



Department of Psychology
& Speech Pathology

Interpersonal and Organisational Development Research Group

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Broadening the Boundaries of Collaborative Research

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Carolyn Kagan*

W. H. Frost 1880

**Broadening the Boundaries of Collaborative research: Report of the
Collaborative Learning Disability Research Conference
Manchester, April 2001**

Edited by Mark Burton, Sue Caton and Carolyn Kagan

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Manchester Metropolitan University*

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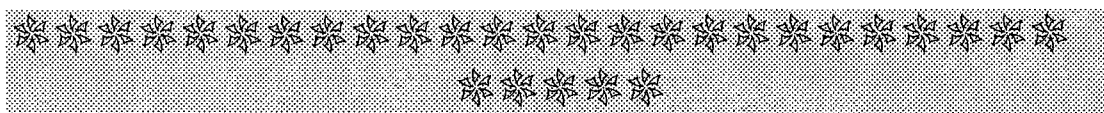
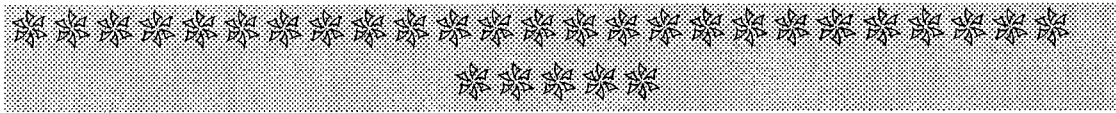


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Introduction to the Collaborative Learning Disability Research Group

The learning disability collaborative research group was established in 1998, funded by the Research and Development division of the Regional NHS office. Colleagues from several NHS Trusts and two Universities established the collaboration: the Manchester Joint Learning Disability Service (now Manchester Learning Disability Partnership) managed it.

The collaboration focussed on four areas, running workshops for researchers and practitioners:

- Physical health
- Behavioural challenges and mental health
- People who offend, or are at risk of doing so.
- Research methods appropriate to research in the 'community learning disability' context.

The collaboration also produced a learning disability research strategy for the Regional Office.

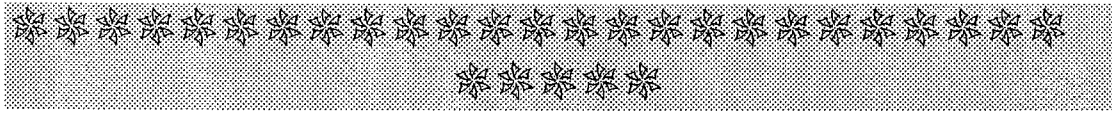
The initiative met its objectives, and identified a network of many people from a variety of organisations who attended the four events. Unfortunately continued funding from the Regional Office was not available (as a result of changes in the funding arrangements nationally). The collaboration therefore 'rested' until Manchester Metropolitan University agreed to part fund it for a further period. Together with some money left over from the original grant, this has meant that someone is available on a part time basis to co-ordinate the collaborative network for a further period of 20 months.

This conference was held to re-launch the collaborative network, and also to broaden it. The idea of **broadening** research with people who are learning disabled was the theme for the conference.

Broadening the boundaries

By broadening the boundaries of research with learning disabled people we mean two things.

1. Broadening the network of people involved beyond the original emphasis on health services and universities, to include local authorities, voluntary organisations, community organisations, as well as, where possible, the people the research is meant to benefit – learning disabled people and their close allies.



2. Broadening our understanding of what research is, to include any kind of organised investigation where some kind of statement can be made about the credibility of the findings.

We will explore each of these ideas in turn: -

Broadening the network

The North West took a lead in the 1980s and 1990s in the reform and redevelopment of services for adults who are learning disabled. It had the most comprehensive strategy for the replacement of hospital institutions – a strategy that was underpinned by a shared approach between the NHS and Social Services. These developments were also forward looking in that they included a variety of other stakeholders – parents, voluntary organisations, university people, as well as (rather later) learning disabled people themselves. As well as large-scale service reform based on a supported community living model, the North West has been somewhere where other far sighted innovations took place. Early projects on socially integrated leisure supports, user groups supported to negotiate with senior managers and authority members, joint training for health and social services staff, service evaluations based on explicit values, management of services across organisations, or independent advocacy schemes, are just some of the examples where the North West innovated early and across the usual boundaries.

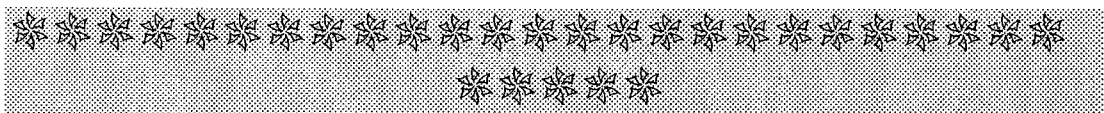
Furthermore, services are now provided by a variety of organisations, with the health service only accounting for a small proportion, and with (in most places) a clearer focus on what only it can do.

That approach has now become commonplace throughout the country, and is embodied in the new White Paper: *Valuing People*¹.

Unfortunately, the funding, development and conduct of research has not always reflected this multi-stakeholder reality. This reflects the greater emphasis on research and development in the NHS than in local authorities: in the NHS research and development has distinct funding arrangements, and it is increasingly seen as a key contributor to effective practice and policy. In the other sectors it tends to be rather marginal. This applies both to the conduct of research and to the use of research findings.

This re-launched collaborative network will work towards involving all sectors and all kinds of stakeholders in discussing, doing, and using the results of research.

¹ Department of Health (2001) *Valuing People: A New Strategy for the 21st Century*



Broadening what counts as research

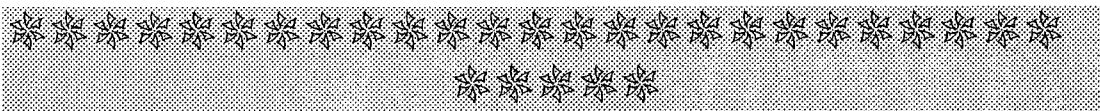
Our second concern is to broaden the definition of what research actually is. As the rest of this report demonstrates, research can be carried out on a huge variety of issues and questions, and by using a variety of methods. The academic roots of research methods extend from the physical sciences, through the biological and social sciences to the humanities and arts. There is no one definition of research, and all kinds of research can yield useful information, knowledge, insights and challenges. We take the view that there are methods that are more or less appropriate for different questions and problems – but it is important to be open to a variety of approaches. Notions of a ‘gold standard’ or a hierarchy of research methods with some better than others make little sense when we consider the diverse kinds of knowledge that we have to have in developing and delivering effective supports to learning disabled people. These knowledges extend from the ‘how are relationships experienced’ or ‘how can memories of difficult times be conveyed to those that weren’t there’, to ‘what causes these physical problems’, or ‘how can someone be best helped with this behaviour’.

If there is no one best model for research nor one best method, then it is also the case that research is not just that activity conducted by professional researchers supported by funds specifically earmarked for research.

The Department of Health, for example, makes a distinction between ‘research’ and ‘audit’, (but rarely speaks of ‘evaluation’ about which numerous books and journals have been published). We find the distinction difficult to sustain, since audit activity typically uses established research methods, and while locally focussed, similar audits producing similar findings in different places indicate generalisable findings (one of the ‘official’ hallmarks of research) – that is if someone connects the different studies together.

A further consideration is that there is relatively little research done in the learning disability field – and much of that which makes it to the technical journals has little obvious relevance to the provision of effective supports. This means that it is important to maximise the effect of what ‘unsung’, small, local studies are being done. The collaborative network will be helping share the learning from local studies, audits, censuses, in order that they begin to add up to a shared body of useful information and knowledge.

So this collaborative network will involve broadening research in the field of learning disability, in terms of who does it, and where it is done, how it is done, and indeed in terms of what can be called research. None of this should be taken to mean that we are advocating a sloppy, anything goes approach: the research should be done well, with high ethical and methodological standards. Appropriate caution should be attached for the claims made on the basis of research. But that is not



incompatible with the development of an inclusive, investigative culture. Just how the collaborative network can help establish this will become clearer as we embark on the project: we have some ideas, but these will become clearer as we try them out. We will (to paraphrase Paulo Freire) *make the road by walking it*.

Overview of current research across the region

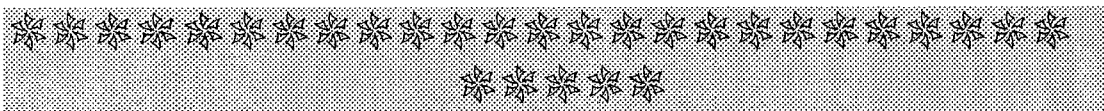
The morning discussion groups at the conference gave participants the opportunity to talk briefly about research in which they, or colleagues were involved and to hear about the research that others were doing. In the spirit of *broadening the boundaries of research*, we took any activity that sought to gain information in an organised way, as research. There was a wide diversity in the purpose, focus and style of research. Thus some research was aimed at gaining a better *understanding* of people or of services; other work was aimed at *change* for people or services research work. Research varied from that which was fully participative of all those concerned with the work, to that which was collaborative, to that which invited external scrutiny from uninvolved outsiders (a dimension perhaps more usually known as objective-subjective, but we find this distinction unhelpful). Figure 1 shows these dimensions. All of the research discussed could be placed along these three dimensions. Of course, the end points of the dimensions are not mutually excluding. Understanding can lead to change and vice versa. Services are created by people and contribute to their experiences. External scrutiny may be combined with participative work, and so on. Many projects were limited or encouraged by the particular context in which they operated, some even exploring that context as part of the research.

Focus of Research

The following projects focused on people, with a view to understanding their experiences or promoting change in their behaviour or attitudes.

