they can have their say is restricted

We want to complain, but there's nothing .. we don't know what to complain [about] .. and how to complain, to whom to complain.

Strategies such as individual planning ('the 'PP meeting'), which ostensibly should provide a safety net ensuring exchanges of information, through which families do not fall, prove unreliable in practice:

There is an IPP supposedly every year. Now it's getting on for nearly two years since Shaun had an IPP. Shortage of staff they can't arrange it because they have not got the staff so everything seems to go down to shortages of staff.

The individual planning process for people with learning disabilities in Britain has been the focus of some criticism (Carnaby 1997) and in this research we have uncovered further cause to prompt debate over the appropriateness of these systems.

Irrespective of the merits or otherwise of current individual planning practices however, many families remain unaware of the range of possible supports available to them. For example, some families know about respite opportunities, whereas others do not:

Respondent : She says 'am I going to that hostel?' and I say 'you'll have to ask Barry,' and she'll come home at night and tell me there's no room.

Interviewer: Does she? Well then would it be useful to know about other places where she could go for a week like a respite place?

Respondent: I don't know where there is any.

Similarly a sister of the person with learning difficulties had been explaining that they would like somewhere where her sister could go and stay overnight, and experience some independence, but said the family was 'not aware of anything'.

Some families were poorly informed about adult placement schemes, even though such schemes are widely used to provide support of people with learning difficulties in Britain (Dagnan 1997). There was uncertainty as to whether such a scheme currently existed:

there was a scheme, you may know whether it's still going or not' where they go and live with another family or something like that you see. I don't know whether it took off the ground or whether it was an idea that was mooted around

and

I think [someone] did suggest something similar to that, erm, find a place in another family who would like to have the care of someone like her.

Issues such as these were discussed at the workshop and prompted service providers present to develop an information leaflet and hold information sessions. It is encouraging if information is increasingly regarded as an essential right and part of citizenship (Moore and Steele 1991; Orlowska 1995). Without information older care-givers and people with learning difficulties are unable to pursue their entitlements. The importance of providing information in accessible formats for everyone to whom it is relevant must not be underestimated.

Some parents find they do not receive information about their son or daughter when they are in respite care. This reinforces a fear that if their son or daughter moved out of the family home, they would no longer have access to information about them. The reality of this fear was highlighted by one family whose son has moved out of the family home:

I went into the centre to see him one Monday and they said 'oh he's not here' so I said 'why ? Where is he?' 'Oh he's poorly'. I said 'why didn't anybody tell me?' So I went straight to the phone in the special care room phoned and said 'when was John taken ill?' So they said 'he wasn't well when he came home on Friday afternoon so we called the doctor out Friday night.' I said 'why on earth didn't you tell me?' The whole weekend and this poor lad with all these strangers around him and Mum wasn't there.

Attitudes to service providers can be linked to information matters. The failed communication documented above has its origins in service providers not knowing what families want, leads to parents' concerns being

ignored and has the unacceptable result of alienating the whole family from the idea that service providers can be trusted with the care of vulnerable people in the community. Professionals who go of their way to possess themselves, and provide for others, more than simple facts about options or entitlements, and who provided families with a deeper understanding of available provision and options, may find themselves invested with trust and greater respect.

Making headway through acknowledging barriers

The issue of trust seems to be the key to whether families will talk to service providers about long-term plans for their son or daughter with learning difficulties. We have already described how trust is found to be a product of the way, and the extent to which, social services talk and listen to families from the outset:

Who can I trust? It is so important to develop partnerships with the local authority, with the health authority, with the voluntary organisations, but it is difficult to know who you can trust. I trust my family and I trust other people who have had the same sort of problems through their life as I have had. So I trust parents, not professionals. History has taught me that.

It is worth reminding ourselves of how long the damage of mistrust can linger. The mother quoted below vividly recalled the first time professionals had shaken her trust' over 30 years ago:

The first time he went into short-term care he was eight months old, and he went into hospital and he was beautiful when he went in. He was the most bonniest baby you've ever seen and he came out like a real washed out Downs Syndrome. He'd lost weight and I was worried. I went to the doctor and he said 'you'll have to get used to it'.

There has to be trust between professionals, older care-givers and people with learning difficulties before plans for the future, and ways in which families and providing agencies might work together, can begin to be explored. At this point' our discussion has almost come full circle, as we return to the importance of acknowledging family's own starting points.

