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Research to practice and people with learning disabilities: Better Services (1971) to Transforming Care (2012) - 40 years on, are services any better?

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A note on terminology and definition

There has been, and continues, considerable debate around terminology and people with learning disabilities across the time-frame of this thesis. In general, I use the term ‘people with learning disabilities’ within the thesis. This reflects its use both as the most preferred term, and as the most consistently used term, amongst people with learning disabilities and practitioners. Terminology in some of the older publications, and references to them in the thesis, differs in accordance with the convention of the terminology in contemporaneous use.

Learning disabilities is the term used in this thesis in the plural form to denote a range of abilities/disabilities in a range of people. Current Department of Health (DH) definition of *Learning Disability* in their policy and practice documents includes:

- significantly reduced ability to understand new or complex information, to learn new skills

- reduced ability to cope independently which starts before adulthood with lasting effects on development.

(Department of Health. Valuing People: A New Strategy for Learning Disability for the 21st Century, 2001).

Learning disability definitions usually include reference to impairment of intelligence (typically scored lower than two standard deviations below the mean on a validated test of general cognitive functioning/equivalent to an IQ score of less than 70), impairment of social functioning and onset in the developmental phase.

Abstract

The aim of this thesis is to present and critique practice and service development for people with learning disabilities across an extended time-period framed by two key events; the 1971 White Paper *Better Services for the Mentally Handicapped* and the BBC's 2011 Panorama *Undercover Care: The Abuse Exposed* which led to *Transforming Care* (DH, 2012). It does this through presentation of ten publications which demonstrate the application of psychology to the care of, and services for, people with learning disabilities in their policy and research context. A synthesis and critical analysis is developed and presented on the thesis *'Research to practice and people with learning disabilities: Better Services (1971) to Transforming Care (2012) - 40 years on, are services any better?'.*

The thesis demonstrates a range of applications of psychology through a range of staff with a range of people with learning disabilities in a range of settings. It critiques the theory, practice, methodology and policy described in the publications through the lens in which they were developed. The critique is then expanded and updated through the lens of current theory, practice and policy. It considers the conceptual and methodological development of my research, and builds on and extends my research findings with broader evidence including social and organisational factors.

The thesis demonstrates how the findings of the studies impact on practice and contribute to the evidence base. It also demonstrates how progress to implement research and policy in practice has been slow and identifies organisational and social factors in supporting, or acting as barriers to, high quality services. It links some of the issues identified to other current key care agendas such as the Francis Report (2013). Implications and recommendations are identified and include greater attention to organisational and social factors in achieving more effective research to practice.

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Many thanks to my supervisor, Juliet Goldbart, for her very wise and encouraging advice throughout; to Piers, Holly and Jess (my *home team*) for their enduring support and patience; to many inspirational colleagues, particularly those who collaborated with work described in the publications and those who kept me going, and, especially, the people with learning disabilities and families who have taught me so much.

Chapter 1

Introduction

1.1 Aims of the thesis

1.2 Structure of the thesis

Chapter 1

1 Introduction

1.1 Aim

The overall aim of this thesis is to present and critique practice, and service delivery and development for people with learning disabilities over an extended period with reference to the research described in the publications and other key research. The extended forty year period is framed by two key events; the White Paper *Better Services for the Mentally Handicapped* (DHSS, 1971) and Panorama *Undercover Care: The Abuse Exposed* (*BBC, 2011)* which led to *Transforming Care* (DH, 2012) . The thesis will identify factors supportive of, and barriers to, positive change, then present implications and recommendations relevant to care and service delivery for people with learning disabilities and other vulnerable people.

The thesis achieves this aim by presenting ten publications of which I am sole or joint author. These publications demonstrate contributions of psychology to the care of, and services for, people with learning disabilities across the time frame (1982 - 2012). This enables a “long view” to frame the presentation of, and reflection on, the selected publications, their critique and drawing of implications. This is particularly pertinent in view of current focus on services for people with learning disabilities following the Panorama television programme (BBC, 2011) exposing abuse at the private hospital, Winterbourne View, and the subsequent police, Social Services and Department of Health investigations , Care Quality Commission (CQC, 2011), Safeguarding Board (South Gloucestershire Safeguarding Adults Board, 2011) and Department of Health reports and recent Action Plan (2012$_{a,}$ 2012$_{b,}$ 2012$_{c}$). Some of the issues identified map onto broader current key care agendas such as poor care at Mid-Staffordshire Hospital and the subsequent Francis Report (Francis, 2013) and link to general health, care of older adults, and those with mental health difficulties and/or neuro-disabilities .

A synthesis and critical analysis is developed and presented on the thesis *‘Research* *to practice and people with learning disabilities: Better Services (1971) to Transforming Care (2012) - 40 years on, are services any better?* In 2011/2012, the Winterbourne View and CQC investigations revealed the continuing extent of poor care for people with learning disabilities. This is despite decades of policy, research and practice, illustrated by the publications presented, and other referenced studies which demonstrate effective psychological interventions with people with learning disabilities which contribute to good quality services and outcomes. Poor access to these interventions continues despite requirements of policy and practice guidance, legislation and regulation. An Auto-ethnography (Appendix 2) traces some of my early experiences as a volunteer in a mental handicap hospital the year *Better Services* was published (Appendix 2, 2.1) and subsequent experience as a Nursing Assistant (Appendix 2, 2.2). Later experiences are cross referenced to relevant research, policy, practice and service development.

The thesis critiques the theory, practice, methodology and policy described in the publications through the lens in which they were developed. The critique is then expanded and updated through the lens of current theory, practice and policy. It considers the conceptual and methodological development of my research, and builds on and extends my research findings with broader evidence including social and organisational factors. It then integrates new theory, evidence, methodology, implementation science, political, economic and social factors.

1.2 Structure of the thesis

Chapter 2 describes the context through presentation of:

- a summary of key policy, practice influences on psychological research and practice and services for people with learning disabilities across the decades and relevant to the publications presented in this thesis

- illustrative timeline matrices mapping temporal and thematic events across the decades to facilitate analysis

Chapter 3 comprises a research narrative which locates the publications within the context outlined in Chapter 2 and, also, my professional development and role as a clinical psychologist in practice innovation and research. It expands some key policy, practice, methodological and theoretical concepts through introductions to, and summaries of, each of the ten selected publications in turn. Each of the ten publications is presented after its introduction and summary. The summaries are written to begin to show how the publications link to the key policy, practice, methodological and theoretical concepts and contribute to a coherent body of applied psychological knowledge in the field of services for people with learning disabilities. Later chapters expand, critique and synthesis these themes.

Chapter 4 presents and then synthesises a critique of the methodologies. First, this is through a contemporaneous lens; second, through a lens of current research orthodoxy. Finally, a broader critique of methodology allows reflection and recommendations.

Chapter 5 presents and then synthesises broader critiques from theoretical, practice, policy and organisational perspectives. It considers the conceptual and methodological development of my research and builds on, and extends my research findings with broader evidence including wider social factors.

Chapter 6 draws out implications and recommendations relevant to the care and service delivery for people with learning disabilities and other vulnerable people, and presents a brief agenda for future research.

The auto-ethnography presented in Appendix 2 traces my professional development and locates the publications within the contemporaneous research/practice, policy, organisational and sometimes, personal context.

Chapter 2: Setting the context

Chapter 2: Setting the context

2.1 Introduction

The overall aim of this thesis is to present and critique practice and service delivery and development for people with learning disabilities over an extended period through the presentation of ten publications of which I am sole or joint author. The selected publications demonstrate a range of contributions of psychology to this field which extend knowledge and practice. The thesis will identify barriers to, and factors supportive of, positive change and the application of evidence-based practice. The thesis finally presents implications, recommendations and ideas for future research regarding care and service delivery for people with learning disabilities and draws parallels relevant for other vulnerable people receiving services.

The context for the thesis and analysis incorporates historical timelines across four central decades: 1970s, 1980s, 1990s and 2000s. It summarises key events and issues in service provision for people with learning disabilities including exposés of poor/abusive practice and inquiries, policy development, research evidence and paradigms, contribution of, and roles for, Clinical Psychology in general. These factors will be related to the selected publications with cross referencing with the auto-ethnography (Appendix 2). Key socio-political and economic issues are considered as part of the later analysis.

Given the chronology and scope, this context setting will not attempt to be comprehensive. Rather, it seeks to present key examples across a number of different timeframes, contexts and connections which enables a longer and broader critical view, synthesis and reflection. Matrix timelines were generated to assist with the context-setting and later conceptualisation, critique and analysis. These matrix timelines map the four core decades with their key events, developments and publications across:

i) exposés of poor/abusive practice, inquiries and policy development
ii) models of disability and service provision
iii) socio-political factors
iv) research evidence and paradigms
v) contribution of, and roles, for Clinical Psychology
vi) auto-ethnography

Similar matrix timelines were generated for pre-1971 and post 2011 to assist identification and analysis of features leading to the 1971 *Better Services for the Mentally Handicapped* White Paper, and of the actions, implications and recommendations going forward. All matrix timelines are presented in Appendix 1.

2.2 Exposés and inquiries

The *Better Services for the Mentally Handicapped* White Paper (DHSS, 1971), which frames this thesis, followed the Ely Hospital exposé (1967) and inquiry (DHSS, 1969). This was the first high profile public exposé of poor and/or abusive practice within service provision for people with learning disabilities. As the timeline matrices show, a series of exposés followed across subsequent decades. The Ely Hospital exposé came to public attention when the News of the World published allegations from a staff member regarding cruelty and theft of patients' food, clothing and belongings at Ely Hospital in Cardiff in August 1967.

The number of scandals and inquiries mounted in the 1970s e.g. South Ockendon Hospital, 1974, St. Ebba's Hospital 1976, Normansfield Hospital 1978, Church Hill House Hospital 1979. The early 1980s saw the screening of the television documentary, *Silent Minority* (ATV, 1981). Produced by ATV, it showed poor conditions and care in two large "subnormality hospitals", St Lawrence's and Borocourt. The 1990s saw the broadcasting of MacIntyre *Undercover: Care* (BBC, 1999). This TV documentary showed footage of abusive behaviour by staff in a care home for people with learning disabilities in Kent.

The new millennium saw continued concerns and investigations. In Cornwall in May 2005, the Healthcare Commission investigated services for people with learning disabilities following concerns raised by the local Mencap branch to them and to the Care Standards Commission and Inspectorate in 2004 (CSCI, 2006). The Inquiry into services at Orchard Hill, Sutton, followed soon in 2006 (CSCI, 2007). In 2011, forty years after the publication of Better Services in 1971, the BBC's Panorama *Undercover Care: The Abuse Exposed* showed footage of staff physically and emotionally abusing adults with learning disabilities at an Assessment and Treatment Unit in the private hospital, Winterbourne View. This was despite concerns being reported by a nurse to hospital management, the local safeguarding board and to the regulator, the Care Quality Commission.

These exposés over the forty year period have showed poor care and abuse across the NHS, Local Authority (LA), private hospital and residential services. Both the Ely and the Winterbourne View exposés which frame this thesis were based on information from whistle-blowers who found themselves unable to have concerns adequately addressed through existing organisational procedures. The exposés utilised a range of investigative journalism supported by both public organisations, such as the BBC, and commercial organisations, such as News of the World and ATV/ITV, and disseminated findings using a range of media including newspaper and television.

Turning to the multiple inquiries which arose from these exposés and their recommendations, a number of themes can be traced across the decades. These themes are identified as a summary of the recommendations of the first inquiry report (Report of the Committee of Inquiry into Allegations of Ill–Treatment of Patients and other irregularities at the Ely Hospital, Cardiff, 1969) presented in Table 1 below within a conceptual map drawing on organisational theory (Argyris and Schon, 1978; Brunning, Cole & Huffington, 1990; Huffington, Cole & Brunning,1997; Katz & Kahn, 1978; Lawrence & Lorsch, 1967). This framework enables the subsequent practice and policy developments to be compared, contrasted and analysed, and for the publications presented in this thesis to be considered within this framework. A summary of recommendations from *Better Services for the Mentally Handicapped* 1971 has been added to the framework summarising Ely recommendations to demonstrate how closely the policy in this White Paper reflected them. Links to relevant publications presented in this thesis are notated by red superscript and are discussed in Chapters 3 and 5.

Table 1 Ely Report (1969) and Better Services (1971) recommendations summary. ([1, 2, 3] denotes related publications presented in thesis)

1 Resources:	**Ely Report (1969)**	**Better Services (1971)**
1.1 Physical:		
1.1.1 Space, size, décor	improve the environment	Min space standards, upgrade buildings, homelike
1.1.2 Possessions, clothes, furniture [2]	improve facilities and equipment	improve clothing & personal possessions; upgrade furnishings, make cupboards available
1.1.3 Food:	provide adequate food and manage food supply (food had been stolen by staff)	improve food
1.2 Staff:		
1.2.1 numbers:	increase staffing	improve staff ratios
1.2.2 types of professionals:	increase multidisciplinary team	
1.2.3 skills: [1, 2, 4, 5, 6, 7, 8, 10]	improve and coordinate staff training for all disciplines not just nursing	carry out staff training (also acknowledged legacy of staff attitudes,
2 Process:		
2.1 Care:		
2.1.1 Relationships particularly between staff and service users: [1, 2, 3, 4, 5, 6, 7, 8,]	improve quality of relationships between staff and patients, quote from NO	should provide sympathetic and constant human relationships
2.1.2 Coordinated multidisciplinary therapy, individual assessment, plan & review: : [1, 2, 3, 4, 5, 6, 7, 8, 9,10]	increase therapy, especially Occupational Therapy	should be proper coordination of relevant professional skills (incl across administrative boundaries), comprehensive assessment & review with a multidisciplinary approach & co-ordinated advice, hospital services to ensure they provide assessment & treatment
2.1.3 Health support:	improve prescribing and review of medication	equal access to the general health & social services available to others
2.1.4 Develop, training, leisure, employment: : [1, 2, 4, 5, 6, 7, 8, 9,10]	improve education, occupation and employment, improve day services:	each person needs stimulation, social training & education & purposeful occupation or employment; education, social & work training, day care & occupation (provided by education & social services)
2.1.5 Routines: [1, 4]	instil routine to support better patient centred (not institution driven)	
2.1.6 Research use &/or do: [1, 2, 3, 4, 5, 6, 7, 8, 9, 10]	utilisation of research, eg continence, habit training	develop research on ways of helping people learn, service evaluation, prevention & detection of mental handicap
2.2 Management:		
2.2.1 Local professional management: [2, 3]	improve nurse management & supervision	improve management

2.2.2 Broader multidisciplinary management: [2]	improve Hospital Management Team & broader multidisciplinary mgt	
2.2.3 External management: [2]	improve external management (external members of HMT/ management oversight, support from Regional Hospital Board)	
2.2.4 Leadership:	improve leadership of multidisciplinary input	
2.3 Information		
2.3.1 Information on services: [1, 4, 8]	develop information booklet on service(s)	
2.3.2 Record keeping:	improve record keeping	
2.3.3 Incident reporting and investigation of sudden deaths:	improve incident reporting and investigation of sudden deaths	
2.3.4 Complaints investigation and follow up:	improve complaints and concerns systems(nurse who gave statement on poor care to the newspaper, had brought their concerns to the attention of colleagues and seniors)	
3 Broader service issues:		
3.1 Community based services: [1, 2, 5, 6, 7, 8, 9, 10]	secure more effective community care	LA flats and group homes, "homes" not hostels, increase community care, reduce hospital places
3.2 Links with/ use of existing community services: [2, 5, 6, 7, 8]	make use of mainstream services, make more links with community; linked up more closely with the paediatric, child psychiatric and adult psychiatric services	close collaboration between services including e.g. child health, education& GPs, and community links ; not be segregated from general life of community
3.3 Greater links with voluntary groups: [2]	greater participation by voluntary organisations; establish a League of Friends	
3.4 Multiagency collaboration: [1, 2, 5, 6 ,7, 8, 10]	develop multi-agency collaboration; more frequent discharge of patients to LA hostel accommodation;	gave :A's & hospital authorities guidance on development of services, education, social and work training, day care & occupation (education& social services) developmental screening & review, services for prevention & early detection of mental handicap,
3.5 Early intervention and children: [6, 7, 8, 9, 10]	double staffing now specified for the children's villas; projected adolescent unit to be accorded higher priority.	developmental screening , services for prevention
3.6 Transition [6, 8, 9, 10]		
3.7 Family and carer support:	accommodation for parents; booklet about Ely, for the guidance of patients, relatives and others,	support and practical help to families
3.8 Short term and respite care:	special accommodation for short-term admissions	respite care
3.9 Emergency/crisis care: [6, 9]		
3.10 Role of hospitals:		hospitals fix date after which they will not admit any more people that need residential, rather than

		hospital care, ensure hospitals provide assessment & treatment
4 Service planning, delivery & review:		
4.1 Planning:		
4.1.1 Joint Planning:		New shift in priority for LA's. Joint planning needed
4.1.2 Numbers and needs:		targets for expansion incl Adult Training Centre places ↑ 43,500, residential places for children ↑ 2,504 & adults ↑24,100
4.1.3 Pathways:		
4.2 Finance:		£40 million additional funds
4.2.1 Joint Finance:		
4.2.2 Costings & financial mgt, VFM: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10		
4.3 Review:		
4.3.1 Joint Reviews:		
4.3.2 Outcome measurement: **1, 2, 3, 5, 6, 7**	task of inspecting hospitals like Ely should be entrusted to an independent inspectorate	
5 Other:		
5.1 Rights 1, 2, 3, 4, 5, 6, 7, 8, 9, 10		greater recognition of the rights of the mentally handicapped
5.2 Individual needs & choices		greater recognition of individual needs
5.3 Equalities, diversity, access 1, 2, 3, 4, 5, 6, 7, 8, 9, 10		
5.4 Service user involvement: **5, 6, 7,**		
5.5 Advocacy:		

Martin's study, Hospitals in Trouble (1984), summarized and analysed seventeen hospital inquiries and reports, from Ely, 1969, to Rampton, 1980. These included hospitals for people with, what were then called, mental handicaps and those with mental health problems. Many common features were identified across the inquiries that were associated with poor, neglectful or abusive care. These include poor management and leadership (nursing, medical and broader "external" management), complaints ignored, poor training, low morale, inflexibility to change and development, isolation (professional, social, geographical). These themes reflect many of the factors identified in Table 1 above from the first inquiry at Ely Hospital, across the other sixteen inquiries over the subsequent eleven years.

Martin’s analysis identifies and explores the role of culture and social-psychological mechanisms in care delivery. He identified a *corruption of care* engendered within such organisations, enabling staff, who usually come into their career with good intentions, to behave in abusive ways. Social and psychological mechanisms allow this corruption of care, in turn, to *domesticate the unacceptable* whereby such practices become normalised.

Staffing levels and poor environment, facilities and equipment were often factors, but not necessarily. In a number of inquiries, the role of trade unions in maintaining the “status quo” of poor professional practice was identified. One inquiry described, Normansfield (1978), differed in that the inquiry followed a strike by nursing staff concerned at the over-restrictive, custodial regime imposed by the Medical Director. Thus, the inquiry was triggered by a group of staff standing up for positive service change and development. They used strike action which attracted public and media attention as other mechanisms had not worked.

Whilst, the Macintyre *Undercover: Care* (BBC, 1999) documentary exposé led to Local Authority and police investigations, comments by Local Authority personnel against the investigative journalist sought to discredit him, his methods and the representation of care shown and, by implication, the validity of the programme. A successful legal case for libel against the Local Authority was raised with support of the broadcaster and expert witnesses from the learning disabilities field. The investigation teams again found similar themes to those above, with particular concerns regarding use of inappropriate physical interventions.

The inquiries following the exposés of the new millennium Cornwall, Sutton and Winterbourne View, became more complex reflecting developments in safeguarding practices, regulation and monitoring. The Panorama exposé of the abuse at Winterbourne View (BBC, 2011) triggered police investigations and also Safeguarding and Serious Case Reviews, a Care Quality Commission investigation of Winterbourne View , and its own performance, function and role, together with a sample snapshot of other learning disability services across England and a major Department of Health Review and subsequent action plan. Themes identified as contributing to the poor or abusive care paralleled those from earlier inquiries: poor management and leadership (nursing, medical and broader external management), poor training, cultural issues, isolation, complaints ignored, low morale, inflexibility to change and development, isolation (professional, social, geographical). This is despite increased regulation (CSCI, CQC), mandatory training in safeguarding (Children Acts, 1989 and 2004, Draft Care and Support Bill, DH, 2012) and policies on whistleblowing (DH 2010, NHS Constitution, DH, 2009.

2.3 Policy development

This section on Policy Development summarises key developments across the 1971-2011 time frame to set the scene for later analysis of the selected publications.

2.3.1 *Better Services for the Mentally Handicapped* (DHSS,1971) White Paper

The 1971 White Paper *Better Services for the Mentally Handicapped* followed the Ely Hospital Inquiry (DHSS, 1969) and laid down aims of increasing community care and reducing hospital places, as well as the greater recognition of the needs and rights of children and adults who were mentally handicapped. It outlined general principles, services required and actions needed. It expected that community residential provision for children would increase by 2,504 places and for adults by 24,100. By 1990, half of all residents of mental handicap hospitals would be living within the community and hospital places would be halved. It acknowledged the difficulties inherent in the legacy of institutions (numbers, buildings, attitudes, staff shortages and poor management) and gave local authorities and hospital authorities guidance on the development of services.

Recommendations included that residential services should be small scale and home-like, existing hospital facilities and food would be improved and hospitals were to fix dates after which they would not admit any more people who needed residential, rather than hospital care. Hospitals were to ensure they provided assessment and treatment. Staff numbers, training and coordination would increase including the range of professionals. Attention to improving relationships between service users and staff and providing comprehensive assessment and review using a multidisciplinary approach was outlined. Multiagency collaboration with generic health services and community services for delivery and for planning was highlighted.

Better Services for the Mentally Handicapped built on the findings and recommendations of the Ely Inquiry, with a community focus, the need to consider children as well as adults (early intervention), attention to both management and training, to facilities and buildings and the need to incorporate and develop research. A new specific emphasis on Joint Planning between NHS and Local Authority was included, as was the need for collaboration between services such as child health, GPs and education. £40 million of additional funds was allocated in the early 1970s for mental handicap services.

2.3.2 National Development Group (NDG) for the Mentally Handicapped Pamphlets 1- 5 (1976-1977)

By the mid-1970s, progress from policy to practice was unsatisfactory so the government established two new bodies to increase the pace of change. The National Development Group (NDG) for the Mentally Handicapped was to advise on policy, strategy for implementation and produce practical guidance on this, whilst the National Development Team (NDT) for the Mentally Handicapped was to help oversee, advise and assist the NHS and Local Authorities (LAs) in planning and implementation in the field. Between July 1976 and July 1977 the NDG published five pamphlets on different aspects of services for people with mental handicaps which were practical and accessible.

The first pamphlet *Mental handicap: planning together* (NDT, 1976) built on the earlier recommendations for joint NHS and LA planning, financing and delivery as essential for collaboration and coordination. Priorities included family support, teamwork (in delivering and planning services), both primary care and specialist teams, urgent attention to developing children’s services, developing a guide to local services and looking afresh at facilities for usage in the community (including leisure, housing, education).

The second pamphlet, *Mentally handicapped children: a plan for action,* (1977) expanded the prioritisation of children and developed the focus on, and detail, for children's services. It recommended specialist help to meet needs in the community, the need for individualised assessment and planning. Prevalence figures and assessment proformas were included. The pamphlet made specific links with the Court Committee report on Child Health (DHSS, 1976) and the District Handicap Teams and Community Mental Handicap Teams it recommended. These had roles to coordinate assessment and plans of management, domiciliary support and respite care (including fostering), developmental planning, information on available services, and, also, review children in hospital.

The focus on youth continued with Pamphlet 3, 1977, *Helping mentally handicapped school leavers*. This noted the fragmented and uncoordinated provision, with existing learning programs disrupted. It recommended that assessment for detailed programs be included for transition planning and provision, needed before school leaving and should include a range of professionals. Options available should include Adult Training Centres, further education, vocational courses, work experience and sheltered employment.

Short term care for children and adults was the focus of Pamphlet 4, 1977 *Residential short term care for mentally handicapped people: suggestions for action*. It highlighted that the range of short term care options for children and adults should include holidays, assessment and treatment facilities, relief for carers and crisis in emergencies and to be available in a range of settings including public, voluntary and private sector. Coordination of access should be the responsibility of a multidisciplinary community team. Joint Care Planning teams should monitor resources available and needs, formulate criteria for admission and discharge and make use of joint finance.

The fifth and final pamphlet, 1977, *Day Services for Mentally Handicapped Adults* emphasised that they should be educational in their broadest sense and recommended re-naming Adult Training Centres as Social Education Centres. Drawing specifically on the 1975 General Assembly of the United Nations Declaration of the Rights of Disabled Persons, the pamphlet highlighted

Independence, Individuality, Education, Personal Relationships, Leisure and Recreation, and Work as areas for action. Detailed advice was given on management, staffing (type, training, numbers), admission and assessment including different assessment tools and individualised goal-oriented development (personal, social and vocational.) There are sections on record-keeping, its coordination and use and on Special Care for those with the most severe handicaps as well as advanced work training. The use of community resources was, once again, highlighted.

Thus, it can be seen that the pamphlets outlined and operationalized the themes arising from the inquiries and the policy and practice recommendations of *Better Services for the Mentally Handicapped*. The NDG pamphlets' brevity, practicality and accessibility were an asset and my auto-ethnography notes the value accorded to these Pamphlets by services actively trying to improve (Appendix 2, Section 2.4).

2.3.4 National Development Group (NDG) guidance *Helping Mentally Handicapped People in Hospital* (1978)

Alongside government recognition that developments in community care were slower than anticipated, there was also a need to improve care for those still in hospital. *Helping Mentally Handicapped People in Hospital* was published by the NDG in October 1978. Recommendations reiterated recommendations of earlier policy including:

- homely and domestic environments
- improved clothing and furnishings
- routines should not be dictated by shifts
- increased training and activities for residents training which should include social education, personal relationships (including sex education) and training for work
- improved management
- prioritising development of services for, and discharge of, children and adolescents

- hospital placement should only occur if needs can only be met by specialist services provided there
- improved coordination between NHS, social services, education, housing and employment and joint finance.

More detailed recommendations were given on developing Training Departments to drive forward more therapeutic developmental activities tailored to individuals' needs and the setting up of residents' committees to influence hospital management.

This NDG report also made a raft of recommendations for more effective monitoring and management, and resource allocation across different levels of stakeholders including hospital staff, District Management Teams, Area Health Authorities, Regional Health Authorities, the Department of Health and Social Services and ministers. For example, Regional Health Authorities and Area Health Authorities and Local Authorities were to prepare strategies and plans for developing comprehensive services, to be submitted to the Secretary of State within 12 months, with progress reports submitted annually, Development Team reports should be followed up with greater vigour, an independent inspector that should be set up, devolved budgets and the government to provide more resources to implement White Paper policy and ensure implementation.

Shortly after publication of this report, the DHSS published their *Report of the Committee of Enquiry into Mental Handicap Nursing Care* (DHSS, 1979), known as the Jay Report. The Jay Report reemphasised the importance of the shift of services from hospital to community and the rights and needs of people with 'mental handicap' to use and benefit from ordinary community services and facilities. It recommended reviewing nurse training to ensure appropriate skills were being trained for community care and broadening the workforce through the introduction of a new social services qualification.

2.3.5 *All Wales Strategy for the Development of Services for Mentally Handicapped People* (Welsh Office, 1983)

In Wales, with the legacy of the Ely Inquiry and frustration with the lack of progress following the policy and practice initiatives outlined above and the developing research base, both from UK researchers and centres (Health Care Evaluation Research Team, Wessex RHA; Hester Adrian Research Centre, Manchester, and specifically Mental Handicap in Wales - Applied Research Unit , Cardiff (see Section 2.6 on Research) led to the *All Wales Strategy for the Development of Services for Mentally Handicapped People* (AWS). Launched in 1983 to

> correct the historic anomaly ... which has left the bulk of public service provision in large and, for many, remote hospitals whilst the great majority of mentally handicapped people and their families receive little or no support in their homes where it is most needed.

The AWS set out three guiding principles and emphasised that these applied to all people with learning disabilities, however severe their disability. The core AWS principles were the right to an ordinary pattern of life within the community, the right to be treated as an individual and the right to additional help and support in developing their maximum potential.

The AWS set a direction for the development of a range of local services and gave explicit guidance on the form of some of the needed services. It built on the legacy of earlier inquiries and integrated a more rights based, personalised approach. It was given an initial life of ten years, during which additional recurring revenue investment would grow to approximately £26 million per annum at 1983 prices. Although, progress was made, neither the initial term nor the additional funding was sufficient to make the pattern of services comprehensively available throughout Wales. The intended financial investment in the first ten years was about a quarter of that estimated to be eventually required.

A review (Welsh Office, 1991) led to refocusing and re-energising, and prioritised some of the areas of least progress (developing children’s services, involving education and re-provisioning the large hospitals. This fed into the updated 1994

Welsh Mental Handicap Strategy Guidance which also re-emphasised the need for each person with a learning disability to have an individual and dynamic plan co-ordinating care throughout their life which properly reflects their needs and choices.

2.3.6 *Valuing People: a New Strategy for Learning Disability in the 21st Century* (DH, 2001) White Paper

The 2001 White Paper *Valuing People: a New Strategy for Learning Disability in the 21st Century* identified people with intellectual disabilities as 'amongst the most vulnerable and socially excluded in our society'. It set out four key principles – rights, independence, choice and inclusion – for improving their quality of life chances (Secretary of State for Health 2001). In *Valuing People*, the Government's objectives for people with intellectual disabilities were built around a person-centred approach enabling them 'to have as much choice and control as possible over their lives and the services and support they receive' (p 4).

Valuing People was also called *a New Strategy for Learning Disabilities for the 21st century. A*lthough titled *New,* it had much in common with previous policy, and as such, represented the failure of previous governments and services to make adequate progress over the thirty years since *Better Services*. *Valuing People's* objectives included maximising opportunities for disabled children, facilitating transition into adult life, enabling people to have more control over their lives, supporting carers, good health, housing, fulfilling lives, moving into employment, quality, workforce training and planning and partnership working. I addition, *Valuing People* had both objectives to make progress towards previous policy goals and a specific focus on equalities with actions outlined to reduce health inequalities.

2.3.7 Mansell Reports (1993 and 2007)

The Mansell reports (1993 and 2007) on services for people with learning disabilities and challenging behaviour or mental health needs provided guidance for Local Authorities and health bodies on the development of appropriate services. Drawing on studies and service descriptions which had demonstrated constructive and effective service provision for people with intellectual disabilities and challenging behaviour (Johnson & Cooper, 1991; Felce & Lowe, 1993), the guidance was focused particularly on service commissioners, because there was ”already ample information about service models available for providers”.

Despite the publication of *Valuing People* in 2001, Mansell’s revised (2007) Report identified a number of continuing problems faced by people with learning disabilities whose behaviour presents a challenge from studies of the nature and quality of service provision (Broadhurst & Mansell, 2007; Beadle-Brown et al., 2008). These included breakdown of community placements, increased use of out-of-area placements and the persistence of poor quality institutional solutions. Fourteen years after publication of the first report, Mansell states in the introduction to the revised 2007 report:

> The analysis set out in the first version of this report and its recommendations remain relevant today (pii).

The Under Secretary of State for Care Services noted some progress in:

> finally reaching the end of the closure of the remaining old long-stay hospitals …. and programme of work to close all NHS residential accommodation or campuses by the end of the decade… and….. that good quality commissioning and service provision is also vital in delivering that vision.

Mansell (2007) refocused support for commissioners in developing local services for people whose behaviour presents a significant challenge, again, with recommendations on commissioning for service development and implementing models that meet individuals' needs in the local community. He referenced the 2001, Government White Paper *Valuing People* and its principles of rights, inclusion, independence and choice, and noted :

> the idea that services should be designed around the individual, relatively new in the first report, is now central to government policy. (p 5)

Mansell (2007) also drew links with more general NHS policy development ie the White Paper “Our health, our care, our say” (DH, 2007, Introduction, paras 1 and 2, p5.) However, Mansell also noted the continued shortage of suitable local services, which is

> often remedied by finding placements outside the local area, sometimes a long way from home. There are over 11,000 people supported out of area by local authorities in England, 31% of all people with learning disabilities supported by local authorities. (p. 5)

This illustrated how learning disability services continued to fail to comply with both Learning Disability specific policy, and broader health care policy.

2.3.8 Post Winterbourne View investigations and reports

Policy following the Winterbourne View Panorama, *Transforming Care* (DH, 2012[b)] and *Concordat: a programme for action* (DH 2012[c]) was driven by the Department of Health Interim Report (DH, 2012[a)] , the Serious Case Review (South Gloucestershire Safeguarding Adults Board, 2011) and Care Quality Commission's Internal Review (CQC, 2011) and Review of Learning Disability Services (2011). Broadly, the recommendations again reiterated much of previous policy, especially Mansell (1993, 2007) and made another raft of recommendations including reviewing and re-provisioning services for the people with learning disabilities inappropriately in hospital beds into supported community settings. Progress towards these recommendations is considered in Chapter 6 sections *Are services any better?*

2.4 Social and Community Aspects

During the 1950s and 1960s, a number of strands brought the appropriateness of institutional care for people with learning disability into question and paved the way for changing attitudes, policy and legislation. The increasing influence of the human and civil rights movements (USA, UK and Europe) contributed to the European Convention on Human Rights (1950). There was increasing recognition of the damaging effects of institutionalisation on the development of the individual (e.g. Goffman, 1961) and the neglect of people with intellectual disabilities (Ryan and Thomas, 1980). Thomas, as a nursing assistant in a large subnormality hospital in 1972, kept a diary that was incorporated into *Politics of Mental Handicap*. This detailed a depersonalising objectification of the patients:

> At arrival all semblance of individual personality was removed – all personal possessions including clothing were not permitted and daily life was controlled by rules and regulations, rather than personal choice. (Ryan and Thomas, 1980: 31).

Alternative service philosophies drawing on rights-based theory developed to underpin service development and delivery. Wolfensberger’s (1972) philosophy of normalisation sought to enable people with learning disabilities to achieve a life as “normal” as possible. This was later defined as using culturally valued means to achieve a culturally valued life. Its principles and influence on service planning and provision in the UK, were interpreted and conceptualised by O’Brien and Tyne (1981) as the five service accomplishments:

- Community Presence – ensuring that service users are present in the community by supporting their actual presence in the same neighbourhoods, schools, workplaces, shops, recreation facilities and churches as ordinary citizens.

- Choice – ensuring that service users are supported in making choices about their lives by encouraging people to understand their situation, the options they face and to act in their own interest both in small everyday matters and in such important issues as who to live with and what type of work to do.

- Competence – developing the competence of service users by developing skills and attributes that are functional and meaningful in natural community environments and relationships, i.e. skills and attributes which significantly decrease a person’s dependency or develop personal characteristics that other people value.

- Respect – enhancing the respect afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, and forms of dress and use of language promote perception of people with disabilities as developing citizens.

- Community participation – ensuring that service users participate in the life of the community by supporting people’s natural relationships with their families, neighbours and co-workers and, when necessary, widening each individual’s network of personal relationships to include an increasing number of people.

These remain elements of goals which services for people with learning disabilities strive for.

The need for broader and more radical social change to underpin progress in achieving both *Better Services* and better lives for people with learning disabilities is identified by a number of authors. For example, Hamlin and Oakes (2008) described a lack of progress in outcomes of living in ordinary houses in ordinary streets, accessing support (especially non specialist support), reducing distress and improving and increasing relationships. They proposed that an analysis of the relationships among people with intellectual disabilities, their supporters, formal services, and the community as a whole and the discourses which characterize them is needed (Hamlin and Oakes, 2008: 49). They traced and explored the themes of protection, power, and humanity across traditional institutional service models and how they endure into modern service models and, possibly, into future models. Social factors such as attitudes and discrimination in society and subsections, such as professions, are identified as contributory factors, as are issues linked to power, both social and economic.

2.5 Legislation

Legislation both dictates and reflects patterns of service provision and care practice with people with intellectual disabilities. It also reflects social and political developments. The NHS was established in 1948 following the 1947 National Health Service Act. Following this, the term *colony* which described the places where people with intellectual disabilities lived and were cared for was replaced by the term *hospital.* Responsibility transferred from local councils to Regional Hospital Boards and people with learning disabilities became patients rather than people.

Eleven years later, the Mental Health Act (1959) sought to re-involve local councils by requiring Local Authorities to make both day service and residential provision for people with mental subnormality and placing a new emphasis on the re-integration into the communities to which they belonged. However, this Act also contributed to the *medicalization* of mental subnormality. Its definitions of subnormality, severe subnormality, psychopathic disorder all incorporated the qualifier, “requires, or is susceptible to, medical treatment or other special care or training of the patient.”

Until 1971, when the 1970 Education Act was enacted, children could be categorised as *ineducable*. The 1970 Education Act legislated that all children would by law receive education with the, then, Secretary of State for Education, Margaret Thatcher, stating:

> For myself, I am determined that these children shall take their rightful place in the educational system and receive their fair share of the resources available.

And recognising the importance of research in giving:

> financial support to enable current research at the Hester Adrian Research Centre in Manchester to be continued. It will be a challenge to the education service to make the best possible use of new knowledge as it becomes available. (Thatcher, Speech to National Society of Mentally Handicapped Children, precursor to Mencap,1971)

Later legislation recognised and protected human rights, with the potential to enable people with learning disabilities to enjoy a more equal life building on UN Declaration of Rights of Disabled People (1975) included the Human Rights Act (1998), Disability Discrimination Acts (1995, 2005) and Equality Act (2010).

2.6 Research and people with learning disabilities

Research both contributes to, and is reflected in, policy and practice development. Key research with people with intellectual disabilities across the four decades showed a development from the early educational and learning theory psychology based studies (e.g. Clarke & Clarke, 1958, 1966; Tizard,1960; Ayllon and Azrin 1968),and moves to more detailed developmental, ecological and staff/carer advice and training studies (Cortazzi, 1973; Clarke & Clarke,1974, 1985; Kiernan, 1975; Kiernan & Jones, 1977; Jeffree & McConkey, 1977; Jeffree et al. 1977; Kushlick 1977, 1978; Blunden & Revill, 1978; Woods & Cullen, 1983), to studies focusing on broader engagement, communication and challenging behaviour (Kiernan & Reid, 1988; Allen et al., 1987; Cullen 1988), active support (Felce & Lowe, 1993;) organisational and process factors, (Cullen, 1992, 1998; Hastings & Remington, 1994; Desnoyers et al., 1998), greater attention to emotional issues (Bender, 1993; Arthur 2003) and extended and adapting psychological therapies such as cognitive behavioural therapy (Lindsay et al., 1989, 1999; Haddock et al., 2004 Dagnan & Jahoda, 2006) and psychotherapy (Waitman & Conboy-Hill, 1991; Beail, 1998). More recently, key research has also investigated epidemiological, social, equalities and outcome issues and factors across wider domains of life including physical health and life experiences such as being bullied (Emerson & Baines, 2010; Mencap, 2007, 2010, 2013).

The early psychological research (Tizard, 1960) investigated the development and physical health (including aspects such as sleep and eating) of children with mental handicaps in two settings. Tizard compared four groups of eight children aged 5-10 years using quantitative and qualitative measures. Two groups continued living in the traditional “mental handicap” hospital and two groups each moved to a small domestic scale residential unit, Brooklands. Key quantitative findings were that the development of the children in the domestic style settings increased significantly (measured by verbal mental age). Qualitative findings included observations of good physical health, alert, cooperative and improved emotional adjustment with strong attachments to care staff and other children in the groups, in the smaller residential settings (Tizard,1960, p. 45.) This study illustrated investigation across a number of domains (development, health and relationships) of both setting and process and the importance of both quantitative and qualitative measures.

Research showing that people with learning disabilities could learn with the right interventions, drew on learning and developmental theory, and included Tizard’s study (1960) above, and Clarke and Clarke (1954). Some research focused on self-help skills (Azrin & Foxx, 1971), play (Jeffree & McConkey, 1977), social skills (Wylie & Thomas, 1978; Sayal & Brigden, 1980) and included people with very complex needs and learning impairments (Cortazzi,1973).

Later research extended understanding of effectiveness of psychological interventions such as general and maintenance issues in social skills training (Kazdin & Polster, 1973; Robertson et al.,1984), conversations (Matson & Andrasik, 1980), the importance of the right environments – both physical, social, staffing and activities including for people whose behaviour challenges and more complex presentations, such as psychosis (Leggett et al., 1977) or offending (Murphy et al., 2007). Further discussion of research and research developments is found in Chapter 3, in the publications and accompanying narrative, and in Chapter 4, the critique of the publications.

2.7 Role of Clinical Psychologists

Clinical Psychologists’ roles developed from an initial supportive role in assessment and rehabilitation needed to respond to the demands of the major wars. Their ‘scientist-practitioner’ model emphasised the research base (applying established psychological knowledge, and being trained to be proficient in undertaking research) was conceptualised in 1949 by the collaboration of American Psychological Association, US Public Health System and Veterans Association (Raimy, 1950 quoted in Wright, 2012). This ‘scientist-practitioner’ model remains central to Clinical Psychologists’ roles.

Formal clinical psychology training in the UK was established in 1957, in London and Scotland. The Trethowan report (DH, 1977) considered the role, training and contribution of Clinical Psychology in the UK. It recognised the ‘scientist-practitioner’ model of clinical psychology and clinical psychology as an autonomous profession in its own right. It recommended training for key roles in clinical skills, research and teaching, across mental health, children and young people, learning disabilities and neurological services. Trethowan also recommended increased numbers of Clinical Psychologists and increased influence through the organisation of psychology services in District or Area Psychology Departments. My auto-ethnography (Appendix 2, 3.1) notes the influence of the Trethowan Report, published the year I commenced my postgraduate professional training, as well as contemporaneous research and policy, on the roles and impact of clinical psychology in this early phase of my career.

Clinical psychology saw a significant increase for a small profession (in numbers and in influence, particularly in learning disabilities). However, by the mid to late 1980s, there was a shortfall in the number of trained clinical psychologists for available posts. This reflected the recognition of the value of clinical psychology across assessment and therapy, staff training and supervision, service development and transformation (e.g. from institutional to community care, or improving care in institutions). The Department of Health reviewed core competencies, preferred service model and levels of staff and skill mix in clinical psychology in the UK through the reviews and reports of the Management Advisory Service (MAS, 1989) and Manpower Working Advisory Group (MWAG, DH, 1990). Recommendations included that clinical psychologists should become fully independent practitioners given equal status with medical practitioners, take responsibility for the provision of psychological care, either directly or with other professionals working under their direction (the *shared-care* model). A large increase in the number of posts in the NHS and training places was envisaged.

The “scientist-practitioner” model was re-emphasised as a core competence of clinical psychologists. Distinctions were drawn in the unique skills of clinical psychologists separate from the broader psychological knowledge and skills used by other professions. A skills framework related to three differing levels of psychological activities was presented. See Table 2.

Table 2 Psychological knowledge, skills and activities framework (MAS, 1989)

Level 1	Basic psychology: activities such as establishing, maintaining and supporting relationships with patients and relatives, and using some simple, often intuitive techniques, such as counselling and stress management.
Level 2	Undertaking circumscribed psychological activities (such as behaviour modification). These activities may be described by protocol. At this level there should be awareness of the criteria for referral to a psychologist.
Level 3	Activities which require specialist psychological intervention, in circumstances where there are deep-rooted underlying influences, or which call for the discretionary capacity to draw on a multiple theoretical base, to devise an individually tailored strategy for a complicated presenting problem. Flexibility to adapt and combine approaches is the key to competence at this level, which comes from a broad, thorough and sophisticated understanding of the various psychological theories

The MAS report identifies clinical psychology as the only profession which operates at all three levels of activities of psychological knowledge and skills. It also recommended staff support, supervision, service planning, management and organisational activities be added to the core roles of clinical skills, research and teaching identified by earlier by Trethowan (DHSS, 1977).

The Division of Clinical Psychology (BPS: DCP, 1992) *Core Purpose and Philosophy* *of the Profession* particularly emphasised the Level 3 skills of clinical psychologists. Subsequent revisions (e.g. BPS: DCP, 2010) retained reference to these *unique* skills of clinical psychologists in transferring, or developing psychological skills in others:

> The transferable skills of clinical psychologists include the systematic application of an extensive range of theoretical models and a broad evidence and knowledge base to novel situations. (p. 4).

and application of the Level 3 psychological knowledge and skills:

> …. what makes this activity unique to clinical psychologists is the knowledge base and information on which they draw. The ability to access, review, critically evaluate, analyse and synthesise psychological data and knowledge from a psychological perspective is one that is unique to psychologists. (p. 5-6).

Chapters 3 and 4 demonstrate the application of psychological knowledge across these three levels and the synthesis of a range of psychological models and evidence within the developing policy, practice and research frameworks described above. My auto-ethnography (Appendix 2, 3.1-3.5) describes examples and Appendix 4 Framework for the contribution of Clinical Psychology in health care, I developed in 1986, provides a visual conceptualisation across layers of organisations.

Chapter 3: Publications’ narrative and presentation

Chapter 3: Publications' narrative and presentation:

N.B. The publications presented in this thesis are authored and co-authored by me under two surnames: Keleher (1981-1991) and Rossiter (from 1992 – present)

The narrative presents and contextualises the selected publications within their policy, practice, conceptual and methodological frame and highlights key findings. The taxonomy of research designs utilised for presentation and later critique is from Barker, Pirstang and Elliot (2002) who draw heavily on Cook and Campbell's (1979) taxonomy with some extension for optimum relevance to research methods in clinical psychology.

Summary Tables of the ten publications presented in this thesis with their related policy, research and findings, and the methodology used are presented in Appendix 7 and Appendix 8 respectively.

Methodological issues are described, discussed and critiqued in more detail in Chapter 4 through a retrospective then a more recent, lens. These and broader conceptual, practice and implementation themes across the publications are synthesised and further critiqued in Chapter 5.

3.1 Publication 1

Keleher, R. J. and Bridgen, P. R. (1982) Increasing Social Interaction. A structured activity group for severely handicapped people. *Mental Handicap*, 10 (2) pp. 61-63.

This experimental study was designed, undertaken and analysed as an innovative research study investigating both a novel format for developing social interaction and the use of care staff in "therapeutic" service delivery. Conceptual and methodological strengths included the research and policy drawn on, robustness of design and empirical data. Research drawn on for the study's rationale and intervention included: changing paradigms and empirical evidence from learning and developmental models and theories applied to mental handicap, such as Azrin and Foxx (1971) increasing toileting skills, Jeffree and McConkey (1977) developing play skills, Kushlick's Health Care Evaluation Research Team's (HCERT) series of studies evidencing benefits of community based, developmental and individualised care and services compared to hospital care (Kushlick,1977,1978). The group planning drew on the developmental-social-psychological model and emerging evidence (rather than the traditional medical model). A further aim evaluated was *giving psychology away* through involving care staff in the group intervention and having an experimental phase where care staff planned and ran the group under a psychologist's supervision.

The design was one group Double Pretest **-** Posttest, mixed methods **(**non-blind, non-selective, pre, post and follow-up). Quantitative data (with reliability checks) and some qualitative staff feedback were collected. It aimed to impact on psychological service delivery directly with service users and through interventions of care staff. The publication was a summary of a longer research report. It was published in a multidisciplinary peer-reviewed practice/research journal for maximum dissemination across a range of professionals interested in applied research.

The findings demonstrate it is possible to provide an intervention to promote social interaction amongst severely handicapped people who are traditionally viewed as socially isolated (p. 63). Social interaction increased and participation stabilised and increased over the experimental period. Learning in service users and/or the staff (who may have been learning to run the group more effectively according to the manual) appeared to occur.

Publication 1

Keleher, R. J. and Bridgen, P. R. (1982) Increasing Social Interaction. A structured activity group for severely handicapped people. *Mental Handicap*, 10 (2) pp. 61-63.

Increasing social interaction:

a structured activity group for severely mentally handicapped people

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Introduction

There is now much literature on approaches likely to contribute to developmental gains for mentally handicapped people. Behavioural principles derived from learning theory have been widely applied to increasing skills such as toilet training (Azrin and Foxx, 1971) and play skills (Jeffree and McConkey, 1975).

So far little attention has been given to improving the social interaction of mentally handicapped people, especially amongst the severely handicapped. A few studies have looked at social skills training with mildly handicapped clients (Brigden and Sayal, 1980; Wylie and Thomas, 1978) but studies on severely handicapped people portray them as being socially isolated (Balthazar and Phillips, 1976; Shastri *et al.*, 1974) and little is said about ways to increase their social interaction.

Given that behavioural principles have proved successful in helping severely handicapped people increase their skills it was decided to employ these in running a structured activity group for severely mentally handicapped people with the goal of increasing social interaction amongst them. The specific aims were to:

- increase awareness of one another
- increase the range and opportunity for experiencing social interaction with other mentally handicapped people.
- increase opportunities for imitative learning
- develop motivation and ability to communicate and co-operate with one another
- increase "sociability", that is, take others into account, share tasks, take turns, more able members to help less able members, and so on
- promote pleasure in partaking in group activities.

The setting for this experimental group was Darlington House, a locally based hospital unit (LBHU). This form of residential care, which has been proposed and evaluated by the Health Care Evaluation Research Team (HCERT), offers an alternative to the specialist mental handicap hospital.

"Traditionalists" (for example, Shapiro, 1974; Royal College of Psychiatrists, 1976) have argued that acceptable levels of care for the mentally handicapped can only be within the framework of a specialist hospital service. Salient features of this model of care include: a single site; specialised trained staff; and special facilities. The HCERT challenged these assumptions, pointing out the disadvantages of many mental handicap hospitals, for example, isolation from the community hindering integration, creating problems for maintenance of family links, and contributing to poor staffing levels due to transport problems. Other organisational factors, such as being able to transfer staff from one ward to another at short notice, the domestic staff being responsible to domestic supervisors rather than to the charge nurse, and the difficult procedure for obtaining equipment, would also seem to detract from the provision of high quality care.