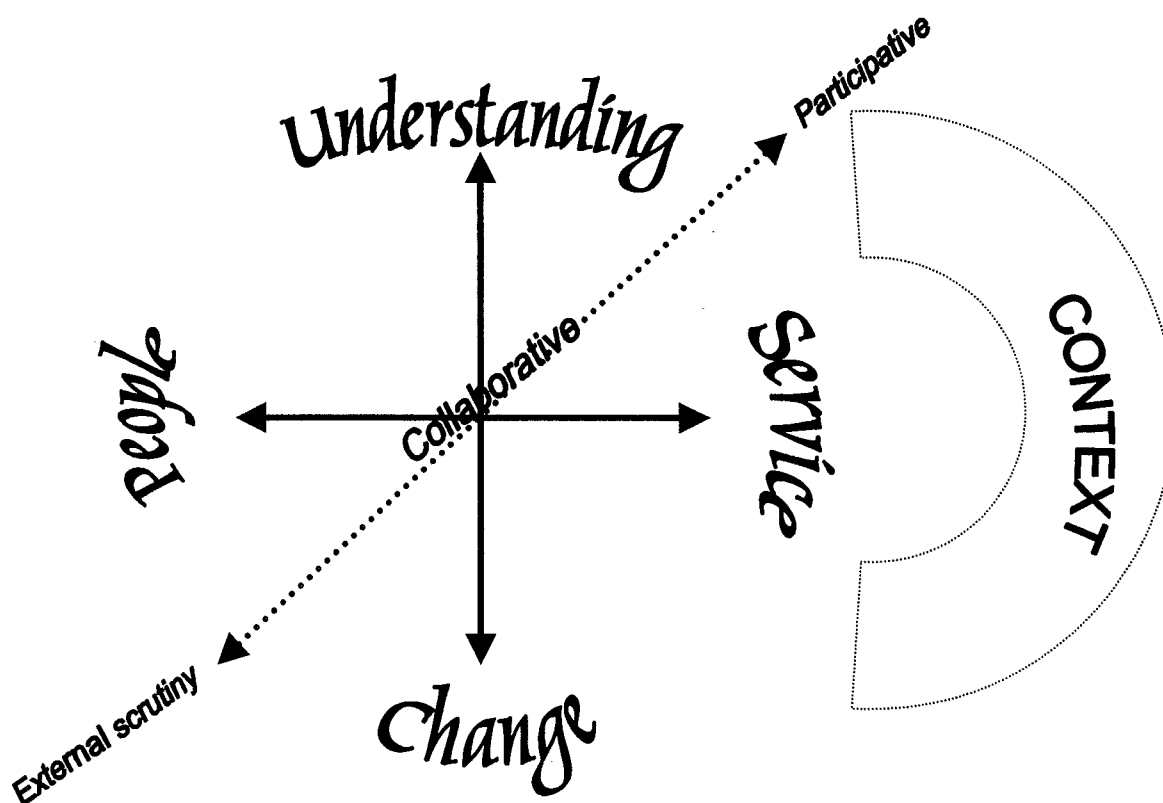
Focus on people with learning difficulties:

- Interview study of people without a care pathway in acute settings across three hospitals. To be followed by interviews of those with pathways.
- Development of methods for finding out what kinds of activities people with profound and multiple learning difficulties want to do, staff involvement.
- Evaluation of self-advocacy.
- Nature of language and learning difficulties in people attending mainstream clinics (PPP Health Care funding).
- Giving a voice to people with autism. Funding being sought for user input to service development.
- Development of different ways of getting people's views – including pictures.
- Difficulties in understanding shown by people with challenging behaviour.
- People with learning difficulties' awareness of cancer.



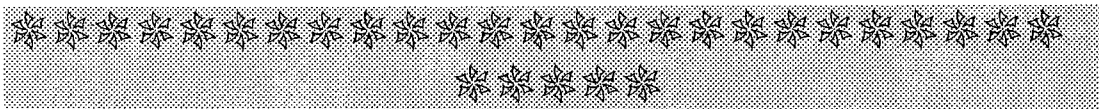
- Rights and justice project for MA Research in Criminology (key informants and interview data) – comparative study.
- The involvement of people with learning difficulties in recruitment for pre-registration nursing and in curriculum planning.
- Manchester cohort transition to adult life – large scale longitudinal study.
- Information needs of children and adolescents with epilepsy.
- Evaluation of people's participation in arts projects.
- Interpretation of White Paper from the perspective of people with learning difficulties.
- Ageing.

Figure 1 Dimensions of Research Activity



Focus on staff

- Participant observation study of attitudes towards signing (part of audit outcomes for clinical psychologists).



- Practice and policy issues to do with sexuality.
- Career destinations for nursing and social work students – longitudinal study using questionnaires and depth interviews.
- Careers and service development in psychiatry and learning disability.
- Credibility of non-clinical managers in the NHS.
- Breast awareness in women with learning difficulties. Mixed method (quantitative, attitudes, questionnaire, shared knowledge). For MSc practitioner research.
- Attitudes of nurses and others to people with learning disabilities in general hospitals (questionnaire and action research workshops).
- Mastery motivation in babies (funded by Downs Syndrome Association).
- Standardisation and development of a competency framework to identify staff training needs on risk assessment.
- Teacher effectiveness in inclusive educational settings.

Focus on family members

- Cross cultural study of children and parents with learning difficulties.
- Hidden needs of people from ethnic communities.
- Continuing care needs of children with severe and complex disabilities.
- Disclosure of diagnosis (funded by Rowntree).
- Family support and disclosures of diagnosis of CP – also infants developing CP (NHS NTA funded).
- Fathers' responses to very pre-term babies.
- Expectations and stress experienced by families (NICU Hospital Trust funded).
- Evaluation of Lovaas interventions for children with autism.
- Family focus group study on access to hospitals. Tracking files. 'Traffic' procedures for discharge and journeys through hospital admissions.
- People with learning difficulties as family carers (43 people identified, questionnaire study).

Purpose of research

The following projects focused on services, with a view to understanding their impact or either implementing or evaluating change:

General services

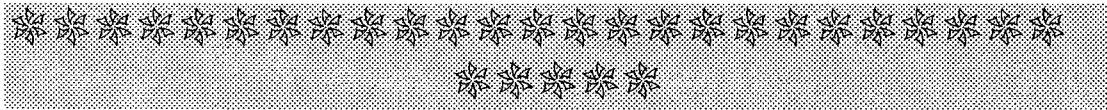
- Evaluation of value based services for the whole services. Questionnaires used before and after training. Encouraged team building and reflective practice.



- Identification of service gaps for people with learning difficulties who are homeless (and/or involved in substance misuse) in terms of health, social and education needs. Bottom up process starting with the people themselves.
- Census of people with autistic spectrum disorders and the identification of service development priorities. Incidence and prevalence of autism.
- Evaluation of language and communication therapy in prison, on re-offending behaviour.
- Action research approach to ethical decision making re. People with learning difficulties acting as witnesses.
- Impact of values led training on service provision.
- Health care needs within Merseyside Health Action Zone.
- Evaluation of person centred planning.
- Development of informal ways of gaining consent to medical interventions (needs evaluation).
- Person centred planning – the involvement of people with learning difficulties as trainers.
- Housing alternatives for people with ‘chaotic lifestyles’.

Health services

- Audits of dysphasia services; hearing impairment; services for people with epilepsy; autism – communications and challenging behaviour; admissions to acute psychiatric wards; psychotic medication; unmet health and primary care needs; patterns and referrals to learning disability services; medical audit on access to psychiatric services (quantitative data from hospital information systems and case notes).
- Outcome measurement of service for disabled children.
- Grounded theory study of risk, raising the dilemma of safety versus opportunities for people.
- Evaluation of treatment intervention for a sex offender, including assertiveness, physical health and CITC.
- Development of health assessment methods.
- Development of dementia screening tool.
- Cognitive-behavioural interventions with people showing psychotic disorders.
- Evaluation of cognitive behaviour therapy and anger management groups.
- Development of clinical practice guidelines.
- Early intervention and identification of psychotic episodes.
- Incidence of substance misuse.
- Multi-agency work on pathway to referrals for autism (statistics, case studies and focus groups).
- Quality of epilepsy management (case notes, check on records against established information).



- Psychological interventions for sleep problems in adolescence – exploratory study.
- Cardiac care: Information and assessment.

Residential care services

- Interview based study of deliberate self harm for offenders.
- The development of neuro-linguistic programming approaches for helping sex offenders manage situations.
- Quality of life in secure units (comparison with Holland) – interviews and standardised questionnaires.

Other services

- Evaluation of outreach studies beyond college (European Social Fund funding).
- Evaluation of citizen advocacy relationships.
- Impact of person-centred planning, staff competence and support to pursue religious interests.
- Use of words/symbols/pictures in day service contexts.
- Practitioner research - evaluation of 20 core signs.
- Service user and client centred evaluation of OT services.
- Evaluation of total communication system.

General Issues

Through the discussions, a number of issues were raised in terms of making it difficult to carry out or publish research, or to turn information gathering into research. A lot of activity revolved around audit. A range of different methods of data collection (and fewer of data analysis) were mentioned, including

- | | |
|---------------------------|-----------------------------------|
| • participant observation | • personal accounts |
| • outcome measurement | • audits |
| • surveys | • use of pictures and photographs |
| • use of questionnaires | • mixed methods |
| • interviews | |
| • focus groups | |

Not everyone felt knowledgeable about them all. Some features of the general context were thought to enable more extensive research activity and some features were thought to inhibit it. Figure 2 summarises the enabling and hindering features.