Some important points remain. It is prudent for all those who read this report to remember that all of the data was collected under the auspices of local social services and health authority providers. The fact that none of the participating care-givers, people with learning difficulties or *service* providers went so far as to challenge the existence and power of these agencies may be a consequence of this. It may be that the self-advocacy movement will, in time to come, generate even more radical options than those posed by our data.

These points have been made elsewhere by people with learning difficulties who themselves wish to stress that the pursuit of realistic change is not necessarily the pursuit of their ideal future (Aspis 1997). In respect of this, it is worth noting that within the research process, people with learning difficulties were keen to extend the agenda, to focus not simply on care in the future and where they would live, but to stimulate broader considerations, at the same time, of what kind of a future they might wish to have.

The pursuit of the ideal should not be forgotten and the small steps of the realistic, need to be placed within this greater framework. However, it is important not to undermine the very tangible benefits that can be brought about through modest changes. Provider and user participants involved in this project, for example, did start to make real differences to the lives of some of the older care-givers and their sons and daughters with learning difficulties by carrying out action plans that were jointly developed in the context of the research workshops.

Real outcomes

Older care-givers bringing about change

Parents were unreservedly determined to take personal steps towards breaking the apparent impasse between themselves and services. As a result of their participation in the workshops they resolved to write letters to key service providers. They invited professionals to come and talk to them about their needs and interests. Service providers in response, pledged to develop a basic information leaflet about the roles and responsibilities of key professionals as they were willing to recognise a great deal of confusion about who does what within the providing agencies.

The research workshop had enabled one older care-giver a rare opportunity to talk at length to providers about the difficulties of making links with professionals who would respond at any given moment' and as a result, she was delighted to receive a list of all social workers and community nurses in her area. However, several months after receiving the list, she still did not know any faces, just names:

changes of staff is the biggest problem, never getting to know the faces behind the names.

This provides a good example of how even the smallest individual action can bring about important change. It is very easy for service providers to make sure that whoever they are talking to does know their name. Like Pilgrim (1997), we have found that certain professionals are repeatedly identified as being the 'human face' of service provision. These people have good interpersonal skills and an open, warm and empathic manner which encourages trust. Often they are people who are involved with a family on an ongoing basis. In addition, several respondents endorsed the relationships being made by a few relatively new service providers. Interestingly, the same few champions of best practice were nominated by families time and time again.

Outcomes from the research workshops have made participant Trafford families much less critical of service providers. Joint discussions have prompted recognition that professionals are themselves aware of possible shortcomings and committed to evolving strategies to enable sustained contact with families. It is important that there is no let up in efforts to bring about this sort of change. Feedback from families about the opportunity to work collaboratively with service providers at the project workshop was extremely positive:

[It was] very nice to meet members of Social Services on a friendly basis, rather than in a formal meeting. [The workshop] was very friendly and it was easy to talk and air one's views.

The value families have placed on relaxed interactions with professionals seems important to hang on to. Another care-giver, whose views were echoed by many, said:

We need more meetings and discussions of our ideas. [We need to] exchange feelings, problems and views and supporting ideas for the comfort and future of our disabled loved ones.

Professionals themselves said 'this type of day should happen more often' and welcomed the chance to 'hear the views of carers' and for 'telling people what makes me frustrated and about what I do'.

Service providers bringing about change

At the workshops, in addition to pledging to develop an information leaflet to clarify their roles, responsibilities and powers, service providers developed many other Action Plans which will help to overcome the problem of perceived distance between themselves and service users. Letting care-givers know about alternative care arrangements and holding information sessions were two suggested innovations.

The research activities have undoubtedly identified many contentious and difficult issues for professionals. Some of the discussion raises questions of human and civil rights and points to substantial changes at the level of service provider, purchasing agency and policy making. Nevertheless, it is important to point out that Trafford based service providers who participated in this project have shown that they are prepared to offer significant support for these changes. An important starting point has been in the personal reflection and reconceptualisation that those who attended the research workshops were prepared to make. Many existing barriers to the support aspirations of older care-givers and their sons and daughters with learning difficulties, have already been brought down as a consequence.

Some providers, for example, have taken immediate steps to enable parents to present their ideas for the future to Social Services. These include arrangements wherein parents move out from the home and their son or daughter stays with co-residents or support staff as required, and readers will recall that several families had told us that enabling such an arrangement would amount to their dreams having come true.