Descriptions of the LBHU model of residential care, and its evaluation, can be found in HCERT research reports 123 and 124 (1977). Salient features include: a maximum of 25 beds; a local, defined catchment area for clients; a unit sited within the community it serves, using local amenities and services; one person-in-charge (who need not be a specialist nurse); unit domestic and catering staff accountable to the person-in-charge. Standards of care in LBHU's have been compared with traditional hospitals using various objective measures, such as: the activities undertaken by staff; clients' participation in activities; frequency of contact between clients and relatives; recruitment and allocation of staff, and maintenance of staff continuity; and contacts made by professionals with residents (HCERT research reports 126 and 140-144).

The comparisons reveal that LBHU's provide a standard of care at least as good, and usually better, than that of mental handicap hospitals. The model has been accepted by the Wessex Regional Health Authority in the development of its mental handicap services. It is consistent with the philosophy of the Jay Committee (1979).

Darlington House deviates slightly from the above criteria by having two people-in-charge. General observations indicate that the Unit staff are providing a high standard of care, in line with the modern philosophy that mentally handicapped people have the right to enjoy a life as near normal as possible. Opportunities for using community facilities such as shops, pubs, cinemas, and sports centres, attention to developing self-help skills such as toileting and feeding (staff taking meals with the residents), and high standards of personal clothing, are all aspects of care in this Unit. In addition, care staff engage clients in some aspects of play, for example, simple puzzles and painting, on a one-to-one basis.

However, care staff expressed uncertainty as to how best to provide occupation and training for the most severely handicapped and difficult individuals in the Unit during the day. In common with many other units, this task still falls on untrained staff. The paucity of qualified staff, and the current economic climate, makes it vitally important to enable untrained care staff to provide appropriate activities. The activity group described was carried out in an attempt to provide additional ideas for the daily programme of occupation, provide impetus for staff to develop the programme, and specifically to see whether social interaction amongst a group of severely handicapped people can be increased.

The structured activity group

HYPOTHESES

The hypotheses were:

1. The provision of a structured activity group will increase levels of social interaction amongst a group of

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Mental Handicap, 1982; **10**:2, 61-63

severely mentally handicapped people, when activities are chosen to facilitate interaction.

2. The provision of an activity group will not increase the general level of their participation or engagement (staff already doing an excellent job in involving them in constructive activities).

3. Untrained care staff will be able to run the group with the same results as the psychologist.

METHOD

The experimental group included all the clients who attended the Unit on Tuesdays:

Clients: 6 residents, 6 day care N = 12
8 male, 4 female
Mean age: 26.5 years. Age range: 17 - 51 years.
Mental age: 2 years (*Bayley*) N = 5
Mental age: 2 - 5 years (*Stanford Binet* or appropriate equivalent) N = 5
Mental age: 5 years (*WAIS* or *Stanford Binet*) N = 2

4 clients were wheelchair bound due to various physical problems and blindness. 5 had no expressive language. Other problems included difficult behaviour, non-co-operation, and poor concentration.

BASELINE

The activities of clients in the day room were observed using the *PLA* Check technique (Risley and Cataldo). The following calculations were made every four minutes:

> The proportion of clients participating in appropriate activity out of the total number of clients in attendance.
>
> The proportion of clients interacting with another member of the client group out of the total number of clients in attendance.

Participation was defined as: engagement in activity specified by staff; watching staff demonstrate activity; attending to instructions; manipulating materials provided by staff; or co-operating with physical prompts from staff or clients.

Interaction was defined as: watching or listening to another group member; helping another group member; being helped by another group member; sharing an activity; or talking to other group members.

Activities likely to promote interaction were collated by reviewing the literature (Jeffree and McConkey, 1977, a, b; Lear, R., 1975; Cortazzi, D., 1973; Portage material) and grouped into team games, large group activities, imaginative/let's pretend play, musical/noisy games, art, and cooking. From this a timetable was prepared using various permutations of 4 x 20 minute sessions.

INTERVENTION

The group was run by the psychologist, with staff help, for eight consecutive Tuesdays from 2.00 - 3.30 p.m. All clients present were invited to join in. Observations were made on weeks 5, 6, and 8. A pre-prepared booklet was then circulated to enable staff to organise and run similar groups. The booklet defines social interaction and explains its importance, outlines the need to teach mentally handicapped people how to play, and contains a list of aims of social play. It shows how to plan activity groups, makes suggestions for running the groups successfully, and gives ideas for activities, including equipment needed, aims, and instructions/ideas for games.

STAFF GROUP

A discussion with the staff identified two volunteers who then ran the group for a trial period of four weeks. The psychologist met them briefly once a week when staff planned the curriculum, ensured equipment was available, and discussed the previous week's session. A follow-up observation was made on the fourth week.

Reliability checks on observation data were made during baseline and intervention periods. The data were analysed using a computer package called GLIM (generalised linear modelling — Nelder and Wedderburn, 1972). This provides a statistic distributed as Chi-square for checking the goodness of fit of various models (for example, steady level, linear increase or drop over time) to the observed levels of interaction and participation over time.

Results

PLA CHECK:

Interobserver reliability for participation
87.3 - 96.6 per cent
Interobserver reliability for interaction
89.1 - 99.1 per cent
(Reliability calculated as laid down in Cataldo and Risley's *Handbook for Observers*)

INTERACTION DATA (see Figure 2)

	Best fitting models	Range
BASELINE	All periods show a good fit for steady levels of 0 per cent interaction	*per cent* 0 - 22 0 - 18
INTERVENTION	Week 5 Linear increase 0 - 29 per cent Week 6 Steady level 25 per cent Week 8 Increase from 34 - 58 per cent	0 - 31 0 - 62 0 - 80
FOLLOW UP	Steady level 38 per cent	25 - 57

PARTICIPATION DATA (see Figure 3)

	Best fitting models	Range
BASELINE	Wild fluctuations:	*per cent*
1	No line of good fit — assume steady 37 per cent	0 - 59
2	No line of good fit — assume increase 25 - 47 per cent	0 - 100
3	No line of good fit — assume increase 13 - 48 per cent	0 - 57
INTERVENTION	Week 5 Steady level 50.4 per cent Week 6 Steady level 50.4 per cent Week 8 Increase from 34 - 78 per cent	25 - 70 27 - 70 20 - 100
FOLLOW UP	Steady level 49 per cent	27 - 63

All intervention data significantly higher than baseline data. P<.001 (sign test).

FIGURE 1. Diagram to show time span of experimental design and observations

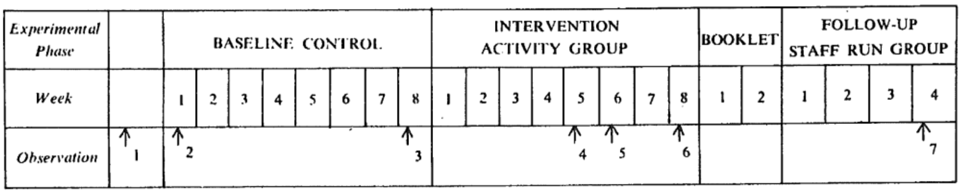


FIGURE 2. **Best fitting models for all interaction data.**

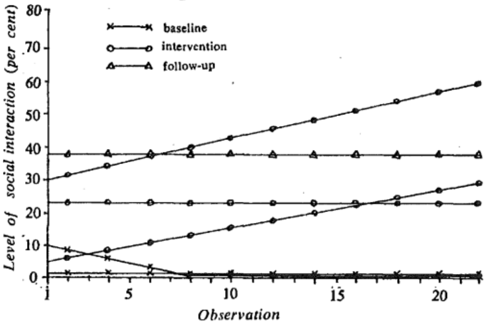
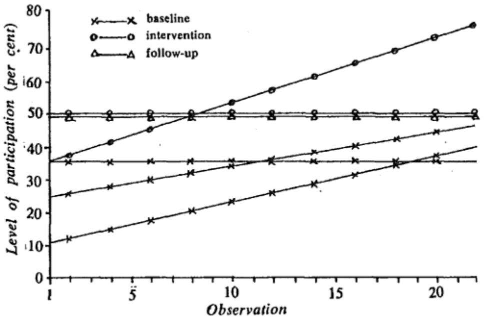


FIGURE 3. **Best fitting models for all participation data.**



Discussion

During the intervention period when a structured activity group was run, the observed levels of interaction amongst clients all showed a significant increase from baseline levels. Thus, hypothesis 1 was confirmed.

The levels of social interaction increased over the experimental period. This may illustrate a learning curve showing (1) that the activity group was bringing about learning in the clients and (2) staff were learning how to run the group according to the laid down principles. Another possible explanation might be that the activities themselves were more popular.

For the participation data, baseline observations showed wild fluctuations. The intervention period revealed two effects namely, (1) an increase in levels of participation (significant at $P < .001$) and (2) a steadying effect with more consistent levels obtained. Thus, hypothesis 2 was disproved.

Follow up data revealed that when untrained care staff ran the activity group themselves the increase in levels of interaction and participation, and the steadying in the level of participation, was maintained. Therefore, hypothesis 3 was confirmed.

Conclusions and questions

This study demonstrates that it is possible to do something constructive to promote social interaction amongst severely mentally handicapped people, who are traditionally viewed as socially isolated. It also demonstrates that increases in levels of participation occur when a structured activity group is implemented. Untrained care staff can successfully organise and run such a group.

These results have implications for planning, organising, and running daily activity/occupation programmes. They suggest that activity groups of this kind can provide a useful addition to an existing programme. They are economical in use of staff time — two untrained staff can provide high levels of participation and promote social interaction with minimal help from a psychologist.

Questions arising from this research include:

1. Does learning and generalisation of social interaction skills occur as a result of the group?

2. How can staff behaviour in organising and running the group be maintained?

3. How can the running of the group be monitored to ensure it is run according to the principles laid down in the booklet?

4. What contribution was made by the booklet itself in enabling staff to run the group?

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This study was submitted by Rowena Keleher in part fulfilment of the BPS Diploma in Clinical Psychology.

3.2 Publication 2

Keleher, R. J. and Cole, C. (1989) Systemic Intervention in Health Care Services: A Case Study. *Journal of Applied Systems.* 16, pp. 55-59.

This case study describes an innovative application of soft systems methodology to case work, staff development and organisational change within a learning disability service. Systems theory was relatively new within general therapeutic and organisational change literature with little application to learning disabilities. Systems theory had been influential in the development of therapeutic work with families (Haley,1963; Minuchin,1974; Palzzoli et al.,1978) initially where the child was the "referred patient". This was beginning to be utilised and evaluated across other care groups, ages and settings as it drew attention to more social and contextual issues in the development and maintenance of mental health problems and to possibilities for effective interventions in e.g. depression (Brown & Harris, 1978) and schizophrenia (expressed emotion, e.g. Brown, Birley & Wing, 1972).

Having researched systems theory and practice and research on systemic approaches in health, public sector and business settings for a modular in-service Master of Business Administration (MBA) assignment, I began to reconceptualise some interventions using this paradigm to provide a helpful theoretical frame across multi-layered interventions.

This multi-layered case study utilised soft systems methodology and was written up to disseminate the application of systems theory and methodology more broadly in health and social care and particularly in learning disabilities services. The specific contribution to knowledge included the innovative application of systems theory and methodology and illustration of how a soft systems approach can be used in effective problem "solving, resolving and dissolving" (Ackoff, 1978) in both clinical interventions and in service development. It also contributed to, and reflected the debate around effective roles for clinical psychologists and whether these should focus on individual therapy approaches or may yield more significant benefit through systemic or organisational change and influencing how care is delivered to be more psychologically informed.

The case study used a clinical referral and a soft systems methodology, multi-layered approach to formulation and intervention. It aimed to impact on psychological care service delivery directly to the referred client through how staff perceived and interacted with them, how the broader network of staff interacted with each other and how management of the service and broader network could work more effectively for all clients. The case study was published in the specialised Journal of Applied Systems Analysis both to give authority and credibility to this use of soft systems theory and methodology, and to illustrate and encourage its use more widely in health and social care and the public sector.

The case study demonstrated the relevance and utility of using systems theory (Soft Systems Methodology) in creating change in individuals and their care delivery contexts. Recommendations for successful application included ensuring a mandate for change, undertaking motivational analyses, attention to resources, data collection and analysis (both quantitative and qualitative). This publication illustrates application of the Level 3 psychological knowledge and skills (MAS, 1989) outlined in 2.7 Roles of Clinical Psychologists.

Publication 2

Keleher, R. J. and Cole, C. (1989) Systemic Intervention in Health Care Services: A Case Study. *Journal of Applied Systems.* 16, pp. 55-59.

Journal of Applied Systems Analysis Volume 16, 1989

SYSTEMIC INTERVENTION IN HEALTH CARE SERVICES: A CASE STUDY

R. J. Keleher and C. Cole

INTRODUCTION

In a 'Note on the Use of Systems Thinking in the Provision of Health Care' Checkland cautions against the inadequate and inappropriate use of systems thinking in the field of human care service systems [1]. This arises, he argues, when any health care system automatically is taken to be 'a system', a concrete entity, rather than a representational construct. Such misuse has the result that the "the limitations of the 'hard', system paradigms are preserved, renewed and passed on". On the other hand, he suggests, "if this limitation can be overcome, interesting possibilities . . . emerge". This would occur when "non-institutionalised arrangements" are thought of as relevant systems, for example "a system to explore and resolve conflicts on resource use"; and when *the process of inquiry* is taken as the crucial relevant system, rather than some entity in the world, such as is done in making use of Soft Systems Methodology (SSM).

This article presents a case study of a multilayered intervention in a care service setting (services for people with mental handicap) to illustrate how Soft Systems approaches can be used in problem solving and service development in such settings and to draw out themes relating to its use.

Firstly, a brief reminder of the development of Soft Systems Thinking and its main features is given. Secondly, the case study describes the setting, the interventions and the outcomes to date, with the root definitions used. The discussion reflects on critical themes in the appropriate use of Soft Systems Thinking and then considers some difficulties. The conclusions contain some pointers for successful use of Soft Systems Thinking in care services.

Soft Systems Approaches

The development of Soft Systems Thinking in operational and/or organisational problem solving grew from dissatisfaction with existing formal, mechanistic, structured, mathematical, reductionist approaches. Thus, approaches capable of conceptualising and working with wholeness were necessary. In systems thinking, it is recognised that the whole is greater than the sum of the parts (a notion described by the Gestalt Psychologists). Moreover, in most operational or organisational tasks and their associated problems, there is a 'people' side which does not lend itself to simplistic, mechanistic analysis and intervention. Psychologists, management scientists and organisational consultants are increasingly emphasising how the behaviour of individuals and groups is based on complex 'personal logic'. Hence, even if a 'solution' to a 'problem' is simple, this does not mean that *implementation* of the solution will be straightforward and effective.

In addition, impetus for the development of alternative methodologies and concepts has come from new perspectives in problem solving (Ackoff [2]). ***Resolving*** yields a 'good enough' or 'satisficing' solution; *solving* yields a best possible solution; whereas *dissolving*, by concentrating on the characteristics of the whole in which the problem is embedded, changes the nature and/or the environment of the problem context so that the problem is removed.

Checkland describes SSM as an approach to tackling (dissolving) messy, ill-structured, real-world problems [3]. Systems are conceptualised as evolving, fluid and systemic perceptions. The methodology for intervention takes an action learning approach, where some relevant (notional) human activity systems are explored

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and described in 'root definitions'; conceptual models are built from these root definitions; and comparison is made with perceptions of the real world with a view to finding possible changes which are both systemically desirable and culturally feasible. SSM is considered to be doubly systemic being a cyclic learning process which makes use of system models. Participative intervention using SSM should facilitate a change in the characteristics of the whole which 'dissolves' the problem situation and leaves the situation better adapted to, and adaptive with regard to, future functioning. Thus SSM acknowledges that human descriptions must inevitably be coloured by the constructs of the observer. It maintains a holistic rather than a fragmented approach whilst providing rigour and discipline by encouraging measurement and evaluation.

There has been considerable interest in, and use of, systems approaches within therapeutic endeavours with individuals and families. Recently, an increased sharing of experience and expertise between the field of clinical therapy and the field of organisational problem solving has become apparent. For example, Nielsen and Shander illustrate how systems approaches from family therapy can be used within organisations [4]. They write:

> On a technical level, our systemic therapy training has prepared us to respond spontaneously to complex and conflictful interaction. As we interact with systems, we examine and utilise multiple levels of meaning simultaneously . . . concepts learned from systemic family therapy have helped us to understand the structure of human social systems at a deeper level and to help them generate more productive options for themselves. Organisations almost always have a plan for the management of action but rarely have a plan for the management of meaning. This identifies what systemic family therapy has to offer business organisations!

Psychologists, with their grounding in behavioural sciences, knowledge of individual and group behaviour, and skills in facilitating change are in a prime position to contribute to the use of systems approaches to improve health care provision. The following case study illustrates just such a multilayered intervention from a Soft Systems Methodology perspective.

Case Study

DETAILS OF THE CASE

Entry 'problem':

Referral for advice and assistance with a lady with mental handicap who has a severe behaviour problem.

Request from:

Community Nurse who had been asked for help by staff from a residential home and day centre.

Referred client:

Alice, a 29-year old lady with severe learning difficulties.

History:

Alice had lived for 19 years in a residential home run by a Christian charity. Her family had been unable to cope with her difficult and demanding behaviour. The intensity and frequency of Alice's difficult behaviour had increased (hitting others, breaking windows and furniture, shouting and swearing, refusing to co-operate in daily routines). Attempts had been made to manage her by pharmacological means.

Current situation:

The local day centre was threatening to exclude Alice because of her behaviour. Residential home staff were frightened by the prospect of managing Alice continuously over a 24-hour period. There had been concern expressed by the community nurse and other support providers that this residential home, and its neighbour belonging to the same organisation, were operating a rigid, if somewhat haphazard, care process which did not really take account of individuals' needs and was not consistent across staff shifts. The 'Management Committee' which oversaw both homes was concerned that Alice would cause major harm and that an enquiry and scandal might ensue.

What was done?

Exploration of the problem situation was carried out by examining a variety of subsystems and perspectives. Information was collected by interviewing separately and jointly those staff directly responsible for Alice in the residential home and day centre. Staff also observed, collected and shared data about her behaviour.

It became apparent that there was much anxiety, anger, uncertainty and confusion within and between staff groups at both the residential home and day centre about how they should be delivering care in general, and how and who should be involved in decision making. Most concern seemed focused on Alice as the reason for everything being unsatisfactory. Once everything 'bad' was neatly packaged into 'Alice', staff could absolve themselves from any need or responsibility to change themselves or the system in which they participated. It therefore appeared inappropriate to the authors to offer a prescriptive 'behaviour modification' programme to improve Alice's behaviour. There was too much invested in keeping Alice bad. Instead, the situation was conceptualised in a multilayered fashion to explore perspectives and possibilities for feasible change. [See Table I.]

Elements from these possible root definitions were used as a framework for exploration in the appropriate forums for discussion, i.e. the real-world manifestations of the Human Activity Systems listed in Table I *and* their interfaces. The information gleaned was used as a basis to probe and test their applicability. The elements were then further explored to clarify shared understandings of the situation and to generate possibilities for feasible and desirable change. This enabled learning opportunities to be utilised by groups of staff with respect to the features and principles underpinning a *good* model of service delivery, and allowed them to raise 'taboo' issues such as staff not communicating, not being consistent, not understanding residents' needs, not supporting one another etc. This was made possible by the non-judgmental process of the problem analysis.

Outcomes

- Clarification of views on Alice's needs.
- Agreement, implementation, and evaluation of an appropriate care plan encompassing increased opportunities for her development, and consistent staff responses to disruptive behaviour with concomitant decrease in disruptive behaviour.
- Improved communication within and across staff groups (residential home/care centre).
- New process for assessing needs of other residents, and planning and implementing care plans.
- Money made available for more therapeutic equipment and staffing.
- Junior and senior staff and the Management Committee began to realise that service improvements *could* take place and that existing staff had ideas and enthusiasm which could be positively channelled with a little support and guidance.
- The Management Committee and trustees became more open to service development ideas, and invited local mental handicap 'specialists' (including one of the authors) to join the Management Committee. This was done for a short while to try to assist the unlocking of the Management Committee/Trustees' earlier perceived ignorance and inertia.
- The Management Committee developed processes for giving positive feedback to both of their local residential homes, so providing support and assistance in problem solving rather than acting as a nebulous 'Big Brother'.

Table 1: Possible CATWOEs [5] of Root Definitions relevant to the situation at the commencement of problem analysis

SYSTEM	Alice's 'Keyworker' and Advocate	Residential House Staff	Training Centre Staff	Management Committee Trustees
Customer(s)	Alice	All residents amongst whom Alice takes an unfair amount of time	Alice (+other residents)	All people with mental handicaps cared for by the organisation and on waiting list
Actor(s)	Self, staff, Psychology advice	Residential care staff	Training Centre staff	Residential care staff, managers, advisers, outside agencies e.g. health and social services
Transformation Process	'Care' for Alice to help her develop	Provision of home-for-life for mentally handicapped people; management of staff to enable this to occur	Provision of day care+some training in safe secure environment	Monitoring provision of residential care and development of residential provision
Weltanschauung (world-view)	"It doesn't look like things can be different round here, but maybe Alice could change"	"People with mental handicap are vulnerable and need care & protection for life – we provide this security therefore we must be doing the right thing"	"People with mental handicaps need guidance and support to develop new skills. Staff at the residential home don't know what they are doing"	"More of the same 'home type' provision is good thing"
Owner	Persons in charge of home	Management Committee	Social Services Department	Themselves
Environmental Constraints	Restrictions imposed by staffing levels, numbers of residents, routines, lack of equipment, lack of training for staff	Restrictions imposed by the building and by the rules of Management Committee. Reliance on a Training Centre for day care. Reliance on mediocre support to date.	Large numbers of trainees. Lack of staff interest in the Rules of the Training Centre. Training Centre staff's skills	Demand for residential care increasing. Significant changes in services for people with mental handicap

The systems approach used here facilitated multilayered and appropriate chang which left the real situation better able to function adaptively and provide hig quality care. It is essential to remember that any human system has to be conceptualised as an open system which will change and evolve over time in relation t external and internal events. Thus, constant re-exploring, re-describing and re interpreting of root definitions may be crucial in maintaining positive change.

Discussion Points

- Soft Systems Methodology is 'constructional' rather than 'pathological': it buil new adaptive repertoires. This is especially valuable in the rapidly changing environment of health care (where for instance, health promotion rather than repair is increasingly the goal).

- Organisations need to 'learn to learn' in order to be successful: it is not so much a question of 'survival of the fittest' (which is an absolute), but 'survival of the best fitting' (i.e. an organisation's responses to environmental demands and changes).
- There is now widespread recognition of organisations' need to manage *soft* aspects (style, staff, skills and supraordinate goals) as well as the hard (strategy, structure, real-world systems).
- Soft Systems Methodology works with people's own points of view: "perception is all there is". It helps make explicit any underlying values — particularly critical if such values or perceptions foster 'maladaptive' or 'least costly alternative' behaviours.
- Soft Systems Methodology encourages multiagency approaches, a notable benefit if many stakeholders are involved in a situation, e.g. health care, where patient, family, professionals, the community, employers, local authorities and voluntary agencies are requested to collaborate.

Conclusions

It is hoped that the example described above, together with the discussion points, convey the potential value of using SSM in order to achieve positive change in problem situations in health care. However, there are a number of potential pitfalls, which would-be problem investigators should be aware of if inclined to utilise a Soft Systems (or, indeed, any kind of problem solving) approach.

Firstly, ensure that there is some clear mandate for the intervention in the problem situation (i.e. beware of lip service or tokenism in problem solving). Secondly, be vigilant for 'chinks' in the real-world systems which may provide possibilities for change, e.g. someone with a more thoughtful approach to the situation, someone with particular imagination and drive etc. Thirdly, carefully observe and check out motivations — what people say they want and what they actually want may not be the same. (Some training and development in interviewing techniques, motivational analysis, observation and interpretation of human behaviour, especially social psychology, may be helpful.) Fourthly, check that adequate resources are available to effect changes (there is nothing more frustrating than attempts at implementing non-feasible change). Finally, make careful and appropriate use of quantitative information in the problem analysis process — numbers and statistics are certainly not the be-all and end-all of identifying and solving problems — but the considered use of such data within a qualitatively defined problem-solving approach can facilitate and contribute to the problem analysis process.

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3.3 Publication 3

Flockhart, K. and **Keleher, R. J**. (1989) Philosophy for Support Staff. *The Health Service Journal.* 9, March, pp. 301-302.

This experimental study was designed, undertaken and analysed as part of a series of action research projects by the Project Team I led from 1985 to 1988. My team initiated and evaluated service development and transformation projects in a long stay mental handicap hospital in collaboration with the management team. This study investigating training for non-care staff arose from the empirical studies on the need for, and effective features of staff training (Cullen, Hattersley & Tennant,1981; Woods & Cullen, 1983), evaluation of our own action research projects involving care staff training and an identified gap and need for training for a wider group of staff. A participative management philosophy and staff development policy had been introduced by the new Unit General Manager into what had been a very traditional mental handicap hospital with poor care practices (the subject of one of the seventeen inquiries described and analysed in Martin,1984). The need for non-care staff also to understand current service philosophy (according to national and local policy) and practical aspects of it, such as values and helpful behaviours in interacting with residents had been recognised.

Innovative aspects of the study and contribution to knowledge included investigation of an extension to staff training materials used, extended and evaluated already with clinical staff to include non–care or support staff (such as administrators, porters, catering, domestic and transport staff) to contribute to improving care provision. Strengths included the robustness of the design and data. The study was an equivalent non-randomised groups (partially controlled) Pretest – Posttest design (non-blinded). The sample of support staff were selected to be representative by department, grade, age, length of service, gender and whether English was their first language and matched on these factors. Quantitative measures of knowledge, attitudes and behaviours and qualitative feedback were collected. The publication was a summary of a longer research report which included policy, research and gap analysis as justification, design and intervention description and data analysis and description. It was published in a peer-reviewed management practice journal to reach an audience who could consider and implement similar initiatives. It therefore did not include significant theoretical or methodological discussion

The qualitative data showed some individuals’ knowledge scores improved greatly though no significant difference between experimental and control groups was found for the total scores (knowledge, attitudes or reported contact with residents) post-training. The value of training in enhancing service effectiveness and individual staff contribution was confirmed by 92% of respondents.

3.3 Publication 3

Flockhart, K. and **Keleher, R. J**. (1989) Philosophy for Support Staff. *The Health Service Journal.* 9, March, pp. 301-302.

SUPPORT STAFF CAN BENEFIT FROM TRAINING IN THE PRINCIPLES OF WORKING WITH MENTALLY HANDICAPPED PEOPLE. KAREN FLOCKHART AND ROWENA KELEHER EXPLAIN

PHILOSOPHY FOR SUPPORT STAFF

DIRECT CARE STAFF are expected to receive service training in philosophy and principles in order that they can function effectively — whether training is provided for a formal qualification or as part of induction or inservice training. Such an expectation for support services staff (such as administration and clerical, catering, domestics, estates, linen and laundry staff and so on) seems less explicit or accepted, despite the fact that they may constitute 50-75 per cent of a workforce.

A study was carried out with a sample of support services staff to investigate the effects of providing some training on service philosophy and principles of working with people with a mental handicap. The aim was to ascertain whether the support service staff would consider such training to be important or useful.

Church Hill House is a traditional mental handicap hospital which is home for about 220 people. About 180 care staff and 100 support staff are employed there. As part of the recent attempts to improve and develop services in order to provide more personalised care for the residents, groups of care staff — including nursing, therapists and training area staff — participated in a structured teaching package known as STEP (skills, teaching, education and programme planning).

STEP introduces the philosophy of normalisation, its application to services for people with mental handicaps, the role of care staff, and skills assessment and training. Support is then given to care staff to implement the ideas and techniques covered in the teaching package in their day to day work.

Some care staff involved in STEP training had suggested that housekeepers, domestics or catering staff might find it useful to learn about some of the issues covered in the training because of their involvement in the overall care team.

Another factor was that one of the objectives for the mental handicap services unit set for 1988-89 was 'to provide a skilled and effective workforce and enable all members of staff to contribute to the aims of the service'.

This was set in the context of an explicit management philosophy of participative decision making and increased communication within the unit, introduced by a newly appointed unit general manager in spring 1986.

Following planning discussions with senior management (UGM, personnel and support services manager, care service manager), two groups of about eight support services staff attended two consecutive pilot sessions on 'Working with people with mental handicap'. During the sessions they were introduced to the philosophy of normalisation and its main

Continued overleaf

Support services staff are usually kept in the dark about care processes.

From previous page

principles; the role of care staff, and how learning can be made easier for people with a mental handicap.

Participants in the study came from the departments in the support services, such as domestic, laundry, catering, works, administrative, clerical and so on. The sample was also representative by grade, with some participants being manual workers, while others had supervisory or managerial posts; by age, sex, length of service; and by whether English was their first language.

To find out if participants learned anything they were required to fill in a questionnaire entitled 'Working with people with mental handicap' at various stages (before participation in training, immediately after training, and after five weeks). A control group of support staff, which received no training, also filled out the questionnaires at the same time for comparison.

The questionnaire looked at participants' knowledge of normalisation and its related issues; their attitudes towards people with mental handicap and their behaviour in terms of contact with residents and care staff and how they felt about such contact.

An evaluation form was completed by participants following training to collect views on perceived usefulness, enjoyment, the quality and length of teaching sessions and the desirability of such events.

A follow up meeting was held to feed back the findings to study participants, and to involve them in interpreting and discussing implications as an example of participative management.

Statistical analysis was carried out on data from the questionnaires. There were some individuals whose scores on the knowledge based section improved greatly, but there did not appear to be any overall significant statistical change in knowledge, attitude or reported contact with residents and care staff over the three times measure was taken.

Thirteen out of 15 evaluation forms were returned, however, and these yielded more definitive results. Everyone said they had enjoyed taking part in the sessions, such as with comments such as 'It is nice for staff who are non nursing (caring) side to be involved'; and 'It made me feel more part of the hospital community and I realised more of the work done with the residents.'

Most respondents (92 per cent) thought that having sessions like the ones they attended was a good idea, with the other 8 per cent unsure.

The general impression from the evaluation forms and throughout the study was that support services staff felt they should be part of an overall team in the unit, and they wanted to be considered as such.

At Church Hill House, the support services not only play an essential role in the running of the service, they also make up a substantial part of the workforce. Many, such as housekeepers and domestics, have extensive contact with residents around the hospital, or the service they provide significantly affects the residents' quality of life, yet they have never participated in any training activity designed to give information about modern philosophies or processes of care.

This study showed that people working in the support services are interested in what happens on the care side and, as expressed at the follow up meeting with the participants, they want to know about new developments in the unit, such as the introduction of life planning (the new care review system). What is more, such staff need to know what is happening in the unit, and to be aware of new developments. As one participant said: 'Policies such as life planning have implications for everyone in the unit.'

In addition, support services staff revealed that they felt unsure what to do when residents displayed odd or unusual behaviours. Residents may be on training programmes teaching them new skills or more acceptable behaviours. If their less acceptable behavio are inadvertently reinforced or they recei mixed messages, confusion results, maki learning harder.

Unless all relevant people sha information on both general philosophy a principles and specific plans of action, t care process is not going to be deliver effectively and progress will be prevente

Essentially, support services staff seem need and want some form of training in t care philosophy and process. This is vital enable them to know how best to play th role within a service. This, in turn, l implications for the system. The serv system must be geared up to support all st to do a good job. All staff need to be gi explicit information on what expected of them in terms of behaviour a why, and be provided with support feedback on their performance.

Staff trying to put good principles in practice can meet endless constraints from t system, and can end up feeling punished f attempting to do their job properly. W changing services and increasing pressure resources, the need for clarity of directic effective communication and involvement l never been greater.

Support services staff have been kept in t dark about care philosophy and process f too long. This may result in a failure to ma the maximum contribution or they m sometimes inadvertently hinder possi progress.

This may be more obvious in a hospital people with mental handicap, where radi changes in philosophy and process of care occurring. However the issue seems to relevant to any service attempting to prov quality care with all care groups.

The response from the sample in this st suggests that staff in the support services want to have opportunities to learn about care philosophy and process side of service. Many of the participants in the st had felt undervalued by care staff colleag and indicated that they appreciated be considered more as part of an overall te as they were when they were involved in study.

A service such as that provided at Chu Hill House surely must be greater than sum of its parts. As one participant sta 'One department cannot function alone, have to work as a team.' Unless everyon the team knows their position, the rules where the goals are, how can they play game effectively and efficiently? Invol support staff in training initiatives is one of making this happen.

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Philip Wolmuth

Support staff were keen to feel part of the department's overall team.

3.4 Publication 4

Williams, T., Tyson, J. and **Keleher, R. J.** (1989) Using Mealtimes to Develop Interpersonal Social Skills in People with Severe Mental Handicap. *Mental Handicap.* 17, June, pp. 74-77.

This experimental study was an equivalent, non-randomised groups (partially controlled) Double Pretest - Posttest design, Mixed methods undertaken and analysed in year 2 of the Project Team initiative. Conceptual and methodological strengths included extension and development of previous projects, drawing on others' research demonstrating further how people with learning disabilities learn and increase their social skills, e.g. Robertson et al. (1984) including using more naturalistic teaching environments, e.g. Matson and Earhart, (1981), that lack of appropriate social and emotional skills often leads to placement breakdown (Pagel & Whitling, 1978; Schalock & Harper 1978). Much of the intervention group work was carried out by the psychology technicians and care staff whose skills had developed through the previous project work. Observational data (and reliability checks) and qualitative staff feedback were collected and analysed

Innovative aspects of this study and contribution to knowledge included investigation of an intervention which developed learning from the study described in publication 1, the “Activity Groups” to increase social interaction along with other clinical practice-based learning from delivering “Social Skills” groups in community settings (described later in publication 8). Study aims included evaluation of an intervention group that was more “naturalistic” and could bring potential benefits of enhanced learning, generalisation and maintenance, investigation of a range of different teaching conditions and use of care staff in the group delivery. It aimed to impact on psychological service delivery directly with clients and through interventions of care staff. The study was published in a multidisciplinary peer-reviewed practice/research journal for maximum dissemination across a range of professionals delivering services to people with learning disabilities.

A key finding of this study was that, even in a short time span, and using very simple teaching methods, meal times could provide a natural and age-appropriate setting for successful social skills development. Feedback from staff indicated that the “practical instruction and modelling” training condition was experienced as “easiest” (i.e. best). In general, this was also associated with the greatest increase in measured social skills. Some individual differences were noted. The benefits of using naturalistic, meaningful environments for skill development (Felce et al., 1984, Masidlover & Knowles, 1982) were observed.

3.4 Publication 4

Williams, T., Tyson, J. and **Keleher, R. J.** (1989) Using Mealtimes to Develop Interpersonal Social Skills in People with Severe Mental Handicap. *Mental Handicap.* 17, June, pp. 74-77.

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Using mealtimes to develop interpersonal social skills in people with severe mental handicaps

Teresa Williams Judith Tyson Rowena Keleher

A short experimental study was undertaken to investigate methods of developing social skills, in people with severe mental handicaps resident in hospital, which are practical, clinically effective, and result in maximum generalisation. It involved direct care staff using the simple training techniques of instruction and modelling in the natural setting of mealtimes. All the methods proved effective, especially modelling and instruction together, and at follow up some of the gains were maintained. The procedure was practical and cost effective. Differences in level of interaction between individual residents and between residents and staff were observed and the implications are discussed. Using mealtimes for social skills training will aid generalisation and may permanently improve the social environment. It will also provide opportunities to develop and practise all aspects of social skills. Other natural settings suitable for social skills training are suggested.

Cumulative evidence from research has shown that people with severe mental handicaps often have deficits in their interpersonal social skills, especially within an institutional setting (Matson and Andrasik, 1982). These skills are important components: in learning from others; adjusting to community living; and being accepted by the community. Lack of appropriate social and emotional behaviour has frequently been quoted as the reason for the failure of community placements (Pagel and Whitling, 1978; Schalak and Harper, 1978). Consequently, the acquisition of social skills would seem to be an important step towards a more fulfilling and normalised life style.

Recent research has shown that a wide variety of verbal and non-verbal social skills can be taught to people with mental handicaps of all ages and levels of handicap with great success, as defined by achievement of target behaviours within an artificial experimental context (Robertson, Richards, and Youngson, 1984). However, success thus defined is not synonymous with clinical utility. The two are separated by problems of generalisation, practicality and cost effectiveness of training procedures, meeting individual needs, and teaching aspects of social skills other than behavioural ones, that is, the perceptual, cognitive, and motivational aspects.

The problem of generalisation is often raised but is rarely adequately addressed (Robertson, Richards, and Youngson, 1984). Assessments are often made in artificial situations using pre- and post-test objective measures, which are of doubtful validity as measures of generalisation. Some studies have observed maintenance of, or only a slight decrease in, trained behaviours (Robertson, Richards, and Youngson, 1984). Unless the skills learned are generalised to natural settings, however, the value of the training procedure is small.

Some studies have attempted to aid generalisation by carrying out the training within people's natural environment. For instance, Kazdin and Polster (1973) trained adults in conversational skills in a sheltered workshop. Matson *et al.* (1980) trained social behaviour within the classroom. Matson and Earnhart (1981) found that training within the natural environment resulted in the greatest degree of generalisation.

The study

The primary aim of the present study was to examine the demands of teaching interpersonal social skills to two groups of hospital residents within the natural environment. It also aimed to investigate the relative effectiveness of various teaching conditions, namely, instruction, modelling, and instruction and modelling together, on four specific behaviours: eye contact, initiation of interaction, continuation of interaction, and requests. Using a natural environment was considered likely to produce maximum generalisation of skills learned. The experimental study was of seven weeks' duration. Mealtimes were used as the training setting. A few previous studies have considered mealtime behaviours (Robertson, Richards, and Youngson, 1984). Perry and Cerreto (1977), for example, used mealtimes to improve behaviours such as asking for and giving items and making conversation.

It was thought that using mealtimes would not only help with skill generalisation but would also provide information about the practicality and cost effectiveness of the teaching methods. An essential component was to use the time and teaching abilities of direct care staff who had most contact with the residents. It was considered that they would have the time available for teaching, and could use their personal relationships with and knowledge of residents to promote teaching success. They could also ensure that opportunities for residents to practise new skills would be available after teaching was completed. In this way the cost-effectiveness of specialist input and advice could be maximised, the specific principles and techniques being applied by direct care staff. The study, therefore, aimed to assess, through direct

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behavioural measures and a staff questionnaire, the efficacy and practicality of both the setting and the teaching procedures.

Method

Teaching sessions took place at mealtimes in the recently refurbished kitchens of a hospital ward that had been upgraded to form two flats. Usually most residents ate in a large dining room. The study represented the start of using the kitchens more frequently. Table settings were as domestic as possible, with food in serving dishes and tea, milk, bread, and condiments on the table.

There were two groups of three residents, for each of which one member of staff acted as session leader. Residents in two groups were of mixed linguisitic and social abilities, matched individually on the basis of knowledge gained from previous skill assessments and standardised vocabulary assessments.

Interaction levels during mealtimes were assessed using a frequency count on a checklist of items drawn up from various existing checklists, such as those of Felce *et al.* (1986) and Holley (1980). Four specific areas of behaviour were assessed: eye contact; initiation of interaction; continuation of interaction; and requests. The checklist was piloted in role play by psychology technicians. Reliability was assessed during the baseline, also by psychology technicians. Residents' interactions were coded to indicate whether they were with staff or other residents.

The teaching procedures were chosen for their relative simplicity. The *instruction condition* consisted of staff verbally prompting residents to interact. For example, they were asked to pass items, to ask for items, or to ask each other questions. The *modelling condition* consisted of staff demonstrating interaction. For instance, they asked for things to be passed, started conversations, and replied to residents. The *modelling and instruction condition* consisted of the two procedures being used concurrently. Positive reinforcement was given, in the form of staff praising residents who had participated in spontaneous or prompted interaction and drawing the other residents' attention to their behaviour. Staff were instructed in how to teach by handouts prepared by one of the present authors, who explained the aims of the sessions and gave examples of model behaviours under each condition.

It was hypothesised that the order of efficacy of procedures would be modelling and instruction together, instruction alone, and finally modelling alone.

Week of study	**1**	**2**	**3**	**4**	**Follow up**
Number of sessions	2	4	4	4	1
Number of data points	2	1	1	1	1
Teaching procedure Group A	Baseline	Modelling & instruction	Instruction only	Modelling only	Follow up
Teaching procedure Group B	Baseline	Instruction only	Modelling only	Modelling & instruction	Follow up

FIGURE 1. Project design

The project design is shown in Figure 1. In week 1 two baselines were taken because of the novel setting. Week 2 to week 4 was the experimental phase during which assessment took place in the last of the four sessions of each week. The order of teaching procedures was varied for the two groups in an attempt to allow comparison of their effectiveness. A follow-up assessment was made three weeks after the end of the experimental phase. All assessments were undertaken by psychology technicians.

Staff completed a 10-item questionnaire which aimed to discover the relative ease and practicality of each teaching method and of running groups within a hospital setting. It also asked if any changes in residents' social interaction had been noticed, and sought ideas from staff on improving mealtimes generally.

Results

The inter-rater reliability was 72.02 per cent. The frequency of interaction for all four categories assessed, and for the sum totals for these categories, increased during the experimental sessions (see Figure 2). Although during follow-up the mean levels of interaction fell, they remained above baseline. In a two-tailed correlated *t-test* between follow-up and mean baseline, the increase for "eye contact and expression" for all six residents was statistically significant ($t = 2.58$, $p < 0.05$).

Meaningful comparison of the teaching procedures was difficult because of the limitations of the experimental design, namely, short duration, no return to base-line group and order of intervention effect, cumulative effects, and lack of "blind" observers. However a tentative conclusion, from comparing levels of interaction for the various components both after each experimental condition relative to baseline and cumulatively across the experimental conditions for Group B, suggests that "initiates interaction" is most affected by modelling and instruction together. This is supported by the finding that both for groups and for matched individual comparisons modelling and instruction was more effective for increasing frequency of "initiates interaction" for Group A than instructions alone for Group B. The reverse was true for "requests" where the same comparison found that instruction in Group B increased "requests" more than instruction and modelling did for Group A. For Group B the baseline for "eye contact and expression" was unsteady and so only data from Group A could be examined. Here, modelling and instruction again produced the greatest increase and the highest overall level. For "continues interaction" the situation is less clear. Modelling and instruction had a greater effect than instruction alone when the first teaching procedures used with Group A and Group B were compared, both as groups and matched individuals. However the differences were small.

In summary, for "initiates interaction," "eye contact and expression," and marginally for "continues interaction," that is, for three out of the four assessed interactions, the hypothesis that modelling and instruction would have the greatest effect was confirmed. However for "requests" instruction alone was most effective; and for "continues interaction" instruction alone and instruction and modelling was very similar.

In the questionnaire staff said that modelling and instruction was the easiest to implement and they felt it was the most natural way of teaching. Mealtimes were considered convenient times for conducting social interaction skills training as they fitted in well with nursing routines. Staff thought the best group size was two session leaders and three or four residents, who should have more equal social skills than those in the study.

Individual differences were observed. Residents who were more socially and linguistically able showed the greatest

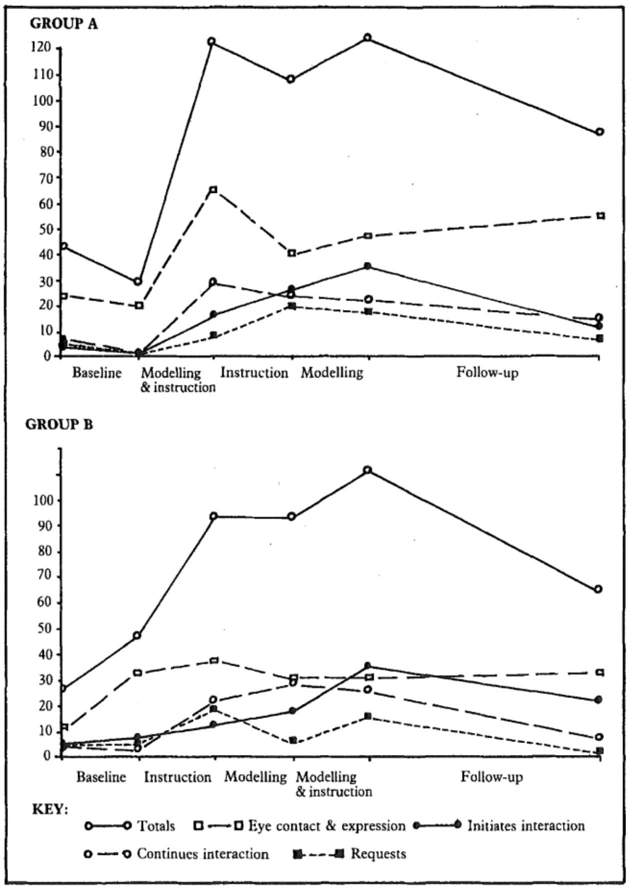

FIGURE 2. Social interaction frequencies during baseline, experimental, and follow-up sessions

increases in their levels of interaction. One, known to be socially anxious, interacted most often under the modelling alone condition. Some residents gave praise to the others, as modelled by the staff when giving positive reinforcement.

Differences were also noted in the interaction between the residents and between the residents and staff when the two categories were assessed separately (see Figure 3). The two categories of interaction seem to have a negatively correlated frequency. Resident to staff interaction was greatest during the modelling condition. Resident to resident interaction was greatest during the instruction and modelling condition. These results were consistent for both Groups.

Discussion

The limitations of this study include group effects and order of intervention which could not be sufficiently dealt with in this small scale study. The tendency for interaction to increase cumulatively made comparison of procedures difficult. Procedures could have included reliability checks during the experimental rather than the baseline phase, and more consistent reinforcement and discrete teaching procedures could have been provided if more explicit staff instruction had been given.

The length of the study was probably insufficient to maintain new skills in the long term (Matson and Andrasik, 1982) as confirmed by the fall in interaction at follow-up. Explicit assessment of generalisation would have provided more direct evidence for this conclusion. Appropriate settings for such assessment could have included mealtimes in alternative settings and other events where social interaction may occur, such as during work, domestic, or leisure activities.

Despite this, the study does demonstrate that a possible solution to the problem of generalisation of learned social skills may be to teach them within a natural setting rather than an artificial situation. If previously developed teaching procedures could be transferred to such settings their usefulness would be greatly enhanced, both in terms of generalisation and in terms of their practicality and cost-effectiveness through direct care staff undertaking teaching with the minimum of specialist supervision.

The study also demonstrates that it is possible to increase social interaction through relatively simple techniques, the most effective of which was modelling and instruction. This is supported by the fact that, taking into account the resident in Group A who was socially anxious and maximised his interaction during the modelling condition, the totals peaked under the modelling and instruction condition (see Figure 2).

Natural settings such as mealtimes can also provide suitable opportunities for teaching of aspects of social skills other than behavioural ones, such as cognition, motivation, perception, and performance feedback which have been largely neglected (Robertson, Richards, and Youngson, 1984). For people with mental handicaps the environment is the most important factor in learning social skills. Many live in impoverished social environments, where opportunity and motivation to socialise appropriately, and positive feedback for doing so, is lacking. Using settings and staff that are continuing features of residents' lives can provide incentives for social interaction in what becomes a natural and responsive social environment which offers appropriate opportunities for using social skills. Attention to the need for carefully structured, naturalistic, and meaningful contexts for skill and communication development echoes themes noted by other authors, such as Felce *et al.* (1984) and Masidlover and Knowles (1982).

The study also demonstrates the need to consider individual differences in investigating the efficacy of procedures for teaching social skills. As previously mentioned one resident, who was known to be socially anxious, made the greatest progress under the modelling condition, and the two who made the greatest increases in interaction were the ones who were most socially and linguistically able. Determining individual differences and deciding on the most appropriate teaching methods will involve complex variables, but present results suggest that these aspects are important. Pre-training assessment to isolate relevant variables could be helpful in facilitating social skills training.

Another interesting observation was that residents occasionally provided praise to one another, confirming the impression of Matson and Andrasik (1982) that they may be useful aides in training other residents.

This study also raises the issue of differences between staff and resident interaction and resident and resident interaction. Given that for Group A and Group B modelling brought about the most staff to resident interaction, and modelling and instruction brought about the most resident to resident interaction, it would appear that different factors control the two. In the modelling condition, for instance, residents may have to concentrate on staff behaviour and on their responses to it rather than their own behaviour. During the instruction and modelling condition, however, their attention may be directed more explicitly towards their own behaviour towards other residents rather than towards staff. These results suggest that as both types of interaction are important to encourage the two types and the teaching procedures that promote them, need to be assessed separately in future.