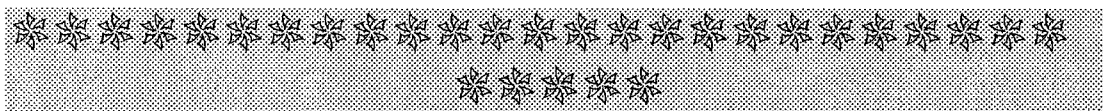
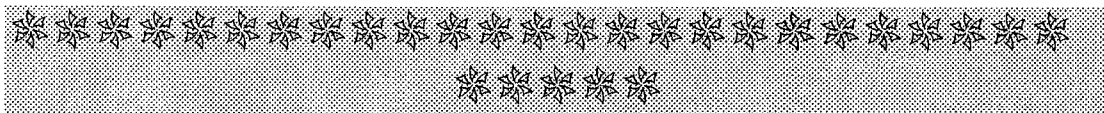


Figure 2: Enabling and hindering features of the context of learning disability research

| Enabling features | Hindering features |
|--|---|
| Who does the research? People with learning difficulties more and more involved in research activities Some people are working towards MSc, MPhil or PhD. University staff collaborate more Some international links Some organisations encourage Support for the development of research capability in the health service Some international collaboration (e.g. North America; Venezuela; Spain; Holland) | Who does the research? Not all staff feel confident in participating in research Relatively little cross-sector collaboration Some organisations discourage and fail to give support Health service dominated. Little culture of research mindedness in other sectors Marginalisation of learning disability with limits on funding opportunities Time and staffing in short supply Fear of research and need to encourage people with skills to do research Lack of strategy in timing and lack of overall structure or organisation for co-ordinating research |
| What research is done Most research small scale, practitioner based Mostly low cost Quite a bit of practitioner research of direct relevance for service development and improvements for people The White Paper may lead to investigations about the role and futures of Community Learning Disability Teams; Management; person centred planning; short term breaks; minority ethnic communities. The White Paper legitimises leading edge work Some use of National priorities | What research is done? It is difficult to 'add on' research to professional practice Emphasis on narrowly defined 'evidence' underpinning evidence based practice Funding bodies favour quantitative research, statistics Sometimes conflicting agendas (between commissioners and participants in research) Political and ethical issues of different research strategies need to be better understood A lot of energy going into audits National priorities can stultify support for other investigations |
| How is the research done? Some use of courses to develop research skills Mostly low cost, but some funding obtained A range of innovative methods are being used | How is the research done? Lack of experience in applying for funding and lack of support for staff new to this Funders prioritise number based cause-effect research There is not widespread understanding of how participative processes, and indirect data collection methods can be introduced into research. Not everyone has a broad understanding of appropriate methodologies Ethics committees – how do they work and do they understand learning disability issues? |
| What happens to the research? Some research feeds into service improvements | What happens to the research? Little publishing of local findings goes on Barriers to implementing research – not everyone understands how to interpret findings Problem with what to do with research findings |

⇒ to move towards an effective learning disability research system, the enabling factors need strengthening and the hindering factors need weakening.



Four different approaches to research

Four talks were given about different kinds of research, ranging from participative life-story work with people with learning difficulties, work that involves collaboration between researchers, practitioners and people with learning difficulties; work on individual cognitive and neuro-psychological processes; and work with service providers on the quality of their services. These talks are summarised below.

This is your Life – Life History Work with People with Learning Disabilities - Georgie Lawson and Mark Naughton

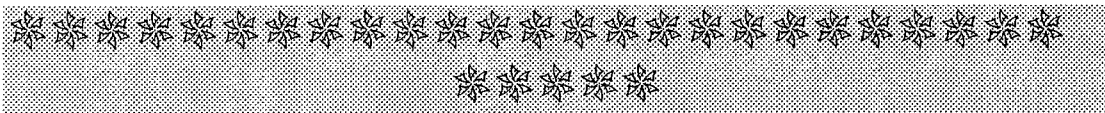
In recent years there has been increased awareness of self-advocacy initiatives amongst various groups and the need to consult with service users about the provision and development of services. There has been a body of work on the topic and I have been involved in research in the area of developing partnerships with people who have a learning disability.

The research presented in this paper was undertaken as part of a 2 year project that looked at enabling adults with a learning disability to have input into the planning and running of services they receive. The research was undertaken using an 'action research' approach, developing ideas alongside the major stakeholders – staff, managers, parents/carers and fundamentally service users; enabling people to put ideas into practice; and then evaluating the process and outcomes and producing a report.

The work we will be describing involved looking at ways of people being more actively involved in 'planning meetings' / reviews etc. We will be looking at the background to individual planning and the role of life history work in this process; looking at one particular case study; and sharing with you our thoughts on the process and the outcomes.

Research methods will be discussed, and comments made on the role of researcher as participant, as this was a qualitative piece of research, which employed both participatory, and action research approaches.

For further details about this talk, please see appendix 1



Collaboration and a consumer involvement project - Jackie Kilbane and Melanie Chapman

The presentation considered some of the salient issues regarding collaboration and research with people with learning disabilities, drawing upon the experiences of both the researcher and the researched. The areas explored included:

- Why collaborate?
- Collaboration for what?
- Collaboration for whom?
- Collaboration for all?

The project that formed the focus of the research established a consumer involvement group to comment on issues of service quality within a statutory organisation supporting people with learning disabilities. The research aimed to document and critically analyse the group's development, explore the impact on service delivery, and inform future consumer involvement initiatives.

For further details about this talk, please see appendix 2

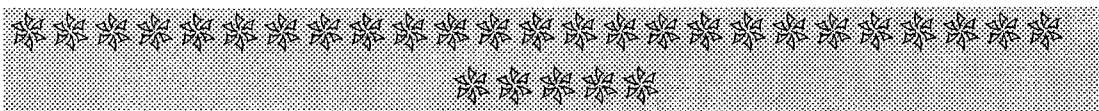
Beyond the Black Box: Developing research into learning disability from a cognitive neuropsychological perspective - Dougal Hare

Much research in the field of learning disabilities has been focussed on a social constructionist model of disability, with both implicit and explicit criticism of research from a positivist scientific perspective. The current paper argues that implicit in the social construction account is a view of people with learning disabilities which reiterates the "scientism" of previous behaviourist research. An alternative biopsychosocial model for research into what is termed learning disability, drawing on contemporary work in developmental psychology and cognitive neuropsychology is presented, together with examples of such research and its relevance to clinical practice and service delivery.

For further details about this talk, please see appendix 3

From Research to Practice (and Back Again): Monitoring Quality in Supported Accommodation for People With Learning Disabilities - Eric Emerson

The Hester Adrian Research Centre and the National Development Team were funded between 1996 and 1999 by the NW Regional Office of the NHSE to develop an audit process and materials for monitoring quality in supported accommodation



for people with learning disabilities (the NW Audit). The product was a two-tier approach to audit involving:

- Simple paper and pencil self-completion measures that could be used across all (or a significant proportion) of people for whom supported accommodation was being purchased
- A detailed team visit that could provide an in-depth analysis of quality for a small number of people for whom supported accommodation was being purchased

Since that time we have been working with Local Authorities (and a few NHS Trusts) in an attempt to further refine the paper and pencil self-completion measures and to develop ways in which the use of these measures can be integrated into routine practice (e.g., used within Best Value reviews). To date information has been collected across 8 local authorities and 2 NHS Trusts on 1,300 people with learning disabilities.

This has allowed Local Authorities to compare practice

- across providers from whom it is purchasing residential supports (within-LA)
- with providers from whom other Local Authorities are purchasing residential supports (across LAs)
- with nominated 'better' providers

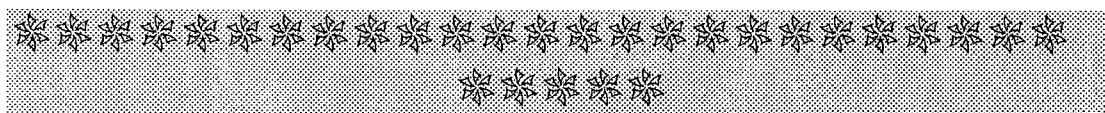
Access to this data (in anonymous form) also provides an opportunity

- for us (as applied researchers) to explore patterns and predictors of outcomes (e.g., medication use, obesity, physical exercise, social and community activity) in large 'typical' samples
- for those involved in wider policy to monitor progress and variation across wide areas.