Participating families have received, and expressed appreciation of; reassurances that providers share their aspiration for the person with learning difficulties to be established in their different circumstances before a crisis ensues. There has been special recognition of the fact that all members of the family are keen to ensure that co-residents or support staff are suitable for, and compatible with the person with learning difficulties. Participating providers have reaffirmed their commitment to keep talking to families.

People with learning difficulties bringing about change

People with learning difficulties have taken various opportunities provided by the project, to explain that when it comes to planning their futures, they want a number of demands to be met. Decisions are not simply a matter of choosing between, for example, long-term placement with another family, or occasional placement with another adult; there are many demands within these choices. People with learning difficulties have told providers that they want to be involved in deciding where the place is, who they will be going to live with and so on. A very important factor for many people, is that they should stay in the area they feel comfortable in, and many wanted to stay in the house or flat they were used to.

At the workshop people with learning difficulties stressed that they wanted acceptance of their right to change their minds about future options, to be able to try a new living arrangement but move on again and try something different if needs be. There is a requirement for services to be flexible. Many people expressed a strong wish for parents to remain involved in their lives if they did leave home, which echoes the preference of many parents, as reported earlier.

People with learning difficulties who attended the workshops felt they were good at making people happy. They highlighted this to reinforce the point that the care-giving relationship is not all one-sided. Adults with learning difficulties give companionship, love and care to their families, as well as being recipients of care. There is scant recognition of the part disabled people play as care-givers and this is an area for research which we think has the utmost importance for provider agencies. We return to this debate in Section 5 of this report. Two quotations have been chosen to highlight the value older care-givers place on what their learning disabled son or daughter brings to their life. The first is often heard, but not so often remembered:

I wouldn't be without her.. oh no, I wouldn't be without her.

The second quotation, highlights reciprocity in the relationship between older care-givers and the people with learning difficulties they support and serves to remind service providers that this care- giving situation is not unequivocally positive or negative. Nor is the experience of disability within the family characterised by personal tragedy:

Even if they are blind they can still feel their parents, they feel the nearness and the closeness, the love. I know he loves me and I know he knows that I love him and it's all worthwhile. It's

sometimes when you're very down and feel very lonely if an arm just comes round your shoulder, you get hugged and that' Shaun does that and I know that it is all worthwhile.

These messages have been publicly aired at least three times now, during the course of this research, via local workshops, the national end of project conference and this report. We would underline our plea for attendant action and maintaining momentum for bringing about change. A vitally important point made by a representative of a national self-advocacy movement at the conference is that most non-disabled people need to learn to listen to people with learning difficulties and find ways of enabling easy and effective communication so that people can speak for themselves about long term care. In the words of this advocate:

[service providers] need to say 'there is a ground swell of pushing by learning disabled people that needs to be tapped'. Because if you do not tap it' you're losing your best resource for making sure services respond to people's lives.

These are powerful words and must remind all of us that it is imperative for disabled people to set the agenda for ways forward. This project has started to access this agenda and we hope that the report not only spells this out but also identifies some mechanisms for maintaining the momentum.

Concluding remarks

At the end of this part of the report then, it is evident that people within the context have identified a range of areas for further exploration. As already said, in Section 5 we present a comprehensive set of research proposals for further discussion, which could ultimately be used to seek funding for advancing the agendas put forward by those who participated in this initial enquiry. Before moving on to these proposals however, we would first like to offer some comments on what has been uncovered so far

PART FOUR - DISCUSSION OF ISSUES RAISED BY THE RESEARCH

What has been achieved?

Quite evidently, this report describes powerful research findings, which demand a great deal of reflection. The first two aims of the project, to explore the experiences of older care-givers and people with learning difficulties whom they support in Trafford, and to build on these explorations by linking service users with key providers and encouraging them to work together to influence policy and practice, have been achieved. Pursuit of the third objective, namely to develop new practical strategies for overcoming the problems faced by older care-givers and people with learning difficulties, has been set underway and now demands co-ordination and dissemination of innovative new practice and policy which builds on the research findings. This report can make recommendations. Families can agitate for change. But it is service providers who are invested with real power for making a difference.