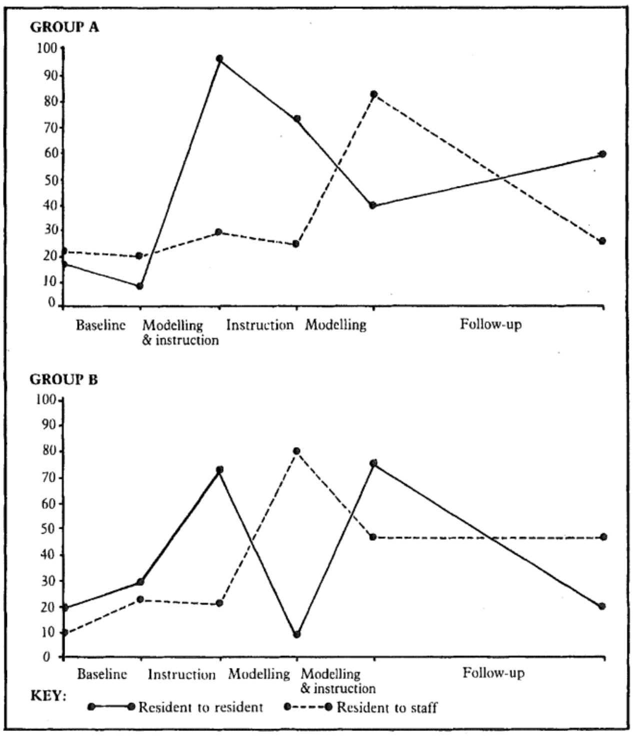

FIGURE 3. Total interactions between residents and residents and residents and staff across baseline, experimental, and follow-up sessions

Conclusion

The most important finding of the study is that, even within a short time span and using very simple teaching methods, mealtimes can provide a natural and age-appropriate setting for successful social skills training. Direct care staff found the setting practical as it fitted in well with existing nursing routines, allowing training to be easily implemented and cost-effective of their time. The teaching method they found easiest was also the one that was most effective in increasing interaction, namely modelling and instruction. In this procedure, instruction seemed to be the most important component, possibly because it is more directive of resident behaviour. As noted, for one of the six residents this generalised conclusion was not valid, so care should be taken to consider people's individual differences and to tailor learning situations to meet individual needs.

Confirmation of the general conclusion of the usefulness of the training has been provided by the fact that the mealtime training sessions continue to take place regularly 18 months after the withdrawal of psychology staff involvement, with specific groups of residents being targeted in turn. The cost-effectiveness and practicality of the procedure allows residents to continue to be given the opportunity to learn and practise social skills.

Other natural settings in which social skills training could be conducted include work, leisure, and domestic activities. Implementing such training in these settings may lead to permanent changes in the social environment, as well as dealing with difficulties of generalisation, practicality, and cost-effectiveness. Such possibilities merit further study as they may well lead to greater provision of effective social skills training with people with mental handicaps.

Acknowledgements

The authors wish to thank all the staff and residents who participated in the study.

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Reviews

Lifelines: an account of the life experiences of seven people with a mental handicap who used the NIMROD service

Edited by Simone Humphreys,
Gerry Evans, Stuart Todd
London: King's Fund, 1987
Pbk: £7.50 138pp

Can the lives of seven people with mental handicaps really fill a whole book? And if so, does it mean their experiences are exceptional? The answers to these questions appear to be "yes" and "no". Yes, the lives and experiences of seven individuals are more than enough to fill the pages of a book, and to keep at least this reader's interest throughout. But no, the experiences of the seven people featured in the present book are mostly not exceptional. Their lives, like those of the majority of people with mental handicaps, have been shaped and framed by services that are not renowned for recognising and meeting individual needs.

The book achieves two things extremely well. First, it is "a good read". It captures people's lives and experiences, and makes for interesting reading. Secondly, its focus on seven individual lives is a message in itself; a message about the *individuality* of people with mental handicaps.

Mental handicap services have traditionally provided for groups, often large groupings, of people. Those described within the pages of this book have been, and are, the recipients of such services. In its design and approach, however, the book counteracts that tendency to group people together. And, through the experiences of the seven individuals, it charts and evaluates the impact of "the NIMROD service".

The NIMROD service aims to provide a range of support services to people with mental handicaps in their own communities. In its use of Individual Plans and its emphasis on the flexible use of resources to meet individual need, NIMROD has approached its task in imaginative ways. It is not a complete success, as this book shows, but it is far ahead of most local provision and has useful pointers for other service providers.

The individual perspective presented is welcome. However, the stories do rely on written records and the accounts of other people, rather than on what the individuals themselves said. Thus, whilst capturing their lives in great detail, the one voice that really matters is mostly missing. There is one exception: Pauline Davies's voice *is* heard. There is a moving moment in her story when she reflects on NIMROD's disappearance from her life two-and-half years previously: "They've talked to me about moving to a new home, and they said they'd teach me to cook. They said they'd let me know about the house, but I haven't heard a thing". Pauline continues, apparently forgotten, to lead her life within the confines of a mental handicap hospital.

The stories are about individuals, but common themes emerge and are discussed. People are at different stages in their "career of handicap", but they have much in common. They have little choice about things that really matter, like where to live and with whom. Their lives are devoid of the closeness and intimacy found in friendship and other close relationships. These challenges still remain to be met.

This book is highly recommended. It does its job well, and will be of interest to a wide audience.

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Autistic children: one way through. The Doucecroft School approach

Ian B. Ashton
London: Souvenir Press, 1987
Pbk £6.95 205pp

This book is essentially an account of the trials and tribulations, and successes and failures, experienced in setting up the Doucecroft School which was founded by the Essex Autistic Society. The author, who is the head teacher of the school, was instrumental in its establishment and in its expansion into nursery education and a Life Care Centre for adults. What emerges is evidence of his considerable energy, drive, and educational skills; assets which were undoubtedly necessary to overcome the many hurdles encountered, including finance, professional indifference, parental resistance, and bureaucracy.

As with a number of other publications in the *Human Horizons Series* it is not altogether clear to whom the book is mainly addressed. There is no doubt, however, that parents — particularly those whose children are autistic — will gain much from the practical and yet insightful approaches used at the school, especially in the areas of conduct, language, and social skills. Professionals, on the other hand, may wince at the "tough" line the author advocates in some instances of unacceptable behaviour; whilst perhaps also secretly hoping that they would have shown as much courage in similar circumstances. Nevertheless the author's humanity and tenderness come through clearly, as does his empathy with parents and with his own staff. Some professionals quite rightly get short shrift.

The book is written in a narrative and informal style with illustrative case vignettes heavily featured throughout. It is easy to read and makes little use of technical language. There is no preaching,

3.5 Publication 5

Rossiter, R. J., Hunnisett, E. and Pulsford, M. (1998) Anger Management Training and People with Moderate to Severe Learning Disabilities. *Brit J Learning Disabilities*. 26, pp. 67-74.

This study of an innovative clinical group intervention investigated whether Cognitive Behavioural Therapy (CBT) could be adapted sufficiently to be an effective therapeutic intervention for people with severe learning disabilities and problems with anger management and/or aggression. Evidence from some single case (Lindsay et al., 1989) and group studies (Benson et al., 1986; Lindsay & Baty, 1989; Turk & Francis, 1990) was beginning to demonstrate effectiveness of behavioural and some cognitive behavioural interventions with people with mild learning disabilities and ways to adapt CBT to be accessible for children (Young and Fanselow Brown, 1996). Groups implemented in 1984, with a colleague had begun to incorporate cognitive elements in social skills groups with people with moderate to mild learning disabilities before published evidence appeared (Brigden and Rossiter, 1989, tape-slide programme, also described in publication 8.

The study was a response to psychology referrals (inpatient and community), the need to develop more effective interventions and a desire to work collaboratively to share skills. Justification for the study built on themes of earlier studies including preventing placement breakdown and inequalities in service provision for, and research with, people with learning disabilities reflecting an increasing rights-focus:

> Unregulated anger is associated with aggressive and antisocial behaviour which, in turn, can lead to placement breakdown, and further undermine the self-esteem and sense of control of people with learning disabilities.

and

> … an encouraging advance as previously people with learning disabilities were denied therapeutic advances which emphasise self-management of behaviour. (Rossiter et al. 1998, p 67)

The aim was to increase accessibility of cognitive behaviour therapy for people with more substantial cognitive impairments through simplifying content, reducing language and concept, increasing visual and “enactive” learning components including role play, video and peer support and prompting. We incorporated behavioural, cognitive and emotional aspects to develop both confidence and competence. The cognitive aspects were particularly innovative as cognitive behaviour therapy (CBT) was in its infancy with almost no published work on its use with people with severe learning disabilities. We drew on available learning disability evidence available, emerging child CBT studies and adult mental health evidence which we adapted. Staff support within the group was a particular aspect we trialled to investigate its effect on increasing generalisation and maintenance of learning.

The design was a one group Pretest - Posttest design, mixed methods (uncontrolled, non-blind, non-selective). Quantitative data analysis of existing clinical data (e.g. incident forms) and qualitative feedback from participants on what they learned, liked/did not like, how the group could be improved and staff feedback were collected. The study aimed to impact on psychological service delivery directly with clients, through broadening staff group delivering (occupational therapist and psychologist) and through involvement of care staff. The study was written up for a multidisciplinary peer-reviewed practice/research journal for maximum dissemination across a range of professionals interested in applied research.

Key findings were that people with moderate-severe learning disabilities were able to make use of the simplified CBT approach to anger management (four of six participants utilising personalised Anger Management Traffic Light System to good effect, two others using some elements), visual resources and active role play were helpful, as were a neutral location, consistent staff accompanying them and a supportive living context.

Contribution to knowledge from this study included demonstration that CBT could be adapted for use with people with severe learning disabilities. It contributed to broader debates regarding methodological issues of valid measures of change for clinical and research purposes in this complex population, ways of enhancing generalisation and maintenance of progress, contextual/social issues in the development and maintenance of emotional problems in people with learning disabilities and a more critical discourse regarding the *medicalisation* of emotional problems.

Publication 5

Rossiter, R. J., Hunnisett, E. and Pulsford, M. (1998) Anger Management Training and People with Moderate to Severe Learning Disabilities. *Brit J Learning Disabilities*. 26, pp. 67-74.

British Journal of Learning Disabilities Vol. 26 (1998) · 67

Anger Management Training and People with Moderate to Severe Learning Disabilities

Rowena Rossiter, Freelance Clinical Psychologist, Oxted, Surrey, **Emma Hunnisett**, Clinical Psychologist in Training, East Anglia and **Mandy Pulsford**, Mulberry Day Therapy Centre, Sevenoaks, Kent.

This paper outlines an Anger Management Programme specifically tailored for people with moderate to severe learning disabilities using the principles of Cognitive Behavioural Therapy in a group setting. The metaphor of a Traffic Light was used in which each light represents a different stage in the process of Anger Management: relaxation, self-instructional training and problem solving. Within the framework of an individualised *Anger Management Traffic Light System*, participants engaged in role-play with video feedback to develop an understanding of their own reactions to anger-arousing situations and learn new skills to manage their anger. This small, time-limited group seemed successful in demonstrating that people with moderate to severe learning disabilities are able to make use of a simplified Cognitive Behavioural approach to Anger Management, to monitor and modify their own thoughts and behaviour. Most progress took place where participants had a consistent, caring, high quality living environment, with carers committed to systematic support and follow-up.

Introduction

In recent years research has shown that people with learning disabilities who struggle with problems associated with uncontrolled anger can benefit from treatments other than behavioural management procedures or medication (Turk & Francis, 1990; Benson, 1992). Researchers are beginning to develop methods of helping such people understand and manage anger by incorporating principles from Cognitive Behaviour Therapy (Benson *et al.*, 1986; Benson, 1992; Lindsay *et al.*, 1994). This is an encouraging advance as previously people with learning disabilities were denied therapeutic advances which emphasise self-management of behaviour. Unregulated anger is associated with aggressive and anti-social behaviour which, in turn, can lead to placement breakdown, and further undermine the self-esteem and sense of control of people with learning disabilities. Therefore, it is important to continually develop new ways of helping people with learning disabilities understand and manage their anger.

Benson's (1992) Anger Management Training Programme (AMT) was based on the work of Novaco (1978) whose Cognitive Behavioural model of anger incorporated the elements of external events, internal cognitive labelling processes, emotional arousal and behaviour reactions. Benson's intervention focuses on relaxation training (regulation of emotional arousal), self-instructional training (the internal cognitive labelling component) and teaching problem-solving skills (as an alternative to inappropriate or unhelpful reactions).

The success of Benson's (1992) AMT programme has shown the effectiveness of Cognitive Behavioural Therapy with people with mild learning disabilities in a group format. However, adaptation of these methods is needed for people whose learning disabilities are more severe. It is evident that problematic anger in moderately and severely learning disabled people poses particular problems in terms of management and future placement (Lindsay & Baty, 1989; O'Neill, 1995). Currently, there is little literature on Anger Management techniques specifically designed for people with moderate to severe learning disabilities.

The aim was to develop a programme for Anger Management primarily for people with moderate to severe learning disabilities, using elements from Benson's (1992) Anger Management Training and modifying her method to tailor it to the needs of people whose verbal ability, capacity for insight and grasp of complex problem-solving processes are more limited. The following were drawn on to adapt the relaxation training, self-instructional training and problem-solving skills components of Benson's (1992) AMT for use with people with moderate to severe learning disabilities:

(1) Literature reporting on successful Cognitive Behavioural methods for the management of anxiety and development of social skills problem-solving techniques in children (e.g. Young & Faneslow Brown, 1996; Petersen & Gannoni, 1992; Petersen, 1992; Sawyer *et al.*, 1995) to seek methods suitable for adaptation.

(2) Research on relaxation training, Anger Management and Cognitive Behaviour Therapy for people with learning disabilities.

(3) Personal clinical experience of adapting techniques from adult mental health to individual and group

> work with people with moderate/severe learning disabilities. For example: use of visual cues (photographs and slides of situational anxiety, tense/relaxed muscle groups) in anxiety management groups; the use of 'cartoon' visual cues for meaning and memory in social skills training.

Petersen & Gannoni (1992) used a framework incorporating the metaphor of a traffic light in their approach to developing social skills problem-solving in children, and Petersen (1992) used the traffic light metaphor in her approach to effective parenting. Each light represents a different stage in the process of problem-solving: *Red* signals STOP (define the problem, recognise feelings and identify goals); *orange* signals THINK (generate solutions); and *green* signals DO (choose a solution and initiate an action). This visually appealing, familiar, concrete aid could fit in well with Benson's (1992) scheme of relaxing (STOP), self instructional training (THINK), and problem-solving (DO). The traffic light metaphor was adopted to put the elements of relaxation, coping statements and problem-solving techniques into a familiar and memorable framework — the *Anger Management Traffic Light System* (AMTLS).

The importance of visual aids as an adjunct to teaching and to prompt memory is highlighted by Turk & Francis (1990) who found that information presented to learning disabled people in the form of instruction without any accompanying memory aids was rapidly forgotten. The metaphor of the traffic light was adopted but further adapted for our participants as it is an easy concept to understand, and is visually meaningful. Petersen's (1992) 3-stage system was simplified to make it appropriate for incorporation into an Anger Management programme for people with moderate to severe learning disabilities. It was planned to make full use of visual aids (photos, slides, flipchart pictures, video demonstration, role-play, prompt aids) throughout group sessions, in homework and at follow-up.

Petersen's (1992) first stage suggested that the signal should include an element of introspection (I feel ... because ...). In the first stage for our adapted AMTLS this was reduced to *'red* = STOP, RELAX'. The idea was to 'stop' the emotional arousal/feelings of anger and actively engage in relaxation as an arousal-reduction strategy. The red signal might prompt relaxation over time, even if clients were unable to consciously think about their feelings. The idea of saying RELAX in conjunction with taught relaxation techniques was to be emphasised, hoping this would eventually serve as a cue control.

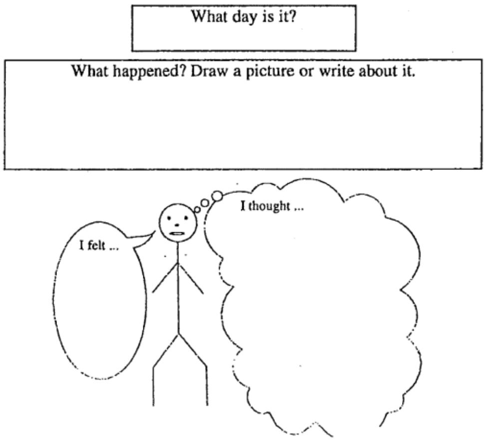
Lindsay *et al.* (1994) have shown the positive effects of cue control relaxation on adults with severe mental retardation. Results showed that cue control words such as *'quiet and still'* or *'relax'* when linked to Behavioural Relaxation Training, could eventually produce a relaxation effect in the absence of a full relaxation procedure.

The relaxation component of Benson's (1992) AMT is based on Abbreviated Progressive Relaxation (ABR) techniques, which requires clients to following instructions to tense and relax their muscles in cycles beginning with the hands, and progressing to the feet. Participants need to conceptualise the internal states of tension and release, and this has been shown to be difficult for people with severe learning disabilities to achieve (Lindsay *et al.*, 1989). These methods suggest that Behavioural Relaxation Training is a more effective relaxation treatment for this client group as it relies on simple modelling and manual prompting of relaxed positions and as such does not require any complex understanding. Therefore, the relaxation component of the proposed Anger Management Group was simplified using some 'symmetrical' instructions, i.e. *not* right hand, then left hand, but both hands together; deep breathing techniques; and overall relaxed body posture, visualisation and using cassette tapes for individual practice.

The second phase of Benson's (1992) programme includes training in self-instructions. The focus is on introducing and increasing 'coping self-statements' during problem situations, instead of 'trouble situations'. Research shows that negative self-statements can undermine the confidence of people who have a learning disability (Lindsay & Kasprowicz, 1987) and can trigger anger arousal. Benson's (1992) approach teaches how to replace identified *trouble statements* (negative/anger-arousing, self-statements) and *coping statements* (positive/coping self-statements connected to anger-arousing situations).

In the adapted AMTLS, the *orange* = THINK signal corresponded with Benson's (1992) self-instructional training phase of Anger Management. The planned adaptation was that instead of choosing a few coping statements to apply to different situations, clients chose one personalised coping statement of their choice which was broad enough to cover a whole range of situations, to overcome memory, generalisation, and reasoning limitations. A technique described for Cognitive Behaviour Therapy for anxiety in children by Young & Faneslow Brown (1996) where 'thoughts and feelings' associated with events are illustrated by drawing pictures using 'thought' bubbles which have words or pictures to show 'thoughts and feelings' regarding the anxiety-provoking incident was used to try to elicit behaviour, feelings and thoughts surrounding incidents where anger was expressed or managed inappropriately.

Figure 1 Thought diary sheet



In the third phase of Benson's (1992) AMT, a four-step problem-solving process is introduced which involves defining the problem, looking for potential solutions, evaluating and choosing a solution and following a plan. This was simplified to a single *green* = GO, DO stage. The relative complexity and combination of concepts at Benson's (1992) third phase is probably too difficult for people with moderate to severe learning disabilities who are also likely to struggle with perspective taking and complex sequential thought during periods of arousal. In Petersen's (1992) original *green = choose solution, initiate action* phase, there was a two-stage choice of action, then initiation. Here, *green* = GO, DO signals one simple, individualised problem-solving strategy for each client to put into practice which would provide an appropriate behaviour to 'deflect' anger, rather than confront others while aroused.

Benson's (1992) AMT recommends 15 weeks for maximum benefit to clients. However, this time commitment can be prohibitive due to constraints of staff time, so it was planned to reduce the frequency of sessions without diminishing therapeutic progress. Due to the modifications made to Benson's (1992) programme, it was hoped that the aims of teaching people with moderate to severe learning disabilities to recognise and manage their anger could be accomplished in a shortened group phase of eight sessions of one and a half hours' duration, plus a follow-up session. Additional staff support and the use of memory aids to reinforce skills learned were used during all sessions and an individually tailored follow-up action plan was prepared, implemented and monitored between Session 8 and the follow-up.

The aim of this study then, was to ascertain whether the positive attributes of Benson's (1992) AMT could be combined with ideas from Cognitive Behavioural Therapy with children to develop an Anger Management training protocol which would be effective for people whose learning disabilities are more severe.

Method

Benson (1992) suggests that the optimal number of participants in an Anger Management group is six to eight. In accordance with this, six participants with learning disabilities were accepted, four from a specialised residential assessment and treatment unit for adults with learning disabilities and challenging behaviour, and two from CLDT/day therapy centre. Co-leaders were a female clinical psychologist and a female occupational therapist.

The need for an Anger Management Group arose from treatment needs identified by the first author in a cohort of referrals for assessment and advice for individuals placed in an assessment and treatment unit for people with learning disabilities and challenging behaviour. Anger Management work was a high priority for three people. The author's previous experience in undertaking Anger Management work with individuals with learning disabilities, combined with experience of providing Anxiety Management interventions both individually and in groups to people with moderate to severe learning disabilities, where the group experience seemed to enhance clinical progress, suggested that attempting a group approach to Anger Management might be indicated. Additional potential participants were referred from disciplines within the local Community Learning Disability Team (clinical psychology, nursing, occupational therapy) where Anger Management work had been identified as a need.

Participants were first screened for suitability for the group using a screening interview slightly adapted from Benson's (1992) *Anger Inventory for Adults with Learning Disabilities.* Interviews were conducted individually, three by the Clinical Psychologist and three by the Occupational Therapist. The interviews indicated that each participant had the requisite verbal skills, attention, concentration and insight into their own feelings of anger, to be able to benefit from the AMTLS. Staff support was identified so that staff working with participants could accompany participants and support the completion of homework and practice.

Participant characteristics

The group comprised two females and four males, ranging in age from 27–64. All participants had identified problems with Anger Management. Characteristics are shown in Table 1. Participants' cognitive abilities were assessed from clinical information available (three participants had been assessed by the first author, two others by other clinical psychologists).

Table 1 Characteristics of participants

Participant	P1	P2	P3	P4	P5	P6
Age	27	29	30	41	49	64
Gender	F	M	F	M	M	M
Ability	? unknown	moderate ld	severe ld	mod/sev ld	moderate ld	mod/sev ld
Residence	Family home	Assessment and treatment unit	Assessment and treatment unit	Assessment and treatment unit	Residential care	Assessment and treatment unit
Additional issues	Additional emotional problems	Asperger's syndrome	Emotionally labile	Physical disabilities and depression		Signs of dementia
Anger problems	Verbal abuse, inappropriate body language, slamming doors	Throwing furniture, physical aggression	Swearing, tearing pictures, breaking windows, refusing medication, verbal and physical aggression	Withdraws, or verbal and physical aggression	Verbal and physical aggression, especially towards females	Banging furniture, physical aggression

Setting

All group sessions were conducted in a large, quiet room at a therapy centre. A video camera was set up in one corner of the room, and whiteboards/flipcharts were available for illustrations of emotions/body language etc. A TV monitor and video recorder were also available.

Structure of sessions

There were eight training sessions, each lasting one and a half hours, with a follow-up session to review and revise strategies (11 weeks after the eighth session). Sessions followed a consistent format, beginning with a review of skills learned during the previous session and feedback on homework, followed by an introduction and explanation of the major session topic and a practice period for the new skills (including viewing video demonstrations and role-playing). The sessions concluded with a discussion of the next homework assignment (Benson, 1992). Evaluation forms were given to each participant and their main staff supporter on Session 7 to be completed by and discussed at Session 8. The content of the sessions followed the overall format of Benson's (1992) *Anger Management for Person's with a Mental Retardation*, specially modified for people with more severe learning disabilities as described in the introduction. A timetable can be made available on request. The key elements and techniques are highlighted in Table 2.

Table 2 Key elements of Anger Management Group sessions

Session	Participant Area	Content
1	Introductions, aims, identifying emotions, trust and self esteem exercises	Introductions and aims with photographic slides of previous groups for people with learning disabilities, showing role-play, discussion, video, practice, use of visual aids. Rules for the group based on Benson (1990) with picture cues and words; trust and self-esteem exercises; identification of emotions (happy, sad, angry, frightened, ok) using slide material, flipchart faces, brainstorm of different words for emotions and situations arousing the four main emotions. Homework: daily mood monitoring chart.
2	Identifying anger and introduction to relaxation	Mood monitoring homework reviewed, each participant described situations where they felt happy, sad, etc. (linked back to material from Session 1). Group leaders role-played anger-arousing situations, on video to model role-play. During play-back of video specific features of anger arousal, signs identifying anger were pointed out, looking at body, face and voice. Drawings on a flipchart illustrated changes in body posture and face as people experience anger, and participants copied these changes. Relaxation techniques introduced with leaders demonstrating tensing and relaxing muscles and deep breathing, use of cue word 'relax' with prompts from leaders to individuals as appropriate. Each participant was given a cassette tape with relaxation exercises. Homework: daily mood monitoring chart, practise breathing techniques.
3	Role-playing emotions and introduction of Anger Management Traffic Light Systems (AMTLS)	Homework recap, review of previews week's videos, role-play with signifiers of anger in the body/face and voice highlighted; participants and staff role played one of the four emotions one at a time facing the video recorder; play back enabled review of body language and facial expression; introduction of AMTLS; focus on *red* — STOP, RELAX; relaxation practise from cassette tape as Session 2. Homework: complete mood monitoring charts and practise relaxation and breathing using the cassette tape.
4	Participant role-play of anger arousing situations and practice. *Red* = STOP RELAX stage of AMTLS	Role-play practise of emotions. Videoed group role-plays of anger-arousing situations, with one leader and one participant arousing anger in another participant (using situations identified from screening or earlier sessions). Role-plays replayed to identify anger arousal signs, then they were re-role-played, practising *red light* — STOP, RELAX, practising relaxation techniques learned the previous week to combat rising anger during the role-play. Video play-back focused on *red* — STOP, RELAX, as the first step in managing anger in such situations enabled review of success of practise, re-emphasises, re-practise, re-role-play elements as needed. Relaxation and breathing exercises practice, suing the cassette tape and modelling/prompts from leaders. Homework assignments — relaxation practice, thoughts/feelings identification.
5	*Orange* = THINK stage of AMTLS introduction of trouble and coping statements	Recap of AMTLS, review of *red* — STOP, RELAX. Trouble and coping statements were introduced using thermometer metaphor; participants brainstormed examples of each (e.g. *I can't cope, I've had enough, I hate doing this; I can cope, I"ll take a break, relax, don't panic*). Role-play of anger-arousing situations practising trouble and coping statements; individual choice of coping statement to which they could best relate; the coping statements explained in the context of the *orange* light of the traffic light system Homework: relaxation practice.
6	*Orange* = THINK, trouble and coping statements	Trouble and coping statements from Sessions 5 reviewed; participants practised personal individual coping statements, then role-played STOP, RELAX, and THINK stages on video. Re-play enabled the highlighting of successful practice and the positive effects of coping statements and how they can allay anger; repeat practice if necessary. Relaxation practice. Homework: relaxation practice.
2-Week Gap		
7	*Green* = Do and problem-solving actions. Preparation for evaluation and group ending	Review homework. Idea of problem-solving. Review of traffic light system with introduction to problem-solving actions for good Anger Management — the *green* = DO part of AMTLS. Brainstorm problem-solving actions, evaluate their usefulness. Choose preferred problem-solving actions for individuals. Relaxation practice. Introduce evaluation. Prepare for ending. Homework: relaxation practice.

Table 2 Key elements of Anger Management Group sessions *continued*

Session	Participant Area	Content
3-Week Gap		
8	Whole system practice and evaluation	Review homework — relaxation. Recap on AMTLS. Practise individual DO actions identified in Session 7, and rehearse STOP, relax, coping statements and actions in sequence in role-play. Videotaped, playback with leaders pointing out good examples of relaxation techniques, coping statements and problem-solving actions in combination — enabled further rehearsal and practice. Feedback and praise. Evaluation discussion from clients and staff. Forms distributed. Follow-up planning. Certificate given. Group photograph. Farewells and good luck. Homework — relaxation tape.
11-Week Gap during which:		
Each member of the group was given prompt cards incorporating their individualised AMTLS personalised with their own coping statements and problem-solving actions. All were sent a copy of the team photographs, a handout with suggestions and reminders of ways to cope with Anger Management difficulties and an individual report detailing attendance, progress, recommendations for follow-up. These were then discussed between client, staff and one of the group leaders at individual follow-up, where an individual 'practice'/'prompt' action plan was drawn up.		
9	Follow-up and review of progress, group problem-solving	Recap on whole AMTLS, individual's coping statements and problem-solving actions. In small groups, participants first shared one experience of successfully practising/implementing Anger Management techniques and reported back to large group, then one experience where they had lost control. Ideas were shared as to what might have helped and then reported back to a large group where more ideas discussed. These ideas were written on a flipchart and later sent to the group as a handout. Relaxation practice. Goodbye and good luck.

Results

Participation and progress throughout the course of the group showed that people with moderate to severe learning disabilities were able to make use of the simplified approach to Anger Management. Table 3 summarises the main results of the group. Four of the participants managed to put the whole AMTLS into practice in a natural and fluid manner during group sessions (when prompts were given), including Participant 2, who was somewhat rigid in thinking and behaviour (linked to Asperger's syndrome). Both females had problems averting eye contact during practice which would mean they may get stuck in anger-arousing situations — hence, the prompts to avoid eye contact. Participant 6 managed to implement some elements with specific prompts, e.g. relax.

In addition a simple evaluation form was completed by participants and by staff supporters individually. These were shared and discussed during group Session 8. Table 4 summarises the feedback.

In general, the results suggest that the Anger Management model devised and delivered through this time limited group was effective and enjoyable to participants with moderate to severe learning difficulties.

Discussion

The simplification of previous models (e.g. Benson, 1992), much visual prompt material, and didactic and active approaches are considered key elements in enabling the framework of the AMTLS to have some success with a group with more significant cognitive impairments than previously reported work. Even though some participants found the role-play difficult, the general view was that it was a worthwhile and vital element. Mixing participants from the assessment and treatment unit with community clients had some benefits in terms of increased motivation and range of problem situations. Having the group take place away from the assessment and treatment unit also appeared to offer the benefit of being on neutral ground where participants may have felt freer to think and behave in new ways. Although participants were mostly able to practise and further develop Anger Management skills with the support of staff according to their individualised *Action Plans*, this was more successful for some.

The most progress seemed to have taken place where participants had a consistent, caring, high-quality living environment, with staff who were committed to support and follow-up in a systematic way (as evidenced by regular carrying out of homework, behaviour change during group and at follow-up, the undertaking of supportive actions without reminders). Least progress appeared to be made when these were lacking and also where participants had significant addition needs, e.g. signs of early dementia affecting concentration, consciousness and learning/memory abilities. Checking abilities and particular difficulties at the screening stage and screening out or grouping more carefully according to matched abilities/difficulties may help. The attempt made to use the Young & Brown (1996) thoughts and feelings picture diary did not meet with success and was abandoned. However, after completion of the described group, a manual entitled *Managing Anger* (O'Neill, 1997) was published containing some potentially more useful *Think, Feel, Do* pictures which could be used as diaries and as a basis for planning more constructive individualised prompts. Other material in this manual would seem to be potentially useful for future groups although in general it seems that the ability level aimed at was borderline/mild rather than moderate/severe, although some ideas and examples for simplification are given.

Table 3 Outcome of Anger Management Group

	General Participation	Progress	Follow-up	Personalised AMTLS
P1	Attended 7 sessions. Participation and commitment high, though some aspects caused considerable anxiety (e.g. role-play). **Homework:** High level of contribution for all tasks.	Developed ability to carry out stages of Anger Management Traffic Light System but continuted to need prompts. Persevered with role-play and discussions despite feeling anxious and improved coping strategies for anger and anxiety.	Managed to control anger during group and no incidents of verbal aggression reported. Able to hold down job.	**STOP:** *Relax.* **THINK:** *Keep calm.* **DO:** *Walk away calmly, avoiding eye contact.*
P2	Attended 9 sessions. Keen participant, undertook all tasks. Enjoyed role-play and video work. social aspects of group. **Homework:** Undertook mood monitoring well. Needed reminding practise relaxation.	Good progress in learning and practising all the main skills within the AMTLS group setting. Continued to need prompts in group because some of his practice and thinking were too concrete.	No aggressive incidents during group or follow-up period. Moved from Assessment and Treatment unit to residential home where the implementation of AMTLS was supported. No further aggressive outbursts.	**STOP:** *Relax.* **THINK:** *I can handle it.* **DO:** *Walk away calmly, go back later to talk about it.*
P3	Attended 8 sessions. Motivation, commitment and participation high despite becoming anxious and tongue-tied. **Homework:** High level of contribution for all tasks.	Managed to grasp and practise all stages of AMTLS when pictures and prompts encouragement are present. Not able to generalise skills.	Despite good progress within group, had difficulty successfully putting into practice even with staff support. Intensity and frequency of aggression reduced.	**STOP:** *Relax.* **THINK:** *Keep calm.* **DO:** *Walk away calmly, avoiding eye contact.*
P4	Attended 5 sessions. Appeared, generally disinterested and disinclined to participate. **Homework:** Did not complete homework.	No apparent progress due to limited attendance at group and competing other issues in life (moving into new flat).	Settled well into new flat. Participation in social activities improved. No aggressive incidents.	**STOP:** *Relax.* **THINK:** *I can cope.* **DO:** *Walk away calmly,*
P5	Attended 8 sessions. Participated in all tasks. Highly motivated within group situation and practised at home. Participated well in role-play despite finding it difficult. Enjoyed social aspects of group. **Homework:** Undertook Anger. Management training system well. Needed reminding to practise relaxation.	Learned and became more confident in using all stages of AMTLS within group sessions and outside. Able to discuss anger-arousing incidents despite finding this difficult.	Frequency of aggression markedly reduced. Staff support high in residental setting.	**STOP:** *Relax.* **THINK:** *Relax.* **DO:** *Can I show you how I usually do it. Walk away calmly,*
P6	Attended 9 sessions. Level of participation varied depending on level of consciousness (dementia) — from vacant/unaware to appropriate participation. Enjoyed social aspects of group but found. concepts and practice hard even on good days. **Homework:** Did not complete very much very often or very well.	Despite frequently appearing not to understand what was going on, by the end of the group he seemed to understand the need to relax and stay calm (when functioning at his best).	No aggressive incidents during group or follow-up. Moved from assessment and treatment unit to residential home. No further aggressive incidents.	**STOP:** *Relax.* **THINK:** *I can cope.* **DO:** *Walk away calmly,*

Table 4 Participant feedback on Anger Management Group

Aspects Enjoyed/Things Learned	Things Not Liked	Improvements Suggested
Specific to Anger Management • Trouble/coping statements. • New ideas/skills. • Ways to control temper/act properly/cope. • Relaxation. • All of it.	**Specific to Anger Management** • Talking about difficult things.	• More sessions. • Ensure same support staff attend all sessions. • More role-play. • Wider availability of Anger Management groups to more clients and staff. • More varied timing (mornings, afternoons evenings). • Plan/think about more situations for future in role-play sessions, e.g. queuing in shops.
Non specific aspects of group • Meeting new people. • Learning that other people share the same problem. • Sharing ideas.	**Non specific aspects of group** • Uncomfortable in front of others. • Timing (clashed with work). • Standing up (feedback from elderly participant).	

It may be that increased progress may result from increasing the number of sessions. Further research would be needed to answer questions regarding optimum length of group sessions compared to support of practice *in vivo* situations. Also, it is not clear if the Anger Management Group itself necessarily led to any reduction in anger/aggression or improvement in anger control and expression. The study was not subject to any kind of control, participants continued to receive additional individualised input (e.g. psychological, pharmacological, occupational therapy) and there was no individualised baseline control period pre-group, nor robust data on frequency, intensity and/or duration of incidents to objectively quantify reductions in aggression in general, or relating to specific incidents identified at the screening stages due to limitations of resources. However, the clinical process within and outside the group, together with the feedback from participants and staff, suggest the group had a positive effect. Future use of the methodology described here will use suggestions made recently by Black *et al.* (1997) on 'Evaluating Outcome' including:

(1) Operationalise the criteria of change or goals of treatment in terms of everyday behaviours and capabilities.

(2) Select or design outcome measures using a variety of assessment modalities. The point is made that as target problems are multidimensional, there may be desynchronies between measures with cognitions, affect and behaviour changing at different rates.

(3) Indicate magnitude of change needed by specifying cut-off points against which post treatment scores can be compared (after Jacobson & Truax, 1991), e.g. post treatment scores falling outside range of a specific dysfunctional population or within the range of the well functioning population or a mean between the two.

An illustration of an instrument for assessing cognitive change is described which is a modification by Black (1994) of the Social Problem Solving Test (SPST) developed by Castles & Glass (1986). This may need further modification for use with people with more substantial cognitive impairments. Alternatively, more reliance on direct observation may be needed.

Additional considerations for ensuring any Anger Management groupwork achieves maximum effectiveness include:

- In screening potential participants, identify aspects in their life which may both assist and hamper change and learning in deciding whether people are going to be able to participate in and benefit from such a group. If there are too many other key current life events (as with Participant 4 for whom alternative semi-independent living accommodation was being planned and who therefore had his mind on other things) or if previous experiences (e.g. abuse, multiple placement breakdowns) have contributed to other psychological difficulties (depression, low self-esteem, relationship problems) as well as anger, other psychological, psychiatric or practical support may need to be given first.
- The group leaders need to be 'in control' of screening and take broader factors into account, such as those above. In addition, individuals need some insight into their anger problems, abilities and specific difficulties. Sometimes other professionals recommend Anger Management input as if it will be a magic wand. Anger Management group leaders and anyone carrying out Anger Management work need to be aware of the broader context for people's anger, its appropriate expression and control. With some people who have long histories of 'failed' placements, aggression, or possible abuse, the provision of Anger Management may result in just another experience of 'failure' — feeding into the cycle of low self-esteem, frustration and anger.

This paper describes an attempt at adapting previously reported approaches to Anger Management Groupwork for use with people with more severe limitations in learning abilities. Feedback from participants and staff supporters and follow-up observations indicate that the participants were able to make use of the strategies and principles, and found the group useful. 'Anger Management' is not a 'panacea for all ills' and account needs to be taken of a broad range of factors in terms of people's profiles, current strengths/difficulties, current and past life events in deciding whether inclusion in an Anger Management group is an appropriate intervention at any given time.

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3.6 Publication 6

Andrews, K., **Rossiter, R.J**., Daynes, S., Goodwill, A. & Preston, A. (2010) 'Emotion management and people with severe learning disabilities: the 'Team Mate' group'. *Learning Disability Practice,* February, 13 (1) pp. 32-35.

This innovative clinical pilot group built on previous investigation and experience of the Anger Management CBT Group (Publication 5) and subsequent clinical CBT based groups (some described in Publication 8). These included groups focusing on single emotional/mood disorders or behavioural disorders including anxiety, depression, anger, self-esteem, sexual offending, and more generic emotion management across a broader range of emotions in an attempt to *normalise* the role and importance of a range of emotions in all our lives, to reduce the *pathologising* or limiting effects of single emotion groups (anxiety and/or low mood and/or frustration can present as anger/aggression). These groups were delivered with a range of children, young people and adults with learning disabilities in community, school and hospital settings by a variety of co-facilitators including nurses, occupational therapists, clinical psychologists, psychology assistants and clinical psychologists in training.

Justification for the study included the growing evidence-base and policy regarding early intervention such as Valuing People (DH, 2001), National Service Framework for Children, Young People and Maternity Services (DH/DCFS, 2004), Every Child Matters (DES, 2004) Social and Emotional Aspects of Learning- SEAL (DCFS, 2005), New Ways of Working (DH, 2007), Improving Access to Psychological Therapies (DH, 2007). However, studies showed a lack of services for, and research into, learning disabilities despite evidence that people with learning disabilities show higher rates of emotional and behavioural disorders than the general population (Foundation for People with Learning Disabilities, 2002; Emerson & Hatton, 2007) and despite the passing of the Disability Discrimination Acts (1995 and 2005). Emerging evidence was demonstrating that CBT could be effective with people with learning disabilities (Rose, 2005; Willner et al., 2002, 2005, 2007). It was also a response to the nature and number of referrals to a Community Team for Children and Young People with Learning Disabilities and a desire to share skills within and across the Community Team and special schools. I led the multidisciplinary team that planned, delivered and evaluated the group.

The design was a one group Pretest - Posttest, mixed (uncontrolled, non-blind, non-selective). Quantitative data included co-facilitator ratings of participants' concentration, comprehension and participation and qualitative feedback from participants on what they learned, liked/did not like, how the group could be improved and co-facilitator and staff feedback. The study was written up for a practice journal aimed across health professionals, especially nurses, working with people with learning disabilities in order to raise the profile of, and demonstrate psychological interventions for emotions and illustrate early intervention, multiagency and multidisciplinary working.

The main finding and unique contribution to knowledge includes demonstration of how CBT can be further adapted for children and young people with very substantial cognitive impairments, broadening the scope for early intervention/mental health promotion , the use of *normalised* environment (as contrasted with a *clinical* setting) and a wider staff group for psychological interventions. Methodological and ontological issues relating to evidence-based practice and practice-based evidence are touched on (p.33) as are paradigmatic issues. These include use of the constructional approach e.g. Schwartz and Goldiamond, (1975) , pragmatics of such interventions in a school-based study population, targeted versus universal interventions, managing other approaches which may be already in use, but do not have an evidence base such as Brain Gym, (p. 34.).

Publication 6

Andrews, K., **Rossiter, R.J**., Daynes, S., Goodwill, A. & Preston, A. (2010) Emotion management and people with severe learning disabilities: the ‘Team Mate’ group. *Learning Disability Practice,* February, 13 (1) pp. 32-35.

Emotion management for people with severe learning disabilities

Meeting weekly, a group of teenagers was helped to cope with issues around change and relationships using techniques adapted from cognitive behaviour therapy. Kirsten Andrews, Rowena Rossiter and colleagues report

Summary

Team Mate was a pilot emotion management group for students with severe learning disabilities, held at their further education unit. The group was run collaboratively by education and health professionals and planned, delivered and evaluated in line with current policy and evidence. Adapting cognitive behaviour therapy for people with learning disabilities, the group focused on feelings, relationships, change and coping.

Evaluation showed that most participants enjoyed the group and learned new skills. The Team Mate approach is undergoing further development based on participant and facilitator feedback.

Keywords
Cognitive behaviour therapy, relationships, coping

TEAM MATE was a pilot emotion management group for years 12 and 13 (sixth-form) students at a secondary school for pupils with severe learning disabilities. Education and health professionals collaborated to run the group, drawing on adapted cognitive behaviour therapy (CBT) for people with learning disabilities. The aim was to enable students to learn to identify and discuss different emotions, relationships, changes and endings, and the feelings they may provoke, as well as to explore strategies that might help them to manage those feelings successfully. The group was also taught simple relaxation techniques.

This approach was developed in response to an identified clinical need, but it also addresses developments in government policy. For example, key outcomes for children and young people from *Every Child Matters* (Department for Education and Skills (DfES) 2003) include being healthy (physical and psychological wellbeing), staying safe, enjoying and achieving, and making a positive contribution. *Valuing People* (Department of Health (DH) 2001) recognises that children and young people with learning disabilities are particularly vulnerable to mental health problems, with adolescence being a time of transition and emotional upheaval requiring support.

Emotionally vulnerable

Although research shows that children, young peopl and adults with learning disabilities have a higher rate of psychological and mental health difficulties – 36 per cent of children and adolescents with a learning disability have a diagnosable psychiatric disorder, compared with 8 per cent of the general child and adolescent population (Emerson and Hatton 2007) – research has also highlighted how th emotional lives of people with learning disabilities have often been neglected (Arthur 2003).

Many other policies, including the national service frameworks for children and young people (DH and DfES 2004) and for mental health (DH 1999), *Improving Access to Psychological Therapies Positive Practice Guide* (DH 2007a), *New Ways of Working* (DH 2007b), National Institute for Clinical Excellence (NICE) guidance (2005), *Social and Emotional Aspects of Learning* (Department for Children, Schools and Families (DCSF) 2005) and *Count Us In* (Foundation for People with Learning Disabilities 2002), all highlight the need for early intervention and better mental health provision. Clinical guidelines for children and young people and adults (for example, NICE 2004, 2005) recommend CBT for anxiety and depression. Furthermore, practice guidance has highlighted the need for, and ways of, providing mental health support for children and young people with learning disabilities (Pote and Goodban 2007, Wolpert *et al* 2006).

Adaptations of CBT provided through groups for people with learning disabilities have appeared in the literature for more than 20 years (see, for example, Benson *et al* 1986, Rossiter *et al* 1998, Whelan *et al* 2007). All report positive outcomes for group CBT interventions with people with learning disabilities. Whelan *et al* (2007) described a group CBT approach with adults with learning disabilities, mental health needs and low self-esteem. They concluded that the approach shows promise with this group of clients and suggest that both the CBT and the group dynamics were helpful for change. Beail (2003), however, cautions that much of the evidence is 'practice-based evidence,' rather than 'evidence-based practice,' and relates to small numbers of case studies. He also notes that lack of evidence is not, in itself, evidence of ineffectiveness.

One of the authors of this article has investigated an adapted CBT programme with adults with moderate to severe learning disabilities, suggesting that group interventions may increase participation in, and effectiveness of, psychological interventions, compared with individual approaches. Furthermore, more generalised emotional management interventions, for example, 'Be Cool-Stay Calm', 'Coping with Change' and 'Anti-Bullying' groups, may be more effective than groups focused on single problems, such as anger or anxiety management. However, there are no studies comparing or researching these factors in the evidence base.

Promoting positive mental health and resilience in younger people should improve mental health in adulthood, reducing the need for mental health services later and improving quality of life. Using schools as a setting for mental health promotion enhances accessibility, links with a growing emotional focus for learning (DCSF 2005), develops skills for life and allows the development of a positive emotional culture with more emotionally aware and developed children in a non-stigmatising way and place (Stallard *et al* 2007).

Planning

The group was planned and facilitated by a teacher and teaching assistant from the school and a community nurse and trainee clinical psychologist from the community team for people with learning disabilities. The group was supervised by a consultant clinical psychologist. Six male students aged between 17 and 19 years were chosen by school staff to participate. They were all identified as having some emotional difficulties and some had been referred for individual specialist intervention. Three of the group's facilitators were male, one was female.

Multidisciplinary planning meetings took place to discuss the purpose of the group, number and length of sessions and when the group could start. Potential content, materials and methods were discussed. It was agreed that feelings, both positive and negative, and changes (and the feelings these can provoke) would be used as the framework for the group. It was considered particularly important to focus on changes because all members of the group were approaching their final years in school and would be experiencing change. As change is a feature of all people's lives, it provides a broad, normalised and constructional framework, as opposed to using a pathologising 'problem-focused' framework (Scwartz and Goldiamond 1975).

Leaving school provided a specific, concrete topic for group participants to focus on in developing helpful coping strategies for managing feelings and change. This major change could be planned for, and any relevant skills learned could be generalised to other changes in life.

Following discussion, detailed draft session plans were produced. Session plans drew on adapted CBT material for people with learning disabilities, including the literature cited earlier and guidance developed by the local NHS trust, adapted CBT and other material for children and young people on the autistic spectrum (for example, Attwood 2001), and CBT for children and young people in a mainstream setting (Stallard 2002) together with the combined experience of the education and health staff.

Weekly sessions

The group met at school for eight weekly sessions, each lasting 45 minutes. All of the sessions covered:

- Introduction, rules, goal setting.
- Feelings: different feelings, what happens when you have a particular feeling (physical, behavioural, emotional and cognitive changes), situations that might provoke certain feelings and strengths of feelings.
- Relationships: different types, who people have relationships with, good and bad things about relationships.
- Coping with difficult feelings: Emotional toolbox incorporating physical, social, relaxation and thinking tools that might help people cope with difficult feelings (Attwood 2001).
- Changes: different changes, how they can make

Leaving school provided a specific, concrete topic for participants to focus on in developing helpful coping strategies

Figure 1 Prompts from the toolbox used in the group's weekly sessions

you feel, how you can help yourself to feel better.

- Endings: end of group, other endings, how you can help yourself to feel better. Preparation of individual plans and prompts, including keyrings with picture cards representing 'tools' from the toolboxes (Figure 1).
- Final session: recap, evaluation, how to keep using what members have learned.

A variety of methods were used including structured group discussion and practical activities, and homework was set, which included tasks and exercises to practise between sessions.

Activities varied in success with this group of students. One activity using a length of rope to help demonstrate different strengths of feelings (Attwood 2001) appeared to be too abstract for the students. Conversely, the 'emotional toolboxes' (Attwood 2001), which contained pictures showing physical, social, relaxation and thinking 'tools' or activities that could be used to help manage difficult feelings, were successful. Members of the group participated well in this session and were able to identify which tools helped them in coping with difficult feelings and situations. The use of visual supports (Figure 1) was considered important because they help keep the students' attention, and aid understanding and communication.

The structure of the Team Mate groups was consistent. The group always began with 'hook ups'; a method to help focus and concentrate, which the students were already familiar with through their use in school. Hook ups are part of Brain Gym, a programme of body-based movement tools, which aim to improve concentration and learning (Educational Kinesiology Trust 2008).

There is no unequivocal evidence base for the effectiveness of Brain Gym (Swain 2008). However, the hook ups technique did appear to help the Team Mate group to identify the start of each session, focus their attention and settle into the group's activities. The sessions ended with the simple relaxation exercise of calming breathing. Each week a homework task was set to encourage the students to think about and practise what they had learned between sessions.

Results

The group was evaluated by the students and facilitators separately. The students were given help to carry out their evaluations, which could have influenced the views that they expressed.

Four of the six students enjoyed the group, with five saying that being with their friends was what was good about it. Students were from a range of classes and the group gave them an opportunity to interact with a wider group of peers. Two students identified learning about their emotions as being good, with others praising the group for enabling them to learn about themselves and talk to other people. None of the students could identify what they did not like about being in the group. Five students were happy that the group had finished, with one being angry, possibly because he thought he was still benefiting and wanted the sessions to continue. Half of the students had found the group beneficial. All of the students could identify one or two others whom they thought the group had helped. The teacher who knew the students before their participation in the group said she had noticed a change in three members of the group and that they had particularly benefited from the group.

All the group facilitators found running the group an enjoyable and rewarding experience, and they all considered that the session length was suitable for the needs of the students. The group size was thought to be appropriate because it allowed everyone present to feel relaxed and to contribute in the sessions. Facilitators thought that it was important to have at least one male facilitator with an all-male student group.

The facilitators agreed that some group activities were particularly good but there was certainty about how much some of the students understood the concepts involved in some activities. It was also thought that the students would have benefited from more visual supports throughout the sessions.