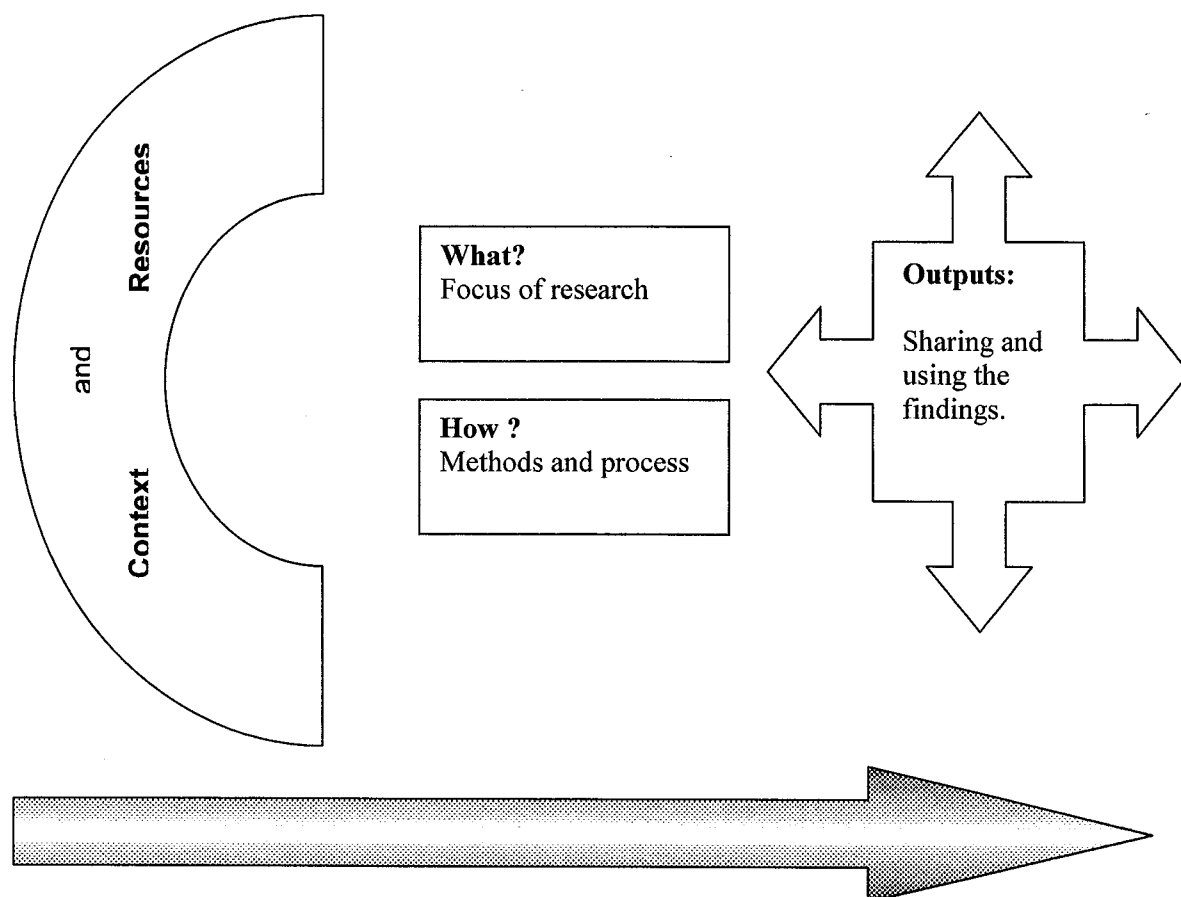
For further details about this talk, please see appendix 4

Ideas for the future work of the collaborative group

The afternoon discussion groups at the conference were asked to identify the barriers to research and development in learning disability contexts across the region. They were then asked to make suggestions for the most useful things the collaborative network could offer.



It may help to consider a simple framework for understanding how research gets done:

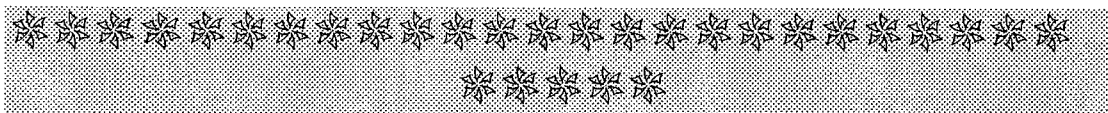


Context and Resources

Research activity takes place within a particular context and depends on the availability of resources.

Most barriers were identified here, and included:-

- Time for research or research related activity
- Money – for example to replace staff time or for equipment and materials
- Staff to participate in research or to carry it out
- Communication – about opportunities for funding, training, or about research initiatives or the purposes of research
- Organisational and service cultures that can be unsupportive of research
- Uni-disciplinary or uni-agency focus in many projects



- The separation between services and academia.

The collaborative network could assist by:-

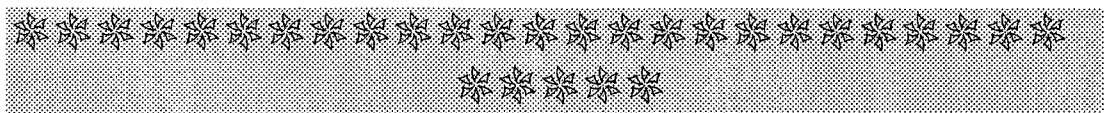
- Publicising resources – sources of funding, advice, student researchers needing projects.
- Promoting research as an important and legitimate activity for service development.
- Promoting and facilitating co-ordinated and linked bids (rather than competition for limited funding).
- Systematically build up programmes collaboratively.
- Submitting perspectives on research priorities to funding bodies.
- Connecting research active people to reduce isolation, and to provide reciprocal support.
- Publicising research and development that is going on, to encourage an investigative culture.
- Promoting and facilitating interdisciplinary and interagency work.
- Bringing academics and practitioners together.
- Acknowledge the value of small scale low cost research.
- Distribute contact lists.
- Establish networks of people doing / interested in similar research.
- Helping to bring a culture of research into Social Services.
- Establish a web site – broadening from the North West.
- Provide information on internet access.

What ?

This concerns the focus of the research – what is to be investigated, and why? Who decides? How to add to what's being done rather than duplicating?

The collaborative network could help here by:-

- Arranging topic based conferences and events.
- Share protocols and designs.
- A list of research that is going on – a 'Regional Learning Disability Research Register' – not just for the NHS.
- Establishing means for sharing ideas for projects.
- Emphasising the importance of collaboration – building on networks already in existence who know what the questions to ask are.
- *Research Focus* themed for common interests.
- Seminars to look at the research agenda implied by the White Paper *Valuing People* – taking our own strategic approach.
- Involve learning disabled people, and parents in setting the local research agenda.



- Always ask the 'so what' question – to keep it relevant to people who are learning disabled.

There were also some specific ideas on what needs to be researched.

How?

This concerns not just the research methods used, but also the wider process of the research – how we conduct ourselves as researchers in relation to the people the research is about, and the people and organisations that support them.

The main barriers identified here were the skills, knowledge, and confidence to conduct acceptable research studies.

The collaborative network could help here by:-

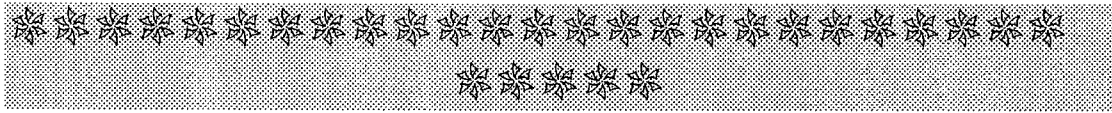
- Facilitating advice and providing information on methods – within a broadened definition of what methods are available and legitimate.
- Linking less and more experienced researchers to increase quality and confidence.
- Promoting plurality of research styles and approaches.
- Sharing findings, positive, negative, and information on the practicalities – mistakes and solutions.
- Contact list, web site, topic based networks, again.
- Setting up a panel of people prepared to comment on proposed projects, proposals.
- Giving information to ethics committees on issues in research with learning disabled people (perhaps have a joint event on research ethics?).
- Sharing protocols and designs.
- Running a day looking at the 'how tos' / skill sharing workshops.
- Networking with editorial boards – discussing and reviewing what research is acceptable (and isn't!).
- Feedback on research that has been done successfully.

Outputs

Outputs covers sharing and using the findings: that is dissemination and implementation.

The collaborative group can help with this through:-

- Publishing findings, both positive and negative, through means such as the *Research Digest*.



- Developing a web site.
- Linking new researchers with co-writers or people to comment on drafts.
- Encouraging diverse ways of reporting – practitioner orientated digests, manuals, video, drama, workshops.
- Provide guidance on presenting studies (e.g. at collaborative network events).
- Run topic based conferences.
- Publicise research carried out regionally.
- Run workshops on implications of research for practitioners, learning disabled people, families, managers.
- Report to networks already in existence.

For a list of participants in the day, see appendix 5

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Appendix 1

THIS IS MY LIFE - LIFE HISTORY WORK WITH PEOPLE WITH LEARNING DIFFICULTIES

Presented by Georgie Lawson and Mark Naughton.

Setting the scene

The research took place in services for people with learning disabilities across both Social Services and the Health Authority. My relationship with the agency at this time was that having been employed for many years directly in day services at both a direct care and managerial level, I had been seconded for 2 years to a project called Developing Partnerships with Service Users.

The project had been instigated as a development of work I had been doing around self-advocacy for some years and also in response to policy and guidance suggesting that services should be developing strategies for involving people.

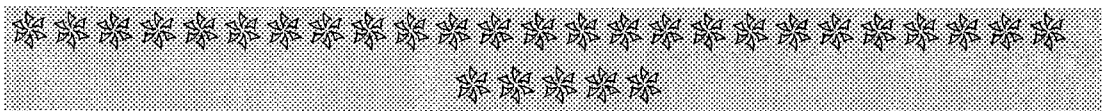
Current emphasis on participation

In recent years the need for partnership and the need for social services to elicit the views of users and give them a say in the development and delivery of services, has been emphasised by both the Children Act and the Community Care Act.

"By the mid 1980's two things were evident from research studies; that greater respect *could* be accorded to user views, and that this *would* be likely to lead to improvements in service." (Marsh, P. and Newton, C. 1993)

To do this however service systems may need to adapt. Community care was held up as an opportunity to empower service users by changing the service system, or in this case including service user consultation in its strategies (Dowson, 1997).

"The development of needs-led assessment and care management systems will help to promote user-led services, as well the division of social services into separate purchasing and providing functions. Increasingly, social services organisations, in both the statutory and voluntary sectors, are placing user involvement at the centre of their purchasing and providing functions." (Morris, 1994. Pg.28)



Disabled people are no longer satisfied with being the subjects of research, research which is defined by academics and funding bodies, principally for their own consumption (Minkes et al, 1995). Pressure groups and self-advocacy groups are wanting to be involved in the commissioning and planning stages, and fully involved throughout.