Further development indicated by the research

The data raises awareness of the concerns of older care-givers and the people with learning difficulties they support. It draws attention to many areas of good practice, but also highlights some serious gaps. The data cries out for bridges to be built between older care-givers, the people with learning difficulties they support and service providers who work with them. Thus the findings promote networking within and between different groups of providers and users. There is also a need for greater contact between different groups supporting older care-givers and/or the people with learning difficulties they support

The partnerships which have been established through this research, between the Disability Studies Research team, MENCAP, Trafford Social Services and Salford and Trafford Health 'Authority, have enabled meaningful questions to be asked of people who have varying interests in family support. We would like to build on this partnership to further the participation of older care-givers and disabled people in implementing change and in research to evaluate subsequent policy and practical development. The most obvious point of departure, namely furtherance of a coalition of providers and users of older care-giver support services has already been taken up by service providers. An agency has been identified with regard to establishing a 'banner' for the launching of a coalition and for the purpose of creating a focusing agent for further development. Key members of providing agencies, across the voluntary and private sectors have indicated that they are keen to become involved.

Towards a coalition of service users and providers

Setting up a new coalition of older care-givers service users and providers will provide a timely response to many of the findings uncovered by this research. It signifies a co-ordinated response to the needs of present older care-givers and people with learning difficulties, which as our research has identified, is a priority. A coalition offers real possibilities for the development of a service strategy which networks organisations, individuals and expertise together within an agreed framework of rights-based values. Our research also shows that accountability of service providers is a priority for older care-givers and people with learning difficulties, and an organisational structure which reflects commitment to maximising this would have many advantages. A further benefit of establishing a coalition would lie in creating a forum which encourages collaboration and debate between all key stakeholders and produces practical outcomes from conceptual aspirations. A coalition could create a catalyst for best practice which currently exists and for the implementation of changing ideas and practices in response to the user agenda. In the long run user and provider members of a coalition could jointly bring about sustainable change that will maximise best practice which is expectant of and responsive to, change.

Many values underpin the setting up of a coalition and these need to be the subject of continued debate from the very earliest stages of drawing such an organisation together. From the research teams bird's eye perspective it would seem helpful if all members of a prospective coalition can agree to a mutually acceptable statement of shared values. This is seen as imperative to ensure members of the coalition are united in their aspirations for, and understandings of optimal support for care-givers and people with learning difficulties. In accordance with the major alliances of disabled people and their representative organisations (BCODP, 1996; Scope, 1997; Campbell and Oliver, 1996), full and proper consideration must be given to the human rights and ethics issues which shape the lives of disabled people and their families.

In relation to this, certain core principles ideally underpin a coalition of those providing services for older care-givers and the people with learning difficulties whom they support. There needs to be full recognition of the impact of oppression on the lives of older care-givers and on the disabled people they support, and commitment amongst members of the coalition to continually facing up to, and challenging the existence of disabling personal, political or practical barriers in service provision. Members of the coalition should not exclude disabled people from their decision making processes and member organisations should not be controlled entirely by non-disabled people. Care-givers and the disabled people they support must be centrally involved in creating and implementing their own responses to service provision issues. These are, at least, some of our personally agreed starting points. In addition, there are relevant existing within-service specifications of shared values which are relevant. The way forward, though clearly sign-posted, is not likely to be an easy one to travel.

The role of research in bringing about change

Likewise, the course of a research project is not always easy, and so as part and parcel of our endeavours we frequently asked participants for feedback on how they thought the research was progressing. The comments received help to illuminate the importance which those who were the focus of the research attach to the sense we were trying to make of their contributions, and so have a bearing on perceptions of our credibility. Several people commented on how the research process itself has prompted change:

the research has opened channels of communication and started some dialogue.

At the conference held to publicise preliminary findings, at the end of the empirical stage of the project, we asked for comments on the findings which were starting to be unravelled. A typical response supports our view that openness to users' own starting points will provide the key to excellence in planning service delivery and purchasing decisions

It is so refreshing to hear that you actually listened to care-givers and people who use services and are labelled learning disabled. Some serious work needs to go into negotiating with service providers regarding your results.

Conference delegates who expressed a view, recognised the power and validity of the data and wished to emphasise the importance of the project fulfilling it's potential

I just hope that the research findings *can* be implemented and *will* be taken on board.

Specific questions were posed about exactly how commissioning agencies will respond to the research, and what they will do to make it possible for the findings to influence the operation of particular policies and practices:

How will the report be used by Social Services ? Will any recommendations be incorporated into the next community care plan?

We were greatly encouraged by the positive reception to this project and intend to respond effectively to what participants have asked us to do

Get as much publicity as possible for the report. raise the issues with the widest audience - don't let it go to waste.