From the evaluation it was clear that the students and facilitators enjoyed being part of the 'Team Mate' emotion management group and that some of the students benefited from their participation. The collaboration between education and health staff was considered to have added value to the group by harnessing a wider range of experience, skills and knowledge.

Future groups

Consideration is now being given to running the group again for another group of students. Recent research has shown positive outcomes for mental health promotion and anxiety reduction in children in mainstream schools though universal programmes such as the *FRIENDS for Life* programme (Barrett 2004, Stallard *et al* 2007). *FRIENDS for Life* has also been piloted using adaptations to enable participation by pupils with special educational needs. We are considering further simplification and adaptation to enable pupils with severe learning disabilities to access the *FRIENDS for Life* programme as an alternative method of running the group. This could also allow comparisons to be made between the Team Mate approach and *FRIENDS for Life* scheme. Other potentially useful resource, such as the SEAL resources (DCSF 2005), may be woven into future groups.

Further changes may include involving parents in the groups, which would assist with practice, generalisation and maintenance of skills. Consideration could also be given to how students are selected to participate in the group. For Team Mate, school staff identified the students they felt would benefit most: these were students with identifiable emotional difficulties, although not all required individual, specialist intervention. An alternative approach would be to run the group with a year group or class of students. This would potentially generate a greater mix of students with and without pre-existing emotion management difficulties, and they may benefit from learning from each other.

Given the vulnerability of young people with learning disabilities to developing emotional difficulties, it seems important that they are given every opportunity to develop their emotion management skills. It may also be appropriate to run the group with younger students and follow up with them again at a later date with a 'booster' session when they are older, or to run the group with students with different needs, such as moderate learning disability or autistic spectrum disorders.

The adapted CBT group approach also has relevance to adults with learning disabilities: it could be run as a general wellbeing and/or mental health promotion group, or as a group focusing on people who are experiencing changes in their lives. Team Mate was a pilot group and we plan to repeat and develop the concept further in the light of what we have learned from the students and from our own involvement in the group.

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3.7
Publication 7

Rossiter, R.J., Andrews, K. and Tulloch, L. (2011) Emotion management for young people with severe learning disabilities. *Learning Disability Practice* July, 14 (6) pp. 22-24.

This publication describes a further innovative clinical pilot group developing from the experience of the school-based emotional management group using adapted cognitive behaviour therapy described above in publication 6. The justification is broadly parallel with this but extends it with more recent policy (Department of Health's *No Health without Mental Health* (DH, 2011), the new government Child and Young People IAPT (*Improving Access to Psychological Therapies)* project, DH, 2011, and WHO *Better Health, Better Lives: The European Declaration on the Health of Children and Young People with Intellectual Disabilities and their families* (World Health Organisation, 2010).

This group targeted younger pupils (earlier intervention) and those with more substantial cognitive and communication problems (broadening access, piloting further adaptations) and drew on a wider evidence and theoretical frame for the intervention. This broader, more integrative frame included the previous CBT model and method, recent application of social learning theory (Bandura, 1986, 2009), narrative approaches (White & Epston, 1990) and group process issues. The intervention also drew on evidence and resources for effective autism-focused interventions including Attwood (2004) and Howlin et al. (1999).

The group was also a response to the nature and number of referrals to a Community Team for Children and Young People with Learning Disabilities, the desire to share skills within and across the Community Team and special schools and a step on a specific journey towards developing a more systematically adapted evidence based group intervention for systematic evaluation. I led the multidisciplinary team which planned, delivered and evaluated the group.

The design was a one group Pretest - Posttest, mixed (uncontrolled, non-blind, non-selective). Quantitative data included co-facilitator ratings of participants' concentration, comprehension and participation and qualitative feedback from participants on what they learned, liked/did not like, how the group could be improved and co-facilitator and staff feedback. The study was again written up for a practice journal aimed across health professionals, especially nurses, working with people with learning disabilities in order to highlight emotional and psychological interventions, early intervention, multiagency and multidisciplinary working.

The key finding and unique contribution to knowledge includes further adapting CBT for young people with greater cognitive impairments and increasing access and engagement through integrating other therapeutic frameworks (narrative, sensory stories), broadening the scope for early intervention/mental health promotion, the use of *normalised* environment again, a wider staff group for psychological interventions and strengthening the links to policy, inequalities and legislation. It locates consideration of a developmental stage and “pre-requisite” skills to engage in CBT and notes the difficulties in finding reliable and valid measures for this population (p. 23)

This concisely written paper was designed to meet the needs of practitioners, primarily nurses.

Publication 7

Rossiter, R.J., Andrews, K. and Tulloch, L. (2011) Emotion management for young people with severe learning disabilities. *Learning Disability Practice* July, 14 (6) pp. 22-24.

Emotion management for young people with severe learning disabilities

Rowena Rossiter and colleagues describe how a group set up in a secondary school has helped pupils develop skills to cope with emotional difficulties

Summary

Health and education staff collaborated to run a group named 'Show Club' which aimed to develop emotion management in students with learning disabilities. The group, which ran for 13 sessions, used visual and physical props, sensory storytelling and role play, games, music, discussion, coping plans and relaxation. Most of the participants enjoyed the sessions and learned some feelings-management skills. Future work may involve a greater variety of groups and tools.

Keywords

Emotion management, cognitive behaviour therapy, learning disabilities

PEOPLE WHO have severe learning disabilities experience relatively high rates of mental health disorder so emotion management is important. Emerson and Hatton (2007) reported a 36 per cent incidence of diagnosable psychiatric disorders among children and adolescents with learning disabilities compared with 8 per cent among the general population. Emerson and Baines (2010) noted concern over the availability of and access to mental health services for people with severe learning disabilities, saying, 'Existing patterns of healthcare provision are insufficient, inequitable and likely to be in contravention of legal requirements under the Disability Discrimination Acts 1995 and 2005, and the UN Convention on the Rights of Persons with Disabilities'.

The Department of Health (DH) (2009, 2011a, 2011b) and the World Health Organization (WHO) (2010) emphasise the benefits of early intervention and attention to mental and physical health, and equity of access for all groups. Children and young people with learning disabilities may be recognised as 'special' but, as is the case with the National Institute for Health and Clinical Excellence (NICE) (2008), no specific guidance is given, and not enough attention is given to this population, their families and relevant service systems.

Pilot group

Andrews *et al* (2010) outlined the requirements for developing emotion management for people with severe learning disabilities. They described a pilot group, Team Mate, for students with severe learning disabilities at their further education unit in a secondary school. Doing such work in schools should enhance accessibility and link with the social and emotional aspects of learning programme (SEAL) (Department for Children, Families and Schools 2005, DH 2009) in a non-stigmatising way and place (Stallard *et al* 2005, 2007).

Team Mate was a collaboration between education and health professionals that was planned, delivered and evaluated in line with current policy and evidence. By adapting cognitive behaviour therapy (CBT) for people with learning disabilities, the project focused on feelings, relationships, change and coping.

Evaluation showed that most participants enjoyed and learned skills as a result of attending the group. Andrews *et al* (2010) identified further questions, including effectiveness for individuals with a wider range of abilities, and undertook a further pilot, the Show Club, involving younger people with more substantial cognitive and communication impairments.

Show Club

As with Team Mate, the Show Club was jointly planned and led by staff from a secondary school, including a teacher, a teaching assistant, the community team for children and young people with learning disabilities, a community nurse and a clinical psychologist. The teacher was the school lead on personal, health, social and relationship education. Participants were aged 12 to 15 years, with lower cognitive and communication skills, and higher degrees of diagnosed neurodevelopmental disorders and behavioural, physical and psychological health problems.

Five boys and three girls were identified for the group by school staff as having 'emotional difficulties'. Some of the children had been referred for individual specialist intervention; three had very challenging behaviour, three had a diagnosis on the autistic spectrum and two showed autistic features.

The facilitators were two female and one male member of staff with an additional one-to-one female support worker for a student with severe emotional difficulties and challenging behaviour. Multidisciplinary planning meetings clarified the purpose, number, duration and timing of sessions.

Potential content, materials and methods were discussed using work from the previous group. These included: earlier initiatives to develop problem-solving skills in the school, their SEAL plans and in-service training on sensory stories, local guidance on CBT for people with learning disabilities and studies of CBT for children and young people in a mainstream setting (Stallard 2002, 2005). Plans also incorporated visual resources from Attwood (2001) and Howlin *et al* (1999), narrative approaches (White and Epston 1990), social learning theory (Bandura 2009) and recent studies on groups with people with learning disabilities on bereavement (Kaur *et al* 2009, Boyden *et al* 2010) and the combined experience of the education and health staff.

The group was planned to run for ten weekly sessions of 45 minutes in school over the spring term as one of its innovative lunch clubs. The plan included an introductory session and a celebration at the end. The Show Club, as it was named, actually ran for 13 sessions over the spring and first half of the summer term, with some interruptions due to weather, staffing and outside activities.

Problematic emotions were played out by the characters using simple story lines and language with an emphasis on action

The sessions covered:

- Introduction, rules, ideas for a name for the group. A vote was taken in session two, with Show Club winning.
- Exploration of feelings, such as worry, sadness, anger and happiness.
- What happens when you have a particular feeling? Physical, behavioural, emotional and cognitive responses.
- What situations might make people have particular feelings? Using games, role plays and visuals, including scenarios from Howlin *et al* (1999) and sensory stories.
- Coping with difficult feelings: what helps, problem solving, use of an 'emotions toolbox' (Attwood 2001) comprising physical, social, relaxation and thinking tools.
- How can you help yourself to cope/feel better? Preparation of individual coping plans and prompts, including key rings with picture cards representing individually selected 'tools' from the group discussions, toolboxes, sensory stories, visuals of 'calming scenes', and personalised relaxation strategies, such as calming breaths, muscle relaxation and visualisation.
- Final session: review, evaluation, how to keep using what members had learnt.

The emphasis was on practical activities, visual supports consisting of laminated posters of feeling, thinking and doing cues, games, including an emotions snakes and ladders game, and sensory stories. The use of visual supports was considered vital to help attention, understanding and communication.

Routine format

The Show Club followed a consistent format. The group always began with calming music and a series of calming photographic scenes on the interactive whiteboard, followed by 'hook-ups'. 'Hook ups' are specific bilateral motor actions of crossing legs and arms while seated and putting tip of tongue on roof of mouth. This is claimed to engage both hemispheres of the brain, relaxes tension in the jaw and supports steady breathing. Hook-ups are part of Brain Gym, a programme of body-based movement tools which aim to improve concentration and learning (Educational Kinesiology Trust 2008).

Although there is no clear evidence base for the effectiveness of Brain Gym (Swain 2008), hook-ups are in routine use in school and did appear to help the participants to identify the start of each session, concentrate and settle into the group's activities. We developed the sensory stories to model problem solving and coping with difficult feelings. Problematic emotions were played out by the characters using simple story lines and language with an emphasis on action.

These emotional situations were familiar, as they had either already been identified in discussions and activities, or were selected by teaching staff as relevant. We used props with high sensory components, such as an African drum to demonstrate a heart beating loudly, shook pictures of butterflies to show 'butterflies in tummy' and held up large laminated visuals to signify feelings, thoughts or problem solving. Staff role-played the sensory story, and checked for comprehension. The group members would then cast themselves in various roles to re-enact a story. Coping strategies would be identified and demonstrated. The participants could also prompt and support other group members.

Sessions ended with relaxation using calming breaths, brief muscle relaxation, and visualisation using individual preferences from calming scenes. Home tasks were attempted but proved too difficult. Staff rated each session for concentration, comprehension, participation and qualitative comments so that improvements could be made and subsequent sessions modified. Due to problems with missed sessions the group continued into the first half of the following term. Two participants stopped attending the sessions: one who had challenging behaviour, which had been very disruptive, and one who had been very anxious.

Evaluation

There were difficulties finding formal, appropriate and valid evaluation measures (Rossiter *et al* 1998, Kaur *et al* 2009, Boyden *et al* 2010), compounded by the irregular days, times and durations of sessions that resulted from getting health staff and education staff together. Some evaluation was carried out in the sessions, including:

- What we liked.
- What we did not like.
- How the group could be better.
- What we learned about ourselves and others.
- What we will practise or try to do differently.

Features such as being together, the games, sensory stories, music, pictures and the celebration were all appreciated, as were some ideas for coping with difficult feelings. However, the lack of independence or objectivity in the evaluation could have affected the views expressed.

Activities varied in success. The emotional toolboxes, which had worked well in the Team Mate group, were less easy for this group to comprehend or use, but the sensory stories were enjoyed and understood much more. Staff reported that the group was an enjoyable and rewarding experience, and well organised to suit the varied experiences and backgrounds.

The collaboration between education and health staff added value to the group by harnessing a wider range of experience, skills and knowledge. Additional improvements included experimenting with more recently published resources and a wider range of frameworks.

Cognitive behaviour therapy Stallard (2005) suggested that children 'may be able to engage in some CBT programmes if the cognitive demands of the intervention are matched to the child's cognitive development'. He also highlighted the need to consider their emotional capabilities, citing randomised controlled treatment trials where children between the ages of four and six years were included in intervention studies using CBT for a wide range of problems such as anxiety, habit disorders and the effects of sexual abuse.

Stallard suggested techniques for simplifying the CBT model, chiefly by presenting abstract concepts and strategies as concrete examples from real life and using concrete or visual cues and props, games and quizzes, storytelling, metaphor, puppets and sentence completion and/or card sort techniques.

Sessional participation data for Show Club suggested that, even with these adaptations, the group members struggled with elements of the CBT framework, while the sensory stories appeared to be a powerful vehicle for engagement and learning about emotions. Bandura (2009) similarly described the effectiveness of appropriate storytelling in promoting personal and social changes.

Looking ahead

Future pilots may explore the use of other group approaches that have been developed. FRIENDS for Life is an existing, well-evidenced group approach that is effective in mainstream schools (Barrett *et al* 2006, Stallard *et al* 2005, 2007). FRIENDS for Life is based on a CBT model and teaches skills to:

- Identify 'anxiety increasing' thoughts and replace them with more helpful thoughts.
- Identify anxious (and other difficult) feelings and manage them.
- Overcome problems rather than avoid them.

Group manuals and workbooks include all activities, games and resources for three developmental levels: four to six years, nine to ten years and 12-14 years (Barrett 2004).

One of the authors is seeking research funds for adapting FRIENDS for Life to be accessible for children and young people with learning disabilities and piloting this adaptation.

Another school-based mental health promotion programme, Zippy's Friends (Partnership For Children 2011), uses stories and is aimed at six to seven year olds. It teaches them how to cope with everyday difficulties, identify and talk about their feelings, explore ways of dealing with these and how to help others with their problems.

The stories cover important issues familiar to young children: friendship, communication, feeling lonely, bullying, dealing with change and loss, and making a new start. For pupils with complex and severe learning disabilities in a residential school, Rowley and Cook (2007) piloted an 'accessible' adaptation of Zippy's Friends, where the stories and activities were simplified into differing comprehension levels and supported with visuals. They found that the pupils, many of whom were also on the autistic spectrum and displayed challenging behaviour, were able to engage and make significant progress, and the whole school is now working with the programme (Rowley and Cook 2010).

Other developments in future pilots include exploring provision of universal groups with whole classes, generating a greater mix of students with and without pre-existing emotion management difficulties, greater involvement of parents and carers, and differentiating between groups for moderate and severe learning disabilities.

Such developments may enhance learning, generalisability and maintenance of groups, and could show what skills would be needed to access particular kinds of groups.

In view of the vulnerability of young people with learning disabilities to develop emotional difficulties, early effective intervention is required to help them with emotion management. We are considering running groups with younger students and following up with 'boosters' when they are older, or running groups with students with differing needs, or with adults with learning disabilities and other neurological/neurodevelopment impairments.

Groups could be run as mental health promotion and/or wellbeing sessions in line with No Health Without Mental Health (DH 2011a) and Increasing Access to Psychological Therapies (DH 2007, 2011c).

The article has been subject to double-blind review and checked using antiplagiarism software

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3.8

8 Rossiter, R.J. (2012) 'A history of the world ..... of groups for people with learning disabilities... in 10 objects'. *Clinical Psychology and People with Learning Disabilities* 10 (3) pp. 15-21.

This publication summarises a range of groups (including those described in publications 1, 4, 5, 6, 7) varying by age of participant, ability, focus, setting, staffing, psychological frame and practice/policy context across five decades. This offers a longer perspective allowing themes in group interventions with people with learning disabilities to be shown as evolving and integrating with others' perspectives (e.g. broader use of staff, wider therapeutic models and other psychological concepts including group process and attachment).

The rationale for this publication arose from collaboration with clinical and research colleagues with an interest in groups and people with learning disabilities. We recognised that these groups, especially the group process aspects, appeared underrepresented within discourses on practice and research, training (for psychologists and other professions) and publications. We submitted and delivered a workshop on Groups for People with Learning Disabilities (Gregory, Heneage and Rossiter, 2011) sharing ideas from practice at the Joint Congress of the European Association for Mental Health and Intellectual Disability, International Association for the Scientific Study of Intellectual Disability, IASSID, Challenging Behaviour & Mental Health Special Interest Research Group and British Psychological Society, Division of Clinical Psychology, Faculty for Learning Disabilities; September 2011; Manchester, UK. Workshop discussions led to an e-survey for clinical psychologists in the Faculty for People with Learning Disabilities to explore the number and types of groups in clinical practice, models, methods and measures used, "tips and hints", and the opportunity to guest edit a Special *Groups* Edition of Clinical Psychology and People with Learning Disabilities. The e-survey asked respondents to indicate if they would be willing to submit a paper for the forthcoming *Groups* edition and advised that the results of the e-survey would be published in this special edition.

The publication utilised the device that Neil MacGregor, Director of British Museum, had adopted in his “History of the World in 100 objects” radio series and book, by selecting objects on which to “hang” descriptions of historical, cultural and social themes and issues. The objects I selected from the differing groups are used to illustrate the focus, frame and method of group they represent and demonstrate the innovative aspects. The publication drew lessons learned from each group for practice, located them in the contemporaneous research and then reflected on themes of access, adaptation, innovative groups and mechanisms of change with people with learning disabilities. The aim of the paper was to raise interest in, and knowledge of, a variety of group interventions focusing on a range of psychological difficulties for practitioner psychologists and the staff groups they collaborate with, hence the choice of publication.

The key lessons included the use of visual, concrete, photographic, video-based and active learning methods and resources to engage people with learning disabilities with a wide range of abilities, ages, presenting problems, in a wide range of settings, with a wide range of staff in groups which were associated with increases in pro-social, adaptive social and emotional skill and/or reduction in anti-social, challenging or inappropriate behaviours; issues in generalisation and maintenance; benefits of natural environments; consideration of neuropsychological abilities and disabilities (broader than Intelligence Quotients, IQ) in maximising engagement; group process, communication and power issues which may underpin development and therapeutic change and link with Attachment process issues as a mechanism of change.

Publication 8

Rossiter, R.J. (2012) A history of the world..... of groups for people with learning disabilities... in 10 objects. *Clinical Psychology and People with Learning Disabilities* 10 (3) pp. 15-21.

A history of the world... of groups for people with learning disabilities... in 10 objects

Rowena Rossiter

WHILST Neil MacGregor's *A History of the World in 100 objects* spans 2,000,000 years, my history of the world of groups with people with learning disabilities spans just five decades! I've therefore limited myself to 10 objects which tell some of a story of a range of groups I've been involved in. These vary by age of participants (and facilitator!), focus, setting, staffing, psychological 'frame' and practice/policy context.

I will list the objects, the decade and the kind of group they represent and some lessons learned. I will end with some reflections around adapted and innovative groups and change with people with learning disabilities (LD) and broader service delivery and development/organisational aspects of groups.

(1) Tube from a carpet roll (1970s) used in a 'structured activity group for increasing social interaction with adults with severe LD' (Keleher & Bridgen, 1982).

We evaluated an innovative group format for developing social interaction and also the use of care staff in group delivery. Studies of 'engagement' and the use of activity groups in increasing engagement had emerged (Porterfield, 1980). Groups had not been investigated where social interaction was the focus.

Our interest was activities as a vehicle for interaction (eye contact, shared attention or action, non-verbal/verbal communication). Our activity group used 'play', sensory and some food related activities and developed a 'manual' explaining the rationale and details of equipment and activities devised across different developmental areas. The carpet roll tube was used in a 'cause and effect' activity where a ball or bean bag was posted into the top and made its way to clatter into a metal bin.

Group participants/co-facilitators had to assist by holding various parts so that the activity could be successful! Initially, we ran the groups with staff assistance. Subsequently, staff planned and ran the groups using the manual with brief supervision. Although the staff were initially somewhat bemused, the group participants seemed to really like the carpet roll activity – even more so than some food related ones. The group drew on learning and developmental theories, a social and psychological (rather than medical) model of learning disabilities and 'giving psychology away'.

Lessons

Doing things together in this structured group format increased social interaction; people who had showed little interest in, or not demonstrated much social interaction, did interact and showed enjoyment; sensory and fun things work well and care staff can run the group with similar effects with a manual and psychology supervision

(2) Thought bubbles containing images on flip chart (1980s) used in social skills groups with people with mild and severe LD (Brigden & Keleher, 1989).

Evidence for the effectiveness of such groups was growing within mental health services (adults, children and young people) but little evidence from people with LD had emerged. Using role play, video and peer support we incorporated behavioural, cognitive and emotional aspects of 'social skills' in developing confidence and competence.

The cognitive aspects were innovative as cognitive behaviour therapy' (CBT) was in its infancy with almost no published work on it's use with people with LD.

Lessons
Group members with LD were able to make use of the 'thought bubble' visuals on the flip chart to help understand thoughts-feelings-behaviour links and to remember key learning points/practice tips, for example, thought bubbles drawn with a picture of a smile, eye contact, standing tall, as well as 'coping' or 'self-instruction' statements. The 'cognitive' elements that people with LD could relate to included images, actions, sensations and words. The group seemed to offer a more energetic and effective forum for change than some individual interventions. Active role play seemed important.

(3) Water jug (1980s) used in a pilot group investigating an extension to the earlier 'social interaction activity' and 'social skills' groups, an approach that was more 'naturalistic' and might enhance learning, generalisation and maintenance (Williams et al., 1989; Keleher & Brigden, 1989).

We focused on mealtimes and substituted the play and sensory activities of the activity groups and the role-play of social skills groups for real-time social interaction modelled, prompted and spontaneous through collaboration in meal preparation, table laying, eating and clearing up. We again investigated the use of care staff in running the group which formed part of a psychology-led Project Team in a hospital for people with LD. We initiated and evaluated projects to improve skills development, care delivery and quality of life rather than accepting individual psychology referrals.

Lessons
Seemingly routine, 'boring' objects can be very effective in promoting social interaction when staff are supported to use them in a structured way. Social interaction and engagement increased. Supervision and monitoring may be important in maintenance.

(4) Video (1990s) used in an innovative Anger Management Group to investigate whether CBT could be adapted sufficiently to be an effective therapeutic intervention for people with moderate to severe LD (Rossiter et al., 1998).

Evidence from single case and some group studies (e.g. Benson et al., 1986; Lindsay & Kasprowicz, 1987) was beginning to demonstrate that CBT could be effective with people with mild LD. We drew on this along with emerging child CBT studies and adapted adult mental health evidence.

Staff attended the group as observers to support between session practice, generalisation and maintenance. Video was used to film and review modelling and role play of emotions especially anger/coping with anger in 'ok/not ok' ways. Whilst all were initially nervous about the video, it proved an enjoyable and powerful vehicle for learning.

Lessons
The use of video enhanced learning and change through offering concrete, visual feedback (co-facilitators, participants, sometimes support staff). Video can be 'freeze framed' so we could carefully observe and consider feelings-thoughts-actions. These could be mapped on to body maps and cartoons with thought bubbles and used to develop individualised 'Anger Management Traffic Light Systems'.

We learned that CBT could be adapted to include people with severe intellectual impairments (IQs 45 to 54) and with autistic spectrum disorder (ASD). We needed to be very concrete and visual and more 'rule bound'. We also learned that people with higher measured IQ's/BPVS scores may not be able to access the simplified CBT and that other information processing factors such as sequencing and executive function may be critical factors.

We learned how people with LD may have good justification for feeling angry, that social and contextual issues are really important, that 'Anger Management' groups are not a 'magic wand' and we must be careful not to feed a 'medicalisation' of understandable emotions, that groups may need to allow people to tell of previous and current experiences and manage this safely, and that having consistent carer/supporters attending groups seemed to enhance effectiveness through increasing inter-group practice, generalisation and maintenance.

(5) Traffic lights and visual prompts on flip chart (1990s) were used in an 'Anger Management' group in a national 'Assessment and Treatment' unit for people with mild LD.

Developing practice from the previous groups, we used the 'Stop, Think, Do' traffic light metaphor and framework (Petersen, 1992; Petersen & Gannoni, 1992) and material from O'Neill's (1999) 'Anger Management' for making personalised 'Coping with Anger' plans. We concentrated on supporting and prompting participants to support and prompt other participants in practicing elements of their 'Coping with Anger' plans, drawn up on the flip charts in role play. This included rehearsing 'calming breaths', other de-arousal strategies, calming/coping self-talk, walking away, etc.

Lessons

The adapted CBT groups seemed to enable people with LD and extremely challenging behaviour, mental health and forensic issues to learn strategies to reduce unhelpful arousal, aggression to others and property; including participants in supporting/prompting others in coping plan practice seemed to place them in increasingly powerful positions and contributed to successful 'overlearning' (Day & Horner, 1986) of strategies which helped generalisation and maintenance.

(6) Feathers and bubbles (2000s) used in an Anxiety Management group on the same Assessment and Treatment unit.

We had some reservations about the blanket term 'Anger Management' for our previous group when some of the 'anger' seemed to be anxiety and sometimes 'frustration' with self, others, the world. The content was similar and did include anger and sadness as well as anxiety. We experimented with different routes to learning 'relaxation' and de-arousal with more concrete activities. Feathers and bubbles were used as concrete props for experimenting with breath control as the abilities of some group members were very limited and many had other neuropsychological difficulties linked to executive functioning, attention and memory.

Lessons

Use of concrete, practical, fun activities can increase the acceptability, accessibility and effectiveness of relaxation and de-arousal strategies in groups. The 'Anxiety Management' focus resulted in similar degrees of change in aggressive behaviours to others, property and self as the 'Anger Management' group, but may have been more acceptable to engage in and less pathologising.

(7) Photos from role plays with personalised thought-bubbles (tailor-made from digital camera and computer) for practice and prompts (2000s) used in 'Be Cool – Keep Calm' and 'Change' groups on the Assessment and Treatment unit.

We began to run groups as broader emotional management rather than single emotion/behaviour problem-focused groups for anger, anxiety, depression, self-esteem. This seemed more 'normalising' of the central and positive role of emotions in all our lives and the need to be able to understand, express and cope with feelings safely. The content remained similar.

We also included some group participants who were even more challenging (considered actively 'psychotic' and/or with extremely challenging behaviours, personality disorder) who may previously been 'screened out' as unlikely to cope with or benefit from a group. As well as using video, we took digital photos in role-plays of general emotions, situations where emotions became 'not ok' and situations where they were coped with/expressed 'ok'. Still photos seemed powerful and engaging. Photos are uncluttered by movement and show the person demonstrating/modelling a range of behaviours.

An assistant psychologist added some personalised thought bubbles (containing images and/or simple words depending on individuals' information processing level and styles) which helped practice in groups and later reminders and prompts for maintenance.

Lessons

Digital photos added a useful dimension to the visuals which assisted engagement. People whom we had previously considered as unlikely to tolerate a group were able to participate and benefit if the group contained appropriately selected activities and visual resources, and was set up to allow some 'mini-breaks' of five minutes to 'de-arouse' twice per session.

(8) Biscuits (2000s), an important element of SOTSEC-ID (Sex Offender Group South East Collaborative – Intellectual Disabilities, Murphy & Sinclair, 2009) according to feedback from participants.

This CBT group protocol, developed by the SOTSEC-ID practice and research collaborative, includes modules on relationships, feelings, sex education, simplified Finkelhor (1984) offending model (including victim empathy and own experiences of being a victim) and 'Keeping Safe' plans over the year-long group.

The use of visuals and group process assisted engagement, as did 'third person' and non-sexual examples of 'not ok'/offending behaviours. Moving into discussion/disclosure of offences, considering effects on victims and experiences as victim was difficult territory for the men and for the co-facilitators. The provision of drinks, fruit and biscuits allowed a break and the opportunity for some more natural interaction.

Lessons

Practical 'non-group-specific' aspects can be important for engagement, motivation, maintenance and some of the social/relational issues which may be key for change and success. This may be particularly important where people may have long histories of challenging and/or offending behaviour and complex personal histories including as victims of abuse. Breaks, biscuits and other refreshments have also been identified as valued by participants in other kinds of groups.

(9) 'Toolboxes' for Emotions (2000s) were used in a pilot group focusing on emotions at a school for pupils with severe LD (Andrews et al., 2010).

It aimed to further adapt CBT for young people with very substantial cognitive impairments, provide early intervention/mental health promotion, use 'normalised' environments and wider staff (school staff and community team staff) for psychological interventions. Evidence-base and policy regarding 'early intervention' in 'mainstream' services is growing. Current evidence-base and research for people with LD is limited, despite evidence showing people with LD have higher rates of emotional and behavioural disorder, experience health inequalities (Emerson & Baines, 2010) and disability is a protected characteristic of the Equality Act.

As well as using visual, concrete activities tailored to interests of teenagers, use was made of Emotional Toolboxes (Attwood, 2004) for identifying and practicing physical, social, thinking and relaxation 'tools'. Pictorial representations of the ideas the group generated for the different types of tools (each category had a graphic signifier) were made. These were placed into the appropriate tool box and participants would select ones to practice in the group and at home. Later, individualised 'Keep Cool' prompt key rings were made with participants' favoured tools

Lessons

Groups in schools can offer additional learning opportunities for emotional and social development; shared planning and co-facilitation across health and education can bring benefits of enhanced skills and experiences; Attwood's 'emotional toolboxes' were popular with the participants (16- to 18-year-olds).

(10) African drum and pictures of butterflies in clear bowl in 'Feelings Sensory Stories' (2010s).

These objects were used in another group at the same school targeting younger pupils (earlier intervention) and those with more substantial cognitive, communication and behavioural problems (broadening access and trialling further adaptations and strategies including games such as emotions Snakes and Ladders and Sensory Stories for understanding and managing difficult feelings).

The African drum (loud heartbeats) and pictures of butterflies shaken in a clear bowl (butterflies in tummy) were props/cues for physical sensations linked with feelings in the Sensory Stories we developed. The stories focused on some challenge and difficulty with a feeling (sad, worried, angry) linked to a familiar situation that had been talked about in the group, followed by some problem solving and a better way of expressing and coping with that feeling (Rossiter et al., 2011).

Lessons

Young people with substantial cognitive and communication impairments and behavioural challenges can participate in and may benefit from groups when creative and concrete ways to engage and educate them in psychological concepts are used, along with attention to process issues. Use of narratives drawn from life experiences played out as sensory stories.

Reflections

Groups with people with LD disabilities can create powerful change that may not be possible by other means across a range of abilities, ages, settings and 'presenting problems'. The dynamic created by facilitated peer interaction, changing roles and behaviours does seem to be 'greater than the sum of its parts'. A group can act as a vehicle to be listened to, share, be empowered, support and prompt others, be supported and prompted, practice, struggle, make mistakes, laugh.

The therapeutic factors outlined by Yalom (1975, 2005) see Gregory and Heneage, this issue, have been seen to operate across the very different groups I have had the privilege of being involved with to create change. Other mechanisms may include experiencing effective communication/attunement (verbal, non-verbal, emotional) which links with attachment (see Holmes, 2010, discussion of this in groups in mental health), more fluid and more equal experiences relating to 'power', social learning (Bandura, 1986), and 'new patterns of interaction' similar to systemic interventions (e.g. Minuchin & Fishman, 1981) with 'the production of new relational experiences for clients through a clinician's facilitating differences in how family members experience each other' (Simon, 2008, p.327) which may be paralleled in groups.

Groups may not be for everyone and they can take significant time to set up and run. However, they can also enable different kinds of staff to develop as well as clients Group participants may become co-facilitators. Groups can be one way to begin to provide more acceptable, accessible, efficient and cost-effective interventions. Long live groups!

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3.9
Publication 9

Rossiter, R.J. and Holmes, S. (2013) Access all areas: creative adaptations for CBT with people with cognitive impairments – illustrations and issues. *The Cognitive Behaviour Therapist,* Vol 6 (e9).

Publication 9 draws together policy (Improving Access to Psychological Therapies, DH, 2011), legislation, Equality Act 2010, research evidence (Lindsay et al., 1997; Green, 2011; Russell et al., 2013) and practice methods, models and materials based on the lead author's clinical experience to illustrate use of adapted CBT with people with cognitive impairments through illustrations from people with learning disabilities and complex mental health challenges (psychosis). The justification includes the policy and legislation requiring clinicians and services to address diversity and equalities including disability, whilst current practice, training and research do not do this adequately. The paper outlines why adapted CBT is important and draws together existing evidence to increase accessibility for people who have cognitive impairments, learning disabilities and/or neurodevelopmental disorders. It demonstrates how CBT can be made accessible through clinical examples using traditional, adapted and personalised assessment and intervention materials. Implications and recommendations are identified.

Its unique contribution to knowledge lies in drawing evidence from a range of clinical groups with cognitive impairments together and applying this in an integrated way to broaden the issue of accessibility across more "care groups," considering attitudes, as well as knowledge of staff, amongst barriers. It provides both a framework and model for adapting and increasing access and shows practical examples to demonstrate practice to enable readers to develop their practice, implement policy and comply with legislation.

The case illustrations are drawn from three people with learning disabilities across a range of age, setting, ability and complexity and include assessment and therapeutic materials. The paper is an invited expansion of a poster co-authored for the BABCP annual conference (Holmes et al., 2011). *The Cognitive Behaviour Therapist* has a wide multidisciplinary reach and, as an online journal, can reproduce the coloured visual examples of the accessible assessment and therapy materials which paper journals do not due to prohibitive costs.

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PRACTICE ARTICLE

Access all areas: creative adaptations for CBT with people with cognitive impairments – illustrations and issues

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Abstract. Policy and legislation requires clinicians and services to address diversity and equalities including disability. Currently, practice, training and research do not do this adequately. This paper outlines why adapted CBT is important and presents some evidence to increase accessibility for people who have cognitive impairments, learning disabilities and/or neurodevelopmental disorders. It demonstrates how CBT can be made accessible through clinical examples using traditional, adapted and personalized assessment and intervention materials. Implications and recommendations are identified.

Key words: CBT, common factors, evidence-based practice, impairment.

Introduction: accessible CBT – why does it matter?

The Improving Access to Psychological Therapies (IAPT) website information on 'Equality Legislation' (IAPT, 2011) reminds us that the Equality Act 2010 outlines public organizations' duty to promote equality and reduce inequalities across 'protected characteristics'. These include age, disability, gender, sex and sexual orientation, marital status, pregnancy and maternity, race (ethnic origin and nationality), religion and belief (including non-belief). Equality objectives and published information will allow monitoring of organizations' ability to 'promote equality' and 'eliminate discrimination, harassment and victimization'. IAPT highlights links between equalities, human rights and social justice which IAPT services support

> by expanding access to NICE approved psychological therapies across all communities, particularly for people that are at higher risk of developing poor mental health due to social, economic and health inequalities (IAPT, 2011).

Accessible CBT is a key component of addressing health inequalities and diversity. The main UK professional body for accrediting training and practice of CBT in its recent Mission Statement and Values and Vision includes:

- fairness and parity for members and public;

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- accessibility;
- fostering creativity and diversity within a CBT framework (BABCP, 2011).

In two consecutive editions of *CBT Today* in 2011, ten articles or news items were published covering diversity and accessibility issues and CBT. These addressed adaptations to CBT for people with learning disabilities (Grant, 2011, report of Singh's mindfulness conference presentation), older adults (Green, 2011), veterans (Kitchiner, 2011), Tyson's work with men (May, 2011), people who are lesbian, gay, bisexual and transgender (Murphy, 2011), a person with Asperger's (O'Connell, 2011), work in Tanzania (Stone, 2011), and working with the Yemeni community in Sheffield (Woolsey, 2011). Yet despite high levels of psychological needs being identified, there is evidence of reduced access to psychological services for people with diverse needs. For example, Green (2011) reports that 3% of referrals to an IAPT service were for older people when population estimates suggest 12–15% would be referred; Kitchiner (2011), May (2011) and Murphy (2011) report, respectively, that veterans, men and people who are lesbian, gay and transgender may not present themselves as in need of input for psychological or emotional difficulties.

By contrast, in two editions of the *Journal of Behavioural and Cognitive Psychotherapy* (2011/2012), among 19 papers only four were on a non-working-age adult population and there were none on people with disabilities. Ability, literacy and language skills are exclusion criteria in most studies. Where this is not specified, it would appear from the method and measures that people with cognitive impairments would be unlikely to be included. Disability gets no mention. The exclusion of people with disabilities is of particular concern for all professions, their journals and reports, all of which should be addressing diversity.

Evaluation of 'equality of access, experience and outcome from the IAPT programme in the North West of England' (Buffin *et al.* 2009) showed poor reach to older people and those who spoke languages other than English. But disability did not even feature in the equality monitoring. While practice examples of working with people from diverse backgrounds may be increasing, in research disability is often overlooked or used as an exclusion category.

Barriers to access for marginalized or 'socially excluded' groups are wide ranging (as identified in the *CBT Today* articles and the Buffin *et al.* report cited above). They include lack of knowledge, inaccurate and unhelpful attitudes and beliefs among referrers, service users and professionals, and services not set up for people with diverse needs (physical location, how inclusive they are across gender, culture, class, disability and mode of delivery). Specific suggestions of how to adapt CBT to increase accessibility for older adults, people with learning disabilities and young children show 'transferable skills' and 'core competences' (such as visual components, involving carers) which might be more usefully considered as 'cross-care group'. 'Core skills' of adapting and simplifying CBT for people with a range of needs associated with disability are essential for people with cognitive impairments and/or learning difficulties and disabilities. Currently, almost 20% of the population are aged <18 years, 18% are aged >65 years (and rising) and learning difficulties or disabilities are hugely under-recognized (Simonoff *et al.* 2006). Therefore, all practitioners, trainers, and supervisors of CBT need core skills in addressing diversity issues including cognitive impairments, learning difficulties and disabilities.

Factors that may impair or reduce cognitive functioning and, therefore, affect accessibility to CBT are numerous and include learning disabilities; pervasive developmental disorders (such as autistic spectrum disorders or Asperger's syndrome) and/or severe trauma and neglect; neurological disorders [such as epilepsy, stroke, head injury, attention deficit hyperactivity disorder (ADHD), dementia]; and there are impairments associated with ageing. Sensory impairments; literacy and/or language difficulties can all impair cognitive functioning. Mental health problems, such as anxiety and depression, can be associated with concentration difficulties; psychosis with reasoning biases, attention, and working memory problems. Medication for both mental and physical health is also known to interfere with cognitive abilities.

Cognitive impairments are frequently undiagnosed in the general population (Simonoff *et al.* 2006). When cognitive impairments are diagnosed (e.g. learning disabilities) then mental health problems often go undetected and/or untreated. Reasons for this include lack of awareness, staff attitudes, gaps in service provision and diagnostic overshadowing (Hatton, 2002). Conversely, in adult mental health services, behaviours associated with cognitive impairments (such as memory difficulties) frequently get wrongly misattributed to 'personality' or 'motivation' and suitable adaptations to interventions are not considered.

This paper summarizes evidence for accessible, adapted CBT and illustrates the use of standard, adapted and personalized CBT techniques and resources.

What evidence is there for 'accessible' CBT?

There is a growing literature on adaptations to improve accessibility of CBT for people with cognitive impairments, learning difficulties/disabilities and/or neurodevelopmental disorders. The research includes case studies, case series, controlled studies and some randomized controlled trials. Studies have shown CBT can be effective with people with learning disabilities (e.g. Stenfert-Kroese *et al.* 1997; Lindsay *et al.* 1997; Willner, 2007; Dodd *et al.* 2011) and autism spectrum disorders (ASD) (Attwood, 2004; Russell *et al.* 2013) and with children as young as 3 years (e.g. Stallard, 2005, Scheeringa *et al.* 2011) and adults with dementia (e.g. Laidlaw *et al.* 2004; Charlesworth & Reichelt, 2004) if highly visual, concrete materials are used and concepts simplified.

Adapted CBT (Arundine *et al.* 2012) for people with acquired brain injury showed improvements on measures of psychological distress and community integration which were maintained at 6 months follow-up. Ramsay (2010) demonstrated how CBT was adapted for adults with ADHD using the 'executive dysfunction' model, highlighting the need 'to make CBT 'sticky' so that people can remember and implement coping strategies in the appropriate context' (p. 41). There have also been studies of adaptations to CBT to increase effectiveness for people with severe mental health problems including psychosis and cognitive impairments (e.g. Leggett, 1997; Collerton & Dudley, 2004; Wragg & Whitehead, 2004; Kirkland, 2005; Haddock *et al.* 2004; Favrod *et al.* 2007; Barrowcliff, 2008).

Illustrations of accessible CBT

The development of skills, guidance and resources for 'accessible' CBT in the NHS Trust the authors worked in included continuing professional development events (psychology 'care group specific' and multidisciplinary), working groups developing practice guidance and resources for CBT with people with learning disabilities and multidisciplinary training. This allowed the integration of a range of evidence-based literature and resources including CBT with children and young people, people with learning disabilities, working age and older adults, neuropsychological and neurodevelopmental disorders and collective 'practice-based evidence'.

The development of a 'cross-care group' CBT peer supervision group allowed the sharing of skills, competencies, experience, knowledge and ideas across traditional care groups. This enhanced accessibility and clinical effectiveness of working with people with cognitive impairments who are too often excluded from therapy provision. Below are illustrations of 'accessible' CBT showing how core elements and skills of CBT have been used in creative ways, adapting standard approaches and personalizing or individualizing them to increase accessibility.

The materials are drawn from three anonymized cases in Holmes *et al.*'s (2011) poster 'Adapting CBT for psychosis: creative ways with cognitive impairments'. Here, the focus is on general principles and techniques for adapting CBT for people with cognitive impairments, learning disabilities and/or neurodevelopmental disorders. The illustrations reflect issues associated with difference in age (Sam 14, Jenny 28, David 66 years), disability, gender, ethnicity, immigration and culture, spiritual beliefs, context (community and family home, residential care, national specialist in-patient assessment and treatment unit), mental health difficulties (anxiety, depression, anger, self-harm, post-traumatic stress disorder, psychosis), duration of difficulties (4–52 years), referral source (school, psychiatrist, court disposal) and complex psychosocial difficulties (abuse, bereavement, bullying, carers with severe mental health problems, poverty, isolation). In drawing attention to this diversity, we hope to demonstrate the breadth of application of adapted CBT and draw out general themes. This increases the opportunity to consider a wide range of diversity needs while predominantly focusing on reducing exclusion and increasing effectiveness of CBT with people with cognitive impairments.

Below are illustrations of some useful assessment and intervention approaches and materials:

(1) Standard techniques are ways of working that might be used with anyone irrespective of difficulties. If these are found to be ineffective or inappropriate, then further adaptation and/or personalization would be tried. (See below for illustrations.)
(2) Adapted techniques are commonly using simplified language and concepts, increased pictorial or visual representation and metaphor to increase engagement, understanding and effectiveness of assessment and intervention. These would be used if standard techniques were not effective.
(3) Individualized/personalized techniques give greater emphasis to specific difficulties a person presents with. They are used when standard and adapted techniques do not work. They may be used to increase engagement with anyone.

What are the common features of CBT approaches adapted for people with cognitive impairments?

These include 'visual' resources used to explore feelings vocabularies and physical signs, psycho-education, and socialization to the CBT model. Formulations and interventions for anxiety, low mood, anger, intrusive thoughts, dreams and voices enhanced with visuals are described below. Models we have drawn on include cognitive and cognitive-behavioral models of depression (Beck *et al.* 1979; Fennell, 1988), anxiety (Beck *et al.* 1985; Clark

1988), and trauma (Ehlers & Clark, 2000). The primary model used for understanding 'psychotic' experiences is described by Garety *et al.* (2001) and by Morrison and colleagues (Morrison, 2001; Morrison *et al.*. 2008) as a cognitive model characterized by appraisal of experiences maintaining distress, reasoning biases, hyper-vigilance and increased emotional arousal. In addition, we integrated ideas from stress-vulnerability (Zubin & Spring, 1977), and normalization models (Romme & Escher, 1989, 2000) and the cognitive model described by Freeman (2007). Carr's (2006) integrative, developmental and contextual approach was used to inform assessment, formulation, intervention and evaluation.

All CBT is, to an extent, adapted to the client and their needs. For example, exploring and challenging negative automatic thoughts is not a theoretical construct, but rather linked to clients own idiosyncratic negative automatic thoughts. How this is done is bound to be different for each person. Typically CBT places greater reliance on written materials rather than pictorial and has an underlying assumption of cognitive ability and psychological flexibility. The skills required to increase accessibility build on standard approaches which 'may' be used with all, and extends evidenced-based and individualized approaches to improve the reach to people with disabilities and diverse needs.

Accessible CBT: illustrations of assessment

Standard approaches

This includes interviews with the person, their family and staff (residential, community, school); file search for history and initial hypothesizing; voices diaries and activity monitoring; feelings thermometers (O'Neill, 1999; Stallard, 2002), Beliefs about Voices Questionnaire (Chadwick *et al.* 2000) and joint assessments with other services such as the Early Intervention in Psychosis Service and Child & Adolescent Mental Health Service.

Evidence-/practice-based adapted approaches

Visual resources and practice 'tips' were collated from evidence-based sources or developed locally. Visual resources were developed or adapted by the therapist with the individual. Line drawings (see Figs 1 and 2), and photographs were particularly useful in assessing the person's naming and understanding of feelings, thoughts-feelings-behaviour links and the role of negative automatic thoughts which can lead to adapted thought records based on Beck *et al.*.'s (1979) cognitive model. Figure 1 shows an example from scenarios suggested by Reed & Clements (1989). Figure 2 shows a completed example of a 'Think-Feel-Do' cartoon sequence for 'wind-up' thoughts. O'Neill (1999, 2006) gives examples of coping 'Think-Feel-Do's' and blank versions to identify individuals 'own unhelpful and helpful 'Think-Feel-Do's'. In addition to line drawings and photographs [e.g. from the Learning Development Aids Emotions pack (LDA, n.d.) or the Department for Children, Families and Schools' Social and Emotional Aspects of Learning (SEAL), 2005], we have used clips from 'soaps' and visual assessment material of situation-based feelings (Howlin *et al.* 1999). Simplified 'feelings body map', 'How you feel', 'thought bubbles' were developed for both distressing events and for calm or coping events. Family and/or staff assisted with recording with these tools. For joint assessment appointments with other services, we prepared and brought the visual materials to aid communication and comprehension and socialize to the CBT model for clients and carers.

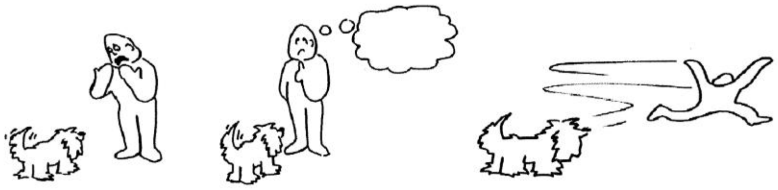


Fig. 1. David's assessment – James and the dog visual.

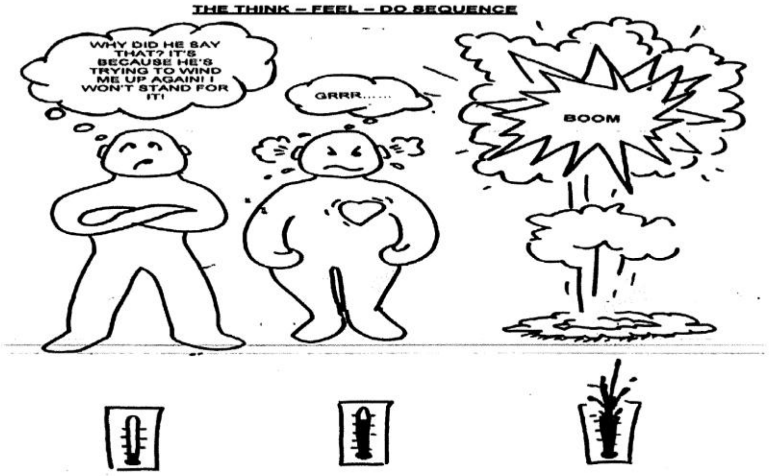
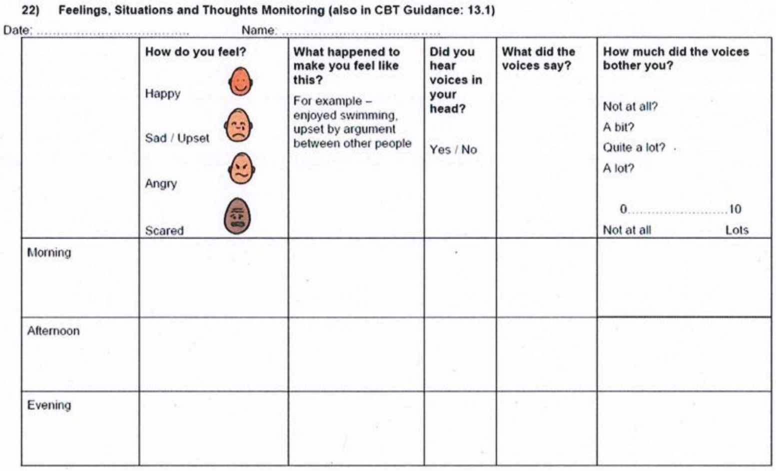


Fig. 2. Sam's assessment. Example of 'Think-Feel-Do' assessment/psychoeducation (blank versions are used for assessing an individual's physical signs, thoughts, feelings and behaviours). [Taken from *Managing Anger*, O'Neill (1999).]