"one role of social research is to make space for the voices to be heard of those who do not usually get a hearing"
(Sapsford and Abbott, 1992. Pg. 159)

Methodology

My research questions were developed as a result of earlier work I had undertaken.

1. **Can service users (and service workers) promote self-advocacy from within?**
2. **Can giving people with a learning difficulty skills with which, and opportunities to, express themselves, effectively change the way services are planned and delivered?**

Oliver (1992) argues that 'research on disability has had little influence on policy and made no contribution to improving the lives of disabled people.'

3. **Are services willing to take on board and act upon the expressed opinions of people with learning disabilities?**

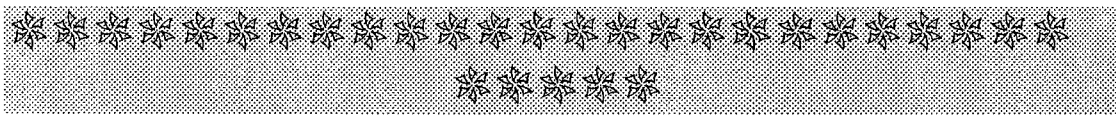
The research involved

- a. looking for models of good practice in this field;
- b. implementing such strategies as would seem to be indicated by the research undertaken;
- c. evaluating the effectiveness of these strategies in achieving their objective.

It was hoped that this research would produce the following general outcomes

1. Recommendations to change service practice.
2. A shift in emphasis in staff training.
3. Learning disability services, as a whole, would involve service users more in service planning and development.

I decided on adopting an action research approach because I wanted to implement work based on what people delivering and receiving services were telling me was



important; and because the projects were being developed alongside stakeholders they would naturally evolve.

So although more traditional methods are used as part of the process of data collection, the way in which they are used and the way the information collected is used, is influenced by the fact that the action research approach presupposes ongoing analysis and change. Many writers talk of the cyclical nature of action research (Lewin's model of action research). It is this adaptability and the notion of involving participants in the process that the author saw as the main advantage of adopting this approach.

"it should be clear that no ideal design blueprint for research on disability can be provided in advance, for satisfactory research can only be constructed by researchers and disabled people participating in the joint enterprise." (Swain et al, 1993. Pg. 66)

Collaboration means that the researcher should involve people in the planning stages; ask for participants' views on the process; and check out conclusions and recommendations.

Collaboration, according to Bell (1987), implies that the researcher should tell people what to expect, should ask for their views, and should check out conclusions and recommendations with them.

The most significant problems with this kind of research are:

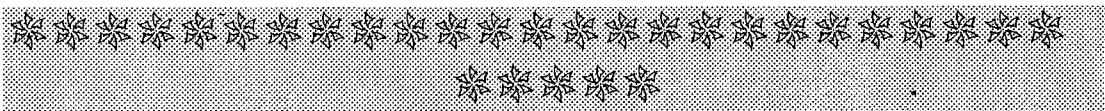
- *Participants know they are part of the research process and so react accordingly (the Hawthorne Effect);

- *Generalisability - will what we have discovered apply elsewhere in similar circumstances.

- *Reflexivity - objectivity could have been compromised. The problems of establishing detachment, standing back from one's own involvement in order to record accurately what is taking place are difficult to overcome but must be achieved.

- *Expectations of stakeholders I power issues - The author was aware that those senior managers who had sanctioned the Project and supported funding applications had expectations, as did the first line managers who actively supported the work in the second stage of the Project. There were no guarantees of course that outcomes they might have expected would be achieved.

- *Ever changing nature of action research - action research of an undertaken over a long period of time, can only be successful if there is commitment of the people



involved. The author feels that this was one of the most important factors in the success of the piece of work.

Involving learning disabled people throws up some other important issues- perceptions of people's ability to take part; issues around communication; and making materials used accessible. We will be looking at these in more detail.

Project outline

Having spent the first six months carrying out research at a wider level across services locally, and looking nationally at new initiatives in learning disability services, I had suggested 5 more specific pieces of work that could be carried out in the remaining 18 months (pilot projects) and it is one of these that Mark and I are going to talk about.

Researcher as participant

Undertaking research in an organisation I have worked for as a manager; with people known to me; and in the area where I live obviously had both advantages and disadvantages.

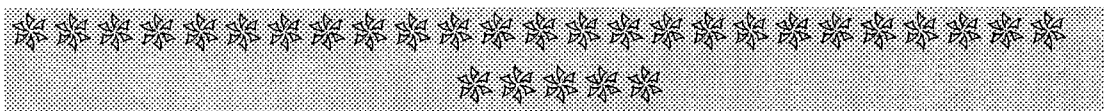
Being part of the process

Bell (1987) in describing insider research looked at both the pros. and the cons. of this position.

The pros. she identified as knowledge of the context of the research and of the micropolitics of the organisation; travel not being a problem; subjects easily reached; and the researcher will have insight into how to approach individuals. I had knowledge of the organisation and of individuals involved in the research and acknowledged the effect it had on the process. It has to be said that I did not always find these things worked in my favour.

The cons. Bell (1987) states were that interviewing could be uncomfortable for both parties; the researcher has to live with their mistakes; objectivity can be difficult to attain; access to confidential knowledge; research 'over-taking' practice; respondents try to please the interviewer (especially service users); vague antagonism; the difficulty in standing back from your own involvement; abuse of relationships. Getting caught up in the doing and not reflecting adequately on the way the work is going was often a possibility and I certainly wrestled with all these constantly.

It is therefore indisputable that in this case that values both personal and related to historical context, influenced the nature of the research but the author then needed to



be particularly careful in evaluating its success not to select evidence on this basis but rather consider all the evidence. The researcher needs to avoid bias but "this does not mean that moral indifference can be accepted." (McNeill, 1990.)

"Agenda setting, whether it be in politics, policy making, or service provision, is part of a process of struggle and this is equally true of agenda setting in disability research." (Oliver, 1990)

BACKGROUND

PLANNING WITH INDIVIDUALS

Why the current interest in planning with individuals?

The notion of planning for and with individuals has been around in learning disability services for almost twenty years. The White Paper, 1989, outlined changes amongst which was "giving people a greater say in how they live their lives and the services they need to help them to do so" (Department of Health, 1989, Pg. 4), and the National Health Service and Community Care Act, 1990, attempted to address this issue.

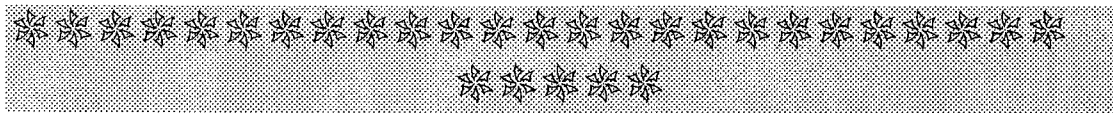
Malin (1995) talks of the principal changes outlined by the Community Care Act as being community care planning, case management and assessment, quality and inspection and extended use of purchasing services from the independent sector. The assessment spoken of refers to a service user's (or potential service user's) right to an assessment, the authority then having to make a decision 'having regard to the results', whether to provide a service or not.

Why it is important.

Our role as professionals. Simons (1995) suggests that professionals often define need solely in terms of the services that are available. Often little or no attempt is made to involve service users, families/carers in a positive pro-active way.

To some care management can seem as though it is "primarily a bureaucratic and organisational response to the problem of targeting resources and containing public expenditure" (Platts, 1995). It can appear as though setting up systems and having written procedures has become the focus. Consequently "assessments and I.P.P.s are based on forms and other official, written materials that make it difficult for service users and their families to share in the decision making process." (Platts, 1995 Pg. 134)

How to go about it.



Simons (1995) states that service users often feel more positive about the process when

- they are the main focus, are listened to.
- .action results which reflects their priorities.
- .they have some control over the process, who attends, where etc.
- .when they help to prepare.

The recent White Paper, Valuing People, states as Objective 3 that people should have "as much choice and control as possible over their lives through advocacy and a person-centred planning approach to planning the services they need". (Dept. of Health.2001. Pg. 26). Sanderson defines this process as "learning about a person; who they are; what has happened to them; what is important to them; what they like and dislike; and what they want from life." (Sanderson, 1998. Pg. 163). However there is pressure on care managers to adopt a procedural model of assessment as from the service point of view it is the quickest, simplest and fairest approach.

SKILLS FOR SPEAKING UP

For people to speak up for themselves, to know their rights, requires a certain skill level and personal attributes which people with learning disabilities have often not acquired. Again time and resources need to be invested.

So it is not the case that these skills can be learnt in a time limited way, separate from anything else, but that they are acquired as part of the process of becoming empowered.

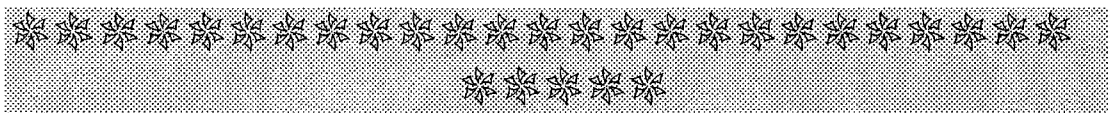
LIFE HISTORY WORK AS AN AID TO PLANNING.

Hilpern (1998) describes life history work and books as providing a real sense of self for those people who have had their stories documented in some way. However too often efforts are half-hearted or rushed.

