



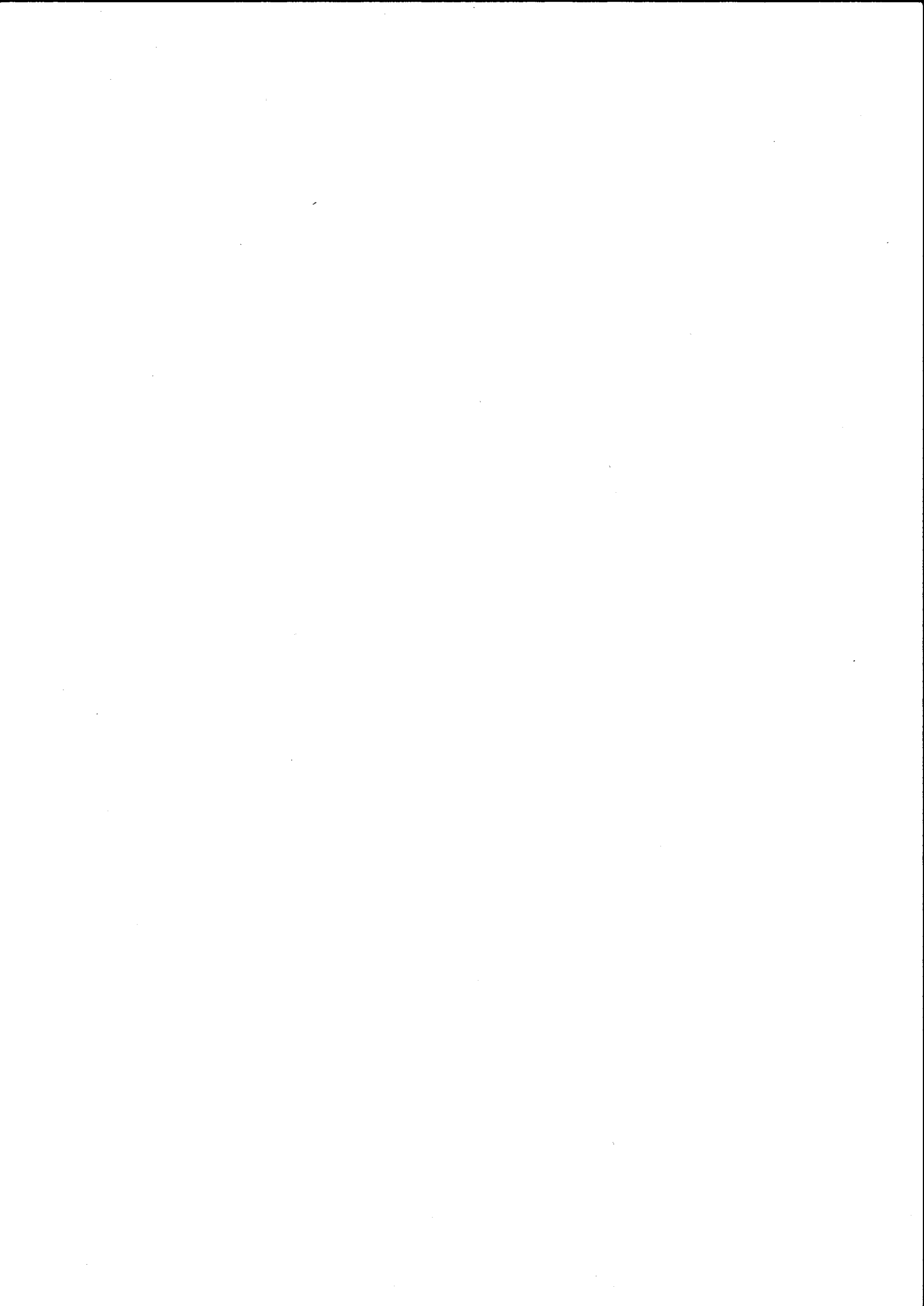
Department of Psychology  
& Speech Pathology

# Interpersonal and Organisational Development Research Group

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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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Martin Patient and June Maelzer**  
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*An earlier version of this report was presented at the Older-Care Givers Conference  
Manchester Metropolitan University, June 1997*

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## ACKNOWLEDGEMENTS

The original ideas for this report arose through the shared experiences of Martin Patient and people with learning difficulties and their older care-givers connected with Sale and Altrincham MENCAP. We are very grateful to Trafford Social Services and Salford and Trafford Health Authority for funding the subsequent research. A great many people have contributed to the project which is the focus of this report and while it is not possible to mention everyone by name we gratefully acknowledge their support and encouragement. We have greatly valued the input and expertise of members of the Advisory Panel for the project, Dave Clemmett, Shirley Godden, Julian Hannah, Nigel Johnson, Carolyn Kagan, Barbara Keeley-Hughett, Joan McClymont, Christopher Scott and Michael Young. Special thanks go to Ann Hampson who undertook the typing of the interview transcripts. Most of all we would like to thank the families whose reflections form the main part of this report, for so generously allowing us to learn about very personal and sensitive issues in their lives and for their kindness and co-operation with the research activities. They will know who they are and we thank them for welcoming us, giving us their time and sharing their thoughts with us. Any merits of this report are due to them.

## 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; Orłowska, 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 publisher<sup>1</sup> 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.

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<sup>1</sup>Moore, 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.