Individualized/personalized approaches

These were used to improve both communication and engagement. Figure 3 shows an individualized format for recording feelings, situations and thoughts used with Jenny and completed with staff support. This is a personalized version of a 'Voices diary' as might be used in CBT for psychosis (Garety *et al*. 2001; Morrison, 2001; Morrison *et al*. 2008).

This helped distinguish different content and types of Jenny's 'voices' or 'thoughts'. Some were 'third person' and seemed to relate to 'replaying' abuse; some were 'first person' and seemed an 'internalization' of these abusive messages and her experiences. In the work with Sam, photos of churches and priests were used to assess the nature and intensity of current and past distress and associated thoughts, dreams, voices and beliefs, along with a card sort for sorting pictures into OK/not OK, and a 'thermometer' card sort (low, medium, high) for rating intensity of distress.



22) Feelings, Situations and Thoughts Monitoring (also in CBT Guidance: 13.1)

Date: .... Name: ....

	How do you feel? Happy Sad / Upset Angry Scared	**What happened to make you feel like this?** For example – enjoyed swimming, upset by argument between other people	**Did you hear voices in your head?** Yes / No	**What did the voices say?**	**How much did the voices bother you?** Not at all? A bit? Quite a lot? A lot? 0..........................10 Not at all Lots
Morning					
Afternoon					
Evening					

Fig. 3. Jenny's personalized feelings, situations and thoughts monitoring.

Formulations were developed, shared and explored using visual representations and included 'Circles of Worry' and 'Circles of Coping'; Kirkland's (2005) visual formulation framework developed from the case series of Haddock *et al.* 2004 with circles containing individuals' antecedents, beliefs and consequences. The circles can be expanded/reduced to illustrate changes in degree of feeling and/or certainty in the belief(s). Personalized pictorial 'narrative' formulations were developed to match individual's information processing styles, strengths and weaknesses.

Accessible CBT illustrations of interventions

Standard approaches included 'listening to' and demonstrating therapist belief in the description of childhood experiences ; exploring cultural issues (voices often contained racial comments), psycho-education to the CBT model, feelings, thoughts and 'voices' and normalization of experiences. A variety of relaxation strategies (trial and practice in sessions, compact discs (CDs) and a prompt sheet made for home use) were used along with activity scheduling and environmental changes to reduce triggers. Behavioural experiments were designed collaboratively to test ideas such as control over 'voices' and thoughts. In addition, family, school and network meetings were held to share assessment, formulation, planning, trialling interventions and maintaining effective ones. These interventions are 'standard' in that, while any approach should be tailored to ability and communication levels, personal history and current context, interests, and goals, the techniques could be used with anyone. They may need to be further adapted as below with more visual material to promote and prompt change and its generalization and maintenance if necessary.

Evidence-/practice-based adapted approaches used include normalization of physical, emotional, behavioural and cognitive experiences and general and specific 'trauma' memories

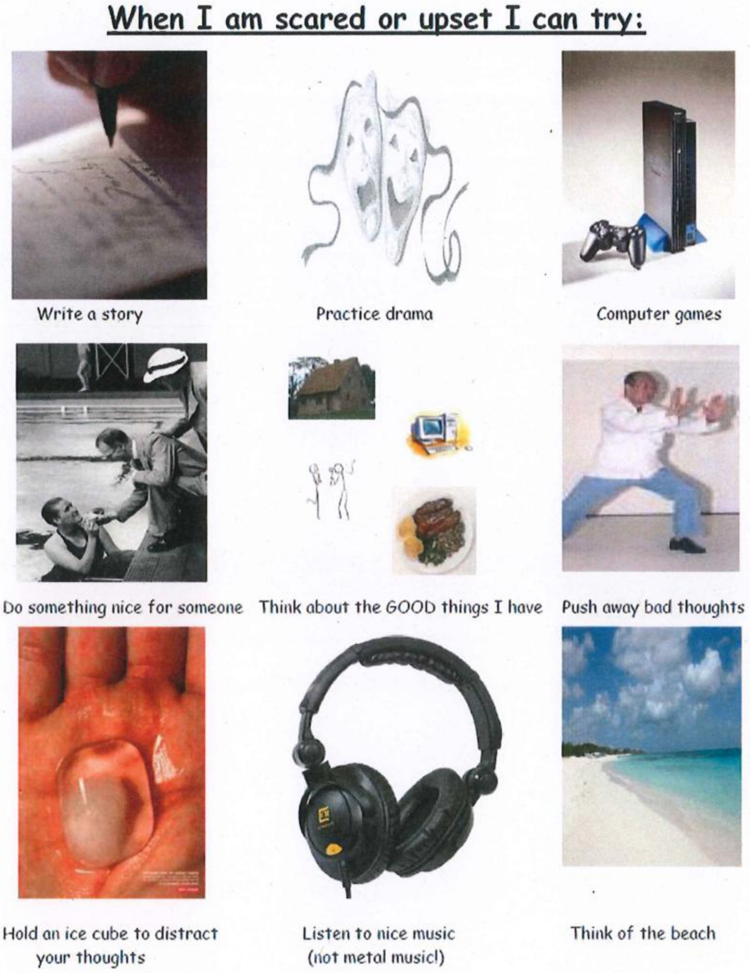


Fig. 4. David's calming activities.

(Ehlers & Clark, 2000) tailored to the client's communication style and level. The use of metaphors, such as thoughts such as CDs playing which can be changed or have their volume reduced was useful. Evidence for thoughts and thinking traps were identified, alternative explanations and coping thoughts developed. A simplified version with visual materials and distraction calming techniques drawn from Leggett's (1997) case description such as naming objects in the room, physical exercise and sub-vocal speech/singing and from dialectical behaviour therapy (Linehan, 1995) with activities across all sensory systems were explored

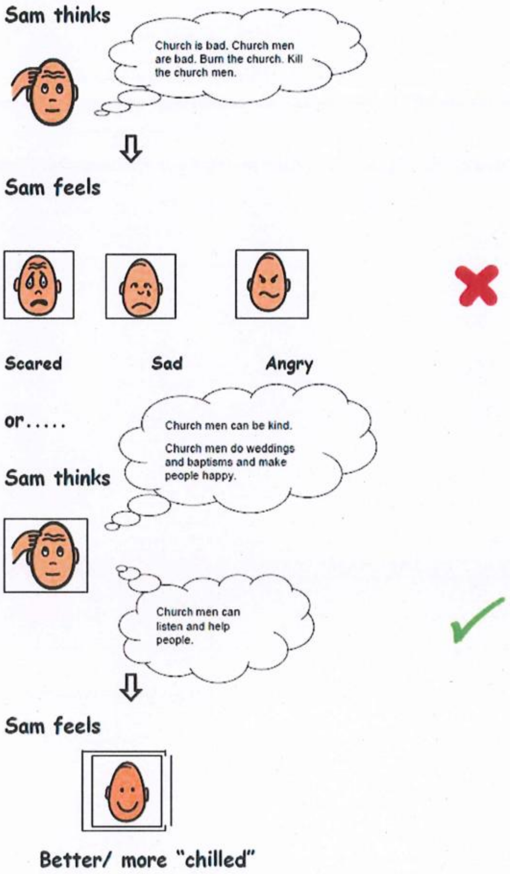


Fig. 5. Sam – example of personalized psychoeducation/therapy.

and practised. This led to a personalized visual calming prompt/recipe sheet (see Fig. 4). The use of music such as recording personalized selections for self-calming, feeling happier, getting motivated has been popular and effective.

Personalized approaches: included pictorial formulation and visual psycho-education, e.g. about possible origins of 'voices' (death of close relative with strong religious faith, bully at school instructing Sam to harm priests and burn churches). This led to development of a coping plan for 'voices' which included limiting time spent alone, a visual prompt for family not to question Sam if he wanted to be in same room with them but not talk, watching comedy and nature programmes not horror movies, and rehearsing alternative thoughts from a personalized prompt sheet (see Fig. 5).

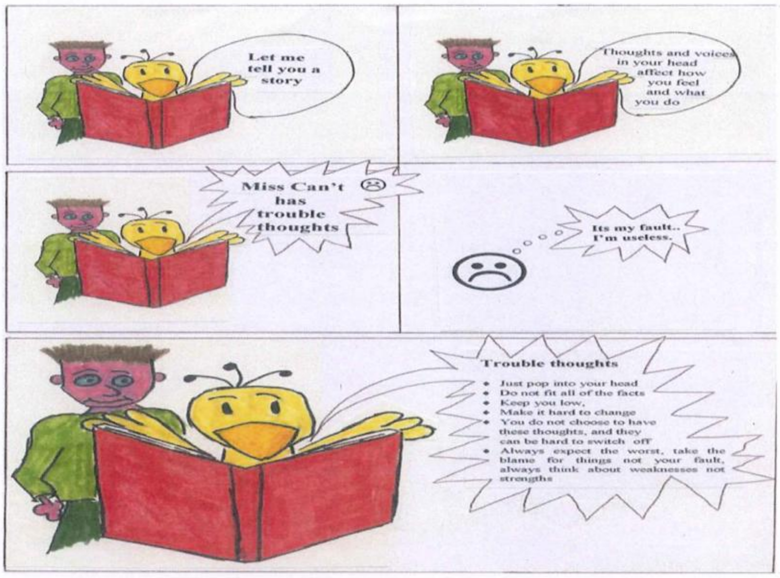


Fig. 6. First page of Jenny's 'Miss Can't, Miss Can' personalized coping.

An individualized formulation of Sam's 'dream'-like experience and rescripted 'dream', with a safe ending was made into 'cartoon' format to increase the likelihood of remembering and recall. This helped reduce his distress.

Personalized coping books were developed for David containing simple and visual information about mental health problems (Morrison *et al.* 2008), and for Jenny – 'Miss Can't and Miss Can' (for depression) and 'Miss Frazzle and Miss Calm' (for anxiety and anger). These used her own artwork and a personally generated 'guardian angel' cartoon character (see Fig. 6).

Personalized coping plans and booklets were shared with family and staff to enhance generalization and effectiveness.

Outcomes were measured using self-report, family and staff report, behavioural observations and simplified diaries, visual ratings for standardized measures, and 'quizzes'. As our illustrations represent 'composite' service-users to maintain anonymity, no individual outcome data is reported. Improvements reported and/or observed included:

- Reduction in symptoms – such as anxiety and depression, distress about and frequency of voices, and reduction in medication.
- Successful use of some coping strategies, increased knowledge and understanding.

- Improvements in social inclusion and skills, for example, making new friends/reconnecting with old friends, going on the bus for the first time, and shopping independently, increased engagement in structured activities, increased independence in accommodation, commencing a supported apprenticeship.

Issues, implications and recommendations

Published studies and these illustrations demonstrate that CBT can be made accessible and effective for people with cognitive impairments. As cognitive impairment is a fundamental aspect of our equality and diversity agenda, we must all work to improve our practice in this area. Adaptations to meet the information processing and neuropsychological deficits in attention, comprehension, memory sequencing, planning and organizing include:

- Individualizing assessment and intervention with visual, concrete materials.
- Use of prompt materials between sessions.
- Plan for shorter more frequent sessions.
- Plan carefully for maintenance and generalization.
- Working within the person's belief system.
- Increased involvement with carers, sharing formulation, and intervention strategies to support the person between sessions to maximize engagement and generalization.
- Considering contextual and systemic issues including access to CBT for carers with their own difficulties arising from depression or anxiety.

Difficulties that can arise with 'labelling', for example, 'thoughts' may be described as 'voices', or 'memories' or as 'hallucinations' can arise for all; however, how these are discussed is crucial. Experiences may be described which remain permanently unclear as to whether they are actual experiences. But these can all be addressed by taking an open-minded, non-judgemental stance, and working within a person's belief system. The use of visual and concrete media can assist communication, comprehension and containment of complex and/or distressing psychological phenomena. Working with carers and staff to assist them in supporting this approach is essential.

Making CBT accessible does not mean abandoning what we know works – the same principles, models and treatment protocols are used as for 'standard' populations with individual formulations derived from the same models. What is adapted are the methods/media used for formulating with and applying these models and techniques. Westbrook *et al.* (2010), makes this point succinctly and calls it 'the golden rule' – i.e. when confronted with a problem in therapy, you should use the CBT model to understand the problem and develop solutions.

Therapists need to attend to their own attitudes and beliefs as well as those of service users, staff and carers. Hopelessness can be associated with diagnosis, with traumatic life histories or life events. As therapists, we can feel inadequate, unprepared and/or unsupported. Using the strategies for increasing accessibility of CBT along with attitudes of hopeful, optimistic concern can create more constructive, resilient and effective approaches.

Some association between verbal ability and ability to engage in CBT has been reported with people with learning disabilities (Rose *et al.* 2005; Joyce *et al.* 2006) and with children and young people (Sams *et al.* 2006; Berry & Cooper, 2012). Although cognitive abilities may be a significant contributor to ability to engage with CBT, services may overlook this aspect.

Alternatively, services and professionals may give an over-simplistic response of 'well, CBT won't work for X'. Studies and our clinical experience show that by attending to a range of cognitive and information processing factors including memory, comprehension, attention, and sequencing, adaptations such as those illustrated above can be made which enhance the accessibility of CBT for people with cognitive impairment.

There are service-wide implications including pre- and post-qualification training and supervision. Creating networks across traditional care-group boundaries can help cross-fertilization of experience, skills, resources and resource development. The assumption of 'need to', and 'skills for' adapting psychological treatments to increase accessibility is vital across all services. Currently this may be restricted to some specific-care groups such as learning disability rather than recognizing the 'cross-care group' and 'core competencies' needed for adapted/accessible CBT. In our NHS Trust, knowledge and practice benefited from a 'cross-care group' CBT and psychosis peer supervision group across Child and Young People, Working Age Adults, and Learning Disabilities.

At a national level, course curricula, trainers and supervisors need to include accessible and adapted CBT within teaching on diversity issues. This should include disability and cognitive impairment, to meet the equality agenda. Ability to adapt CBT needs to be recognized as a core competence and essential set of skills rather than an 'add-on' to traditional CBT training for all service provision and for developments such as IAPT and New Ways of Working.

Working with people from diverse backgrounds is central to the provision of effective psychological interventions. It is crucial that professionals are competent and confident in individualized approaches to assessment, formulation and intervention not only 'manualised' therapy. We need to ensure that difference; diversity and complexity are appropriately assessed and incorporated into intervention. Diversity should not be a 'tick box' exercise. It is an important theme to revisit throughout the journey of assessment and intervention. Adapting CBT is possible, can lead to change for people using services and increases CBT's accessibility for people who might otherwise be marginalized and unable to engage in psychological intervention. In summary, our message for making CBT accessible for people with disabilities arising from cognitive impairments, learning disabilities and/or neurodevelopmental disorders is 'You can do it!'

Summary

This paper has:

- Shown why accessible CBT matters for people with cognitive impairments, learning disabilities and/or neurodevelopmental disorders to address health inequalities and diversity, enhance effectiveness and meet requirements of equality legislation. Evidence has shown barriers such as low referral rates, inadequate/inaccurate knowledge and attitudes of referrers, professionals and service users. Demographics show that people who use services are very likely to have some cognitive impairment, learning disability/difficulty and/or neurodevelopmental disorder.
- Synthesized some of the evidence base for adaptations to increase accessibility of CBT from research with children, people with learning disabilities, neurodevelopmental disorders such as ASD and ADHD and people with dementia.

- Illustrated the use of both standard, adapted approaches and personalized practical adaptations to increase accessibility of CBT through the use of visual, simplified assessment and intervention resources.
- Signposted relevant evidence-based practice and practice-based evidence for accessible CBT across the lifespan and various cognitive impairments and made recommendations for training and supervision.

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Declaration of Interest

None.

Recommended follow-up reading

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Learning objectives

(1) To show why accessible CBT matters for people with cognitive impairments, learning disabilities and/or neurodevelopmental disorders to address health inequalities and diversity, enhance effectiveness and meet requirements of equalities legislation.
(2) To summarize some of the evidence base for adaptations to interventions which make CBT accessible.
(3) To illustrate clinical adaptations to increase accessibility of CBT through three case descriptions and examples of 'accessible' assessment and intervention resources.

3.10
Publication 10

Wiggins, J., Hepburn, S. and **Rossiter, R.** (2013) Reducing Harmful Sexual Behaviour in Adolescents. *Learning Disability Practice,* October, 16 (8) pp. 16-23.

This publication describes an innovative clinical group with more specialised and complex service users. It is focused on young people with learning disabilities (earlier intervention) through drawing on appropriate developmental theory and evidence, adapting and building on an evidence based intervention for adults with learning disabilities and integrating findings from previous group work. The rationale included policy recommendations (National Safeguarding Report, OFSTED, 2008) and research on need (e.g. Youth Justice Board, 2005, 2008$_a$ 2008$_b$; Rossiter et al., 2010; Criminal Justice Joint Inspection, 2013) and on practice and service delivery (O'Callaghan, 1999; Murphy & Sinclair, 2009; Murphy et al., 2007), The group integrated models of CBT, Finkelhor's (1984) offending model and Ward and Brown's (2004) Good Lives model together with consideration of developmental tasks and factors of participants along with group process issues.

The group was also a response to the nature and number of referrals to Community Team for Children and Young People with Learning Disabilities across the county, the desire to develop an earlier intervention (adults had been engaged in SOTSEC-ID Sex Offender Treatment Services Collaborative –Intellectual Disabilities as an intervention with potential and to collaborate in research) and to explore the case for this type of group as the focus for a future research study. I led the multidisciplinary team which planned, delivered and evaluated the group and supervised it.

The design was a one group Pretest - Posttest, mixed (uncontrolled, non-blind, non-selective). Quantitative data included measures of sexual knowledge and attitudes and reports of incidents of sexually harmful behaviours; qualitative data included feedback from participants on what they learned, liked/did not like, how the group could be improved and co-facilitator and staff feedback.

Key findings and unique contribution to knowledge included positive feedback from participants, networks and co-facilitators on this group adapted from the protocol based SOTSEC-ID groups for adults , some change on quantitative measure of Sexual Knowledge and Attitudes, no reported incidents of harmful sexual behaviour during and at six month follow-up, and the recommendations for further work locating this specialised group in a stepped matrix for primary, secondary and tertiary intervention and within safeguarding responsibilities along with the need for more appropriate measures.

The work was published in a multidisciplinary practice journal for maximum dissemination.

Publication 10

Wiggins, J., Hepburn, S. and **Rossiter, R.** (2013) Reducing Harmful Sexual Behaviour in Adolescents. *Learning Disability Practice,* October, 16 (8) pp. 16-23.

REDUCING HARMFUL SEXUAL BEHAVIOUR IN ADOLESCENTS

Joshua Wiggins and colleagues discuss the work of a therapy group for young people with learning disabilities who have behaved inappropriately

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Abstract

Children and young people with learning disabilities are over-represented among perpetrators and victims of sexual offences. This article describes how a group approach was adopted for a series of complex and risky referrals of adolescents with learning disabilities and harmful sexual behaviours. The approach draws on a version of the Sex Offender Treatment South East Collaborative: Intellectual Disabilities, a treatment protocol for adults with learning disabilities, that has been adapted for teenagers. Successful aspects of the approach include the use of visual resources and multi-sensory activities, which led to improvements in sexual knowledge, and social and emotional skills, of clients. Areas that still need development include appropriate assessments for formulation and outcome measurement, and multi-agency commissioning and support for this vulnerable group.

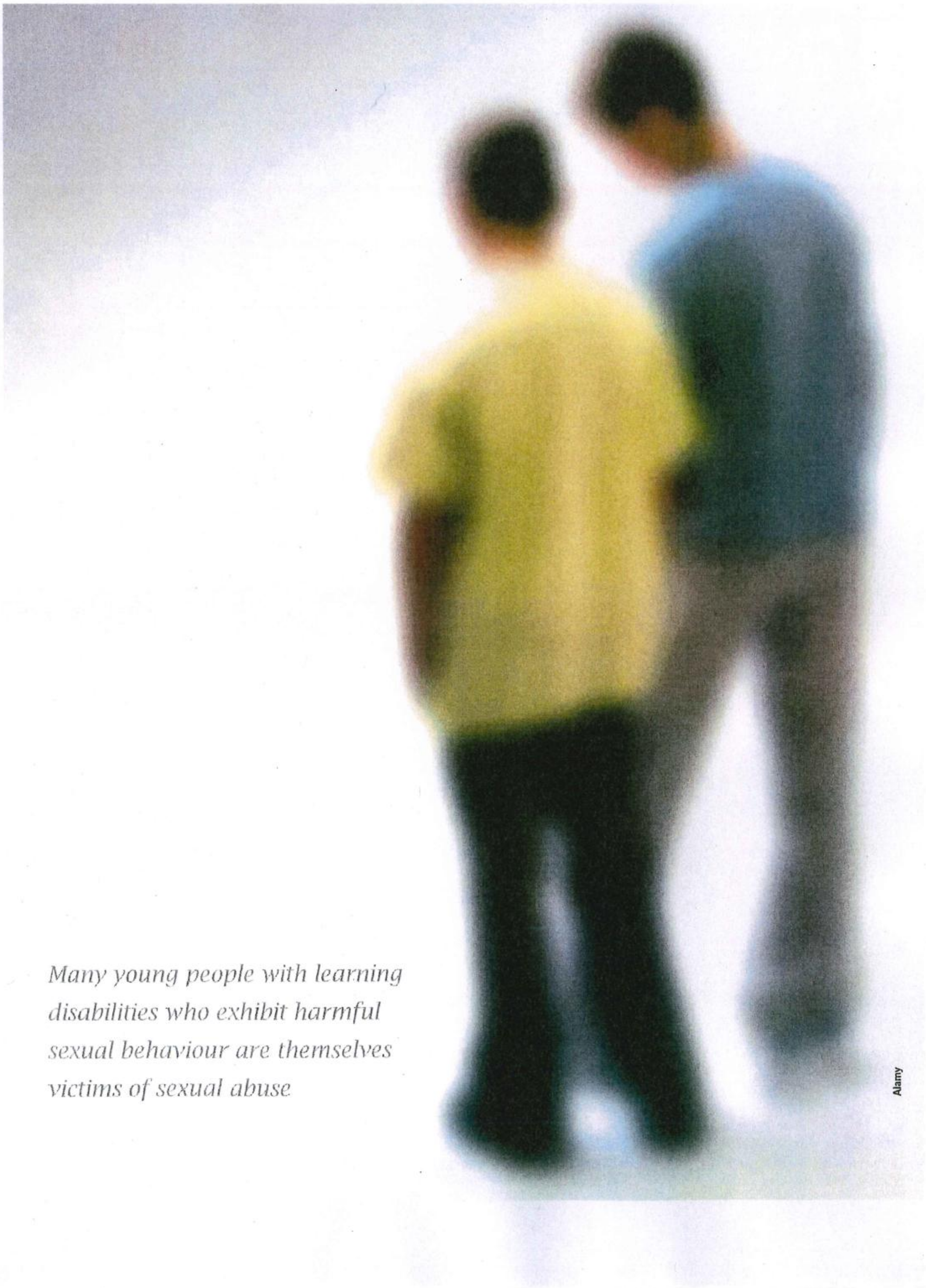
Keywords
Children and young people, group work, learning disabilities, sexual offending, therapeutic interventions

THIRTY-FIVE PER cent of all sexual offences are committed by children and young people, and those with learning disabilities are over-represented as perpetrators and victims (Youth Justice Board for England and Wales 2005, 2008a 2008b, Criminal Justice Joint Inspection 2013, Hackett *et al* 2013).

A national safeguarding report (Office for Standards in Education, Children's Services and Skills 2008) calls for 'necessary provision' for these children and young people, yet few services exist and the research base is low (Rossiter *et al* 2010). Research shows that a significant proportion of children and young people with learning disabilities who exhibit harmful sexual behaviour are themselves victims of sexual abuse. They may also show social skills deficits and a lack of sexual knowledge, and many experience social isolation and anxiety, poor self-esteem, loneliness and dysfunctional family environments. High rates of poverty, domestic violence and neuro-developmental difficulties such as post-traumatic stress disorder, attention deficit hyperactivity disorder and/or conduct disorder are also reported (Vizard 2006, Craig *et al* 2010).

In 2011, the authors set up a time-limited, multidisciplinary peer interest group to share resources, research and working practices in this area of practice. As a result, they gathered evidence that:

- Referrals of young people with learning disabilities whose behaviour was sexually inappropriate, harmful and/or offending to community teams in Surrey was increasing, yet there was a lack of specialist services for these clients.
- Early interventions (Department for Education and Skills (DfES) 2004, Department of Health and DfES 2004) can reduce the likelihood of offending among young people while safeguarding potential victims.
- Sexual offending behaviour often begins as inappropriate sexualised behaviour in childhood and adolescence (Murphy and Sinclair 2009, Murphy *et al* 2010).



Many young people with learning disabilities who exhibit harmful sexual behaviour are themselves victims of sexual abuse

Alamy

Box 1 Sex Offender Treatment Services Collaborative: Intellectual Disability

The Sex Offender Treatment Services Collaborative: Intellectual Disability (SOTSEC-ID) has developed and evaluated a form of cognitive behavioural therapy for men with intellectual disabilities who have been or are at risk of sexual offending. More than 90 per cent of participants complete the therapy and there is evidence that it increases their sexual knowledge and victim empathy, while reducing their cognitive distortions and offending rates (Murphy and Sinclair 2009, Murphy *et al* 2010).

- That therapy groups organised by the Sex Offender Treatment South East Collaborative: Intellectual Disabilities (SOTSEC-ID) can reduce offending and cognitive distortions, and increase sexual knowledge and victim empathy, among men with learning disabilities who exhibit sexually harmful behaviour (Murphy and Sinclair 2009, Murphy *et al* 2010). The work of the SOTSEC-ID is described in Box 1.

In light of this evidence the authors were prompted to develop a group-therapy intervention for young people with learning disabilities and sexually harmful behaviours. The aims of the intervention were to:

- Reduce harmful sexual behaviour and cognitive distortions related to sexual offending, such as the tendency to minimise or deny sexual offences, or to blame the victims, among the young people concerned.
- Encourage positive changes in their sexual attitudes and knowledge leading to, for example, greater empathy for victims of sexualised behaviour,
- Encourage emotional regulation.
- Improve their social skills.

Young people with severe or significant learning disabilities, defined by the British Psychological Society (2000) as an IQ of between 50 and 70, were referred to the therapy group if they were exhibiting harmful sexual or offending behaviour. Such behaviour includes, for example, compulsive masturbation in public, forced touching and exposing their own or others' genitals.

The group adapted the SOTSEC-ID cognitive behaviour programme for adults with learning disabilities who are at risk of harmful sexual or offending behaviour to ensure that it was appropriate to, and could be understood by, teenagers. In doing so, the authors drew on the work of O'Callaghan (1999) and G-map (2013), an independent organisation that provides services for young people who display inappropriate sexual behaviour.

It was intended that up to six clients would take part in the therapy. Initially, pre-group assessments were undertaken to screen participants, and to determine their sexual knowledge and attitudes.

The authors used the SOTSEC-ID protocol to review various forms of assessments and found that the general Sexual Attitudes and Knowledge (SAK) (Heighway and Webster 2007) assessment was most appropriate to adolescents with learning disabilities.

Other forms of assessment, such as the questionnaire on attitudes consistent with sex offences (Lindsay *et al* 2000), the sex offender self-appraisal scale (Bray and Forshaw 1996) and the adapted Victim Empathy Scale (Beckett and Fisher 1994), were found to be inappropriate for the young people who had been referred.

Participants in the group were assessed against the general SAK protocol before the sessions began, six months and at the end of the group period to identify gaps in their sexual knowledge to inform the development of keeping-safe and relapse-prevention plans, and to evaluate changes in knowledge.

Four clients, aged between 14 and 16, were chosen to take part in the therapy. All have significant or severe intellectual impairments, and were attending schools for children with special educational needs when they joined the group. Three had been diagnosed with autistic spectrum disorder (ASD).

The sessions were run by four learning disability nurses supervised by two clinical psychologists and helped by an assistant psychologist, with two or three nurses working at any one time.

The group met in a central location, and transport funded by education and social services was provided, to ensure that participants from across the county could attend. The therapeutic sessions ran for two hours, once a week, during school term times and lasted for 13 months.

'Feelings diaries' were drawn up so that participants could indicate whether they felt angry, happy, sad or upset, or worried on a given day; to indicate what had happened to make them feel these ways; and to indicate what they said, thought and did as a result (Figure 1).

The group sessions consisted of four modules: Module 1 comprised:

- Understanding and managing feelings.
- Understanding social rules.
- Sex education and relationship development, body parts, the difference between public and private, issues of consent and the law.

Module 2 comprised:

- Behavioural responses to emotions and thoughts (adapted cognitive behavioural therapy).
- Positive ways to express and manage emotions and thoughts.

Module 3 comprised:

- Generalised harmful and offending behaviour, and taking responsibility for behaviours.
- Inappropriate and offending sexualised behaviour and taking responsibility for offences.
- Empathy for victims.

Module 4 comprised:

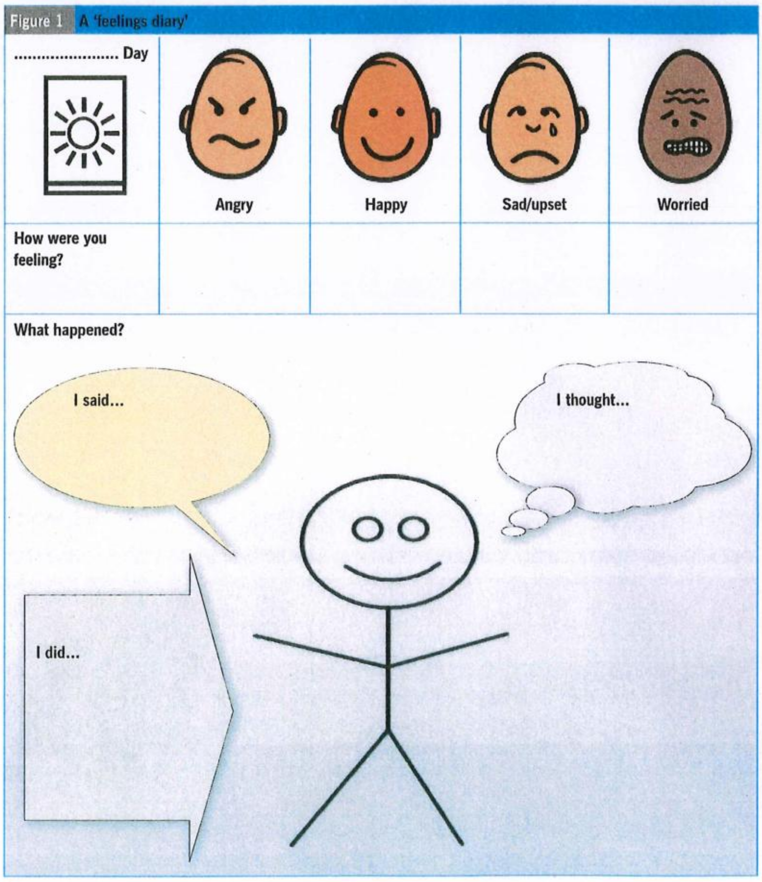
- Drawing up keeping-safe and relapse-prevention plans.

Practice

All four clients completed the programme and attendance was exceptionally high.

Module 1 Participants were encouraged to develop a sense of ownership of the group. They named it the Teenagers Group, and discussed concepts of confidentiality and privacy. To help break down barriers and identify the clients' knowledge, ground rules were developed to allow group members to use slang words, including those for body parts. They also made privacy signs to hang on the door when the group was in session. Juice and biscuits were offered, in part to help develop interpersonal relationships among group members.

Figure 1 A 'feelings diary'



Participants explored their feelings so that they could develop a shared understanding of emotions. Activities focused on the roles of emotions in relationships, appropriate behaviour and emotional communication and management.

The three participants with ASD have impairments in reciprocity, social motivation and flexibility of thought, and they found these activities challenging. All group members had problems understanding that other people have emotions or beliefs different from theirs, identifying facial expressions, and recognising emotions in themselves and others.

Nurses and participants worked together to complete 'feelings diaries' for specific scenarios. Video clips of scenarios from the television programme Eastenders were shown to illustrate emotions and prompt discussions about identifying emotions in others. This allowed for the freeze-framing and discussion of specific situations, and the emotions and behaviours they involved. Role-play enabled participants to match emotion face-masks to the scenarios being acted out by the facilitators and group members. Visual action-based learning seemed most effective.

All group members had received sex education at school within six months of the first session, but subsequent assessments showed there were limitations to their knowledge. Sex education based on Puberty and Sexuality for Children and Young People with a Learning Disability (NHS Leeds 2009) was therefore repeated. This education included the appropriate identification and naming of body parts, and activities to clarify 'public' and 'private' places, and 'OK' and 'not OK' sexual behaviours.

The participants find generalisation difficult to imagine and struggled with the idea that, for example, the living room in a family's home can be public or private depending on who is present.

Module 2 Foundations laid in the first module were reinforced in module 2. Learning on emotions, cognitions and behaviours were explored further and applied to different social scenarios. Participants explored how feelings and thoughts link together, and how they can be managed more appropriately. Role play continued as a visual and active medium to explore scenarios from the feelings diaries. The use of the feelings diary and video clips also continued.

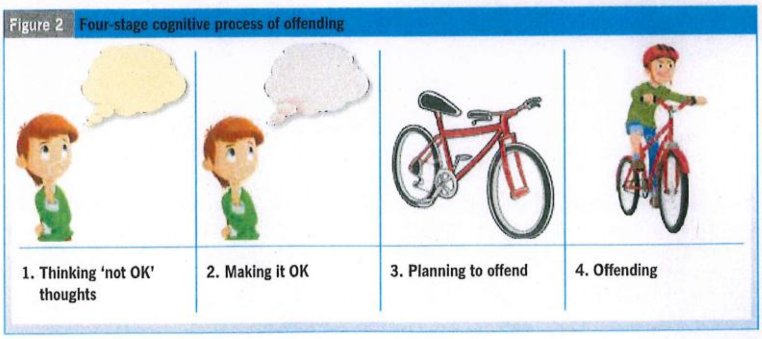
Module 3 This module, which covered offending behaviour, began with an introduction of the general offending behaviour model. This was thought to be less intrusive than the sexual offending behaviour model, and more easily comprehensible given participants' concrete and black-and-white thinking. The module also included some discussions of scenarios shown on flipcharts and role-play to illustrate non-sexual 'not OK' behaviour, such as losing one's temper and shouting at someone.

A simplified version of Finkelhor's (1984) 'precondition' model of sexual offending behaviour was then adopted to explore sexual behaviours that were 'not OK'. The model's four stages, namely motivation to sexually abuse, overcoming internal inhibitors, overcoming external inhibitors, overcoming the resistance of the victim, were adapted to become:

- Thinking 'not OK' thoughts.
- Making it OK.
- Planning to offend.
- Offending.

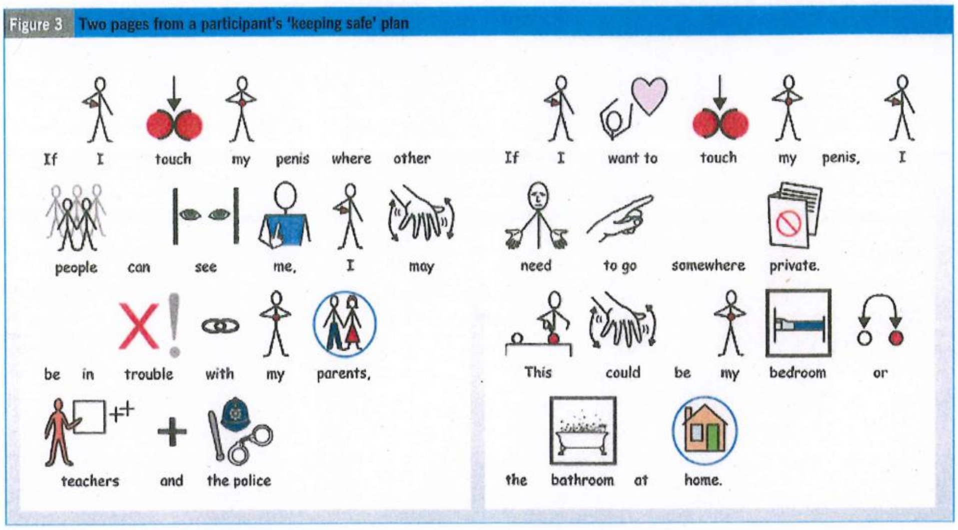
One participant was willing to share his experiences of non-sexual offending, including theft from shops, bicycle theft and criminal damage, and the group completed a diagram illustrating his four-stage cognitive process of offending (Figure 2) based on a system devised by Finkelhor (1984).

Figure 2 Four-stage cognitive process of offending



1. Thinking 'not OK' thoughts
2. Making it OK
3. Planning to offend
4. Offending

Figure 3 Two pages from a participant's 'keeping safe' plan



If I touch my penis where other people can see me, I may be in trouble with my parents, teachers and the police

If I want to touch my penis, I need to go somewhere private. This could be my bedroom or the bathroom at home.

Participants understood these experiences and the group was able to discuss associated behavioural, emotional, cognitive, social and legal issues.

Careful management by the facilitators was needed because some group members, including the perpetrator, responded to parts of the discussion with amusement. While laughter in such situations can signify embarrassment and anxiety, it can also foster unhelpful fascination with antisocial behaviours that are perceived as 'heroic'.

The group explored and identified more helpful thoughts about the behaviours and the group split into two, with one group, representing 'good thoughts', shouting out reasons why the perpetrator should not engage in the offence and the other group, representing 'bad thoughts', encouraging the participant to engage in the crime. The group responded and interacted well to this approach.

When the simplified Finkelhor model was applied to sexual offending behaviour, the participants found the process more challenging. The sexual dimension gave rise to feelings of guilt, shame and embarrassment about the behaviour, which may have been exacerbated by the participants' own experience as victims of abuse.

The participants could apply the model to their own and other people's non-sexual 'not OK' behaviours but found applying it to sexual offending more difficult. In discussing their own sexual 'not OK' behaviour, some participants said they felt or believed that they had not offended.

Their denials took several forms, including denial of offence, of intent, of responsibility and/or of harm to victim (Lakey 1994). For example, one participant had a fixed belief that if he exposed himself in a park empty of people, he was committing a private act and therefore no offence. During these discussions, rules were developed as part of individuals' 'keeping safe' plans for specific behaviours and situations that group members found ambiguous.

Participants also found empathy with victims to be challenging and tended to identify themselves as victims, for example because they had been told off. This sense of victimhood was increased in those who had been bullied and abused. Only one member of the group had been involved with the police for an offence in which the victim had been clearly identified.

Because of confidentiality issues, and the location and duration of the group, participants were not expected to disclose details of their inappropriate behaviours. Instead, they explored anonymised scenarios based on actual behaviours and situations. This helped to encourage discussion about sexual offending and increased participants' engagement. One-to-one work was undertaken with individuals to focus on their reported offences.

Module 4 During this module 'keeping safe' and relapse-prevention plans were developed with the individuals concerned, in a form they can

Table 1 Strategy for prevention of sexual offending: children and young people with intellectual disabilities

	Primary prevention	Secondary prevention	Tertiary prevention
Population to which strategy applies	Children and adolescents with intellectual disabilities	Children and adolescents with intellectual disabilities, particularly those from families exposed to risk factors and who exhibit 'yellow flag' behaviours.	Children and adolescents with intellectual disabilities who display 'red flag' or illegal behaviours
What the strategy involves	■ Development of materials for sex education for families of children with intellectual disabilities ■ Collaborative work to develop a comprehensive sex education curriculum for students with intellectual disabilities ■ Cross-divisional co-operation to identify and support families with children and adolescents at risk of becoming sex offenders	■ Training of teachers and case workers to identify children and adolescents who display 'yellow flag' behaviours ■ Identification of children and adolescents exhibiting 'yellow flag' behaviours and the implementation of appropriate responses to such behaviours ■ Immediate and appropriate intervention with children and adolescents who display 'yellow flag' behaviours and support for families 'at risk'	■ Access to treatment programmes for which there is scientific evidence of success ■ Development by mainstream agencies of treatment programmes for adolescents with intellectual disabilities ■ Development of protocols to ensure consistency across services

(Victoria Disability Services 2002)

understand. Two pages from one participant's 'keeping safe' plan are shown in Figure 3.

These plans identify the risks involved in participants' offending behaviour, identify gaps in their knowledge and describe strategies to help keep them safe. The individualised plans were tailored to each young person's communication strengths and needs, supported by the use of visual resources.

The plans were shared with referring agencies and key people in the adolescents' network, with the strategies and individuals' gaps in knowledge being highlighted.

Feedback from referers indicated that the group sessions had met their original treatment aims. After the sessions had finished, the young people were discharged from the service and referers made aware that they could be referred again if necessary. The service has not received any re-referrals.

Reflection

In reviewing the approach the co-facilitators and supervisors had adopted, they identified what they had learned and what had gone well.

What was learned

- The group was feasible and useful.
- The SOTSEC-ID group framework was applicable and helpful, but needed tailoring for adolescents. Of the assessment tools SOTSEC-ID involves, only SAK was appropriate.
- Infrastructure support, such as transport, supervision, good venue, and assistance with resources from, for example, a psychology assistant, is important.
- Sufficient time for planning, preparing, reviewing, liaising and reporting is required in addition to the face-to-face group time. This makes the group labour intensive, especially if only four participants are involved. Between six and eight participants would have been preferable but due to lack of time and the closed nature of the group, only four participants could be chosen.

What went well

- Video clips and visual materials.
- Role-playing, active learning, quizzes.
- Collaboration of people from different professions, such as nursing and psychology. Co-facilitators enhanced group planning and provision.

Challenges

- Maintaining momentum and motivation, especially during discussion of more difficult topics, areas and concepts
- Finding sufficient time for supervision, planning, resource development and review"

Conclusion

Groups therapy of the kind described in this article are feasible and useful, and is

Chapter 4

Methodological analysis and critique

4.1

In this Chapter, the publications are summarised by presenting their methodologies categorised according to a taxonomy of research designs adopted to critique them in a logical and consistent way. The taxonomy is taken from Barker et al. (2002). Barker et al. (2002) draw heavily on the often-used Cook and Campbell's (1979) taxonomy. In order to optimize the coherence and relevance for research methods in clinical psychology, Barker et al. (2002) consider the distinction between quasi-experimental and experimental designs where:

> Quasi-experiments are defined as "experiments that have treatments, outcome measures, and experimental units, but do not use random assignment to create the comparisons from which treatment caused change is inferred. (Cook and Campbell, 1979; p. 6, quoted in Barker et al., 2002)

Barker et al. propose the use of the more precise terms *non-randomised* and *randomised* designs instead of *quasi-experiment* and *experiment* "…. in the light of our earlier discussion about the term *experiment* being too narrowly defined within psychology."(Barker et al. 2002, p. 146)

Barker et al.'s taxonomy is used as the convention to categorise the publications for analysis and critique. Initially, the methodologies are critiqued through a contemporaneous methodological lens followed by a critique through the lens of the current orthodoxy of evidence- based practice (Sackett et al., 1996; ScHARR, 2000). Finally, a critique is presented considering the dominant evidence-based practice paradigm both in general, and specifically for, service development, delivery and research with, and for, people with learning disabilities.

4.2 Experimental research designs of studies described in publications

For this section, the publications are presented grouped according to Barker et al.'s taxonomy starting with the most robust designs. A summary Table of methodological factors presented in chronological order of publication is found at Appendix 8, p. 262.

Brief critical comments are made with reference to the design and implications for internal and external validity of the studies. Internal validity refers to the degree to which causality can be inferred from the intervention (is the independent variable, i.e. intervention, producing the changes in the dependent variable(s), i.e. the variable(s) of interest such as behaviours, emotions, learning). Major potential threats to internal validity identified by Cook and Campbell (1979) and re-emphasised by Barker et al. (2002, p.146) relevant to researching the effects of psychological interventions include endogenous change and maturational change (especially relevant for studies with children), measurement reactivity, secular "drift" arising from broader social trends , interfering events i.e. significant events other than the experimental intervention that occurred between pre-test and post-test and regression to the mean. External validity refers to the degree to which the results may be generalised overtime, settings or persons to others situations.

More detailed critique, including the other elements of validity such as external, social and ecological validity is presented in the synthesis, Section 4.3.3.

4.2.1 Equivalent, non-randomised groups (partially controlled) Double Pretest - Posttest Design. Mixed methods

Publication 4, Mealtimes Group Intervention (Williams et al., 1989).

Methodological strengths of this study and design included the "double" pre-test baseline measures (enabling participants to act as individual and group controls), post-test and follow up, the use of mixed methods (quantitative, observational data and qualitative, staff feedback data), inclusion criteria targeting people with a range of learning disabilities living together and not excluding people on the basis of cognitive or communicative ability or behavioural challenges; inter-rater reliability calculated for observational data (eye contact, initiation of interaction continuation of interaction, and requests) with a mean level of 72.09%; design allowing analysis, identification and reporting of differential results for the different teaching conditions (instruction, modelling, instruction and modelling) on different aspects of social interaction and with different individuals (showing the need for individualised analysis, and individualised planning and intervention). It has high external validity having been carried out “in the field” and included routine staff.

Methodological weaknesses identified in the publication were linked to their impact on “Meaningful comparison of the teaching procedures...” noted as:

> … difficult because of the limitations of the study design, namely, short duration, no return to base-line group and order of intervention effect, cumulative effects and lack of blind observers. (Publication 4; p.75).

Other methodological weaknesses included baseline measures only across a one week period which does not adequately control for maturational or endogenous changes and/or secular drift, lack of randomisation, lack of no intervention or comparison group control and lack of explicit collection of user- feedback from participants with learning disabilities. There could also have been further analysis and reporting of any differences in inter-rater reliability rates across the four behavioural measures (eye contact, initiation of interaction, continuation of interaction and requests).

4.2.2 Equivalent non-randomised groups (partially controlled) Pretest – Posttest Design. Mixed methods

Publication 3, Support staff training (Flockhart and Keleher, 1989).

Methodological strengths of this design included two intervention groups and a control group, groups matched for departmental representation, length of service, grade, English as first language, gender; use of pre-test, post-test and follow up measures; use of mixed methods and multiple measures (knowledge, attitudes, behaviours) and participant feedback. It has high external validity having been carried out “in the field” and included routine staff.

Methodological weaknesses include only one pre-test measure point which does not allow any control for maturational or endogenous changes and/or secular drift, reliance on self-report measures and lack of observational data (though this may not have been appropriate), and lack of randomisation.

4.2.3 One group Double Pretest - Posttest Design, mixed methods

Publication 1, Social interaction activity group intervention (Keleher and Brigden 1982).

Methodological strengths of this study and design included the double pre-test baseline measured across a time-frame which matches the intervention phase which enabled participants to act as individual and group controls, and controls for maturational or endogenous changes and/or secular drift), post-test and follow up; the use of mixed methods (quantitative, observational data and qualitative, staff feedback data), inclusion criteria targeting people with a severe degree of learning and communication disabilities and challenging behaviour who could not access the Local Authority Day Service and not excluding people on the basis of cognitive or communicative ability or behavioural challenges ; inter-rater reliability calculated, 87.3% - 96.6% for participation; 89.1% - 99.1% for interaction; high replicability (clear description of methods and manual for intervention available, explanation of method for calculating inter-rater reliability. It has high external validity having been carried out “in the field” and included routine staff.

Methodological weaknesses identified in the publication are identified as:

Questions arising from this research include:

1. Does learning and generalisation of social interaction skills occur as a result of the group
2. How can staff behaviour in organising and running the group been maintained
3. How can the running of the group be monitored to ensure it is run according to the principles laid down in the booklet
4. What contribution made by the booklet itself in enabling staff to run the group. (Publication 1; p 63)

Other weaknesses include lack of randomisation, lack of blind/independent observation; whilst user feedback is implicit from observations of participation and interaction in varying activities and staff participation, there is a lack of explicit collection of user feedback from participants (people with learning disabilities and staff).

4.2.4 One group Pretest - Posttest Design, mixed methods

Four of the selected publications use this design: 5, Anger Management Group intervention; 6, Emotion Management group 1; 7, Emotion Management group 2 and 10, Group intervention for adolescents with learning disabilities and harmful sexual behaviour.

First, the strengths and weaknesses common to the use of this design across the four publications are presented followed by any strengths and weaknesses specific to individual studies.

Methodological strengths of this design across the four publications included addressing clinical and policy priority needs; building on previous research (author's and others') and extending interventions with evidence-base for typically developing participants to those with different abilities, age-range, setting; focus on under-researched, unpopular, neglected populations (people with severe learning disabilities, challenging behaviour, aggression, mental health issues, offending and sexually harmful behaviours); data collected from service users, co-facilitators and others (e.g. staff, referrers, families); details of study design and intervention methods, structure and tools sufficient for replication including examples of intervention materials; high external validity having been carried out in the field and included routine staff.

Methodological weaknesses of this design across the four publications included lack of the following: control group, blind/independent observation and measures, and randomisation. In addition, the challenge of finding psychometric, appropriate and valid measures for children, young people and adults with learning disabilities is highlighted (Publication 5, p 73; Publication 7, p 23 and Publication 10, p 23).

Additional strengths relevant to individual publications based on the One group Pretest – Posttest Design, mixed methods include the description and demonstration of how intervention scheduling (extending the gap between group Anger Management sessions in the later stages of the intervention to enhance generalisation and maintenance) and use of staff (as group observers who participated under supervision in role play and were better prepared to support inter-session tasks and practice) may mitigate restrictions on time/resources in trying to replicate and extend other’s published studies (Benson’s, 1986, Anger Management Groups) and how timing of evaluation can feed in to optimising intervention delivery in gathering feedback in the Anger Management Group (Publication 5, pp 70-71) and emotions groups (Publication 7, p. 23).