Enabling people with learning disabilities to tell their story is one way of helping them

reassess the past and, perhaps to emerge with a much more positive sense of identity. (Simons, 1995 Pg. 176)

For people who have spent a long time in institutions of one sort or another it is often very difficult to put together histories. He also goes on to say that examining individual histories, as a basis for planning, is useful because it encourages professionals to reassess the impact of the services they provide. Atkinson (1998) talks of "empowerment through oral history and personal stories and says that on a



personal level it "it presents the ideal opportunity for people with learning difficulties to look back at, and make sense of, their own lives

MARK'S STORY

Mark is a very able young man in many ways and at the time of the work we are going to talk about was living independently with minimal support, and accessing various activities locally.

He had been experiencing problems where he lived which had given cause for concern, not only to the staff team that provided support, but also to his parents. I knew Mark because he had attended a personal development course I ran some years before. Mark is articulate in one-to-one situations but finds it difficult to express himself adequately at meetings.

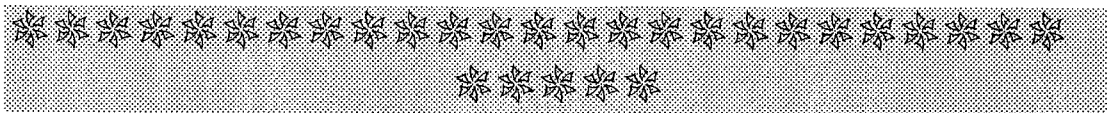
CASE STUDY

I explained to Mark about the work I was doing on futures planning and asked him if he would be interested in taking part. We spent time discussing how he might overcome the difficulties he was experiencing, given that it appeared that it would become necessary in the not too distant future for him to attend meetings to discuss his future.

As Mark had good language skills and plenty to say about his past, present and future, we decided to move away from using photos as an aid to discussion and make a video that he could use at meetings. Mark compiled a list of things he would like to include on his video, things that had been important landmarks in his life or hobbies that he was interested in. He was keen to include music on the video and as not everyone in his immediate circle was keen to be filmed we decided it would be necessary to use photos. He also decided to include photographs of favourite places and holidays.

I sought advice from a media consultant I had met through other work and a final format was agreed upon. I would interview Mark telling his life story and talking about his life now and this interview would be filmed. The resulting tape would be edited and photographs and other film footage (some shot by the Mark himself) would be inserted to illustrate what he was saying. This work took place over several months.

The resulting 20-minute tape could then be shown, as a preliminary to any discussion of his future needs. The tape clearly demonstrated Mark's life experiences but the viewer would also hear those experiences described, sometimes quite emotionally,



by him. The powerful image this portrayed was something that could not have been produced in a formal meeting setting.

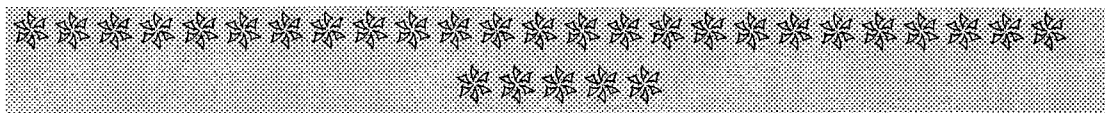
When the video was completed it was arranged Mark and I would meet at his parents' house in order that they should view it. The video prompted much discussion around incidents in his life that had led him to the position he was now in and much information that was new was gained. His mother remarked that some of the things her son had said on the tape expressed feelings she had never heard him mention before; and also she did not realise how vividly he could recall things that had obviously been very important to him (such as the way he had been treated at school). He had been able to say to camera perhaps what he found difficult to say to them in person.

WHAT DID WE LEARN

There have been various meetings at which Mark's difficulties have been discussed since the video was made, and he has shown the video to people who are involved in helping him make decisions about his future. He found the whole process stimulating and watching the finished video gave him a sense of achievement. He has reported that using the video at meetings has enabled him to feel more confident about expressing himself.

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Appendix 2

Collaboration and a Consumer Involvement Project

Jackie Kilbane

Senior Quality Development Officer

Melanie Chapman

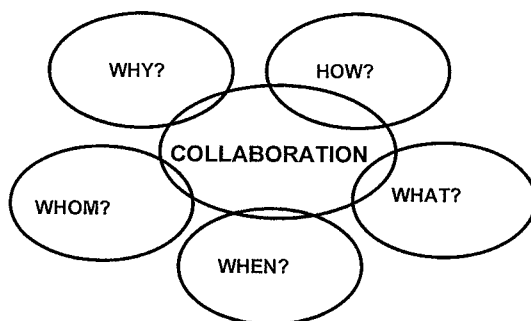
Research Associate

Manchester Learning Disability Partnership

Background to Project

- Manchester Learning Disability Partnership decided to establish a group to widen the contribution made by people with learning disabilities to quality and development within the service
- The research project aimed to describe and evaluate the development of this group using *Participant Observation*

THINKING ABOUT COLLABORATION



WHY?

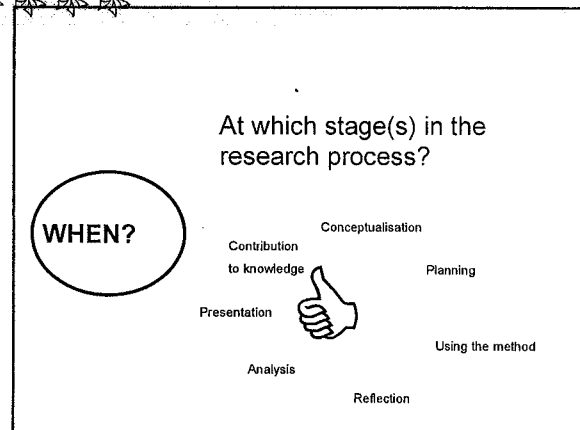
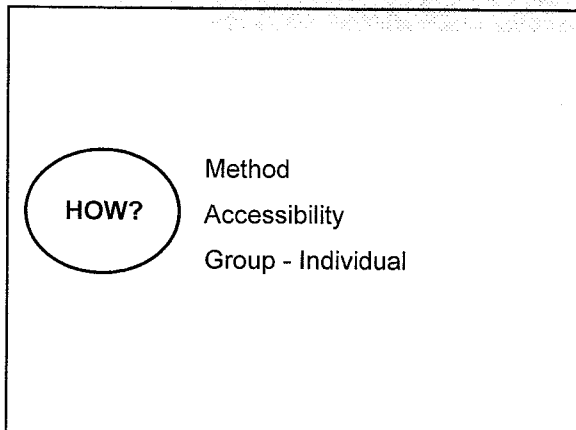
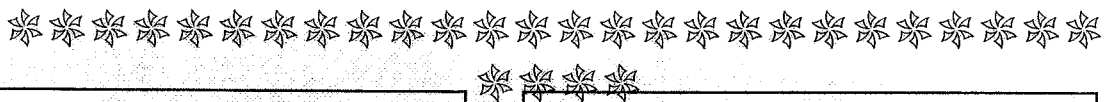
Shift balances of power and control
Raising voices
Policy guidance

WHAT
FOR?

Give voice to participants
Increase quality of research
Varies according to the research question

WITH
AND FOR
WHOM?

Stakeholders:
People with learning disabilities
Carers
Advocates
Service providers
Service commissioners



Practicalities

- Discussion - aims, methods, analysis
- Circulation of drafts for comment
- Introducing self and research
- Openness
- Balancing demands of research and development of group
- Co-researcher

And finally.....

- Chaotic, messy and uncertain
- Learning about collaboration (its uses, potential and limitations) comes from *doing* collaboration
- Potential conflicts between stakeholders
- Different levels of collaboration, participation and involvement
- Linking back to 'why?' and 'what for?'



Appendix 3

Beyond the Black Box - Developing research into learning disability from a cognitive neuropsychological perspective

Dougal Julian Hare - Clinical Psychologist
University of Manchester / Manchester Joint Partnership for Learning Disabilities

An argument for a particular type of research based upon:

- Examinations of dominant paradigms in learning disabilities research
- Why cognition matters
- A new approach to understanding learning disabilities from a cognitive neuropsychological perspective
- What research could be undertaken with people with learning disabilities

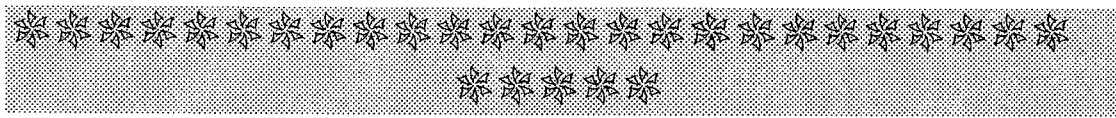
Behaviourist psychology

Much psychological research with people with learning disabilities has been and continues to be profoundly influenced by the Behaviourist psychology of Skinner

- Person as blank slate
- Environmental contingencies as primary (only ?) influences on behaviour
- No unobservable or metaphysical elements permitted
- Little interest in inner world of person, except as reflecting 'lawful' patterns of contingencies and responses

Cognitive revolution in psychology

From early 1970's to the present day, a dominant mode of investigation and explanation in psychology has been the cognitive model



- Information processing processes and structures paramount
- Analogy of computer program
- Active engagement with environment
- Internal to person
- Dynamic processes
- Increasing investigation into relationship between cognitive processes (“mind”) and human physiology and neurophysiology (“brain”)

Learning disabilities research and the “cognitive revolution”

- Cognitive approach in psychology coincided with social constructionism
- Social models of disability dominant in both service provision and research in field of learning disabilities
- Cognitive psychology included within notions of “medical” models of learning disabilities, being described as positivistic and empiricist
- A persistence within the field of learning disabilities of simplistic reified models of “IQ”, often coupled with simplistic genetic determinism

But ...

Does a lack of interest in neurocognitive functioning combine with the subtle tendency to ‘victim blaming’ in normalisation to the detriment of people with learning disabilities ?