Certainly, dissemination of this report will play a major role in securing motivation for key players to take up the challenges of implementing change, forging a coalition and participating in future evaluative

research. We agree with the person quoted above. Research is an immensely powerful tool for bringing about change (Vernon 1997). Expedient and widespread dissemination of this report may prompt individual action, particularly if readers are willing to heed the many pointers to individual action which we have tried to identify, and to reconsider their own roles and responsibilities in dismantling disabling barriers.

Future research directions

As researchers, we might feel that our own responsibilities stop here, with the completion of this report and its submission to those who commissioned the project. However this would not tally with the emphasis we have tried to place on the part each of us plays in recycling disablement and oppression if we do not constantly question the extent to which we can measure up as disabled people's allies. For this reason we have taken this research account a stage further and tried to identify strategies for maintaining the momentum gathered by these initial investigations, through instigating further projects.

As is generally the case with research, this investigation has raised more questions than it has answered and identifies scope for further studies in the area. The findings show that recipients of the changes implemented by service providers following the research workshops have responded very positively and that there is a great deal of enthusiasm to see change evaluated and expanded further. The project has provided an excellent opportunity to pick up on this enthusiasm and energy. Crucially for future proposals, the project has allowed examination of critical issues which underpin effective collaboration on rights-based disability research, and identified topics of real significance to those in the context. This will make for future research which really can place older care-givers and people with learning difficulties at the centre of the enquiry and so has a good likelihood of bringing about meaningful and relevant changes in their lives.

Our research has brought to light interest in documenting experiences more fully to uncover practical directions for development of further support. At a local level there is scope to review the progress of service changes in the wake of the project workshops, for example. There are wider indications concerning the need for research and development with the capacity to influence debates about full citizenship and equality of opportunity - such as to do with analysing the role that different professional agencies have to play in the evolution of a coalition of providers and users who will work together to advance the family agenda. In addition, the project has touched on the need for in-depth research designed to enhance knowledge of people with learning difficulties as care-givers. Such research would enable a more critical approach to the factors that might preserve family unity when, and if this is what families want. Moreover, evidence is needed to challenge negative and emotive images of the position of people with learning difficulties within the family. All of these areas for further research have clear practice implications and would specify gateways to new service responses to the situation of older care-giving.

In conclusion, we hope that this work contributes to the encouragement of further debate, although we are of course, aware that we can make only a small contribution to the framework of further areas for investigation. We have tried to open up a range of practical possibilities which might service as the basis for further change. This is the spirit in which draft proposals for developmental research, to take service responses to the aspirations of care-givers and people with learning difficulties forward, are now presented.

PART FIVE - CONCLUSIONS

What difference?

There have been two aims of this report; first to give an account of research project undertaken to explore the aspirations of older care-givers, people with learning difficulties and related service providers, and second, to explore further possibilities for research and development which have been stimulated by this project. The crucial importance of *making research make a difference* is the central theme of the report and we hope that the discussion will help to promote commitment to the idea that the best disability research is about dismantling disabling barriers and takes its lead from those who are the most oppressed by those barriers. We hope that those who have been involved in the study don't just read the report, but try to ensure that it changes understandings and practices.

Earlier on in the report we have recognised the value and strengths of the collaborations which have made this research possible. Many excellent ideas have emerged, from the experience and knowledge of those in the field, on future directions for research. We hope to have demonstrated our credibility for moving these ideas forward, most explicitly through the package of funding bids, and to have shown our enthusiasm for further work by offering to convene a follow-up workshop to advance the formation of a coalition of older care-givers, people with learning difficulties and service providers.

As with all of our research undertakings we have found yet again that disability research involves debate, listening and earning the respect of others, particularly in relation to the voices of disabled people, but even well-intentioned research acts can leave disabled people outside of, and alienated from, the process of research production. As researchers, we are committed to highlighting the role of research in dismantling oppression in disabled peoples' lives, and the proposals we have framed for possible future projects all reflect this stance. Changes already made by Trafford Social Services with Salford and Trafford Health Authority and Sale and Altrincham Mencap during the course of this project signify a timely opportunity for bringing about further changes which disabled people and their families want.

The combination of the innovative policy and practice for people with learning difficulties and older care-givers that is being established by Trafford Social Services with Salford and Trafford Health Authority and Sale and Altrincham Mencap, plus the research expertise and recognition of the wider human and civil rights of disabled people which can be offered by the Disability Studies research team provides a formidable force for breaking the mould of a disabling world (Barnes and Mercer 1997). The task remains to discuss this report and pursue further avenues for research.

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