4.2.5 Case series

Publication 9, Access all areas – adapting CBT, three “single case” examples

Strengths of this case series included that it addressed a complex clinical area to illustrate interventions relevant to a range of professionals across different services. The examples of assessment and intervention resources reproduced in the journal and the description of measures offers practice-based evidence with potential to contribute to practice development for the IAPT Severe Mental Illness stream which does not have additional resources to train existing or new professionals. Effective and appropriate assessment and intervention methods and resources are demonstrated across a range of age, ability, gender, setting and culture. High external validity is achieved through the complexity of the service users and the clear examples of assessment and intervention methods and resources.

Weaknesses included lack of controls, blind/independent observation and measures, comparison with other interventions and no randomisation,

4.2.6 Case study

Publication 2, Systemic Intervention in Health Care Services: A Case Study.

Strengths of this case study, which utilised the application of soft systems methodology to an individual service user and their organisational network/context, included addressing clinical need, use of quantitative (observational data) and qualitative data (feedback from staff), describing and illustrating examples of soft systems across four layers (individual, immediate residential team and broader management team, and day services team) with high and broad applicability and identified implications for practice and caveats.

Weaknesses included lack of replication, small sample (N=1), lack of blind/independent observation; lack of direct user voice or feedback.

4.2.7 Synthesis and reflective study

Publication 8, History of world of groups – draws on publications 1, 4, 5, 6 and six other clinical groups

Methodological issues of publications have been critiqued above in Sections 4.2, 4.4 and 4.5. These issues apply to the other clinical groups described. However, an additional strength is that the synthesis allows a long view of groups, identification of key practice, process and theoretical issues developing over time. This provided a reminder of effective methods and models and enables issues identified in older studies to be considered, integrated or contrasted with later developments.

4.3 Research designs, current evidence-based orthodoxy and people with learning disabilities, a critique

In the prevailing evidence-based hierarchy, Randomised Controlled Trials (RCTs) are considered the “gold standard” to ensure that the “best evidence” for effectiveness is achieved from research. Greenhalgh (1997, 2010) outlines a hierarchy for evidence and methodologies with systematic reviews and meta-analyses (of RCTs) at the top, then randomised controlled trials, non-randomised controlled trials, cohort studies, case control studies and case reports at the bottom.

Key features of RCT’s are:

- use of valid, reliable, clinically-relevant outcome measures
- appropriate sampling so findings will be generalisable to practice settings
- effective randomisation to intervention and control groups to eliminate bias from extraneous or unknown variables
- at least one comparison or control intervention against which to test the therapeutic benefit of the experimental intervention
- effective blinding procedures for patients, clinicians, data collectors and analysts in order to eliminate bias from placebo and other social induced responses
- standardisation of the intervention or treatment package to ensure the findings are capable of replication in practice

(Walker and Sofater, 2003, p.318).

There is a range of critical conceptual, contextual and methodological issues which warrant consideration leading to a need to reappraise the gold standard and primacy currently associated with RCTs. Some of these are presented below and implications and recommendations summarised/ identified in Chapter 5, Section 5.8.

4.3.1 Conceptual Issues

Conceptual issues requiring further consideration in a critical analysis of RCTs have been identified from a number of sources. These include general texts on social science research (Robson, 2002), psychology research (Dyer, 2006), health research (Walker and Sofater, 2003, on pain), mental health research (Freeth, 2007) and more specific populations (e.g. Hatton et al, 2004, on research with people with intellectual disabilities.) General and specific conceptual principles, themes and issues are identified including philosophical underpinnings of RCTs (ontology, epistemology and their ensuing paradigm) and some linked social and political issues.

Dyer (2006) describes *ontology* as "concerned with providing an account of the nature of being as applied to social entities", whereas *epistemology* "or theory of knowledge concerns itself with questions about what knowledge is, and how it may be validly achieved." (p 4). He goes on to identify two fundamental questions for science and research:-

- how can true information be distinguished from false?
- what general approach or procedure is most likely to provide access to the truth about things. How may knowledge be reliably achieved?

Empiricism is identified as the dominant doctrine in science for over three hundred years, based on the belief that:

> reliable knowledge about the world can only be acquired if it is based on information that is available in some form to the senses. (p 4).

Empiricism's effectiveness as a guiding principle in science is explained by Dyer (p 4) as based on:

- its focus on the active collection of evidence ensuring there will be correspondence between what is discovered and the reality that is external to

the observer
- the evidence can be made public and available to others (errors can be corrected, findings verified)
- the only source of knowledge about the world being the world itself
- this knowledge can be acquired by anyone able to acquire the necessary skills of scientific method.

Science, as a process of inquiry to understand the world through description (including systematic observation and measurement), explanation (theories of why/how processes and phenomena occur), prediction and control and the scientific method of hypothesis generation and testing developed from the natural sciences, became applied to the newer social sciences including psychology and clinical psychology as well as much health research. This provided an underpinning for the notion of empirical, scientific Randomised Controlled Trials as the ‘gold standard’.

Criticisms and alternatives have developed based on a range of factors. As Dyer (2006, p 4), pointed out:

> The doctrine of empiricism by itself provided only the necessary, but not the sufficient, conditions for the generation of new knowledge……. direct experience of the world is an essential ingredient of knowledge but it is not enough by itself……. Something further is required before it can provide a basis for knowledge. This, as Popper (1974) argues, is human reason. Information always requires interpretation.

Popper’s work (1972, 1974) influenced the development of scientific method with investigation and development of links between data, hypothesis testing, and theories and the nature of a good theory. Dyer (2006) argued the development of knowledge, from this viewpoint, as a gradual and cumulative process.

Kuhn (1970) proposed an alternative account of the growth of scientific knowledge with scientific disciplines organized around core systems of ideas/world views with science progressing though *paradigm crises* and *paradigm wars*. Examples of such paradigm wars include the transition between Creationism and Evolution in nineteenth century biology, or anti-behaviourist, cognitive revolution of the 1960’s (Leahy, 1992.) Science is seen as a social activity, therefore, the growth of knowledge is seen fundamentally as a social as well as a scientific process.

Choice of research questions, methodologies, interpretations will reflect dominant paradigm/values of researchers. This may not equate with lived experiences of people who may live with problems with health, mental health and/or intellectual disabilities and calls into question the validity of much research based purely on the empirical tradition.

4.3.2 Contextual Issues

Social, political and economic factors influence the context in which scientific endeavour takes place. Between the 1960s and the present day, there have been considerable developments, understanding of, and views about human rights issues and discrimination (UN Convention on Human Rights, anti-discriminatory/equalities legislation, feminism) and developments in thinking about thinking, for example, in post-modernism where reality (knowledge) is considered a social construct, located in a particular cultural environment. All these factors contributed to dissatisfaction with *old paradigm* research. *New paradigm(s)* began to develop to address the experiential and cultural aspects of research with a wider range of methodologies. Broader methodologies included qualitative research, emancipatory research and use of more participative, ethical and socially valid goals and methods and the development of critical disability studies.

Many aspects of health research and the revered position of RCTs as the ‘gold standard’ appear based on *old paradigm* epistemology. This may reflect further factors such as continuing social values privileging use of *medical* models rather than *bio-psycho-social* models (explored by Szasz, 1960, in relation to mental health, and Illich,1995, in relation to general and mental health), power and privilege in health professions and the influence of commercial and economic factors with pharmaceutical companies interests in clinical trials, product development and marketing (Freeth, 2007). The “medical” model may also feed into broader current values of focusing on efficiency, performance data, measurable outcomes and economic gain.

4.3.3 Methodological Issues

A critical analysis of RCT methodology needs to consider the issues identified by Robson (2002) for establishing trustworthiness in fixed design research and RCT's. These include a number of threats to validity including:

- construct or face validity: is the study measuring what it set out to measure?
- internal validity: does the study demonstrates a causal relationship between treatment and outcome?
- external validity: or generalizability (across service users, settings, professionals)
- reliability: the stability and consistency with which phenomena are measured
- ethics (Hatton, 2004).

Tensions arise from the competing demands for internal validity (maximizing control of samples and interventions, measures for standardization, reduction of bias/error to enable causal relationships to be found or discounted) and external validity, or generalizability, of approaches to a range of settings and patients.

In RCTs, half the participants may receive no intervention or 'placebo' intervention which may create problems in getting representative samples. Staff may inadvertently 'cue', second guess or push for active inclusion (Hatton 2004). This may alter expectations and measures, even where 'blinding' is in operation, as a result of beliefs and desire for people to improve. Placebo and Hawthorne effects are difficult to control for. Two different active interventions or treatments may be compared to improve 'ethics' of the study. It is not then possible to conclude that any intervention is better than no intervention, unless there is also a no intervention condition. Hatton (2004) and Beail (2004) highlight that both ethics and the rigour and validity of research can be compromised by the selectivity of specific groups both into research (e.g. using college students or institutional populations) or out of research (e.g. not including people from minority ethnic groups or those with intellectual disabilities).

Other issues in the selection of subjects which may compromise the validity of RCTs include skew due to recruitment strategies, potential participants' awareness of the research, having the time, transport and interest to participate, being a clinic attender (as opposed to non-attender for a particular diagnostic category), cut-off points on scales which measure symptoms and age criteria (Hatton, 2004).

Many commonly used, so-called *diagnostic categories* (especially within mental health) may have their own reliability and validity problems. Considerable variation and overlap has been identified in use of DSM-IV, now DSM-V, and ICD 10 which reduces confidence in selection and comparison of participants and interpretation of results. An exploration of problems within diagnostic systems is found in the *Position Statement on the Classification of Behaviour and Experience in Relation to Functional Psychiatric Diagnoses: Time for a Paradigm Shift (*British Psychological Society, Division of Clinical Psychology, 2013). Published just before the publication of DSM-V, the position paper argues for affirming publicly that:

> the current classification system as outlined in DSM and ICD, in respect of the functional psychiatric diagnoses, has significant conceptual and empirical limitations. Consequently, there is a need for a paradigm shift in relation to the experiences that these diagnoses refer to, towards a conceptual system not based on a 'disease' model. (p. 1).

The DCP recognises the influence of current classification systems in underpinning much research and theory and in shaping the structure and delivery of mental health services. Such classification provides "…seemingly 'tangible' entities for use in administrative, benefits, and insurance systems" (p. 1) which are broadly accepted by most professional groups, many service users, the media and the general public.

However, the position paper also highlights the importance of noting that:

> functional psychiatric diagnoses such as schizophrenia, bipolar disorder, personality disorder, attention deficit hyperactivity disorder, conduct disorders and so on, due to their limited reliability and questionable validity, provide a flawed basis for evidence-based practice, research, intervention guidelines and the various administrative and non-clinical uses of diagnosis. (p.2).

Hatton (2004) suggests that for people with intellectual disabilities, there may be even less reliability in such ‘diagnoses’. An increased rate and range of co-morbidities occur (associated with neurological conditions such as epilepsy, particular syndromes such as Prader-Willi, pervasive developmental disorders such as Autistic Spectrum Disorders and for significant adverse life events such as increased incident of being victims of bullying and living in poverty). Hodapp and Dykens (2004) note that “within syndrome variability” can be substantial, in their discussion of studying behavioural phenotypes. Such complexities of presentation and categorization may nullify attempts at randomisation and control.

The ethical imperative to gain informed consent can also skew sampling. Factors such as communication and decision making abilities and capacity (ability to understand what is proposed, weigh up pros and cons, and make a valid choice and communicate that decision), power differences between researcher and participant, bias (researcher wanting participants to consent), participants understanding their right to withdraw and the confidence/competence to exercise this right if appropriate, may result in selecting only participants of a certain ability level and ‘with capacity’ ever being able to participate in research. There may be a requirement to tape record the gaining of consent for people who do not read and write leading to the question of the need for consent to tape the consent (Griffin & Balandin, 2004).

Factors associated with ‘treatments’ or ‘interactions can also introduce variance which may compromise the rigour of the study. Multiple component interventions, for example, in attempting to reduce challenging behaviour in people with intellectual disabilities, may incorporate antecedent, environmental manipulations, development of functionally-equivalent behaviours, manipulation of consequences and reinforcers such as extinction and/or positive reinforcement of alternative or incompatible behaviours. Analyzing overall effectiveness, causal links, impact of specific components and any ‘scaffolding’ or additive effect where multiple treatment components operate can be problematic (Newton & Horner, 2004).

In randomised controlled trials, the treatment conditions should be standardised in order to demonstrate functional relationship between independent and dependent variables. In some types of treatment or intervention, this may be counter to the therapy process (for example, some client- centred psychotherapeutic approaches.) In other methods or models, standardisation may, in theory, be possible through manualised treatment protocols, for example, Anger Management CBT Groups (Rose et al., 2005; Willner, 2007). However, studies rarely report measures or observations of treatment integrity or fidelity. Even where a study purports to be investigating a type of therapy such as Cognitive Therapy, it may involve a number of components including behavioural components such as relaxation and behavioural activation (Dagnan & Lindsay, 2004). Lack of clarity in description and provision of interventions confounds the research process and contributes to lack of methodological and conceptual rigour. Snell's (2003) analysis of the need for, and methods to, undertake applicable research with people with intellectual disabilities notes that randomized trials are rarely applicable for students from a low incidence population (p.143).

Reliable and valid measures of the phenomena under investigation are another major factor in ensuring RCTs are robust and meaningful. Problems in measurement with people with learning disabilities include unreliability of self-report, lack of comparability of measures and the need to undertake measures across a variety of domains (symptoms, functioning, quality of life; multiple informants – participants and carers; costs). Measures standardized on people without learning disabilities may not be understandable or valid for people with learning disabilities.

In some kinds of intervention research, measures may be expected to worsen as part of a therapeutic process, so timing and interpretation is critical. For people with learning disabilities, acquiescence and "desire to please" are recognized as more significant (Douglass et al., 2007) with a resultant skewing effect on pre and post measures (pre-measures may reflect a less valid score, as participants attempt to give the right response, post measures may be less prone to this and give more valid responses which yield a "worse" score. Hence, "worse" results may accurately reflect positive process changes. For example, people with learning disabilities may be more able to give valid responses to measures following an intervention which has components of psycho-education about emotions and opportunities to explore emotions in a context in which they can be heard and with appropriate communication and support to enable them to participate.

Methods of measurement may be selected on the basis of the research or therapy paradigm/model espoused by clinicians/researcher. This influences what is looked at, for, found and reported. Schectman and Pastor's (2005) comparison of outcomes and processes in cognitive and behavioural with humanistic group treatment for children with learning disabilities found in favour of humanistic approaches. The measures selected were those reflecting humanistic process phenomena. Whitehouse et al.'s (2006) review of adaptations of psychotherapy (cognitive-behavioural and psychodynamic) from the literature, report higher incidence of adaption to communication and developmental levels within psychodynamic approaches. It may be that such adaptation is identified as unusual or noteworthy within a psychodynamic framework and therapists who may not frequently work with people with learning disabilities. Such adaptation may be taken for granted and not referred to specifically for other frameworks or by therapists who are more familiar with working with people with learning disabilities.

The independence or blindness, as well as the competence of those undertaking the measures are further potential sources of bias or error within research. In a review of anger management with people with intellectual disabilities, Whitaker (2001) found no blinding for raters in the studies reviewed. A mini systematic review, I undertook of five studies on CBT and people with intellectual disabilities published 2005-2007 found that none of these studies involved independent raters (although Willner included carer raters). A summary table of these studies is found in Appendix 6.

Randomised controlled trials are reliant on identifying statistically significant differences between groups to demonstrate causal relationships. As Hatton (2004) pointed out, measures may have shortcomings in validity or reliability which render statistical analysis meaningless. Hatton (2004) also emphasized that statistical significance is not the same as clinical significance.

Snell (2003) broadens the debate regarding appropriate methodologies for research with people with learning disabilities to issues of implementation and application.

Snell states:

> More pervasive than the problem of disagreement over research methodology is the problem of applying what we know about learning to what we do in schools, or the research to practice phenomenon. (p 144).

This broader critique and reflection on critical issues in the conceptual and technical foundations of research paradigms and methodology demonstrates the complexities of selecting, implementing, analysing and reporting appropriate designs. Good quality health and psychological research with people with, and without, learning disabilities needs to be ethical, appropriate and utilize the least intrusive method with the highest validity. This requires broader ranges of measures (including quality of life as well as symptom focused), involvement of users in planning research (Goodare & Lockward, 1999; Triveli & Wykes, 2002; DH 1999, 2000) and a range of research designs and approaches (single case, case series, staggered/multiple baselines: qualitative and quantitative methods) appropriate for the research question and stage of research (Snell, 2003, Odom et al. 2005).

Heyvaert et al. (2012), drawing on earlier work of Horner et al. (2005) on the value, appropriateness and features of Single Case Methodology with people with learning disabilities compared meta-analyses and reviews of interventions for challenging behaviour and single-case and small-n intervention research. Compared to the meta-analyses and reviews focusing on group-studies, whilst showing broadly similar results, their multilevel meta-analysis of single-case and small-n intervention research provided more detailed knowledge on which specific challenging behaviour and intervention components moderate the interventions' effectiveness.

Recently, the National Institute for Health and Care Excellence (NICE) has accepted Single Case Methodology as appropriate and legitimate for the first time, in their preparation of Guidance on Challenging Behaviour and Learning Disabilities. The NICE methodologists and systematic reviewers accepted the justification based on evidence such as Heyvaert et al, after representation from experts in the field and their own subsequent analysis (Murphy, 2014, personal communication).

The RCT as “gold standard” and its place at the top of the research hierarchy should be questioned given the above identified shortfalls. Many of the problems levelled at RCTs in this section (lack of ‘blinding’, unreliable or invalid measures, poor robustness of study, design or analysis) can be levelled at many other methodologies. Marshall (2002) outlined criticisms relating to misunderstandings and misrepresentation, whilst Slade and Priebe (2002) described some of the conceptual limitations of RCT’s.

Perhaps the ‘gold standard’ should be to recognise and incorporate a more robust critical analysis across a much wider range of methodologies. Judgements are needed about the appropriateness of methodology, fitness for purpose, analysis and interpretation across the research, practitioner and publishing communities. Studies which find equivocal or ‘negative’ results are a crucial part of the pursuit of knowledge where they are found in the context of robust studies and should form part of the published literature. Young et al. (2008) and Fanelli (2010, 2012), however, note evidence of, and concern about, publication bias. Finally, further attention is needed to the social/economic context behind models and methods of health, illness, treatment and research (Triveli & Wykes, 2002; Read, 2005; Marmot, 2004, 2010; Davis et al., 2012). This is further explored in Sections 5.4 and 6.5.

The role of the pharmaceutical industry in prevailing models, practice and research may be an area for particular attention. As the American Psychiatric Association (2005), quoted by Read (2005) stated:

> There is widespread concern at the over-medicalisation of mental disorders and the overuse of medications. Financial incentives and managed care have contributed to the notion of a ‘quick fix’ by taking a pill and reducing the emphasis on psychotherapy and psychosocial treatments. There is much evidence that there is less psychotherapy provided by psychiatrists than 10 years ago. This is true despite the strong evidence base that many psychotherapies are effective used alone or in combinations with medications.

Practitioners, clinicians and researchers concerned over the apparent uncritical acceptance of only RCT research for evidence-based practice may do well to read practice guidance very carefully as it may not be as uncritical as is supposed. NICE guidance on Depression (NICE, 2007), for example, states:

> In using guidelines, it is important to remember that the absence of empirical evidence for the effectiveness of a particular intervention, is not the same as evidence for ineffectiveness. In addition, of particular relevance in mental health, evidence-based treatments are often delivered within the context of an overall treatment programme including a range of activities, the purpose of which may be to help engage the patients, and provide an appropriate context for the delivery of specific interventions. It is important to maintain and enhance the service context in which these interventions are delivered; otherwise the specific benefits of effective interventions will be lost. Indeed, the important of organising care, so as to support and encourage a good therapeutic relationship, is at times more important than the specific treatments offered. (p 9, quoted by The Midlands Psychology Group, 2007).

Spring (n.d.), building on Sackett et al. (1996), highlights the need to integrate research evidence with values, characteristics and circumstances of service users and clinical expertise within clinical psychology (Figure 1)

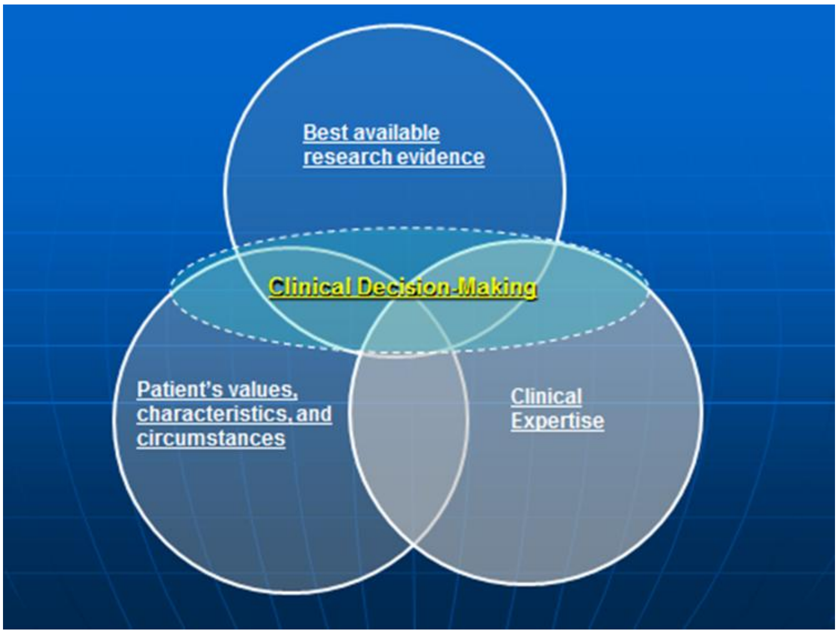


Figure 1 Model for evidence based practice (Spring, B. n.d.)

This is now becoming integrated with practice guidance across a range of health interventions and countries. For example, Charman and Barkham (2005) describe

Australia explicitly incorporating social and cultural factors, linked to health inequalities, into their evidence-based models of early intervention and prevention to improve the social and environmental factors impacting on health and the delivery of health care.

Chapter 5

5.1. Introduction

Chapter 5 presents and synthesises a broader critique which considers a range of theoretical, conceptual, practice, policy and organisational factors across the presented publications and considers factors across the development of my research within the 40 year time-frame. It draws together a of number themes linking the publications' contribution to knowledge to selected and related research and to reflections on the thesis focus *'Research to practice and people with learning disabilities: Better Services (1971) to Transforming Care (2012) - 40 years on, are services any better?'* Implications and recommendations including a future research agenda are presented in Chapter 6.

The selected publications described research that developed and evaluated a range of psychological interventions for people with learning disabilities within key policy, conceptual and methodological contexts. The publications demonstrated innovative applications of, or developments to, existing concepts and methods. In nine out of ten publications, these were delivered indirectly through staff training using creative methods of service delivery by co-working (publications 4, 5, 7), training and supervising (publications 6, 10), developing manualised groups (publication 1) and service development/organisational change projects (publications 2, 3, 4). Publication 9 describes innovative psychological interventions directly with service users

The orientation and place of publication of the majority of the papers was designed to focus on practitioner readership, particularly multidisciplinary, rather than uni-disciplinary, with the intention of informing and influencing practice. The dissemination strategy was deliberately targeted to broaden readership across disciplines and ensure the findings were widely accessible to improve implementation and application.

A matrix framework (Appendix 5) was generated for initial conceptualisation and analysis to begin to identify themes across:

- Levels of intervention (micro ↔ macro i.e focus on service users; carers, staff, parents; service system or organisation; social, community, society)

- Context or frame for intervention (professional practice; policy; legislation; economic, social, political)

- Methodology, ontology, epistemology (experimental, quantitative; qualitative, mixed methods; action research; user involvement)

- Audience (practice journals, academic journals, training materials, clinical materials)

This matrix framework enabled these themes to be considered across the chronology of the publications. The earlier publications contribute to lines of argument relating the themes across practice, policy, methodological and organisational issues over time. The recent publications demonstrate I am research active and show a renewed focus of energy and commitment to research as evidenced in paragraph 5.2 of my auto-ethnography (Appendix 2)

The critical analysis developed and described here in Chapter 5 describes coherent themes from the selected publications illustrating my research across 30+ years. It relates them to significant or seminal contemporaneous and current evidence. The presented publications drew on, extended and evaluated novel applications of psychological theory and evidence. They were/are relevant to, and at the forefront of, the development of new knowledge regarding improving lives and wellbeing of people with learning disabilities, who remain amongst the most marginalised and disadvantaged people in society. My critical analysis will demonstrate that some of the lack of progress in services becoming *Better* lies in managerial, organisational and social factors among the barriers to research to practice.

My critical analysis will also consider how research for people with learning disabilities has fared with the current national research agenda and with changing roles/demands within the profession of clinical psychology. Among the critical conceptual and methodological themes presented are demonstrations of original contribution to knowledge in the field. The studies were often the first, or among the first, of their kind, with the focus of investigation located within current and emerging policy and evidence. The contributions to knowledge, understanding of theory, practice and application, derived from my studies can be seen to be extending:

1. **Focus:** for example, the activity groups (publication 1) to promote social interaction when existing research was evaluating activity groups only to increase engagement (Porterfield, 1977)

2. **Process:** for example, novel use of naturalistic situations such as mealtimes (publication 4), to evaluate effectiveness, generalisation and maintenance of increased social interaction

3. **Level for interventions/context of interventions**: for example, through co-work/modelling and training care staff and nursing staff to deliver interventions (social interaction activity groups in the 80s,publication 1; anger management groups in the 90s, publication 5; and the Emotion Management groups, publications 6 and 7, in the new millennium)

4. **Range of ability**: including people with more severe learning disabilities, often overlooked in intervention delivery, development and research. This may be because of wider perceived differences from non-disabled people and/ or the prediction that the interventions may not be effective (bias in selecting populations and/or areas for research; not wanting to report non-effective results, despite this being equally valid and important for scientific advancement and endeavour).

The chapter will initially review the nature and contribution of the publications across these themes of focus, process, level of intervention and range of ability/complexity. It will then consider relevant conceptual and theoretical issues (paradigm, social and contextual validity).

5.2 Extending focus

The focus of the publications presented demonstrates innovation in, and investigation of, the key areas of social and emotional development and functioning. Studies have investigated both innovative formats for developing social interaction, and the use of staff in therapeutic interventions and psycho-educational aspects of service delivery (social interaction activity groups, publication 1; mealtimes social interaction groups, publication 4; anger management groups, publication 5; emotional management groups, publications 6 and 7). This signifies an awareness of the core significance of relational aspects of development and human functioning and how this applies equally in people with learning disabilities.

The central role social interaction plays in psychological well-being, learning, behaviour, presence/absence of psychological or behavioural disorders and quality of life is recognised. Ways of applying psychology to develop key social and emotional skills directly with people with learning disabilities or through staff who work with them is at the core of the publications and demonstrate this focus has spanned my entire research time-frame. It represents a broader developmental focus and conceptualisation than other research which focused more on behavioural or skill development (for example, Azrin & Foxx, 1971).

Earlier papers drew on the, then, seminal developmental and behavioural learning research of the late 60s and 70s (Tizard 1962; Clarke & Clarke 1966; Azrin & Foxx 1971) which provided an evidence base to justify the *de-medicalisation* of learning disabilities. I applied these learning theories and the accruing evidence-base to social and relational aspects of development. Broadly, the developmental, educational and learning theory based research and applications were welcomed as demonstrating that people with learning disabilities could learn if given opportunities and appropriate support which opened the path to changes in policy, legislation and service delivery such as access to education. The early activity group engagement research (Porterfield, 1977) was undertaken within the Applied Research in Wales Team which followed from the Ely Inquiry (DHSS, 1969) recommendations. The Activity Groups engagement studies aimed to improve both the amount and type of activities, in both hospital and newer community settings. It fed into the later, and still current, Active Support research of Mansell et al., (2005) and Mansell and Beadle Brown (2012).

In the 1970s and 1980s, there were some critical voices and concerns (e.g. Smith C., 1983) over mechanistic application of learning theories. Smith's criticism focused on what was perceived as an oversimplified errorless learning approach used in Portage early intervention (Smith J. et al., 1977; Blunden & Revill, 1978) and drew attention to research in Social Cognition. Portage as both a method and a model, integrated the broader growing research base. A revised communication assessment and goal planning tool, the Wessex Revised Language Checklist (White & East, 1983) was developed. This was included in the Portage training along with the central role of play into the developmental activities and vice-versa.

Over the time-frame and developmental phases of my research, integration across and between, different aspects of social and emotional development and functioning becomes more central. In addition, the conceptualisation and publications include some broader critical contextual perspectives to counter the creeping *re-medicalistion* of learning disabilities and behavioural or mental health difficulties. The need to integrate new evidence, other perspectives and extend conceptual and pragmatic aspects of service delivery and evaluation is important. Hence, the introduction to, and justification of, the first emotions group (publication 6) explains a development building upon my previous work which had included groups focusing on single emotional/mood disorders or behavioural disorders

> …. including anxiety, depression, anger, self-esteem, sexual offending, and more generic emotion management across a broader range of emotions in an attempt to normalise the role and importance of a range of emotions in all our lives, to reduce

the pathologising or limiting effects of single emotion groups (anxiety and/or low mood and/or frustration can present as anger/aggression).

Another key focus of the publications has been to identify if, and how, staff can be involved or the “giving psychology away” focus (the LC = Level carer code in the matrix Appendix 5 signifies an intervention targeting carers/staff). This is discussed further in Section 5.4.

Given the relative lack of research with people with learning disabilities and psychotherapy, the publications’ innovative interventions show how they drew on evidence across other care groups such as mental health,(Haddock et al., 2004) early adaptations of Cognitive Behavioural Therapy to make it accessible for children (Young & Fanselow-Brown, 1996) along with emerging evidence for people with mild learning disabilities (Lindsay et al., 1989; Turk & Francis, 1990) as referenced in publications 5, 6 and 7. The integration of practice-based evidence and evidence-based practice in the application of psychology across care groups drew on all the above sources and further adapted these applications based on my clinical and research experience. The later Publication 9 widens the scope to consider relevance across research and practice with other neurodevelopmental and neurodegenerative conditions associated with cognitive impairments. This illustrates the “scientist-practitioner” role of clinical psychologists role and their unique Level 3 skills (MAS Report, 1989) as outlined in Section 2.7.

5.3 Process/ Intervention

Innovation, extension and integration of components of effective application of learning theories within the process aspects of interventions under investigation are demonstrated within the selected publications. As noted in Section 2.6, empirical evidence had been drawn on from early applications of learning and developmental models and theories to skill development in people with learning disabilities (such as Azrin & Foxx, 1971, for continence; Jeffree & McConkey, 1977, for play), and extended in a number of ways including use of naturalistic environments or situations and issues of process, timing and power.

The use of naturalistic situations was demonstrated in publications 4, 6 and 7, and in publication 4, more fine- grained teaching/learning conditions were compared through investigation of the three conditions of modelling, instruction, instruction and modelling in the meal-times social interaction group design. Robertson et al. (1984) and Matson and Earhart (1982) had demonstrated strategies for enabling people with learning disabilities to learn and increase their social skills and the added benefits of using more naturalistic teaching environments. The benefits of using naturalistic, meaningful environments for skill development, generalisation and maintenance of other skills such as independent living skills was demonstrated by Felce et al, (1984), and by Masidlover and Knowles, (1982) with communication who also emphasised the need to apply this across other skills such as social interaction and emotion skills. Innovating and evaluating psychological interventions focusing on the development of social interaction and emotion skills is a key focus of the publications presented in this thesis. Pagel and Whitling (1978) and Schalock and Harper (1978) had identified the lack of appropriate social and emotional skills as often leading to placement breakdown. The risk of placement breakdown associated with unregulated anger or aggression was one of justifications identified for the Anger Management Group (Publication 6, p. 74).

The issue of age appropriateness entered the practice and research community partly through the service philosophy route. As normalisation emphasised the use of *culturally valued means* (Wolfensberger & Glenn, 1975) among standards with which to judge service provision, some of the interventions using equipment for children to assist development in adults with learning disabilities would be judged unfavourably against this criterion. Impetus also came from recognition of important developmental and life cycle factors, and the need for attention to natural and functional contingencies. Felce et al. (1984) who had initially developed their assessment and goal planning system, Bereweeke, based around early developmental skills with puzzles and stacking games for hand eye co-ordination, shape and size recognition, developed an adult age appropriate version replacing such skills with functional adult equivalents e.g. putting milk bottles in fridge, cutlery in drawers and posting letters. A key goal is ensuring activities, equipment and interactions are simple, or more accurately described as tailored to an individual's strengths and weaknesses in information processing and communication, rather than childish. Nind and Hewitt (2006) use the term *developmentally appropriate* which can be misconstrued. Publication 4, which used mealtimes for developing social interaction, also developed eye-hand coordination and self-help skills in an age appropriate setting and process.

Publication 1's social interaction activity group could also be criticised for age-inappropriate activities and equipment. Attempts were made to include adult-sized and age-appropriate or age-neutral equipment e.g. large carpet roll, adult-sized musical instruments, food-related activities.

The studies over time also demonstrate extension and development of the author's previous projects and the drawing on others' research. Within the range of group interventions developed and evaluated with people with learning disabilities, this includes consideration and use of group process issues, such as in publication 8. Other examples include broader use of staff (see section 5.3), wider therapeutic models and other psychological concepts including systems approaches (publication 2), narrative approaches and multisensory stories (publications 7 and 8) and attachment as a factor and a possible mechanism of change (publication 8).The themes can be seen to be both evolving and integrating others' perspectives, evidence and methods.

The studies also demonstrate need for innovation in and investigation of other intervention/process elements, such as timing of intervention, engagement and power issues. Publications 6, 7 and 10 focus on earlier intervention (at a younger age, at an earlier stage in problem development. Publications 6 and 7 broadening the scope for early intervention/mental health promotion to a more public health, universal resilience based focus; publication 10 evaluates an intervention earlier in the life cycle for the complex and under-researched area of young people with learning disabilities and harmful sexual behaviours. The reflective summarising and synthesising in publication 8, identifies the role of groups in enhancing engagement, accessibility and change for people with learning disabilities with opportunities for acting in different positions of power in groups through both the presence of peers and activities which place people with learning disabilities as agents of support and knowledge. A poster based on this, *Groups – more than the sum of the parts? Engagement and empowerment: illustrations and reflections from groups with people with learning disabilities,* demonstrating broad cross-care group relevance was presented at BABCP Annual Conference (Rossiter et al., 2013).

Attention to more contextual and systemic issues in the development and maintenance of emotional, behavioural and mental health problems, and to possibilities for effective interventions, was an important element identified. Evidence on the role of social factors in depression and family interactions and expressed emotion in schizophrenia (e.g. Brown, 1972) and broader contextual analyses and practice of systemic family therapy (e.g. Minuchin, 1976) contributed to the systemic reconceptualization of interventions using a systems paradigm. This provided a helpful theoretical frame across multi-layered interventions of case work, staff development and organisational change within learning disability services (Publication 2). The importance of considering contextual and life events issues in the development and maintenance of emotional problems, and in planning effective interventions for people with learning disabilities is highlighted in the adapted Anger Management group (publication 5, p. 73). Contextual and systemic frameworks, formulations and interventions have become increasingly recognised as key elements in effective psychological approaches (Carr 1999, 2006). More recently their role in broader health inequalities, interventions and impact has also been highlighted (Chief Medical Officer's Report, 2013, *Our Children Deserve Better: Prevention Pays*).

The studies described in the publications makes both explicit (publications 2, p. 55, and 6, p. 33), and implicit use of the constructional approach, (Schwartz & Goldiamond, 1975; Cullen et al., 1981). The constructional approach seeks to build new repertoires of skills across different systems levels so that problems reduce both currently and into the future. It maps on to the soft systems problem solving approach of Ackoff (1978) of solving, resolving and dissolving problems. The use of constructional approach in clinical interventions and in service development contributes to a broader debate around effective roles for clinical psychologists and whether these should focus on individual therapy approaches or may yield more significant benefit through systemic or organisational change and influencing care delivery to be more *psychologically informed*. It links with other strengths-based approaches, for example, Solution focused therapy (de Shazer, 1988).

5.4 Level of intervention

The publications illustrate the investigation of the application of psychology across different levels of intervention from direct focus on service users through carers and staff to service systems or organisations and finally to social, community, society levels. This can also be conceptualised along the "micro to macro" dimension, and the conceptualisation of the contribution and roles of clinical psychologists. This partly maps onto the MAS conceptualisation of unique contributions of clinical psychology outlined in Table 2, Section 2.7, and also the schematic *Framework for the contribution of Clinical Psychologists in healthcare,* Appendix 4.

As I note later in Chapter 6, other multi-layered models such as Bronfenbrenner's (1979) nested ecological systems model (Figure 2), and Frienden's (2010) health impact pyramid (Figure 3) may usefully be drawn on to assist formulation, intervention planning and review and research.

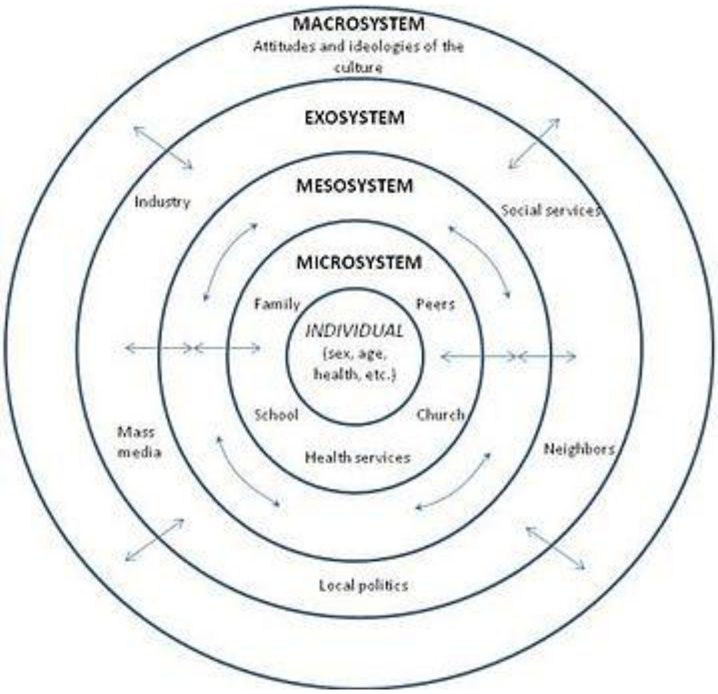


Figure 2 Bronfenbrenner's 1979 ecological systems theory

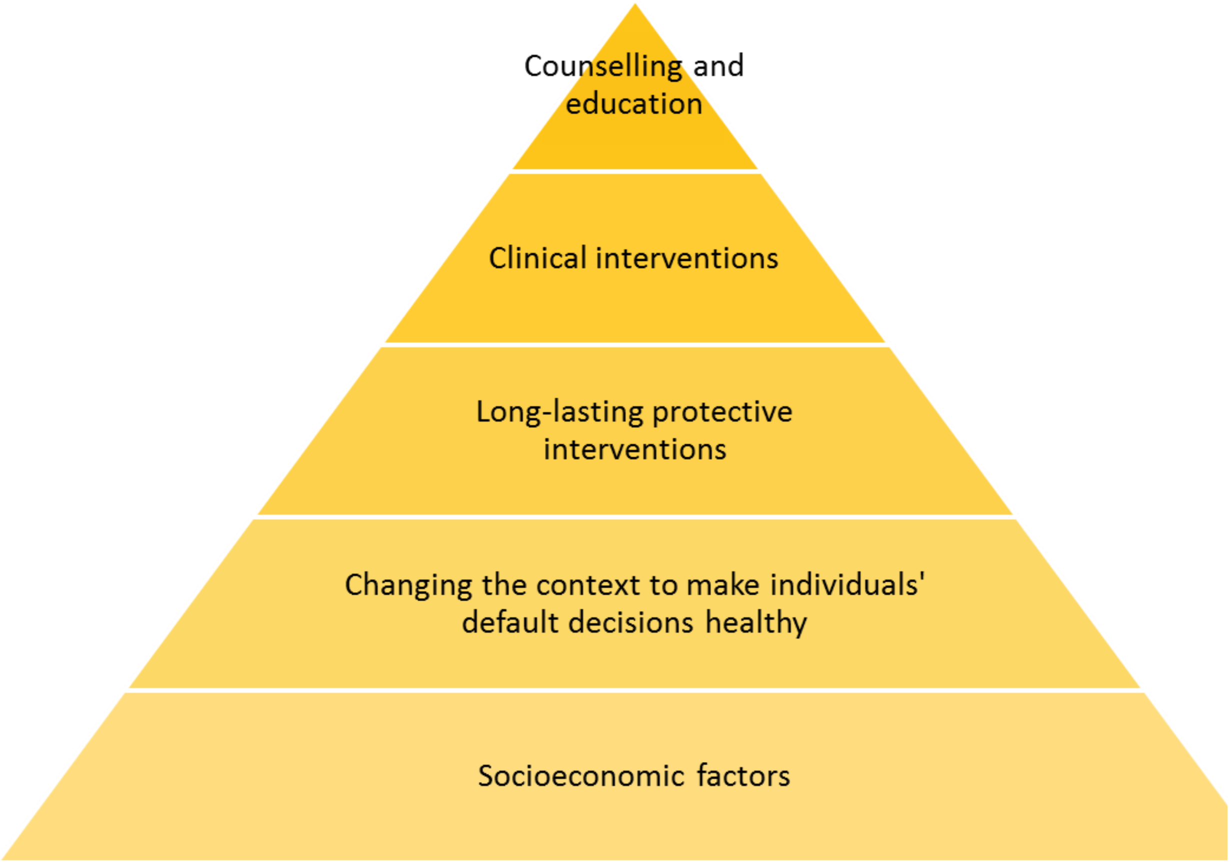


Figure 3 Frieden’s Health Impact Pyramid (2010)

Drawing on, and conceptualising these models in planning, delivery and evaluating may also enhance effectiveness and value for money dimensions.

Appendix 5 summarises the levels that interventions in the publications were focused on, and being delivered to or through. Different levels of intervention include co-work with, modelling for, supervision of and training care staff and nursing staff to deliver interventions (publications 1, 4, 5, 6 and 7). The publications extend the range of staff involved by broadening staff involved in delivery of interventions (nurses, occupational therapists, clinical psychologists, psychology assistants and clinical psychologists in training, other professions in training, school staff).

One publication (3) investigated an intervention with non-care support staff, such as administrators, porters, catering, domestic and transport staff, arguing that they had an important contribution to the total organisation involved in improving care provision. The setting for this study was one of the hospitals whose inquiry was summarised in Martin’s (1984) Hospitals in Trouble where staff had been prosecuted and imprisoned for cruelty. The wide range of support staff included in the intervention received an adaptation and extension to staff training materials used, extended and evaluated already with the clinical staff and demonstrates an intervention across a whole organisation. Publication 2, on the use of soft systems methodology, also demonstrates a multi-layered intervention across service user, staff groups (residential and day service) and employing organisation.

Whilst the majority of the studies investigate applications of psychology through, and with, a wide range of multidisciplinary staff, at a range of levels in a range of settings, publication 8 is written specifically for clinical psychologists. The aim of the publication was to raise interest in, and knowledge of, a variety of group interventions focusing on a range of psychological difficulties for practitioner psychologists and the staff groups they collaborate with, hence the choice of publication. Thus, the focus remains on describing effective interventions which share psychological skills and deliver “psychology” to more service users through working with and through others.

The setting, or location, of the studies varied considerably including community, residential, hospital, day service, day centre and school. Attention to the *enabling* or *disabling* role of environments was considered as an element in design of interventions for example, the use of the familiar location for the social interaction activity groups (Publication 1). In Publication 4, the refurbished dining rooms were used which could set the scene for more domestic style meals to create a more natural context for social interaction and offer a different space for meals which may free people to behave differently. In Publication 5, the use of a neutral day centre for the Anger Management groups which included complex service users from an inpatient unit was considered a factor in supporting change as was the use of familiar and *normalised* school environments, as contrasted with *clinical* settings, for the emotions groups, Publications 5 and 6.

A later development is an explicit attention to attitudinal factors in staff, which may be reflective of society in general, and which may act as barriers to developing skills for, and organising services to be more inclusive, diverse, inequalities-challenging. Publication 9, Access all Areas, contends that current practice, training and research do not do this adequately and highlights attitudes, as well as knowledge, of staff as a barrier.

5.5 Range of ability and complexity

Analysis of the publications presented shows a focus on studies which aim to extend the ability range and complexity for applied psychological interventions, a key element to improve quality of life and service provision for people with the most substantial disabilities (Mansell, 2010). This element is particularly innovative and, arguably, of more scientific significance, as studies with people with more severe learning disabilities test the applicability of psychological methods, models and theories at a fundamental level. The findings provide evidence of promising, or effective, interventions with people with severe learning disabilities as well as examples of appropriate methodologies and levels for intervention which have the potential to challenge and influence themes of equalities and accessibility.

The focus on studies of applied psychology with people with severe learning disabilities can be traced across the complete time-frame of the studies presented from the social interaction activities group (publication 1) and mealtimes social interaction intervention (publication 4) through the adaptation to CBT in the Anger Management group for people with moderate to severe learning disabilities, and the emotions groups in the school for pupils with severe learning disabilities (publications 6 and 7). The second group investigated “how CBT can be further adapted for children and young people with very substantial cognitive impairment” with the group targeting “those with more substantial cognitive and communication problems” (pp 21-22) as a design strategy to broaden access and trial further adaptations to the intervention.

A further dimension of study relating to the service users participating in the interventions is their complexity, or the complexity of their presenting problems. Arguably, ability may be considered as one element of this dimension. Other elements include severe challenging behaviour, additional neurodevelopmental disorders such as Autistic Spectrum Disorders and/or Attention Deficit Hyperactivity Disorders, neuro-degenerative disorders such as dementia, severe and complex mental health and forensic presentations.

The challenging behaviour of some participants in the social interaction activity groups (Publication 1) had resulted in them being excluded from Local Authority Day Service or assessed as too challenging and in need of health day care, participants in the Anger Management group (Publication 5) had been referred because of severe problems with aggression and anger (including some who were inpatients in a specialist assessment and treatment unit, and who had comorbid conditions such as dementia, autistic spectrum disorder), pupils included in the emotions groups included those with severe challenging behaviour in need of 1:1 staff and others with significant health issues, such as a pupil requiring a constant oxygen supply in its large heavy metal canister on a trolley. As the pupil requiring 1:1 had a major dislike of the pupil requiring oxygen, this provided both a challenge to manage and a natural focus for development of appropriate emotional management and communication skills.

Service users with additional neurodevelopmental disorders such as Autistic Spectrum Disorders and/or Attention Deficit Hyperactivity Disorders were included, rather than excluded, in interventions and evaluations (publications 1, 4, 5, 6, 7, 8, 9, 10,) as were service users with neurodegenerative disorders such as dementia (publication 5). Later interventions also drew on emerging evidence and resources for effective autism focused interventions such as publications 6 and 7, drawing on the work of Attwood (2004) and Howlin et al. (1999).

Severe and complex mental health problems, including psychosis and post-traumatic stress disorder, were experienced by participants with learning disabilities in Publication 9, which described adaptations to assessment and interventions to increase accessibility, engagement and effectiveness. Publication 8 describes groups which were evaluated in a national specialist assessment and treatment unit and demonstrates strategies used to include service users in groups who would previously have been excluded on the basis of active, psychotic symptoms. Service users in this unit, and the groups described, had significant forensic histories and presentations. These included fire-setting, assault, sexual offences, grievous bodily harm and manslaughter. The adolescents in the group, described in Publication 10, had histories of sexually inappropriate/offending behaviours, some non-sexual offending such as assault and theft.

The need for more “cross-care group” or “pan-care group” integration of research, practice and attitudinal elements of psychological service is identified in Publication 9, along with the importance of drawing evidence together from a range of clinical groups with cognitive impairments, and applying this in an integrated way. This is essential to broaden and collate issues relating to accessibility across more care groups with potential to increase equality, diversity and effectiveness of psychological interventions. This is part of all our professional and organisational responsibilities. The BPS report on social issues and parenting interventions, Technique is not Enough, (Davis et al., BPS, 2012) gives illustrations of how these interventions need to be tailored to match experience and expectations of different social groups for successful enagagement.

5.6 Conceptual and theoretical issues

This section expands on, and adds to, the themes of psychological mechanisms, methods and theories utilised in the interventions in the publications in above section 5.4 Process/ Intervention. It does this by highlighting key developmental, psychological, social psychological and paradigmatic themes which are a focus of, and/or a mechanism for, the interventions, at individual, group and social levels. These include the communication and relational aspects, social learning, integrative approaches, information processing (which might be conceptualised as application of core psychological issues) and values, equalities and models for service delivery (which might be conceptualised as broader social themes).

Use of a broader developmental-social-psychological model focusing on communicative and social relational aspects, in addition to the application of behavioural learning models and theories, can be traced across the publications. The focus on social interaction in publication 1 links to the key developmental significance of preverbal communication in typical and atypically developing infants investigated in my undergraduate research and dissertation. This feeds into the mealtimes intervention, which again focused on social interaction by investigating mealtimes as a more natural setting and as a vehicle for increasing social interaction, rather than focusing more narrowly on the self-help skills elements of mealtimes. The central role of communication and approaches for assessing and developing communication skills in people with severe learning disabilities were beginning to appear in the literature, resources and conferences in the mid-80s, for example, Coupe and Goldbart (1987) and Kiernan and Reid (1987).