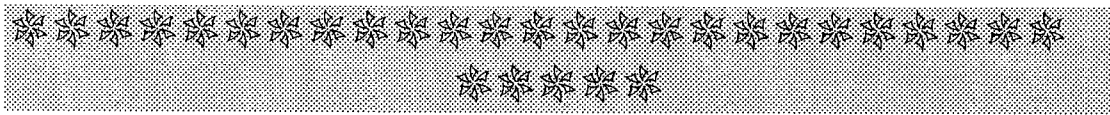
Cognitive models in learning disability research

Three main areas of research can be identified:

1. Attempts to map patterns of cognitive functioning by age and/or syndrome

Many such approaches still heavily driven by *technology* of psychometrics, rather than cognitive neuropsychology research and theory.

2. Investigations of specific cognitive processes using ‘dissociation of function’:



- Theory of mind research in autism
 - Visual perception in Williams syndrome
 - Executive functioning in Prader-Willi syndrome
3. Research into brain and behaviour facilitated by an embodied cognitive neuropsychology:

Research into relevance of site of self-injurious behaviour and possible relation to endogenous analgesic systems

Why do we need to carry out research from a cognitive neuropsychological perspective with people with learning disabilities?

- To prevent victim-blaming – the ‘forgetting’ of learning disability
- To build up accurate information about cognition and neuropsychological functioning in people with learning disabilities:

How much “normal” functioning in people with learning disabilities is misinterpreted as psychopathology and chemically treated?

We don’t know ...

- To understand therapeutic approaches and develop them further:

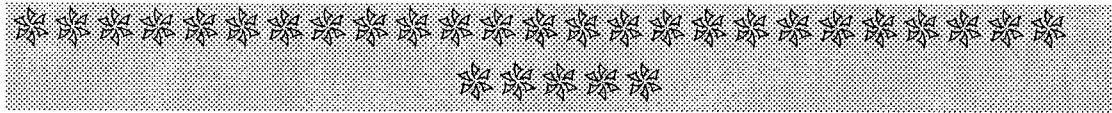
Sensory integration is increasingly used with people with learning disabilities, but according to theories of cognitive psychology it should not work ...

A research-derived understanding has shown intensive interaction to be ‘contra-indicated’ for people with autistic spectrum disorders

- To take account of contemporary research and theory in cognitive science

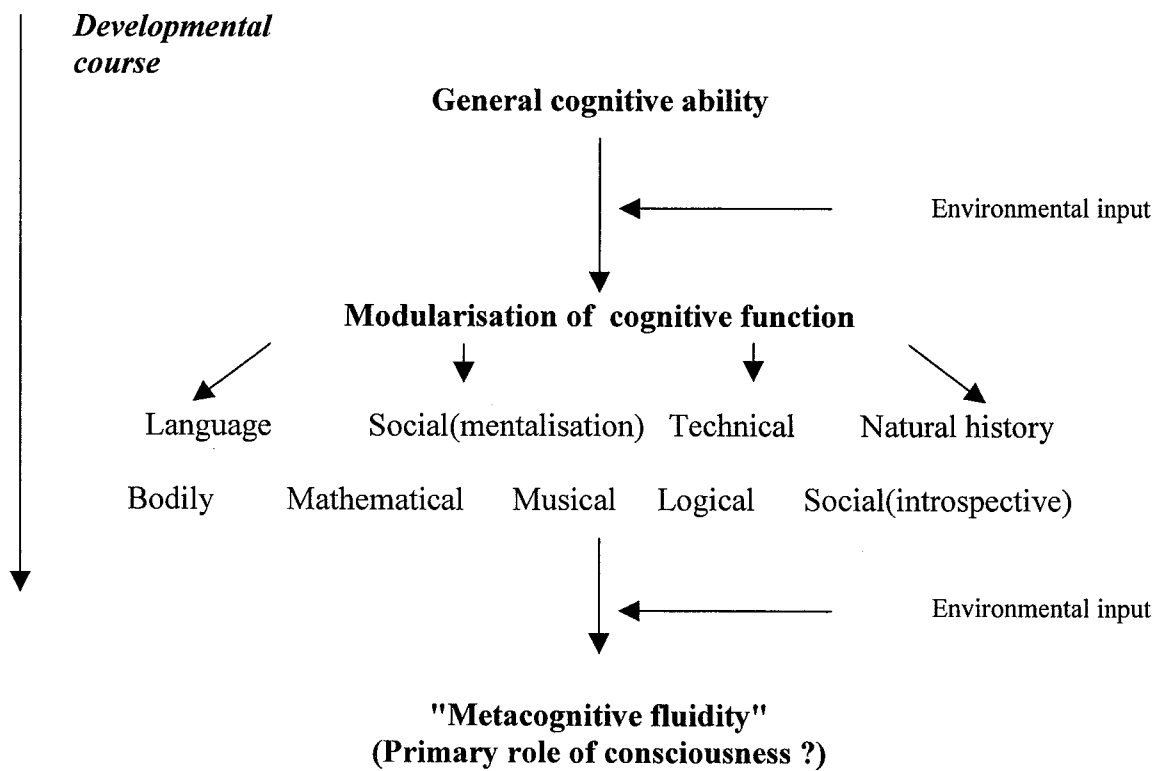
Much research in the field of learning disabilities either:

- *Makes use of outmoded concepts of “IQ”, or ‘g’*
- *Ignores cognitive processes all together (or makes lay assumptions about people with learning disabilities)*

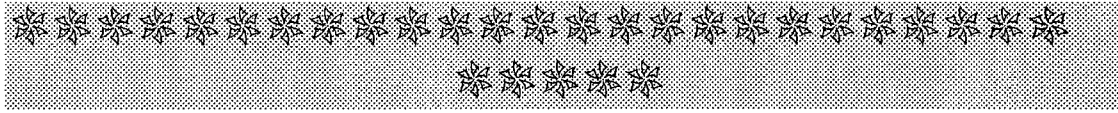


- *Brains* make themselves
- Brains and environments make *minds*
- The brain-mind system is not a general-purpose computer

Generalised model of cognitive development



After Mithen (1996)



This enables learning disability to be variously re-conceptualised as:

- Effects of genetic difference prior to post-natal development
- Impaired general cognitive ability
- Failure of one or more modules to develop (e.g. mentalisation in autism)
- Failure to develop metacognitive fluidity essential for rapid and flexible learning

Role of consciousness

Conclusions

An important aim of working with people with learning disabilities is to reduce their isolation from the non-learning disabled.

The integration of contemporary cognitive neuropsychology into clinical research practice is a small step in this direction.

Appendix 4

Monitoring Quality in Supported Accommodation

Why Invest in Monitoring?

- Reducing inequalities
 - Geographical
 - Organisational
 - Race, culture & gender
- Current performance falls short of our aspirations (but does represent an historical improvement)

The NW Audit: Aims

- To develop an audit process which will provide accessible and relevant information on outcomes to ...
 - providers of residential supports
 - purchasers
 - users
 - user's families
 - advocates

What Do We Mean by Quality?

- Focus groups/interviews with stakeholders to identify relevant outcomes
- Questionnaire to prioritise outcomes

Indicators of Quality

- | | |
|---|--|
| ■ choice over day to day matters | ■ user satisfaction |
| ■ emotional & social support | ■ practical support (everyday participation) |
| ■ day-time activities | ■ safeguards from abuse |
| ■ relationships with families | ■ practical support (general lifestyle) |
| ■ respect, commitment & motivation of staff | ■ user preference over daytime activities |

Similarities & Differences

- General agreement
 - highest ... managers & professionals
 - lowest ... users & purchasers
- Key differences
 - friendships with people who do not have learning disabilities (users > inspection officers)
 - appearance of users (families > professionals)
 - having a front door key (users > everyone)

Monitoring/Auditing Quality

- **Systemic monitoring**
 - questionnaire completed by provider
 - comprehensive
 - need, inputs, 'hard' outcomes
- **Person-centred audit**
 - participant observation & interview
 - sampled
 - organisational process, 'soft' outcomes

Standards

- **Activities & Relationships (4)**
 - work/leisure activities outside of their home
 - participation in everyday activities within the home
 - support to keep in touch with their family
 - help to meet people outside of their service
- **Choice (3)**
 - day to day
 - with whom & where they live
 - influence over supports provided

Standards

- **Health & Security (5)**
 - Healthy lifestyle
 - Generic & specific health needs
 - Emotional support
 - Freedom from exploitation & abuse
 - User satisfaction

Standards

- **Staff & the Service (6)**
 - Clarity about aims
 - Staff qualifications & experience
 - Role clarity & accountability
 - Supports responsive to individual need
 - Staff respectful
 - Commitment & motivation

The Audit Process

- **Recruitment of team (users, carers, providers, purchasers ...)**
- **Training**
- **Identification of 'focus' users**
- **Visit(s) in pairs**
- **Feedback & debrief**

Results

- **To date**
 - Information collected in 2000/01 by seven SSDs in North
 - 1,254 people with learning disability
 - 54 to 254 people per authority
 - Variety of sampling methods

The People

- Gender
 - 53% men
- Ethnicity
 - 98% white
- Age
 - 70% over 40
 - 26% over 60
- Additional Needs
 - 28% epilepsy
 - 19% sensory impairment
 - 42% challenging behaviour (16% within last month)
 - 26% reported psychiatric disorder

The People

- Moved from ...
 - Hospital (30%)
 - Family (21%)
 - Hostel (14%)
 - Group home (11%)

The Nature of Supports

- Registration status
 - User tenancy (64%)
 - Registered RCH (16%)
 - Small CH (8%)
 - Nursing home (5%)
 - Adult placement (5%)
 - NHS (2%)
 - Home owner (0.4%)
- Separation of housing and support (70%)
- Housing managed by
 - Housing Association (49%)
 - SSD (13%)
- Support managed by
 - SSD (80%)
 - Voluntary org (16%)
 - NHS (12%)
 - Private org (9%)

The Nature of Supports

- Size
 - Average 4.7
 - Range across SSDs 3.3 to 10.6
 - 40% living with two or fewer other people, 10% living with six or more other people
- Staffing ratios (staff per user)
 - Average 1.6
 - Adjusted range across SSDs 1.1 to 1.9
- Staff Training (50% of staff group received training in area over last year)
 - Moving/lifting (69%)
 - First Aid (55%)
 - Health & Safety (50%)
 - Individual planning (35%)
 - Challenging behaviour (35%)
 - Health (35%)
 - Abuse (29%)
 - Sexuality (20%)
 - Teaching new skills (15%)
 - Complaints (12%)
 - Advocacy (12%)

The Nature of Supports

- Staff Roles
 - Advocate (77%)
 - Social coordinator (60%)
 - Housekeeper (38%)
 - Friend (30%)
 - Teacher (24%)
 - Crisis manager (16%)
 - Chauffeur (7%)
- Keyworking
 - 81% have keyworker,
 - 61% have case manager
- Individual Plans (80%)
 - Common goals
 - Self care (62%)
 - Community activity (61%)
 - Social relationships (55%)
 - Social skills (52%)
 - Communication (50%)
 - Domestic activity (42%)
 - Transport (39%)
 - Challenging Behav (36%)
 - Academic activity (21%)
 - Sexuality (18%)
 - Work (17%)

Day Activity

- On the average people received
 - 16 hours per week of structured day activity
 - A wage of £1.37
- Type of activity (any degree of use)
 - ATC (53%)
 - Adult/Further Ed (20%)
 - Any employment (16%)
 - Voluntary work (10%)
 - Supported employment (9%)
 - Work experience (8%)
 - Sheltered employment (7%)
 - Open employment (2%)

Health Checks & Healthy Lifestyles

- In the last year
 - General health check (86%)
 - Dental check (85%)
 - Mammogram (18%)
 - Testicular check (12%)
- In the last two years
 - Vision (79%)
 - Hearing (53%)
- In the last five years
 - Cervical smear (30%)
- Physical Activity
 - Overall, 9% physically active (range, 4%-15%)
- Obesity
 - Overall, 23% of men clinically obese (range, 12%-36%)
 - Overall, 33% of women clinically obese (range, 0%-60%)

Challenging Behaviour & Medication

- Written programme
 - Overall 41%
 - Range across SSDS 10% to 80%
- Anti-psychotic medication (all people)
 - Overall 29%
 - Range across SSDS 20% to 97%
 - Polypharmacy 25%
 - Range across SSDS 6% to 59%
- Management of episodes of CB (of people who show CB, strategies used in last 6 months)
 - Seclusion (39%)
 - Sedation (26%)
 - Physical restraint (24%)
 - Mechanical restraint (2%)

Social & Community Activities in Last Four Weeks

- Social Activities
 - Overall 8 (range across SSDS, 6-12)
 - 66% had participated in at least one social activity with a friend with LD (range 54%-78%)
 - 24% had participated in at least one social activity with a friend who did not have LD (range 18%-36%)
- Community Presence
 - Overall 23 (range across SSDS, 16-34)
 - 98% had participated in at least one community-based activity (range 96%-99%)

Predicting Obesity

- Predicted with 75% accuracy by model containing following variables (in order of statistical significance)
 - Gender (woman)
 - Ability (more able)
 - Locality
 - Having moved into supported accommodation from family
 - Being supported by staff group who have had more training in area of health & safety



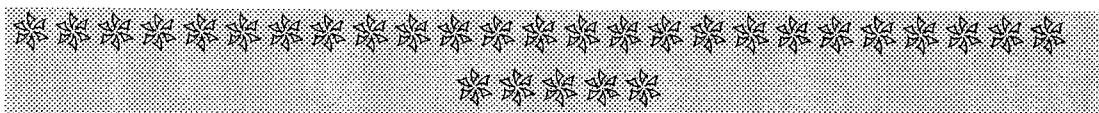
Appendix 5

Conference Participants

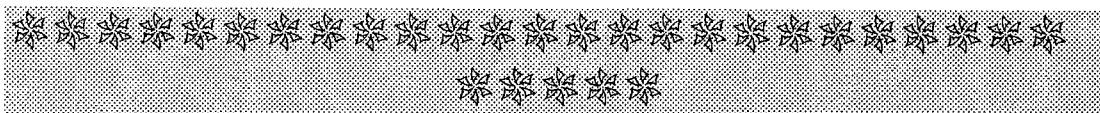
| | | |
|---------|----------------|--|
| Yvonne | Ashworth | CLDT - Altrincham |
| Sally | Adams | Bridges Learning Centre, Widnes |
| Paul | Anderton | University of Manchester |
| Angela | Anslow | Rochdale Healthcare NHS Trust |
| Barbara | Bailey | Whiston |
| Sandra | Bailey | CLDT – The Hesketh Centre |
| Carl | Bell | Oldham Learning Disability Service |
| Carol | Baker Longshaw | Trafford General Hospital |
| Mike | Bentley | Rochdale Healthcare NHS Trust |
| Mark | Burton | MLDP |
| Rachel | Brown | Salford Community Health Care |
| Sue | Caton | MMU |
| Mike | Craven | MLDP |
| Melanie | Chapman | MLDP |
| Helen | Cooper | Alternative Futures |
| Darren | Chadwick | MMU |
| Iain | Carson | Manchester University |
| Clare | Chappelow | Altrincham |
| Janet | Cobb | North West Training and Development Team |
| Dave | Clemmett | Cheadle |
| Rohhss | Chapman | Open University / People First |
| Louise | Darlington | Salford Community Health Care NHS Trust |
| Alison | Dunkerley | Manchester |
| Teresa | Davison | Learning Disability Service, Oldham |
| Su | Dutton | Leigh |



| | | |
|-----------|------------|--|
| Mike | Dignan | West Lancashire Primary Care Trust |
| Mark | Dyer | Mencap |
| Paul | Dulson | Mencap |
| Eric | Emerson | Lancaster University |
| Ruth | Evans | Manchester |
| Lynne | Elwell | |
| Maria | Farrar | Preston |
| Chris | Fieldhouse | Altrincham |
| Vince | Fraga | Learning Disability Service – Oldham |
| Ian | Fleming | Rochdale |
| Sarah | Gore | MLDP |
| Juliet | Goldbart | MMU |
| Sheila | Glenn | Liverpool John Moores University |
| Dougal | Hare | Manchester University / MLDP |
| Nicola | Hayton | Bridge College |
| Elizabeth | Hindley | Leigh |
| Laura | Horsley | Patterson Unit, Southport |
| Saeeda | Hussain | MLDP |
| Moirra | Johnston | Sefton Health Authority |
| Carolyn | Kagan | MMU |
| Gifford | Kerr | Salford and Trafford Health Authority |
| Libby | Kitt | North Mersey Community Trust |
| Jackie | Kilbane | MLDP |
| Chris | Lynas | Social Services, Wigan |
| Kate | Limb | MLDP |
| John | Lobley | Calderstones |
| Georgie | Lawson | Salford University |
| Chris | Linus | Leigh |
| Fiona | Marbury | Clayton Brook Clinic |
| Linda | Moss | Edge Hill College Aintree Complex |
| Joanne | Morris | Whiston |
| Judith | Millward | Bolton Adult Placement |
| Caroline | Malone | MLDP |
| Sandy | Millard | MLDP |



| | | |
|-----------|---------------|--|
| Stephanie | McComb | Wigan and Leigh NHS Trust |
| Duncan | Mitchell | Eccles |
| Trudi | Manning | Seymour Grove Health Centre |
| Carole | Nemec | Salford Community Health Care NHS Trust |
| Mark | Naughton | Salford University |
| Brenda | Nally | The National Autistic Society |
| Maria | Nelligan | Wirral and West Cheshire Community NHS Trust |
| Joanne | Osburn | Oak House |
| Pradig | Patel | Chorley and South Ribble General Hospital |
| Michelle | Perkin | MLDP |
| Ann | Parkinson | Clayton Brook Clinic |
| Lorna | Pink | Whiston |
| Catherine | Pratt | MMU |
| Linda | Prinsloo | MLDP |
| Dick | Perkins | Clayton Brook Clinic |
| Gill | Parkinson | University of Manchester |
| Carole | Proctor | Learning Disability Service, Oldham |
| David | Race | Salford University |
| Martin | Routledge | North West Training and Development Team |
| Steven | Rowe | John Mckay Clinic, Bolton |
| Judd | Skelton | Mencap |
| Maurice | Seisay | Stockport |
| Barbara | Speake | North Mersey Community Trust |
| Paul | Swift | IAHSP King's College London |
| Helen | Sanderson | |
| Caron | Swann | Liverpool John Moores University |
| Julie | Toms-Ashcroft | Edge hill College |
| Chris | Tupman | Bridges Learning |



| | | |
|----------|-----------|------------------------------|
| | | Centre, Widnes |
| Janet | Tusley | Cheadle |
| Jenny | Underwood | Chorley and South Ribble |
| David | Whalley | |
| Jim | Williams | North Mersey Community Trust |
| Richard | Whitehead | North Mersey Community Trust |
| Lorraine | Yearsley | Independent Advocacy |
| Sheila | Wright | Trafford general Hospital |
| Deborah | Windley | MLDP |
| Louise | Whiteland | MLDP |

inside bark coat

Book cover