This interactional, relational perspective continues through the publications' focus on groups with eight of the ten describing evaluations of innovative applications of psychology in groups. This is, again, as both a setting and a vehicle for creating change in both service users and staff. In addition to benefits of groups in enhancing engagement, access, peer support and learning and changing the power dynamic between co-facilitators, or therapists, and service users; the central role of attachment, social learning and systemic factors as possible mechanisms of change is suggested in publication 8. Having drawn on the work of Yalom (1975, 2005) on groups and universal group processes, the analysis is extended:

> Other mechanisms may include experiencing effective communication/attunement (verbal, nonverbal, emotional) which links with attachment (see Holmes, 2010, discussion of this in groups in mental health), more fluid and more equal experiences relating to *power*, social learning (Bandura, 1986), and *new patterns of interaction* similar to systemic interventions (e.g. Minuchin & Fishman, 1981) with "the production of new relational experiences for clients through a clinician's facilitating differences in how family members experience each other" (Simon, 2008, p. 327) which may be paralleled in groups" (Publication 8, p. 19, italics added for emphasis)

Another element of the application of psychology demonstrated in the publications is the information processing, and other aspects of cognition, which are sometimes overlooked in formulation and intervention planning. The application of learning theories and behavioural analysis and therapy included cognitive and motivational elements before the advent of cognitive behaviour therapy and cognitive therapy. These internal events could be conceptualised as both *setting events* (or an internal environment with both beliefs and memories) and *processing sequelae* of strengths and weaknesses in information processing or neuropsychological functioning. The information processing factors include functioning across verbal, perceptual, attention, memory, sequencing, planning and response-inhibition. These cognitive factors contribute to, and act as antecedents and consequences and mediating process. Consideration of these aspects could assist formulation and planning for effective interventions, especially with people with learning disabilities, who are a more heterogeneous population than typically developing people.

Use of cognitive factors in enhancing engagement and effectiveness includes the thought bubbles containing images (as distinct from words) in social skills groups (publication 8):

> Group members with learning disabilities were able to make use of the “thought bubble” visuals on the flip chart to help understand thoughts↔feelings↔behaviour links and to remember key learning points/practice tips, e.g. thought bubbles drawn with picture of a smile, eye contact, standing tall, as well as *coping* or *self-instruction* statements. The cognitive elements that people with learning disabilities could relate to included images, actions, sensations and words. (p. 16).

Tape–slide programmes describing and illustrating these groups were commissioned and published as a potential more effective route to adult learning and dissemination to practitioners (Brigden and Keleher, 1989; Keleher and Bridgen, 1989).

As noted, Publication 8 demonstrated drawing on and adapting evidence from other care groups as the effectiveness of such groups was growing within mental health (adults, children and young people) as there was little evidence with people with learning disabilities.Through use of concrete, practical activities, matched to participants’ cognitive strengths and weaknesses such as role play, video, peer support, we incorporated behavioural, cognitive and emotional aspects of social skills to develop both confidence and competence.

This information processing element is further developed in Publication 5’s adapted

Cognitive Behaviour Therapy Anger Management Group with people with moderate to severe learning disabilities. Visual resources and active role play including use of video were all identified as helpful. Consideration of information processing and taking account of strengths and weaknesses and learning styles, informed later investigations, including the emotions groups (Publications 6 and 7) and the three clinical illustrations in publication 9. Publication 8 specifically draws attention to the need for consideration of neuropsychological abilities and disabilities, such as sequencing and planning, and broader than Intelligence Quotients, in maximising engagement and group process (p. 17). The initial submission of Paper 7 which investigated the emotions groups, considered some of the discussion and evidence for a developmental stage approach to, and pre-requisite skills for engagement in CBT, with more conceptual and theoretical analysis and discussion. This was edited down by the practice-focused journal suggesting, perhaps, that the editors did not recognise the relevance of theoretical and conceptual issues to practitioners.

A broader, more integrative application of a range of psychological models is utilised in the later interventions and evaluations. Publication 7 describing the second emotions group included the previous CBT model and method, and also incorporated recent applications of social learning theory (Bandura, 2009), the narrative approaches (White & Epston, 1990) and group process issues. In addition, it integrated other modalities/frameworks including multisensory stories (Grove & Park, 2001, Mitchell & van der Gaag, 2002), some of the communication strategies and resources described in Goldbart and Caton, 2010 and some strategies used in Intensive Interaction (Nind & Hewett, 2006) to increase access and engagement.

Chapter 2 and the timelines of policy related to people with learning disabilities described the increasing role of rights, equality, humanisation, normalisation and participation in community and mainstream life and services. The selected publications, across the timeframe, all sought to contribute to these agendas. They focus on enabling people with learning disabilities to develop skills which to assist with this, particularly the social and emotional skills fundamental to relating. The social and emotional aspects of development underpin both participation and sense of self/identity. The publications have also attempted to use valuing means through which to do this. This includes the broadening in ability range and access by including those excluded from other services and, also, in enabling staff and service systems to experience more equal experiences with, and effective developmental processes in operation with people with learning disabilities through co-working, modelling, training and project work.

In earlier papers, this is more implicit. Publication 1, for example, makes reference to the Health Care Evaluation Reports led by Kushlick, assuming that the readership will be aware of the equalities and community focused nature of this evidence. In later publications, equalities, or rather inequalities, are explicitly referred to as justification and as foci for intervention. In publication 5, inequalities in service provision for, and research with, people with learning disabilities was noted with the group demonstrating "…an encouraging advance as previously people with learning disabilities were denied therapeutic advances which emphasise self-management of behaviour" (p. 67). Inequalities are identified as one of the factors in the justification for the emotions group (Publication 7) and attention is also drawn to legislative responsibilities in that studies showed a lack of services for, and research into, learning disabilities despite evidence that people with learning disabilities show higher rates of emotional and behavioural disorders than the general population (Foundation for People with Learning Disabilities, 2002; Emerson & Hatton, 2007) and despite the passing of the Disability Discrimination Acts (1995, 2005) (p. 21), and Publication 9 quoting the more recent Equality Act 2010 as part of its rationale (p. 1). This publication also illustrates, and calls for, increased accessibility to psychological interventions for people who have cognitive impairments, learning disabilities and/or neurodevelopmental disorders with reference to policy, and practice context, as well as legislative, for more equal and diverse service provision along with attitudinal aspects of practice, practice development, research and society which all act as barriers. It gives clinical illustrations of assessment and intervention materials and methods, offers a heuristic for accessible intervention from standard through adapted to personalised assessment and intervention. This represents a richer understanding of the need to provide both a practice framework and model for adapting and increasing access, and also the need for broader social and attitudinal change.

5.7 Medical model and the re-medicalisation of emotions

The social and policy context presented in Chapter 2 traces the movement away from the earlier medical model of learning disabilities to a social developmental model. More recently there appears to have been a more general medicalization of emotions. There appears to be a range of drivers including the uncritical use of diagnostic systems (as discussed in Section 4.3.1), the need for diagnoses in order to access and record psychological interventions, referrals for anger management or anxiety management. Publications 5, 6 and 7 include a critical discourse regarding this medicalization of emotional problem; groups focus on broader range of emotions in an attempt to *normalise* the role and importance of a range of emotions in all our lives, to reduce the *pathologising* of difficulties with emotions and in recognition of complexity in identifying and naming emotions with anxiety and/or low mood and/or frustration presenting as anger or aggression). As diagnoses, case-ness and thresholds increasingly become prerequisites for service access, tensions are created for the roles of psychologists and other professions (specialised therapists vs public health and well-being; prevention/early intervention vs specialist care) and the frame and funding for research.

5.8 Chapter Summary

In summary, the publications demonstrate strengths of a high degree of what Snell (2003) identified as *social* and *contextual fit* validity, key factors in maximising the translation of research to practice. Factors Snell highlighted include the importance of the research goals to practitioners, the practicality of the intervention procedures and the value of the outcomes for the participants and society (p.144 -145). Nine of the ten publications included working with and through non- psychologists to deliver psychological interventions with the goals of relevance to them, practical interventions seeking outcomes in line with policy. All nine have involved the collaborating staff in planning, delivery and evaluation.

Contextual fit, as described by Snell (2003), included:

> ….. the involvement of practitioners in the design of the intervention and any assessment, match between intervention and values, skills and resources of those who implement the intervention. (p.145).

High contextual or ecological validity is further demonstrated by including participants who were complex, clinical referrals and use of few exclusion criteria. The high social and ecological validity demonstrated compares favourably with Snell's review finding of a social validation in only 36% of the 114 studies in their review of intervention research, 1990 - 1996 with school-aged individuals with intellectual disabilities.

Professional practice journals have been the publication route of choice reflecting the high social and contextual validity and to maximise dissemination. The publications themselves illustrate the use of *applied psychology* through detailed yet concise descriptions of assessment, intervention and research methods, materials, timetables to enable replication, and choice of journal to those which will reproduce the coloured visual examples of the accessible assessment and therapy materials.

The publications also fit the framework proposed by Burton and Chapman (2004) in considering problems of evidence based practice in community based services with people with learning disabilities, critiquing Evidence-Based Orthodoxy (EBO). They note that:

> ….. randomised clinical trials-the gold standard for EBO-in particular give
> us little understanding of why and when things do or do not work. p 59.

Burton and Chapman (2004) also suggest that useful, applicable research needs to take account of social, psychological and practical aspects of real life problems, in real settings, with staff who generally want to do a good job but may not have access to research, training or support. They argue that appropriate evidence which does do this can be conceptualised over three levels:

- Micro evidence: from practice with individual people or small groups
- Meso evidence: from local studies, evaluations, audits
- Macro evidence: from published studies

Another change over time apparent from the chronological analysis of the presented publications was a decrease in the robustness of the methodology used. Reflecting on likely factors for this, possibilities include reduction in access to assistant psychologists, narrowing of expectations of roles of psychologists driven by a need to maximise individual direct client contacts, pressures of reduced psychology resources and a decrease in the priority afforded to research by psychologists in general clinical work (by both psychology services and the services in which they are embedded). The publication of the *Research Governance Framework for Health and Social Car*e (DH, 2001) increased the demands of the research governance framework with the intention of driving up research quality. *Good Practice Guidelines for the Conduct of Psychological Research within the NHS* (BPS, 2005) noted that some of the framework's impact was acting as a barrier to clinical psychologists undertaking research, one of our core skills. The conduct of Research Ethics Committees, for example, was recognised of value in refining a project and ensuring that it is ethically acceptable, however, "… not infrequently the comments seem to reflect confusion and ignorance about the nature and value of psychological research to the NHS" (p.5).Consequences for clinical psychologists included delays necessitating extension of periods for professional training and research projects which delay qualification, and clinical psychologists being discouraged from planning and applying for research because of the burdensome and inconsistent bureaucracy.

The involvement of service users within the publications increased over the time. This reflects the recognition of the importance and value of service users in planning, undertaking and evaluating research (INVOLVE, 2004, 2009; DH, 2006). With links to consumer-focused and democratic concepts of involvement in policy, practice and service development (Beresford, 2002), service user involvement in research is characterised along a continuum from no involvement through consultation to collaboration and service user led research. Issues of diversity, communication, professional, institutional and social attitudes and power influence the nature of service user involvement and how collaborative or tokenistic it is. The involvement of services users in the publications presented includes feedback and individualised interventions developed onto date. The use of service user feedback enabled triangulation of data across quantitative and qualitative data and across multiple informants (i.e. both service users and carers). The role of user involvement in the two research developments I currently lead has increased. Service users have collaborated in the identification of the research questions, planning the design, preparing funding applications, development of materials (information, invitation, consent, and intervention resources) and will participate in evaluation and dissemination (see Auto-ethnography, Appendix 2, 5.2).

6 Conclusions, reflections and recommendations

6.1 Chapter Introduction

This final section examines the thesis question, *'Research to practice and people with learning disabilities: Better Services (1971) to Transforming Care (2012) - 40 years on, are services any better?'* in the light of evidence presented, issues described within the selected publications and broader research and policy. Evidence is presented which indicates that, after forty years of research to practice, services for people with learning disabilities *are not* any better. Other evidence indicates that, after forty years of research to practice, services for people with learning disabilities *are* better. Some possible underlying factors and mechanisms are identified along with implications and recommendations for action and future research.

6.2 'Research to practice and people with learning disabilities: Better Services (1971) to Transforming Care (2012) - 40 years on, are services any better?'

NO :

Evidence demonstrating that after, forty years of research to practice, services for people with learning disabilities **are not** any better includes:

- recent investigations and service reviews as described in Chapter 2:
    - the Winterbourne View Panorama (BBC, 2011) and subsequent Department of Health (2012$_a$, 2012$_b$, 2012$_c$), CQC (2011), and South Gloucestershire Safeguarding Board (2011) and police investigations demonstrated not only the lack of progress in service provision and development, but criminal levels of ill treatment and abuse

  - reports from Sutton and Cornwall (Commission for Social Care Inspection, 2006, 2007) demonstrated totally unacceptable environments and care process including lack of treatment plans, excessive use of pro re nata (PRN) medication, poor record keeping, illegal use of physical restraint, training not prioritised and poor governance arrangements did not allow senior managers to monitor services effectively. The reports noted that the services did not reflect the principles of Rights, Independence, Choice and Inclusion, set out in the White Paper Valuing People strategy and that assessment and treatment centres and supported living services did not meet the best practice as detailed in the Mansell Reports (1993, 2007).

  - A more recent CQC report into Slade Hospital in December, 2013, demonstrated continued problems in care (Care Quality Commission 2013, Inspection Report: Slade House). The review found none of the ten standards monitored were met. Immediate enforcement action had to be taken on six of these and follow up action needed on the remaining four. The report noted an impoverished environment which was not suitably clean; medicines were not always safely administered, expiry date checking was not carried out adequately, the emergency oxygen was significantly out of date, and appropriate arrangements were not in place for the storage of medicines; few social or therapeutic interactions, little therapeutic intervention or meaningful activities; quality monitoring was inadequate and ineffective monitoring of health, safety and welfare

- Epidemiological and health outcome measures which show whilst people with learning disabilities are 2.5 times more likely to have health problems than other people (Disability Rights Commission, 2006), they have higher levels of unmet physical health needs (Mencap, 2007; Michael, 2008) and also mental health needs (Emerson and Baines, 2010). They have difficulties accessing support for mental health needs. Inequality of access to both physical and mental health needs persists despite legislation for public organisations' responsibility for reasonable adjustments to ensure equal access to services (Disability Rights Commission, 2006, 2007; Equality Act, 2010).

- Reports of widespread experience of loneliness, cruelty, being bullied and/or victims of hate crime or mate crime. Gravell (2012) found experiences of incidents which ranged from name-calling and taunting to financial abuse, assault and attacks on property. One in four people with learning disabilities interviewed were lonely and did not have any friends, leading them to spend time in hostile public spaces bringing them to the attention of bullies, exploitative people and criminals. Beadle-Brown et al. (2013) found almost half of survey respondents with learning disabilities (sample size 255) reported having experienced victimisation. The report identified a range of effects of the victimisation (emotional and social difficulties, avoiding going out) and a range of barriers to reporting the experiences to friends, families, staff or police. Mencap (2007) found 82% of children with learning disabilities had experienced bullying with 79% scared to go out for fear of being bullied (sample of 500+ children with learning disabilities across England, Wales and Northern Ireland).

- In forensic services, No One Knows (Howard League, 2011) found people with learning disabilities over-represented in prisons and young offenders' institutions, yet under-recognised and rehabilitation programs not adapted, appropriate or accessible for people with learning disabilities.

- The Learning Disabilities Public Health Observatory compendium of national statistics relating to people with learning disabilities in England (IHAL reports 2011/12, and 2010/2011 (www.ihal.org.uk/publications/1185/People_with_Learning_Disabilities_in_England_2012 ; www.ihal.org.uk/publications/1063/People_with_Learning_Disabilities_in_England_2011) show how far from inclusive, ordinary lives people with learning disabilities are with:
    - over one in five of looked after children has special educational needs associated with learning disabilities

- the risk of being looked after continuously for at least 12 months by the LA (as of March 31 2012) was 1.1 per 1,000 for children with no special educational need; 19.9 per 1,000 for children with moderate learning difficulty; 25.1 per 1,000 for children with severe learning difficulty and 31.2 per 1,000 for children with profound multiple learning difficulty)
- for adults with learning disabilities, residential support was most frequently delivered in independent sector residential care (31,960), adult placements (3,960), LA staffed residential care homes (2,315) or nursing care (2,035) ie over 40,000.
- Although Transforming Care (DH, 2012) envisaged appropriate community re-provision by June 2014, the Learning Disability Census (DH, 2013) identified 3,250 inpatients with learning disabilities, autistic spectrum disorder and/or behaviour that challenges in 104 NHS and independent provider organisations on 30 September 2013. Count Me In (2010) had found 3,376 service users with learning disabilities receiving inpatient services in England. Whilst this represented a decrease from 4,435 in 2006 to 3,376 in 2010, the expected progress outlined in the DH Transforming Care Action Plan and the Concordat following the Winterbourne View abuse has been slow. The slow progress is likely affected by both the current economic landscape and the major reconfiguration of health services following the recent Health and Social Care Act. Primary Care Trusts ceased on 1 April 2013 with their functions taken over by new clinical commissioning groups (CCGs) and local area teams (LATs) whose responsibilities include commissioning services for their local communities. All GP practices are now belong to a CCG which will commission most services on behalf of patients, including emergency care, community care, planned hospital care, and mental health and learning disability services in their local areas. Many do not have the relevant commissioning expertise for services for people with learning disabilities. The reconfiguration has also seen large change of staff, structures and responsibilities at local and national level with losses of experience in both provider services and commissioning.

The above gives a bleak view of lack of progress in implementing the evidence base of constructive interventions with people with learning disabilities and/or the policy imperatives presented and described in this thesis. However, it is important to identify any evidence of progress in services for and lives of people with learning disabilities.

6.3 'Research to practice and people with learning disabilities: Better Services (1971) to Transforming Care (2012) - 40 years on, are services any better?'

YES :

Evidence demonstrating that after, forty years of research to practice, services for people with learning disabilities **are** better includes:

- Data showing numbers in hospitals were decreasing substantially, in particular, for children in mental handicap hospitals. Decrease from 7,000 in 1971 to 2,800 in 1979, with few children being admitted for long-term care (Hansard written answer, Norman Fowler, Secretary of State for Health, 29.10.81).

- All children receive an education, irrespective of level of learning disabilities following the Education Act (1970). Education for children and young people with learning disabilities in inclusive or special settings provides productive, individually focused/differentiated learning opportunities, with community participation and engagement, often in a multidisciplinary framework with psychologists, speech and language, occupational and physiotherapists and based on evidence (Carpenter, 2007) and within a values and policy base (Every Child Matters, DES, 2004; Valuing People, DH, 2001) as evidenced by OFSTED Inspections. The Children and Families Bill 2013 (DfE) anticipates education, health and care planning should improve coordination of services.

- People with learning disabilities are protected by legislation (Equality, Mental Capacity, Human Rights, Children's and Care Standards Acts) and practice guidance (Allen, 2003, 2009, 2011) for access to services, upholding of rights and safeguarding.

- People with learning disabilities, including those whose behaviour is severely challenging, do receive individualised interventions and support for development of pro-social skills and minimisation of challenging behaviour through evidence-based positive behaviour support (Allen et al., 1987, 1997; Emerson et al., 2000, 2001) within an ordinary living framework (O'Brien, 1987; Mansell, 1993, 2007) in some parts of the country such as Salford, Liverpool and South Wales (DH and Challenging Behaviour Foundation, 2011, 2013)

- Person-centred active support (Mansell et al., 2005) can increase engagement of people with complex needs and make a real difference to people's lives. In one organisation, use of person-centred active support enabled people with learning disabilities with the lowest skills levels to move from being largely disengaged in 2000 to being engaged up to 50% of the time in 2005/2006. Increased use of photos, pictures and other forms of alternative communication were a key element, with 76% of staff reporting using them regularly. This study also demonstrated the importance of effective practice leadership. Support staff were more likely to practice Person-centred Active Support when the frontline managers showed effective practice leadership (modelling by example and supporting and monitoring staff).

- Whilst Beadle-Brown et al.'s 2013 study of victimisation showed a high proportion of people with learning disabilities had experienced victimisation, it is also noted that being a victim of disability hate crime or harassment is not an inevitable feature of having autism or learning disabilities, and that many people with such disabilities live in the community without being victimised.

- increased life expectancy of people with learning disabilities. In the 1930s, average life expectancy was estimated to be less than 20 years of age (Holland, 2008). Mean life expectancy is now estimated to be 74, 67 and 58 for those with mild, moderate and severe learning disabilities respectively (Bittles et al., 2002). A differently calculated set of figures (IHAL Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), 2013) suggested a smaller, but still large, gap in life expectancy between those with learning disabilities and the general population. Their figures show the median age of death for people with learning disabilities as 65 years for men; 63 years for women was significantly less than for the UK population of 78 years for men and 83 years for women. They state that men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population, with 22% overall under the age of 50 when they died. However, life expectancy for people with learning disabilities is higher than in the 1930s and, proportionally, has increased more than for typically developing people. General UK life expectancy in 1930 was on average 60 years (+ 2 years for females, - 2 years for males). The difference in life expectancy, therefore, was more than 40 years. In 2010, general life expectancy was on average 80 years (+ 2 years for females, - 2 years for males), showing this difference has reduced to close to 20 years (ONS, 2011).

Given the mixed evidence presented above, identification of factors supportive of change, improvement, high-quality services and the application of evidence based practice may be useful.

6.4 Factors supportive of change, improvement, high-quality services and the application of evidence-based practice include:

As this thesis has shown, factors supporting better services and positive change have been known and laid down as policy for decades. These factors are identified within inquiries' recommendations (Ely Report, DHSS, 1969), through White Papers (Better Services, DHSS, 1971 and Valuing People, DH, 2001) to Transforming Care (DH, 2012) and by research (Martin, 1984; Mansell, 1993, 2007) of both organisations and care delivery. As the publications presented in this thesis demonstrated, there are practical applications of psychology, deliverable by a range of staff to a range of people with learning disabilities in a range of settings which enable those people to develop, achieve, have fun, and contribute to reducing problematic behaviours and emotions.

Chamberlain and Davies (2013) recently summarised the factors supportive of high quality care which:

> invariably involve identifying a person's unique needs through a person-centred planning process and then organising resources, in a community setting that allows these needs to be suitably addressed. (p.10)

In their paper *The abuse of people with learning disabilities: What clinical psychology can do to prevent it happening again,* they urge psychologists to be aware of both success factors and risk factors that limit effective person centred work. Risk factors might raise concerns about the quality of care and of the ability of a service to make effective use of psychological input. A framework is provided to identify the *high risk factors for unacceptable services* and the *conditions under which psychological interventions are most effective* and includes:

- <u>Client Issues</u> : absence/ presence of advocacy; individual, person-centred action plans which are actioned and recorded
- <u>Staff Issues</u>: absence/ presence of staff meeting to discuss plans, monitoring of goals/progress, keeping records, appropriate training
- <u>Nature of Facility</u>: ordinary houses, ordinary streets, privacy, acceptable décor
- <u>Management Issues</u>: manager sets respect, dignity, values agenda, understands person-centred agenda, monitors staff and service, ensures incidents recorded
- <u>Procedures</u>: clear accessible complaints procedure, low level of complaints,

> no use of restraint/seclusion, low use of medication, all clients have person-centred plans, guidelines up to date and accessible, meetings occur and are recorded

A similar framework is provided by the Driving Up Quality in Learning Disability Services Alliance (2013):

1 Support focused on the person
2 An ordinary and meaningful life
3 Being happy and quality of life
4 Good culture and the organisation
5 Lead and run the organisation well

Both these frameworks echo the Table 1 factors of the *Ely Report* (DHSS,1969) and *Better Services* White Paper (DHSS, 1971) of structure and process. The importance of culture, management and leadership is emphasised as is the role of relationships between staff and service users, amongst staff and within communities. Chamberlain and Davies note:

> institutional care is characterised by staff treating people on a group basis rather than as individuals with unique needs…more likely to happen and/or staff turnover is high and relevant staff training is poor or inadequate. Staff simply do not have the time or the skills to get to know their clients…. Supportive relationships fail to develop and staff spend their time performing “hotel” skills rather than communicating with and understanding those people who are dependent on them. Such group treatments, when poorly monitored, can escalate quickly into dehumanising treatment and abuse. The less able you are to communicate with an individual and understand their unique needs, the more likely you are to objectify them and stop seeing them as people like you. p. 10

The key importance of relationships was identified within the recommendations of Ely (Table 1, 2.1). Reflecting on the centrality of interaction and relationships, a core focus of the publications presented in this thesis, this seems to have got lost in the target-driven landscape of public services. Publication 2, drawing on systems methodology and evidence for effective organisations, highlighted the need for organisations to manage both *soft* and *hard* aspects of user focused and organisational interventions (p. 10). *Soft* aspects include style, staff, skills, superordinate goals; these mediate relationships and interactions, and link with group norms, beliefs and values. They are often aspects of the informal and social power base, rather than an organisation's explicit mission statement, policy or procedures, as identified in Martin's analysis of *Hospitals In Trouble* (see section 2.2). *Hard* aspects of organisations include strategy, structure and resources. The organisation that ran Winterbourne View, Castlebeck, had demonstrated impressive policy and procedures regarding aims, objectives and quality which had satisfied previous regulatory and investigative inspections yet the reality of care delivery was very different (South Gloucestershire Serious Case Review, 2012). Hastings (1994, 1996) identified the importance of understanding and working with the emotions and attitudes of staff, and understanding their organisational context from his studies of the behaviour of staff and outcomes for people with learning disabilities. He concluded that effective 'technologies' for helping people with learning disabilities with various challenges to lead fulfilling lives are all about people, relationships and practices, not about buildings.

The central role of these *soft* aspects of organisational culture and relationships (among staff as well as between staff and service users) has been found in other care groups. Maben et al., (2012) investigated links between staff experience of work and acutely ill older people's experience of hospital care through survey, observation and interview. They found that a high-demand/low-control work environment, poor staffing, ward leadership and co-worker relationships added to the "inherent difficulties" staff face in their caring role. They observed staff needing to seek job satisfaction through increased interaction with, and caring for, service users identified as *poppets*. *Poppets* were "those patients they enjoy caring for and for whom they feel able to 'make a difference'…. This left less favoured – and often more complex patients – to receive less personalised care" (p. 84). Other patients – noting dehumanising aspects of their care – felt like *parcels*.

Brooker et al. (2013) provide a further illustration of the importance of culture and relational aspects in their description of the development of an observational tool of the experience of care for people living with advanced dementia. These service users “are often the most vulnerable to neglectful and abusive practice in care homes” (2013, p.37). The tool, PIECE-dem (**P**erson **I**nteraction **E**nvironment **C**are Experience in **D**ementia), provides a framework for observation across key areas including how a person exerts control in their life, signs of withdrawal, distress or engagement; nature of interactions and impact of the environment. Brooker et al. note that neglectful, or supportive, practice is linked to the care home culture (p. 43) confirming earlier work in 100 care homes (CSCI, 2008; Brooker, 2011). They highlight relationships as central to:

> … the importance of conceptualising the care culture…. a structure like the “senses framework” (Nolan et al. 2008) that focuses on the interdependence of relationships between residents, staff and families in determining the quality of the care environment (Brooker et al. 2013, p. 44).

Maben et al. (2012) similarly noted that:

> “Older patients’ and their relatives’ experience of good hospital care highlights relational care issues as being of primary importance (Bridges et al., 2009) but Iles (2011) describes how ‘transactional’ models of care (where the individual is cared for) often eclipse ‘relational’ models of care (where patients are cared about). p.84

Maben et al. draw on Nolan’s six senses framework finding that, if staff are to create a culture in which older people experienced the senses of security, belonging, continuity, purpose, achievement and significance, then staff also had to experience them in their day-to-day work.

These findings highlight common mechanisms operating across care groups (learning disabilities, older adults, older adults with dementia) and across settings (hospital, residential care) and staff (health and social care) and a need for more joined up action for improving services following the *Francis Report, Transforming Care* etc with increased attention to organisational factors especially *soft* human factors.

Attention is also needed to structural factors, as these may also act as barriers to delivering high quality services. Examples include the major and numerous NHS and LA reorganisations and reconfigurations, separation of purchaser/provider and health and social care, substantial, bureaucratic regulatory and policy demands which allow abusive and neglectful care to continue as at Winterbourne View.

6.5 Implications and recommendations:

Reflection on the above, and my experiences of service delivery, development and research across organisations and timescales, confirms the importance of *hard* and *soft* factors across structure and process and teamwork within different levels of organisations. My reflection also suggests some additional key conceptual and practical issues which are listed below with recommendations for action:

- Goals and activities need to be aligned across different organisational levels (individual care planning and delivery, ward or unit, locality, Trust, commissioners) for sustained high quality and learning-by-doing. There needs to be integrated, practical, needs-led commissioning, delivery and monitoring. Small pockets of good practice are generally unsustainable unless there is wider organisational support. This is reflected by my experience of innovative service development and delivery along with research and dissemination/publication outlined in my Auto-ethnography (Appendix 2) where often the most energetic and effective services demonstrate these features.

  Action*:*

    - *Develop timetabled action multiagency plans based on policy and research on what works in services for people with learning disabilities, i.e. Table 1 recommendations; quarterly reports to DH*
    - *Apply the psychology of information processing (Miller, 1956, the magic number 7, + or – 2) to identifying a manageable and relevant number of key performance measures which focus on outcomes for individuals (rafts of policy, recommendations and regulations cannot be actioned*

    or monitored)
    - *Aggregate data across different organisational levels; shorten and simplify policy and practice guidance (e.g. Bro Morgannwg NHS Foundation Trust has an A4 table listing 7 indicator examples of acceptable and not acceptable practice).*
    - *The nature and pace of organisational change needs to slow, to allow effective organisational change (Georgiades & Phillimore, 1975)*

- Service settings where there is good alignment of organisational purpose and practice are often those which support the undertaking of innovation and research and the use and application of research. As above, my auto-ethnography indicates such organisations were also ones which made use of the application of psychology across all organisational levels. In 2010, the NHS Confederation and SDO Health Services Research Network noted evidence that high performing organisations which encourage research, innovation and evaluation have a stronger capacity and capability to achieve and sustain change.

  Action*:*
    - *Find and publicise good examples, (e.g. DH Learning Disabilities Good Practice Project, 2013, describe people with learning disabilities as quality checkers visiting care homes and identifying simple practical things to improve people's lives; shared ownership scheme with details of how it can work, improving access to public health initiatives; local supported living for young people who would otherwise be in secure services; individual Life Maps and Life Stories including their use in schools for discussion of bullying, difference)*
    - *build practice and support networks*
    - *Increase inclusive and translational research across a range of domains (development, physical and mental health, community participation) and a range of levels (service, community, public health). Whilst the Research Governance Framework (2005) emphasised the need for research to " … respect the diversity of human culture and*

    conditions and take full account of ethnicity, gender, disability, age and sexual orientation in its design, undertaking, and reporting" and that the body of research evidence available to policy makers reflects the diversity of the population, people with learning disabilities are often excluded from research and/or learning disability specific studies are not funded and learning disability focused research centres have been closed down (Hester Adrian Research Centre, Manchester; Health Care Evaluation Research Team, Wessex RHA).
    - *Increase the role of people with learning disabilities in prioritising, planning and participating in research*
    - *Increase understanding of appropriate methodologies for research with people with learning disabilities such as single case design*

- Services, research and models of care reflect broader social factors and mechanisms. Wider social factors such as the social gradient (Marmot, 2010; Friedli, 2009) and both institutional and societal disablism may contribute to lack of progress. Oakes (2013) drew attention to the work of Goodley and Runswick-Cole (2011) and their identified elements of the "violence of disablism" (real, psycho-emotional, systemic and cultural). Suggesting that the violence experienced by disabled children and their families says more about the dominant culture of disablism than it does of the acts of a few seemingly irrational, unreasonable, mean or violent individuals, Goodley and Runswick-Cole call for extensive cultural deconstruction and reformation.

  ***Action**:*

  - *Broader models for organisational, community psychology and development, social change and research may need to be utilised. As suggested in Section 5.4 these might include Bronfenbrenner's (1979) ecological nested systems model of micro ↔ macro influences (Bronfenbrenner & Ceci, (1994) and/or Frieden's (2010) health impact pyramid conceptualising five levels of intervention (counselling and education; clinical interventions; long-lasting protective interventions;*

changing the context to make individuals' default decisions healthy; socio-economic factors). Hatton (2014), Co-Director of Improving Health and Lives, in a recent blog looks to the potential of Frieden's pyramid to broaden and embed a range of community-based and public health initiatives that "the new Health and Wellbeing Boards should be interested in, particularly with the potential within local authority settings to knit together communities in ways far beyond services". Examples might include Community Safety Partnership work tackling disability hate crime.

- *Increase participation by, and portrayal of, people with learning disabilities in the media (factual and non-factual, across all media platforms) and in all social, political and cultural activities and institutions is needed. Allday (2009) outlined the history of discrimination towards people with learning disabilities in relation to museum and described examples of more positive representation and inclusion (Bristol City Museum and Bristol and South Gloucestershire People 1st exhibition: The Journey to Inclusion, 2007; Colchester and Museum of London's participative work). Increase and monitor people with learning disabilities in media e.g. in radio and TV drama (BBC 2012, The Pursuit of Darleen Fyles; BBC 2014, Meet the Midwife) and talk radio (BBC 2013, Saturday Live).*

- *Researchers can take a lead, for example, the Tizard Centre (University of Kent), which focuses on research, teaching and consultancy with people with learning disabilities, their carers and service systems was recently awarded a Queen's Anniversary Prize for Higher and Further Education for its contribution to improving the lives of people with Intellectual and Developmental Disabilities (IDD) and their families. Perhaps, as the press release states, this is:*

  > recognition at the highest level that people with IDD deserve the best possible quality of life. All too frequently, they are at a real disadvantage in society…... We hope this award signals the need for a step change by policy-makers and the wider society.

  (See https://www.kent.ac.uk/research/stories/qapbuckinghampalace/2014)

6.6 Conclusions

This thesis has presented ten publications describing the application of psychology with people with learning disabilities in the context of policy across four decades. It has demonstrated a range of applications of psychology through a range of staff with a range of people with learning disabilities in a range of settings. Results included evidence of skill development, increased engagement in activities and social interaction, improved emotional regulation. The thesis examined and critiqued the methodologies used, and justified the use of small samples and non-randomisation in pursuit of high external and social validity. The thesis demonstrated how the findings of the studies impacted on practice and contributed to the evidence base. Contribution to knowledge included extending the application of psychology by focus, ability range and complexity. The thesis also demonstrated how progress to implement research and policy in practice has been slow and identified organisational and social factors in supporting, or acting as barriers to, high quality services. Implications and recommendations included greater attention to organisational and social factors in achieving more effective research to practice and progress towards better services, equal opportunities and quality of life

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Appendices

Appendix 1. 1 Timeline 1: summary of key events: pre 1971

Year Pre-1971	Government	Policy LD	Policy NHS	Legislation	Social	LD research: content & paradigms	Role of clinical psychologists	Auto-ethnography & pub no
	1959			Mental Health Act 1959		Clarke & Clarke 1958, 1966		
	October 1964					Brookland study, Tizard 1964		
	March 1966							
		News of the World allegation of cruelty at Ely 1967						
		Ely Hospital Inquiry Report 1969						
	June 1970			Education Act (1970)- Royal Assent				

Appendix 1. 2 Timeline 2 : summary of key events: 1971-1980

Year	Government	Policy LD	Policy NHS	Legislation	Social	Role of clinical psychologists	Auto-ethnograpy & pub no
1971	1970	Better Services 1971		Education Act (1970)			Volunteer “Mental Handicap” Hospital
1972							Volunteer “Mental Handicap” Hospital
1973			NHS Reorganisation				Nursing Assistant “Mental Handicap” Hospital
1974	Feb Oct						1st Psychol. degree Volunteer Toy Library
1975					UN Dec - Rights of Disabled Persons		
1976		National Devt Group Pamphlet 1	RAWP Report Child Health Court Report				
1977		National Devt Group Pamphlets 2-5				Trethowan Report	Post Grad Prof Clin Psych Training
1978		National Devt Team Group: Helping Ment Hand People in Hosp Normansfield Report 1978			Winter of discontent		
1979	May	Jay Report 1979	Royal Commission on NHS				1 Social Int Activity Groups

1980		Black Report DHSS

Appendix 1. 3 Timeline 3: summary of key events: 1981-1990

Year/ decade	**Government**	**Policy LD**	**Policy NHS**	**Legislation**	**Social**	**Role of clinical psychologists**	**Auto-ethnography & pub no**
1981	1979	Silent Minority Documentary All Wales Strategy	*Care in the Community*				Basic grade Clin Psych Normans field
1982			Area HA's abolished. *Acheson Report* Prim Care London				**1**
1983	June		*Griffiths Report.* Audit Comm re Community Care				Senior Clin Psych, B'stoke & N.Hants Social Skills groups
1984		*Hospitals In Trouble Martin*					
1985							Senior Clin Psych & Project Manager, E.Berks HA
1986			Intro Gen Mgt. Joint Plang Circ. Green Paper Neighbrhood Nursing				MBA
1987	June		White Paper *Promoting Better Health*			MAS Report	
1988			Green Paper Community Care				
1989			White Papers: *Working for Pts & Community Care, next decade*				**2, 3, 4**

1990	NHS & Community Care Act- internal market	Head of Specialty, WSNEHHA

Appendix 1. 4 **Timeline 4 : summary of key events: 1991-2000**

Year	Government	Policy LD	Policy NHS	Legislation	Social	Role of clinical psychologists	Auto-ethnography & pub no
1991	1987	All Wales Strategy Review	Patients Charter. 1st NHS Trusts				Head of Specialty LD; W Surrey & NE Hants
1992	April		White Paper Health of the Nation				Consultant Clin Psych & Manager CISS, Cardiff
1993							
1994		Macintyre Undercover	NHS Reorg- RHA's reduced to 8. Primary Care led NHS				
1995		*Health of the Nation: Strategy for people with LD*	Patients Charter				Clin Psych, Weald of Kent
1996			3 White Papers: Choice; Primary Care, Ambitions				Self-employed
1997	May	*Mansell Report* 1 & MHF *Don't Forget us*	Patients Charter Revised. White Paper: *New NHS, modern, dependable*	Primary Care Act			
1998			*First Class Service.* NICE established. *Acheson Report.*				**5**
1999			White Paper *Our Healthier Nation*				

2000	PCT's established

Appendix 1. 5 Timeline 5 : summary of key events: 2001-2010

Year	Government	Policy LD	Policy NHS	Legislation	Social	Role of clinical psychologists	Auto-ethnography & pub no
2001	1997 June	Valuing People	Modernisation Agency. CHI est	Health Act 1999			Cons Clin Psych SABP NHS Trust
2002	↓		NHS Reorg. DHA's abolished. *Wanless Report* rec increase health & soc funding	NHS & Health Care Professions Act 2002. RHA's to SHA's			
2003	↓	DH/DE/Guidance on Phys Interventions (Allen)	New dr's contracts. A4C. Foundation Trusts. CHAI, CSCI	Health & Soc Care (Community Health and Standards) Act			
2004	↓		Monitor. White Paper, *Choosing Health; Comm pt-led NHS*				
2005	May		*Creating a patient-led NHS*, practice based commissioning				
2006	↓	Cornwall & Sutton inquiries	NHS Reorg. SHA's 28→10 PCT's 303→152, White Paper, *Our health, our care, our say*,				
2007	↓						
2008	↓		*High quality care for all*.				
2009	↓		*NHS Constitution* CQC, £4bn savings nec, White Paper, *Building Nat Care Service*				

2010	May Con/Lib coalition		Mid Staffs Hosp inquiry; White Paper, *Equity & excel Liberating the NHS; Healthy lives, healthy people; NHS reorg planned*				**6**

Appendix 1. 6 Timeline 6 : summary of key events: 2011 →

Year	Government	Policy LD	Policy NHS	Legislation	Social	Role of clinical psychologists	Auto-ethnography & pub no
2011	2010	Panorama on Winterbourne View	new NHS Commissioning Board, PCT clusters, SHA's to 4 regional bodies				Cons Clin Psych SABP NHS Trust **7**
2012		DH Transforming Care. Serious Case Review		Health & Social Care Bill, first Mandate to the NHS Commissioning Board.			Honorary Researcher SPFT & Tizard Centre **8, 9**
2013			Francis Report; NHS England: Clinical Commissioning Groups; Health & Well-being Boards; CMO's Annual Report-*Our Children Deserve Better: Prevention Pays*	Children and Families Bill			Research Fellow Tizard Centre **10**

Appendix 2 Autoethnography

1 Pre 1971- Reflections on contact with, and attitudes to, disability:

I recollect very little awareness of disability or mental handicap as general issue whilst growing up. One of our neighbours where I lived, from birth – four years, and again, from six to eleven years, had severe facial disfigurement and scarring from wartime injuries. As he was our friendly, kind neighbour, I did not notice this, think it unusual or imagine it could be a problem.

A “Mental Handicap” hospital stood very seperately on a hill two miles from where we lived. I remember my mother taking her car to a car wash where people with mental handicap washed the cars when I was about 12-13 years old. I recollect, with shame now, saying when I had a car I would go to the automatic car wash as I wouldn’t want to go where there were “scary”people. I didn’t know where this view came from. Both my parents were generally thoughtful, considerate, open- minded on issues of difference; supportive of, and generally lived according to “social justice” principles. On reflection, perhaps it was an indication of broader social influences outweighing parental influence as I entered my adolescence. I do not recall it being a ploy to annoy/disagree with my mother (though this was also part of my adolescence!). I was genuinely puzzled that my mother would go somewhere with, what I thought were scary, different people when she could have gone for a safer automated option.

2.1 1971- 1973; Volunteering at “Mental Handicap” Hospital:

In our “O” Levels year, myself and a friend signed up for a week’s volunteering in the summer holidays organised by University students at the local “Mental Handicap” Hospital. We had felt OK about it when we signed up months before. The night before we were due to start, we were feeling very nervous and asking ourselves why we’d been so foolish to sign up to do things with people who were different, may be scary and with whom we may not be able to communicate.

We were linked with children with learning disabilities. Fifty six of them between ages of 6 and 19 lived on the upper two floors of a Victorian institution. The children and young people were “herded” from dormitories (top floor) to dayroom (middle floor) and back again each day. As volunteers, we were allocated 1:1 with a child (sometimes 2:1 if they had very unusual behaviour) and we would all go off for a day trip (beach, countryside, zoo). Tremendous fun was had with the children, the other volunteers, the university student organisers and nursing students. Despite their extreme deprivation and institutionalisation, whilst out on these trips, the children were like other children- laughing, singing, running, splashing. Some did display what would later be termed “challenging behaviour” e.g. running off, pushing others, taking clothes off. The student organisers were unfazed and gave support as necessary. They framed the behaviours as likely resulting from the children’s lack of experience of life and how to behave outside the hospital, and not having been being helped to learn appropriate behaviour.

A student magazine, Tranzfusion, of Bristol University March 21, 1972, I kept from my early volunteering days, describes some research, policy and social issues relevant to the care of people with mental handicap as well as personal reflections. There was reference to the new Education Act 1970 and it’s heralding by the Secretary of State, research on the new community based units, by Kushlick and team and the developing polarisation between innovative developments and traditionalists supporting continuation of hospital care.This was my first exposure to any research and to consideration of social and policy issues and models.

Personal reflections of volunteers included:

> ….. a ward containing 56 children ………it is situated on the top floor of a three story building, thus not allowing any outside play area. There are not enough chairs for all the children to sit down and not enough room for playthings of any size. When the only movable object in an otherwise barren and overcrowded day room are the chairs, it is little wonder that the docile become more docile and the active become aggressive to the other children, to the room (especially windows) and to themselves. Deprived children are merely further deprived.
>
> With limited staff and facilities, there has to be a strict routine on the ward, a routine that inevitably conflicts with the natural diversity and perversity of children. It is an evil situation which should not exist, but in fact it becomes

> the norm and moral standard by which other children are judged. Thus many children on my ward are labelled overactive; in fact they are merely active like a normal child and the ward is overcrowded. Other children are labelled “attention seekers” when they are normally affectionate but the nurses are too busy. Children who run off the ward off are bad, when getting away shows remarkably healthy instinct. In brief, instead of subnormal children being made normal, normal children are pressured to become abnormal institutionalised Stoke Park children.” (p 5 & 6)
>
> Ivy may not be a typical ward, but with 105 patients it perhaps typifies the care of institutionalised mentally subnormal people…… The majority just sit and stagnate. …. The room is bare, with windows just above head level, and just a few chairs scattered around the edge, as a result these women simply sit on the floor and rock back and forth, or walk aimlessly around in circles. (p 26)
>
> Are we as volunteers at Stoke Park still questioning, innovating, improving what we do at the moment? If volunteering at Stoke Park is losing its youth vibrancy, it is because there is not a flow of ideas, it is because we are retreating from our sand of regarding the patients as people like us, who happen to be mentally handicapped. p 44

As I enjoyed being with the children, I continued volunteering at weekends in term time and holidays and eventually persuaded my parents that I would work as a Nursing Assistant there for a year after my A levels.

2.2 1973-1974: Nursing Assistant, Mental Handicap Hospital:

As a Nursing Assistant, I worked on one of the children’s wards which had by then been split to two seperate living groups across the two top floors. I worked on the middle floor with 32 children and young people with severe mental handicaps aged 7-19 years. We might have only 2 staff on a shift with no qualified staff and myself (aged 18 years) as the most experienced.. Some of the children and young people had complex epilepsy and many had “challenging behaviour”. Some were small, frail and had some physical disabilities and were vulnerable from the more energetic, boisterous children and young people. With these staffing levels, we would “herd” the children and young people from day room to dining room to dormitories. We did a lot of laundry sorting and making up “bundles” of clothing for each of them. As many were doubly incontinent, changes of clothes were frequently needed. We had insufficient staff or toilets to assist them develop continence skills. There were no toothbrushes, so teeth were not cleaned either morning or evening. We might be either posted as “dayroom duty” by the door, so the energetic children would not escape. In the evening, children would be undressed by the day room door in front of all the others. The other staff was posted by the one shower cubicle, a few yards down the corridor, and received the undressed children to “hose down” (rather than properly shower them), dry, dress in nightwear and take back to the dayroom.

As I enjoyed working with these children and young people so much, I’d started considering future possible careers which would enable me to work in, and contribute to, the field of mental handicap. I asked advice from some of the medical student volunteers who still came to take children out at weekends. A few were undertaking intercalated degrees in psychology and identified psychology as the key discipline likely to make the major contribution in the coming years (more than nursing, therapies, medicine). I began to look into psychology degrees and routes to Clinical Psychology Training.

In the final summer months of my year’s post, I had some radically different experience of the children and young people. I was the sole hospital staff to accompany groups of four children and young people to a cottage in Wiltshire for a week’s holiday along with volunteer students from Bristol University. The volunteers organized the cottage, transport and food and one trained nurse, who was a sibling of one of the volunteers, who was allowed to oversee medication and any health issues. I learned a huge amount about children and young people with learning disabilities during those weeks and about expectations, stereotypes, development and myself! Possibly, I learnt more than I have subsequently learned in the 40 years between that experience and now. The children's mood, energy, skills, communication and behavior changed markedly with a change of environment, closer adult attention and higher expectations of participation and learning. Extracts from a report on the holidays I wrote for the senior management illustrate:

> ….golden opportunity for the children to have a taste of living in a home environment, for them to have a real holiday …. and for me, as a staff, to

> observe the change in their behaviour as a result of this change in environment. Generally, they became more adventurous than usual, certainly far less withdrawn than when on the board as they were given the freedom and encouraged to use their own initiative in matters of choice, even in simple cases e.g. whether to stay inside or play in the garden, whether they wanted a drink and if so, to help themselves.
>
> There was an improvement in their self-help skills and social habits especially in their table manners. At meal times they behaved well and tried hard to use the cutlery provided. Some of them would help by carrying dishes to the kitchen for second helpings or for washing up. Dressing and undressing was improving, toilet habits were cleaner than usual as there was enough time and people to ensure frequent and worthwhile visits to the loo. The children settled down quickly at night and slept deeply from genuine tiredness caused by the activity of the day. During the day, they were usually eager to join any walking expedition or trip in the minibus but were given the chance to stay at the cottage if they seemed particularly tired or happy in their own game in the garden. All the children seemed brighter and happier than usual; they sang more, played more, were more affectionate and responsive than usual. It was an opportunity for them to show their individual capabilities and potential which are overlooked because of staff shortages on the ward. The holiday was an invaluable experience for the children, and for the accompanying staff.
>
> Having seen the great improvement in behaviour and change in character in such a short space of time, my belief that these children need to live in a family environment to develop was proved. Surely more could be done in the hospital to try and obtain a more homely atmosphere, for example, with more staff, a grouping system and improvements to the ward environment.(Wells ‘B’ Cottage Holiday Internal Report to Hospital Management, September 1973, Rowena Rossiter, p.1)

2.3 1974-1977: Psychology Degree

During my first degree, I continued to work in vacations as a Nursing Assistant at the same Mental Handicap Hospital until the economic situation led to a ban on any short term appointments.

In the first and second years of my degree, I volunteered at the Toy Library organised by the lecturer in Abnormal Psychology . This lecturer had adopted a daughter with Downs Syndrome and had an active role, as a parent and professional, in the Downs Children’s Association (as it was then named). My role at the Toy Library was playing with children with disabilities, making and serving refreshments for them and their parents, talking with parents, sitting in on some talks given by professionals.

During my degree, Child Development, Abnormal Psycholgy, Social and Cognitive Psychology and developing and utilising research skills wre of particular interest. In the second year, participating in data gathering data with a senior lecturer for a series of studies in infant schools investigating aspects of Piagetian theory extended my interest in applied research. My final year research was a compartive study of mother- child interaction in preverbal Downs Children and typically developing children. Based on Colwyn Trevarthen's early work (Trevarthen,1977) and using fine grain video analysis, it identified and compared elements of interaction and communication, attachment behaviours and reported on some of the technical issues in measurement of interaction. My research dissertation was awarded the highest mark for the year. This, along with advice and support from my supervisor, encouraged me to think more positively about research in general, and this area in particular. I was accepted to extend this work and undertake a PhD (thinking I would be unsuccessful in gaining a Clinical Psychology Training place- whereas I was successful). Some of the issues from this initial research have been developed and revisited in subsequent practice and research including the focus on social interaction and skills (publications 1, 4), relational issues and use of groups in developing emotions management skills (publications 5, 6, 7, 8,) in people with learning disabilitiesemotional issues.

2.4 1977-1980 Postgraduate Professional Clinical Psychology Training and Research:

I was really fortunate to undertake my 3 year Clinical Psychology post-graduate training as a Probationer Clinical Psychologist on the Wessex Regional Health Authority Clinical Psychology Training Scheme. The Health Care Evaluation Research Team, headed by Kushlick, was part funded by Wessex Regional Health Authority and was based there. Hence, there was a vast amount of excellent research regarding learning disabilitiy services occuring and being published. Service provision and development in the region was heavily influenced by this across the lifespan from Portage, preschool home based early intervention (Smith et al., 1977) through to evaluation of the adult Locally Based Hospital Units (Kushlick, 1977, 1978)

On my core Mental Handicap placement, this research was already influencing re-provisioning plans for community provision to replace hospital services and also plans to improve services within hospital . Helping Mentally Handicapped People in Hospital (1978) and the other National Development Team pamphlets (1977) informed our clinical practice and priorities (for example, a newly formed Training Team, as recommended in Helping Mentally Hanidicapped People in Hospital, and Joint Planning for, and oversight of, Day Services and sectorised community developments were part of my experience. My supervisor had moved from St Lawrences, Caterham, where a series of "action research" projects led by Diana Cortazzi (Cortazzi, 1973, 1974; Revans and Cortazzi, 1973) had created postive change and an understanding of the utility of this approach and need for attention to organisational aspects. The organisational "buy-in" and commitment across all layers of the organisation and service provision, along with energetic and effective professionals and managers enabled significant developments within both operational units, District and Regional Health Authorities. Community provision was developing including smaller residential units, day services with innovative activities; staff training initiatives across health and local authority staff were being trialled. Clinical psychology was at the forefront of many of the developments as a key member of the Management Team, leading projects and training.

On my elective, specialist placement, I spent my final year working three days a week in a community-based Mental Handicap"service with an additional one day for my research which was carried out in this service, and one day in community Adult Mental Health. The Mental Handicap residential services were fairly unique in that there was no large Mental Handicap Hospitals in the District, only two "Kushlick" Locally Based Hospital Units (albeit for 20 – 25 adults). There was a newly established multi-agency Portage service modelled on the initial research based service in the neighbouring Health District (Smith et al., 1977) and good links with schools, educational psychologists and day services.

In addition to a wide range of innovative clinical experience directly with service users, their carers and the services, I undertook a research study to develop and evaluate structured activity group to increase social interaction amongst adults with severe mental handicap, produce a manual and train staff and compare psychology and staff led groups. A substantial report of this was written up for my Postgraduate Clinical Psychology Qualification and a summary was published (Publication 1).

Contextual issues influencing my and others roles included the Trethowan Report (1977) expanding roles for psychologists with more intervention and application and a more independent professional identity. Understanding the history of the NHS as well as key psychological theories and evidence (learning, developmental, social, systems) and critical models of disability and mental health (Szasz, 1974). I observed others, and was supported myself, to work in more innovative roles, conceptualising, developing and delivering psychological interventions at a range of levels, undertake research, psychology integrated into management (all levels)

3.1 1980-1982 Basic Grade Clinical Psychologist, Kingston and Richmond Health Authority, during this time an NHS reorganisation necessitated a split of localities, I stayed in the reconfigured Richmond, Twickenham and Roehampton Health Authority.

My first qualified clinical psychology post was based at Normansfield , which had been subject of a enquiry in 1978. It was a really exciting post, at a really exciting time, following appointment of a post-enquiry Department of Health appointed Task Force including Dr Joan Bicknell (who became first ever Professor of Psychiatry of Mental Handicap), Sue Gardner, Senior Psychologist (who later served as President of the British Psychological Society) and David Sines, then Nursing Officer, now Professor). Sue Gardner, my lead psychologist, had worked in Cardiff, where the Applied Research Centre with key research figures, for example Jim Mansell, who was to lead the Tizard Centre at University of Kent, and Roger Blunden, were energetically undertaking, disseminating and encouraging research (NIMROD, Cardiff and Vale of Glamorgan Community Health Councils, 1977; Mathieson & Blunden, 1980; Blunden & Revill, 1978) which led to the All Wales Strategy (1981).

Working with highly skilled colleagues, in an exciting period of service change, in hospital and community settings involved a range of psychological service delivery at direct service user level (such as neuropsychological assessment, sexuality assessment), staff, families and carers (such as behavioural and systemic interventions, coworking with, training, supervsion and consultation with other professionals including nurses, therapists) and across whole service sysyems (such as devising and implementing a new person-centred care planning and review process in hospital, co-developed and delivered staff training on behavioural principles and goal planning with in-built evaluation and follow-up, developed and co-supervised Portage Home Advisory Service for pre-school children with developmental delays,” Therapeutic Advsory Group” to move from medical and care model to a developmental model – role as Secretary; innovative Community Mental Handicap Team (CMHT) development and delivery- role as Chair of Richmond CMHT in last year. Research and publication was encouraged, hence I coauthored the chapter ‘Working with Pre-School Children’ for the new text book “Community Care for the Mentally Handicapped” text book (Bicknell and Sines, 1982) and Chaired a multi-disciplinary Research Working Party (Professor of Human Nutrition; Consultant Paediatrician; General Practitioner; Clinical Psychologist) which successfully prepared and steered our research bid through local Ethical Committee, through to Regional Research Application (granted) to investigate effects of Portage Service and Nutritional Supplements on the development of preschool children with developmental delays.

As Mental Handicap Clinical Psychologists, we were part of an Area Psychology Department which supported innovative service and professional developments, cross specialty learning and collaboration, advice to the Area Health Authority and consideration and problem solving of professional issues with links with our professional body (Division of Clinical Psychology of the British Psychological Society) and a Regional Psychology Advisory Committee. Newly qualified psychologists met as a specific group to consider our specific issues relevant to our grade and as a development opportunity. Five of us co-organised and Chaired a Regional Clinical Psychology day conference in 1982 with key national speakers including the Clinical Psychology Adviser to the DH.

The removal of the NHS Area tier of organisation, leaving only Districts following the 1982 NHS reorganisation created considerable consternation in relation to its effect on services and psychologists. Options for reconfigurations were collaboratively discussed, Option Appraisals developed and reports sent to appropriate layers of management at unit, district, AHA and RHA levels. This helped inform possibilities and practicalities for the “new world” and enabled the choices and tranisitions to be as transparent as possible. A freeze on gradings and new posts followed the reorganisation leading me to move back to the District where I’d spent my final year of training for a Senior position.

Clinical Psychology Trainees were routinely on placement and I was involved in supervision and academic teaching. Influences on my practice and development included energetic, motivated multidisciplinary colleagues and managers, integrating a range of applied theories and evidence: behavioural, developmental, systems (families, teams, service systems, organisations), normalisation/social role valorisation, involvment in developing and evaluating training and new service delivery e.g. Portage, Community Teams. Psychologists were seen and used as innovators and evaluators and linked to and in management at all levels. Clinical, service development and organisational contributions led to my coauthoring a book chapter

3.2 1983 –1985 Senior Clinical Psychologist (Acting Principal covering maternity leave), Basingstoke and North Hampshire District Health Authority

I returned to the service in which I had spent much of my final year of training with increased skills in, and conceptualisation of, applied clinical psychology. The Clinical Psychology service was expanding (my post was new, other new posts included one in Physical Disability as part of an innovative multidisciplinary team and mental health).

Clinical, service development/innovation and research examples included provision, co-ordination, management and development of multi-agency Portage, developing related in-service training and liaison across all the whole preschool landscape of specialist and non specialist professionals (therapy, medical, education, social care) and agencies, design, delivery and evaluation of three day Portage Workshop for district and regional staff and at national level, user evaluation (parents) of Portage service (user involvement in this research planning, implementation, analysis) led to service improvements and I presented the project at the National Portage Conference; development and co-ordination of localised Community Mental Handicap Teams, provision of clinical services within the community team and residential services for people with mental handicap; initiating and collaborating in key staff training projects for community and residential staff (behavioural approaches, normalisation, goal planning, induction programmes, Health Visitor workshops) and pilot of innovative social skills groups for people with severe learning disabilities incorporating behavioural and cognitive elements and collaborating with with day service staff (tape slide training package commissioned, publication 8 and more strategic service developments such as services for people with learning disabilities and challenging behaviour, roles of psychiatrists

Regional Applied Psychologists in Mental Handicap (Clinical, Educational, Social Service, Applied Research Psychologists from Health Care Evaluation Team) collaborated to discuss practice and ethical issues, develop and deliver multidisciplinary and multiagency training, (day workshops on Goal Planning and Behavioural Approaches), service development, research and maximising contribution of psychology at diiferent service levels and different service settings.

There was psychology representation on Service Management Teams and high profile interest in psychology services and developments e.g. the District Genral Manager and Planning Manager’s involvement in setting up the multiagency Portage service.

Clinical Psychology Trainees were routinely on placement and I was involved in supervision and academic teaching.

My interest in “giving psychology away” by influencing service development and delivery to improve psycholgical skills of a range of staff, elements of care delivery and integration led to a desire to undertake a modular Master of Business Administration (MBA).

My work was influenced by the legislation (new Education Act), rich conceptualisation of, role models and encouragement for different levels of work (psychology as innovators in individual interventions and groups, cognitiveand social aspects in addition to behavioral; psychology in management - all levels) and contributed to publications, national Portage Conference, tape slide programme development (Publication 8).

3.3 1985 –1988: Senior Clinical Psychologist/Project Manager East Berkshire Health Authority

East Berkshire were keen to appoint a Clinical Psychologist to lead and manage a project team to improve and transform care within another hospital which had been the subject of an inquiry and staff imprisoned for cruelty. Another very challenging and supportive service environment and phase for innovating and applying psychology. The Management Team and Psychology Service appreciated the benefits that my MBA inservice projects could bring. I lead a team of four graduate “Psychological Technicians” on yearly fixed term contracts. Initially this was a one year trial, extended to an ongoing service commitment because of the positive outcomes.

Clinical, service development/innovation, project management and research included the introduction of action research projects to improve quality of service and achieve a high quality developmental resident-centred model of care within a traditional mental handicap hospital such as piloting and developing clinical and support staff training material (use of packages, development of new material including tape slide and video, see publication 8), successful networking with all levels of management and staff within care settings so selection, initiation, implemention and evaluation and disemmination of projects were integral to the organisations priority goals and lessons from the projects were woven more broadly into organisational and care processes.

Action Research Projects I planned, managed,supervised evaluated included:

Clinical :

- Creating change in ward based services - towards personalised care
- Consolidating and maintaining change in ward based services (also MBA inservice project)
- Developing Social Skills through Mealtimes (publications 4 and 8)
- Development and pilot of "Learning to Learn" a multi-disciplinary assessment for identifying 'pre- requisites for learning' to help carers plan appropriate goals and effective teaching methods for children and adults with complex learning disabilities.
- Design, implementation, evaluation of "Life Planning" Personalised Care Planning and Performance Review System and training video).

Organisational:

- Design, implementation, evaluation of training for Support Staff within hospital to support new model of personalised care (publication 3)

Broader based MBA inservice projects:

- Evaluation and Enhancement of Management Development programme
- Design and Implementation of Appraisal and Performance Review System
  Value for Money Issues in the Planning and Provision of Health Services
  Dissertation

Other MBA assignments (literature reviews, analysis, application to action research projects and programme and broader NHS development and delivery issues) included :

- Strategy and the NHS
- Relevance of Marketing to the NHS, led to lecturing commissions on marketing for Health MBA at Keele University and Clinical Psychology Management and Leadership Programme at the NHS Training Centre in Harrogate)
- A Model for Change in the NHS

I contributed to training clinical psychologists through supervision of core and specialist placements, to the overall psychology service development and management, to strategic developments such as community reprovision, challenging behaviour services with an innovative model of outreach team linked with only a small number of inpatient assessment and treatment places (Keene and James, 1986, Who needs hospital care?) and Regional Psychology Advisory Group Briefing Paper development on Challenging behaviour services.

Project based post and MBA extended skills and interest in “giving psychology away”. Although promotion was offered into specialist Challenging Behaviour Lead role, this seemed narrower than scope and contribution I wished to make so I moved to a Head of Specialty post.

Contextual issues and influences included integrating behavioural, developmental (more focus on early communication and sensory factors), systems, organisational, adult learning, team functioning, action research, assessment and goal planning, operating across multi levels with psychology as innovators, creaters, evaluators, maintainers of change at organisational level (no individual referrals, project work only) and psychology involved in management at all levels
Publications 2, 3, 4.

3.5 1988 – 1992 Consultant Psychologist, Head of Specialty – Clinical Psychology Services for People with Learning Difficulties, West Surrey and North East Hampshire Health Authority

A really interesting developmental phase in service delivery and development.

Successfully recruited excellent staff to vacant posts in time when psychology recruitment, especially in Learning Disabilities, was difficult. Clinical, service development and projects/research included extending and developing clinical psychology service through successful recruitment and increasing psychology establishment for community and resettlement initiatives, priortising clinical and service development goals with senior managers across health, social services and education; peer support mechanisms within psychology and multidisciplinary teams (hospital and community), practice development (integrating developmental, cognitive-behavioural, systemic approaches), development, collaboration and supervision of groups (including Trainee Clinical Psychologists' major research project comparing verbal and visually based relaxation groups), staff training initiatives (goal planning, Challenging Behaviour), chaired Joint Strategy Group Challenging Behaviour Sub-Group to develop an agreed shared framework for service development and delivery, successful Joint Finance bid for a Service Manager, managed the newly appointed Service Manager, prepared bid for ordinary housing and peripatetic team, co-authored Regional Psychological Advisory Committee Position Paper and Briefing Paper on ‘Service for People with Mental Handicap and Challenging Behaviour’ and the resulting review of services for this client group within the region, circulated to RHA and purchasers/providers in all District Health Authorities, initiating, piloting, evolving and maintaining new Life Planning Process; resettlement, planning and implementation (database and project work for initial phases and research supervision for related Trainee Clinical Psychologists' major research project investigating community understanding of normalisationand the implications for service change).

Clinical Psychology was seen as key to the overall service management and development and I chaired the Mental Handicap Management Team during the six months when the Mental Handicap Services were between substantive Operational Managers.

Broader roles for the application of psychology included advising on the new Project 2000 Nursing Curriculum for the Mental Handicap Branch, completed Regional ‘Change Agents’ Consultancy Skills modular programme,
Invited by Director of Finance, NHS Management Executive, to contribute to

planning, implementing and evaluating collaborative initiatives between service providers and the National Health Service Management Executuves's VFM (Value for Money) unit (from previous VFM research undertaken for my MBA.

Contextual issues and influences included expansion of systems, organisation, normalisation frameworks and incorporation of positive behavioural approaches, adapted cognitive behaviour therapy (Lindsay 1986), All Wales Strategy to contribute to client centred work, community service development, resettlement, innovative challenging behaviour services and psychology in management at all levels (see Appendix 4 Framework for Contribution of Clinical Psychologists in Health Care, developed in this post).

Publications were focused on practice and service related issues e.g. briefing papers on Challenging Behaviour.

4.1 1992 – 1995 Consultant Clinical Psychologist and Manager, Children's Intensive Support Service (for children with learning disabilities and challenging behaviour) Welsh Centre for Learning Disabilities/South Glamorgan Health Authority (following NHS reorganisation, Cardiff Community Health Care NHS Trust)

This move of post was prompted by my partner's relocation. This took us to South Wales where the All Wales Strategy, launched in 1981, had a 10 year review to identify progress and key current priorities. These included greater attention to the development of services for children and young people which had been neglected. Although, the move was a shock, as the intention following my first maternity leave was to return to my familiar and loved Head of Specialty role, it was fortunate timing as my post in Wales was in a specialist Intensive Support Service (for children with learning disabilities and challenging behaviour). A total service transformation was needed so it could offer appropriate assessment and intervention rather than specialist respite which was what it had initially been funded as. The Adult Intensive Suport Service was a nationally recognised example of good practice (Allen, Banks and Staite 1991) and it particpated in the county multiagency Working Party and subgroups to define and implement the new service model.

Clinical, service development/innovation, project management and research included direct involvement in, supervision of, training staff for assessment and intervention with very complex children and families prior to, during and following the service transformation. Having chaired the “Model Services” Task Group, I had researched relevent models, methods, outcomes nationally and internationally to inform debate, I completed the final report whose recommendations were all accepted by the Executive Management Team. In actioning the recommendations, I led the development of the service practice framework, Operational Policy, Code of Practice and Quality Standards, recruitment and training of staff, took the Deputy Manager role for the new service (initial substantive management was invested with the adult service management to ensure we faithfully adopted their model and methods with any necessary adaptations for child, young people, their families and networks). The clinical and service evaluation framework we developed included user-feedback (children, families, referrers, colleagues) which was used to inform service development and external reviews. I steered and supported the Children’s Intensive Support Service through two external reviews in its first two years with the service being given permanent funding (initially set up a 3 year trial) and the service attracted national interest eg contributing evidence to Mental Health Foundation Committee of Inquiry into services for children with learning disabilities and severely challenging behaviour , working-group facilitator at Mental Health Foundation/Foundation for People with Learning Disabilities national conference.

Input to academic programme for South Wales Training Course in Clinical Psychology- roles, history, assessment, adapted CBT for LD.

Contextual issues and influences included clinical psychology completely integrated across management and development (Clinical Director was a Clinical Psychologist), history of psychology-led research driving innovation and service improvement (Applied Research in Wales, Blunden, 1998; Felce, 1986; Porterfield et al 1977, 1980, 1987), All Wales Strategy. Energetic, commited colleagues worked collaboratively across ages, localities, specialties to adapt new interventions (e.g. adapted CBT individual and trial Anger Management Groups; develop positive behavioural support, integrate trauma focused work systemic, organisational change, service transformation, management and service user focused quality assurance.

Busy post combined with personal factors (house moves, birth of children and ailing parents led to part-time post for family commitments) meant little time for publication.

4.2 <u>1995 – 1997: Clinical Psychologist;</u> Weald of Kent (Invicta NHS Trust following reconfiguration) Community Learning DisabilityTeam

Another move of post prompted by partner's relocation and only a lower grade vacancy available close by. Clinical, service development/innovation, project management and research included complex direct clinical work, cowork, supervision and consultation, with children and adults with learning disabilities with mental health problems, challenging behaviour, forensic presentations in homes, schools, day, residential and specialist inpatient Assessment and Treatment services provided by statutory, voluntary and private services; develop and evaluate innovative, multidisciplinary CBT based groups eg feelings, bereavement and "change" groups with day service staff, develop adapted CBT intervention for anger in adults with moderate to severe learning disabilities and challenging behaviour (community and inpatient participants, presented publication 5); training (assessing and changing Challenging Behaviour -specialist Assessment and Treatment Unit and non specilaist community staff; development of 'Assessment and Goal Planning' system for Assessment and Treatment Unit for adults with learning disabilities and challenging behaviour; contributions to development of Clinical Audit/Quality Measures for Psychology Speciality and planning Specialist Service for Children with Learning Disabilities and Challenging Behaviour.

Contextual issues and influences included further NHS reconfiguration taking up energy and resources, developing adapted CBT groups, behavioural, systemic and integrative approaches eg drawing on some psychodynamic concepts with colleague who had undergone training by the RESPOND charity.The geographical demands of the post were unworkable and I thought I could contribute more in a specialised/developmental psychology role.

4.3 1997 – 2001: Consultant Clinical Psychologist (self employed)

This move was prompted by my desire to undertake more specialised work and achieve more flexible working pattern to fit family commitments. Negogiated sessional or short-term contracts for complex clinical and service development and project work, supervision and training and research with NHS Trusts and academic partners, residential schools (third sector) and Youth Offending Team/Youth Justice Board.

Complex Clinical Work included specialised assessment and treatment packages for individuals with multiple needs – learning disabilities, mental health problems, forensic history, history of abuse; independent specialised second opinions (eg complex service planning; service complaint investigations); clinical consultancy on most challenging pupils/patients, eg those facing permanent exclusion.
Service Innovation/Development/Project Work included set up and supervise therapy groups e.g. Anger Management, Anxiety Management, Stay Calm, Keep Cool and Moving On for adults on specialist national inpatient Assessment and Treatment unit (publication 8); set up, run, evaluate Anti-Bullying/Anger Management Group for pupils and young offenders; user Feedback Survey and Report involving service users on Assessment and Treatment Unit for People with Learning Disabilities and Challenging Behaviour – particular focus on Mental Health Act issues; development of individually tailored and group sex education packages for offenders and vulnerable adults with learning disabilities.

Research included Lead Clinical Supervisor for major Department of Health funded research on Prevention of Behaviour Disorders in Children with Learning Disabilities (Maudsley NHS Trust/Institute of Psychiatry), protocol development (intervention), supervision of Clinical Researchers, contribute to data analysis and interpretation, preparation of reports and publications (Chadwick et al 2001); clinical supervision for Youth Justice Board funded research to pilot community CBT based social/thinking skills groups (Think Smart) in Southwark Youth Offending Team (YOT), protocol development , develop supervision framework, supervise Research Assistant and YOT practitioners, evaluate project and report project progress; contribute to research planning for DH funding for multisite trial of SOTSEC-ID (Sex Offender Treatment – Services Collaborative - Intellectual Disability) adapted CBT group intervention, funding awarded (grant holder- Professor Glynis Murphy, Tizard Centre).

Contextual issues and influences included expanding and training others in adapted CBT (including forensic), increased Community Care meant more challenging/risky folk in need of psychology support, contracts with innovative organisations where psychology interwoven into management and service development roles, more NHS reconfiguration.

5.1 SABP 2001 - 2011: Consultant Clinical Psychologist – Children & Young People with Learning Disabilities (+CAMHS 2010-2011), Surrey Oaklands (then Surrey& Borders Partnership NHS Foundation Trust following reconfiguration)

This move was prompted by my desire to refocus on work with children and young people with learning disabilities again (having enjoyed this in Wales) and to rejoin a substantive psychology service to contribute more to overall service development, developing the profession through academic input to, supervision and examination of Trainee Clinical Psychologists.

Clinical, service development/innovation, project management and research included assessment, intervention advice for complex case presentations of children and young people with learning disabilities (from 2010, also children and young people without learning disabilities in a Tier 3 Child and Adolescent Mental Health Service, CAMHS), training researchers for national multisite CBT Group Intervention Protocol for Adults with Learning Disabilities (SOTSEC-ID: Sex Offender Treatment – Services Collaborative -Intellectual Disability), supervision of local SOTSEC-ID groups, development , delivery/supervision and evaluation of adapted CBT based Teenage Keep Safe group (publication 10) and school based emotional management groups (publications 6 and 7); pilots of accessible sex education/keeping safe material for young people with severe learning disabilities in schools; psychology Working Group developing guidance and resources for adapted

CBT with People with Learning Disabilities (lead for Anger and Psychosis modules), chair multi-disciplinary/multi-agency group developing “Better Sleep” guidance and resources for assessment and management of sleep problems; conference/workshops, eg, ‘Working with People with Cognitive Impairments’ multi-professional CBT for Psychosis Conference; “None of Them Are At It – Assessment and Management of Young People with Learning Disabilities who behave in ways which are sexually harmful” at multi-professional ‘Sexual Harm’ Conferences (countywide 2005, national 2010), “Psychological Approaches to Sleep Problems “(Sleep Scotland- national, and local Child Health Promotion Events); professional/service representative locally egTrust CBT Steering Group, CAMHS Local Implementation Group (LIG), Trust Safeguarding Children Steering Group, Operational Management and Quality Action Groups and nationally eg National Association of Independent Schools & Non-Maintained Special Schools (NASS) on emotional health issues in children and young people with learning disabilities.

Research interest and developments building on clinically innovative groups led me to assemble two research teams to progress research plans and funding. The research teams include internationally renowned academics/specialists and user group representation. As Principal Investigator, I have progressed proposals in preparation for NIHR Research for Patient Benefit (RfPB) funding (adapted FRIENDS for Life development and feasibility trial – emotional well being, and adaptation; feasibility trial of Keep Safe groups for children and young people with learning disabilities and harmful sexual behaviour based on learning from SOTSEC-ID and other sources), contributed to DH funded multisite research trial (research design, protocol development, clinical/research training, research site supervision) through SOTSEC-ID (Sex Offender Treatment – Services Collaborative -Intellectual Disability); updated research knowledge/skills through part-completion of Doctoral Programme in Clinical Psychology (Research) - I realised I would need funding for the time requirements to complete the research to the required standard of my research proposal which had been accepted. The RfPB application based on this for the adapted FRIENDS study went through to full Committee- revisions required.

Supervision of Doctoral Clinical Psychology Trainees on Learning Disabilities and Child core placements and examiner for their Critical Review assignments.

Contextual issues and influences included further reconfigurations, pressures to limit roles of psychology (less project, development work and training, more individual case work that can be counted on new electronic records system, child/adult service split- less continuity and less support from relevant colleagues, economic squeeze, government change).

5.2 2011- present: Consultant Clinical Psychologist/Researcher **:** Self employed/part time researcher

Move prompted by desire to develop research activity and strategic professional contribution which seemed incompatible with the ever-increasing service, managerial and governance demands of the post, with significantly and ever-decreasing resources and a reconfigured organisation where research was no longer supported.

Clinical, service development/innovation, project management and research to date has included assessment, intervention consultation and supervision for complex case presentations of, and specialist services for children and young people with learning disabilities; Chair ySOTSEC-ID (young Sex Offender Treatment Service Collaborative - Intellectual Disabilities, subgroup launched March 2012, of the national clinical and research network, SOTSEC-ID, Sex Offender Treatment Services Collaborative - Intellectual Disabilities http://www.kent.ac.uk/tizard/sotsec/ySOTSEC/ySOTSEC.html); member National Challenging Behaviour Strategy Group for Challenging Behaviour Foundation and Expert Advisory Group Core Specification for Children and Young People with Learning Disabilities who have Challenging Behaviours; CYP-IAPT Outcomes and Evaluation Group ; working to increase accessibility of psychological therapies for people with learning disabilities through dialogue with national initiatives/policies (Division of Clinical Psychology, IAPT, BABCP, DH Winterbourne View Review) and practice (e.g. posters at BABCP 2011 and 2013, guest co-editor of Clinical Psychology and People with Learning Disabilities special edition on Groups, Groups Guidance for Royal College of Psychiatry/British Psychological Society Psychological Therapies and People with Intellectual Disabilities (in press), CYP-LD Outcomes papers (Rossiter et al 2013)).

Research development, as Chair of two Research Teams working up proposals/applications for NIHR Research for Patient Benefit (RfPB) funding:

1. Feasibility Study:adaptation and pilot of "FRIENDS for Life" programme for the prevention and treatment of anxiety in children and young people with learning disabilities. Study duration 20 months. Legacy funds awarded from Foundation for People with Learning Disabilities and matched partner resources for small development project (January- October 2013) to adapt and trial FRIENDS for Life group activities in collaboration with service users. Web reports launched 2014: http://www.learningdisabilities.org.uk/content/assets/pdf/publications/friends-for-life-background-paper.pdf and http://www.learningdisabilities.org.uk/content/assets/pdf/publications/friends-for-life-guide.pdf , presented at national conference October 2013. Paper in preparation. Revised NIHR submission scheduled for September 2014

2. Adaptation and pilot of Cognitive Behaviour Therapy group intervention *Keep Safe* (ySOTSEC-ID - young Sex Offender Treatment Services Collaborative - Intellectual Disability) with children and young people with learning disabilities. Grant awarded (September 2013) by Paul Hamlyn Foundation for protocol development and a proportion of feasibility phase. Part time Research Fellow at Tizard Centre, University of Kent and support by a bursaried PhD student/Research Assistant from same date. Service users contribute to development and feasibility study. Revised NIHR submission under consideration for more formal pilot to be submitted late 2014.

Training linked to above e.g. "Assessment and intervention with adolescents with learning disabilities who behave in ways whch are sexually harmful" (Community Care Conferences, National Offenders Treatment Association workshop); adapting CBT for people with cognitive impairments (posters at national conference 2011 and 2013; papers in submission, workshop); group work and people with learning disablities (workshop for international conference, 2011, papers, guidance development for BPS/RC, coedited special edition of BPS/DCP Clinical Psychology and People with Learning Disabilities), clinical eg Psychological Aspects of Sleep and Attachment and Sleep (Sleep Scotland -national charity).

Register for PhD by Published Work (Route 2) at Manchester Metropolitan University to allow reflection and synthesis of my, and related, published work, taking a long view of LD services. My hope is that this may enable me, and others, to make more effective research, operational and strategic service development contributions in future.

Contextual issues and influences include further economic pressures, new NHS/LA structures and responsibilities go live, reductions in psychology workforce (numbers and grades – British Psychological Society/Division of Clinical Psychology Faculty of Management conference September 2013), progress on implementation of Transforming Care and Concordat slow as demonstrated in Chapter 6.

Appendix 3 Declarations of contribution

Ten publications are presented in this thesis. One is single authored and nine are co-authored. This reflects the collaborative approach to innovation, research and development of colleagues I have favoured. For the co-authored publications, my contribution ranges from 33% to 90%. These contributions reflect contributions to the publications rather than contributions of each author to the clinical development, project or research on which the publications are based. My contribution to each publication is given in the table below.

As the publications span thirty-one years, this posed some challenges for contacting all co-authors for confirmation of Contributions to Publications via the RDPUB forms. For seven of the ten publications, all authors have confirmed my contributions. For two publications, all co-authors who could be located confirmed my contribution. In one publication, (5), it has not been possible to locate either co-author (one is known to

have retired).

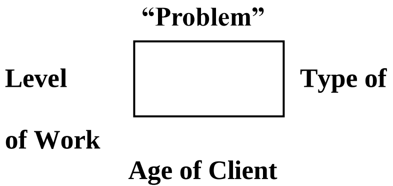
List of publications presented in this thesis

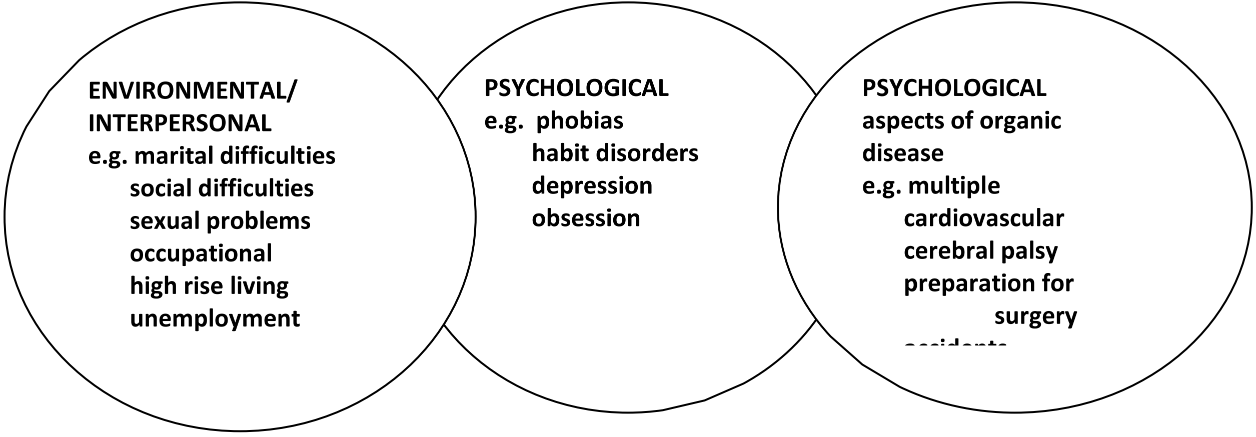
Public-ation	Full reference	Contrib-ution
1	**Keleher, R. J.** and Bridgen, P. R. (1982) Increasing Social Interaction. A structured activity group for severely handicapped people. *Mental Handicap*, 10 (2) pp. 61-63.	90%
2	**Keleher, R. J.** and Cole, C. (1989) Systemic Intervention in Health Care Services: A Case Study. *Journal of Applied Systems.* 16 (no issue) pp. 55-59.	90%
3	Flockhart, K. and **Keleher, R. J**. (1989) Philosophy for Support Staff. *The Health Service Journal.* 9, March, pp. 301-302.	60%
4	Williams, T., Tyson, J. and **Keleher, R. J.** (1989) Using Mealtimes to Develop Interpersonal Social Skills in People with Severe Mental Handicap. *Mental Handicap.* 17, June, pp.	55%

	74-77.	
5	**Rossiter, R. J.**, Hunnisett, E. and Pulsford, M. (1998) Anger Management Training and People with Moderate to Severe Learning Disabilities. *Brit J Learning Disabilities*. 26 (no issue) pp. 67-74.	60%
6	Andrews, K., **Rossiter, R.J**., Daynes, S., Goodwill, A. & Preston, A. 2010 Emotion management and people with severe learning disabilities: the 'Team Mate' group. *Learning Disability Practice,* February, 13 (1) pp. 32-35.	45%
7	**Rossiter, R.J**., Andrews, K. and Tulloch, L. (2011) Emotion management for young people with severe learning disabilities. *Learning Disability Practice,* July, 14 (6) pp. 22-24.	48%
8	**Rossiter, R.J.** (2012) A history of the world..... of groups for people with learning disabilities... in 10 objects. *Clinical Psychology and People with Learning Disabilities*, 10 (3) pp. 15-21.	100 %
9	**Rossiter, R.J**. and Holmes, S. (2013) Access all areas: creative adaptations for CBT with people with cognitive impairments – illustrations and issues. *The Cognitive Behaviour Therapist,* 6 (e9).	80%
10	Wiggins, J., Hepburn, S. and **Rossiter, R.** (2013) Reducing Harmful Sexual Behaviour in Adolescents. *Learning Disability Practice,* October, 16 (8) pp. 16-23.	33%

Appendix 4 Framework for Contribution of Clinical Psychologists in Health Care

Take one element from each side of the square





“PROBLEM” (From France 1982)

LEVEL OF WORK

(From Bender 1979)

Level (1)
- **Individual client**
- **Group of clients**

Level (2)
- **Family**
- **Caretaker**
- **Staff**

Level (3)
- **Unit**
- **System**
- **Service**

TYPE OF WORK

i) Assessment/data collection:
e.g. behavioural observation
standardised tests
interview techniques
surveys
service measures – PASS

ii) Interpretation:
e.g. behavioural principles
environmental factors
motivation
philosophy of service

iii) Intervention:
e.g. psychological strategies
staff training
education

iv) Evaluation:
e.g. single case studies
comparative studies
project
maintenance of change
monitoring and feedback

LIFE SPAN

BIRTH ←---→ DEATH

Appendix 5

Matrix for conceptualisation, commentary and critique of publications

1 Focus/Level of intervention: Codes

LSUD = Service User(s) directly
LO = Service system/organisation
G = Group

LC = Carers/parents/staff
LS = Society, community
I = Individual

	1 ScInt ‘82	2 SystInt ‘87	3 SupStf ‘87	4 ScMeal ‘87	5 AngMg. 98	6 Em1 ‘10	7 Em2 ‘11	8 Grps ‘12	9 Access ‘13	10 Teen ‘13
LI	✓	✓		✓	✓	✓	✓	✓	✓	✓
LC	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
LO		✓	✓					✓	✓	✓
LS									✓	
G	✓		✓	✓	✓	✓	✓	✓		✓
I									✓	

2 Context/Focus for intervention: Codes:

CProf = professional practice
CLeg = legislation

CPol = policy:
CE/S/P = economic/social/political

	1 ScInt ‘82	2 SystInt ‘87	3 SupStf ‘87	4 ScMeal ‘87	5 AngMg. 98	6 Em1 ‘10	7 Em2 ‘11	8 Grps ‘12	9 Access ‘13	10 Teen ‘13
CProf	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
CPol	✓	✓	✓			✓	✓		✓	✓
CLeg									✓	✓
CE/SP			✓						✓	

3 Methodology for intervention: Codes:

Codes: ME = Experimental, quantitative data
MQl = Qualitative data
MAr = Action Research
MUi = User involvement

	1 ScInt ‘82	2 SystInt ‘87	3 SupStf ‘87	4 ScMeal ‘87	5 AngMg. 98	6 Em1 ‘10	7 Em2 ‘11	8 Grps ‘12	9 Access ‘13	10 Teen ‘13
ME:	✓		✓	✓	✓	✓	✓	✓		✓
MQl			✓	✓	✓			✓	✓	✓
MAr		✓	✓			✓	✓	✓		
MUi					✓	✓	✓	✓	✓	✓

4 Publications: **Where/Audience: Codes:**

APrP = Practice focused journals
AA = Academic/practice journals
AM = Management journals
MD = Multidisciplinary
APrTS,Tr = Tape-slide programmes, Training materials
M/C = Manual/Clinical materials

	1 ScInt ‘82	2 SystInt ‘87	3 SupStf ‘87	4 ScMeal ‘87	5 AngMg. 98	6 Em1 ‘10	7 Em2 ‘11	8 Grps ‘12	9 Access ‘13	10 Teen ‘13
APrP	✓	✓		✓	✓	✓	✓	✓	✓	✓
AA	✓	✓		✓				✓	✓	
AM			✓							
APrTs, r	✓		✓		✓	✓	✓	✓	✓	✓
M/C	✓	✓	✓	✓	✓	✓	✓		✓	✓
MD	✓	✓	✓	✓	✓	✓	✓		✓	✓

5 Chrono (Time) dimension Codes:

TE = Early (80s) TM = Mid (90s) TR = Recent (00s- current**)**

	1 **ScInt** **‘82**	**2** **SystInt** **‘87**	**3** **SupStf** **‘87**	**4** **ScMeal** **‘87**	**5** **AngMg.** **98**	**6** **Em1** **‘10**	**7** **Em2** **‘11**	**8** **Grps** **‘12**	**9** **Access** **‘13**	**10** **Teen** **‘13**
TE	✓	✓	✓	✓						
TM					✓					
TR						✓	✓	✓	✓	✓

Appendix 6

Matrix of studies of Anger and Anxiety management Groups and People with Learning Disabilities (2002-2007)

Author	Number of Participants (Completors)	Setting	Anger/Anxiety Measures	Therapist(s)/ Facilitators	Accompanied by Carers	Random Allocation	Rate – blind
1 Willner et al 2002	7 treatment 7 controls	Day Service	Anger Inventory (1) Provocation Inventory (2) Clients Carers	2 psychologists	✓ n = 4	✓	X
2 Hagiliassis et al 2005	14 treatment 15 controls	?	Novalo Anger Scale (3) Outcome Rating Scale (4)	2 psychologists per group	✓ n = 2	✓	X
3 Rose et al 2005	50 treatment 36 controls (11 of whom later treated)	?	Anger Inventory (1) Anger Interview (7) BPVS (8)	3-4 facilitators 1 clinical psychologist + nurses, assistant psychologists	✓ (n =?)	X	X
4 Douglass et al 2007	6 (no controls)	?	Structured Clinical Interview (service users + carers) Glasgow Anxiety Scale (9) Reliable Change Index RCI (6)	Assistant psychologist, trainee clinical psychologist, nurse, OT technician, supervised by clinical psychologist	✓ all	X	X
5 Willner et al 2007	11 (no controls)	Day Service	Provocation Inventory (2) PACS (5) - clients - day service staff - home care staff Reliable Change Index RCI(6)	Assistant psychologist, day service staff, supervised by clinical psychologist	✓ n = 11 (day service staff)	X	X

Appendix 6 continued

Matrix of studies of Anger and Anxiety management Groups and People with Learning Disabilities (2002-2007)

	Length of Treatment	**Components Specified**	**Mean and Standard Deviation Start**	**Mean and Standard Deviation End**	**P Value**	**Follow Up**
1 Willner et al 2002	9 x 2 hour sessions	▪ relaxation ▪ cognitive approaches ▪ role play ▪ review ▪ homework	Figures not quoted	Graphics presented for Anger Inv + Provocation Index	Group x Time $P < .01$ Within group Effect size .68 (moderate) For clients .46 (small) For carers .84 (large)	3 month
2 Hagiliassis et al 2005	12 x 2 hour sessions	▪ self-instruction ▪ problem solving ▪ assertiveness ▪ pictographs	NAS Treatment $M = 81$ Control $M = 80$	NAS Treatment $M = 97.5$ Control $M = 81$	Anova Significant trt effect $P < .05$ $P < + .01$ for follow up	4 month NAS Treatment $M = 101$ Control 82 $M = 80$
3 Rose et al 2005	16 x 2 hour sessions	▪ self + carer monitoring ▪ role play/video ▪ cognitive components ▪ relaxation ▪ problem solving	Anger Inv Treatment 103.8 (12.2) Control 99.9 (13.2)	Anger Inv Treatment 93.7 (12.1) Control 102.9 (12.7)	Anova Significant treatment effect $F1, 82 = 25.76$ $P < .001$	3-6 months Anger Inv Treatment 92.9 (13.2)
4 Douglas et al 2001	12 x 2 hour sessions	▪ diaries ▪ feelings ▪ cognitive components ▪ role play ▪ relaxation		2/6 clinically significant improvement (RCI) 1/6 Non-clinical improvement 3/6 Raised scores		3 weeks
5 Willner et al 2007	12 x 2 hour sessions	As "1" Plus pictorial (Widget) Hassle Logs	Figures not quoted	Graphs presented (PI, PACS) Service user, day service and home carer	$P < .001$ main time effect P1 + PACS including following RCI 73% met post trt	RCI 71% met at follow up

1 Anger Inventory – Benson; 2 Provocation Inventory (PI) – Novaco; 3 Novaco Anger Scale (NAS); 4 Outcome Rating Scale – Miller & Duncan 2000; 5 Profile of Anger Coping Skills (PACS) – Willner et al 2005; 6 RCI Reliable Change Index (Jacobson and Truax 1991); 7 Anger Interview – Benson; 8 British Picture Vocabulary Scale; 9 Glasgow Anxiety Scale – Mindham & Espie.

Appendix 7

Summary table of policy, research, conceptual/theoretical issues in publications

Publication: number & focus- yr of int- bold, yr of pub- not bold	Policy	Research	Other	Theory	Findings & implications
1 Social interaction activity groups **1979/80** 1982	Traditionalists vs comm (Royal College Psychiatrists 1976), NDG; Jay Committee 79	HCERT, Kushlick 1977,Azrin & Foxx 71, Cotazzi, 73, Jeffree & McConkey 1975, Portage 79;NDT & NDG 76-78, Sayal & Brigden 80, Wylie & Thomas 78	Resources: Lear 75, Play Helps, McConkey & Jeffree Let me Play, Envt/philosphy	Learning theory, developmental incl social aspects, staff training, engagement, Learning & generalisation /maintenance.	Is poss to do something constructive to promote social interaction in sevy h'capped people trad viewed as socially isolated p 63. Social interaction increased; participation stabilised & increased over experimental period (poss learning in clients, and/or staff-learning to run grp according to manual
2 Systemic intervention case study (ind & orgl) **1985/86** 1989		Shwartz & Goldiamond, Cullen & Hattersley, Neilsen & Shander 86		Systems theory; gestalt problem solving; systemic approaches in family therapy & organisational change'; constructional vs pathological p58/59	Relevance of systems theory in change in health care. Recommendations- mandate, motivational anal, resources, data- quant & qual
3 Support staff training **1987** 1989	Change of service model,(Better Services, NDG) Intro of General management (Griffiths Report)	Staff training, Cullen & Woods STEP	Need "Skilled & effective workforce, enable all members of staff to contribute to service" p 301, "participative decision making & increased communication"	Management /organisational	Qualitative data showed some individuals knowledge scores improved greatly. Overall no significant difference between experimental & control groups (knowledge, attitudes or reported contact with residents) post training. 92% respondents thought having sessions like this was a good idea,
4 Mealtimes groups **1987** 1989	NDG, Comm living	Defs in soc skills Matson & Andrasik 82, lead to placement breakdown Schalak & Harper 1978. Soc skills training, gen & maint issues Roberston et al 84, Kazdin & Polster 73 conv in wksp, Matson et al		Learning, behavr, cog/mot aspects commn/soc skill	Most imp finding of study, even in a short time span and using very simple teaching methods, mealtimes can provide a natural & age approp setting for successful soc skills trg. Feedbk staff, practical instr & modelling easiest (best) Ind diffs, cost effect, other poss eg leisure. Naturalistic, meaning ful Felce et

		80 soc behave class, M & Earnhart 81, natural envt trng best. Errorless learning, Cklts Felce et al 86, Holley 80 (p76)			al 84, Masildover & Knowles 82
5 Anger Management Group mod-sev LD **1996** 1998	Community Placement breakdown	Broader ther than behave Turk & Francis 90, Benson 86,92, Lindsay et al 94; Novaco 78; CYP Young & Franselow Brown, Petersen & Gannoni92, Self esteem p 67,68	Scheduling of groups, staff support; Issues in eval; screening; context, not panacea p73	Behavioural & Cognitive aspects, abilities-SLD, other neuro developmental ASD	Participation & progress throughout group showed people with mod-sev LD were able to make use of the simplified approach to AM. 4 whole ATMS, others some elements. Vis elements, active role play, p71, location neutral, supportive context. CYP BTF diary not helpful , O'Neill 97 helpful
6 Emotion mgt group 1 **2008** 2010	Every Child Matters 2003, VP 01, IAPT &Pos Pract, NICE,	Emerson & Hatton 07, Arthur 03, SEAL 05, Count us in 02, NICE, Pote & Goodban 07, Benso 86, Rossiter 98, Whelan 07, Beail 03, Stallard 07, Attwood 01	Parents inv, FRIENDS, universal, practice & gen, adapted CBT broader…well being , change, adults service users, EI	See left & right cols	Methodolol/ontol/ebp-pbe p.33 Paradigms-constructional approach; pragmatics?-pop, school based, managing other approaches…no science base - eegBrain Gym
7 Emotion Mgt group 2 **2009** 2011	DDA 95, 05, Un Conv, DH, WHO, SEAL, NICE-CBT, No Health without Mental Health, 11, IAPT 07,11	NICE gap LD,, our 2010 pub, Attwood 04, Howlin et al 99,Kaur 09, Boyden 10	Abilities, FRIENDS, Zippy's Friends, universal, practice & gen, adapted CBT broader…well being , change, adults service users, EI	Soc learning theory Bandura, narrative approaches, Ban; White & Epstein	Difficulties finding val measures + refs p 23 Locate in develt psych- stage when can engage in CBT Longer paper with more concept/theory-edited down (check earlier version)
8 History of world of groups **1979-2011** 2012	Health inequal, Early int	Pubs 1, 4, 5, 6 Clin grps-soc skills Attwood 04	Sensory, motivation, social, video, Widen access, ability/MH, group process	Learning & developmental, staff development, CBT, Medicalization, context/life hist, narrative, soc learning, attachmentsystems,	Visual, photos/video Generalisation & maintenance, "natural" environments, neuropsych/abilities, "toolboxes", group process, communication, power
9 Access all areas – adapting CBT **2000-2009** 2013	IAPT, Eq Act	Diversity pubs LD Singh 11, older ads Green 11, Aspergers' O'Donnell 11, CBT LD, Linds 97, Asd Att04, Russell 13, Arundine 12 Leggett, Kirkland, Clements, O'Neill		Models- cog & cog behav, dep- Beck 79, Fennell 88,anxy Clarke 88, trauma Ehlers & Clarke 2000, psychotic,Linehan 95 Garety et al 2001, Morrison et al 08, Extend "deficit/distortion" model for CBT & LD	Visual, own vocab Ind, Heuristic standard, ebp adapted, personalised Contextual/systemic Own att & beliefs More than IQ/verbal ability Cross care group, core competence, revisit thru intervention journey

10 Reducing harmful sexual behaviour in adolescents **2009** 2013	National Safeguarding Report 2008, OFSTED 2008,	Need- YJB 2005, 2008, Rossiter et al 2010, CJJI 2013, Hackett et al 2013, Murphy & Sinclair 2009, Murphy et al 2010; O'Callaghan 1999, G-Map 2013	Implications: stepped approach needed, safeguarding stat resp but budgetary pressures ; commissioning	CBT, Finkelhor offence model, developmental, group process, Good Lives,	Gp seemed feasible & useful; some resources & methods worked v. well; SOTSEC-ID framework applicable- need tailoring to adolescents,; measures need developing (SAK OK); infrastructure & sufficient planning, review & supervision time

Appendix 8

Summary of methodological factors in chronological order of publication

Publication: number & focus	Experimental Design	Participants	Data collection	Data analysis
1 Social interaction activity groups	One group Double Pretest-Posttest Extended baseline and follow up. Mixed methods	12 adults with severe learning disabilities Mean age 26.5 (17-51 years) 6 residents, 6 day care 8 male 4 female	Observations of participation & social interaction Baseline, intervention & follow up (staff run) (author, supervisor, staff)	Inter-observer reliability Generalised linear modelling (Nederer & Wedderburn 1972 Stat distrib as Chi – square for checking goodness of fit
2 Application of systemic methodology (individual & organisational)	Case study	1 service user, Residential and day services	Clinical data- behavioural observations, meeting minutes, equipment budgets, staff feedback	Synthesis of clinical and organisational data
3 Support staff training	Equivalent Groups (partially controlled) Pretest-Posttest Follow up Mixed methods	Support staff (domestic, laundry, catering works, administration, management Control group	Quantitative questionnaire (knowledge, attitudes, contact with residents) Qualitative questionnaire Before, after & 5 week follow-up	Statistical analysis of quantitative questionnaires Content analysis of evaluation questionnaires 13/15
4 Mealtimes	Equivalent, non-randomised groups (partially controlled) Double Pretest-Posttest Follow up Mixed methods	6 adults with severe learning disabilities; 2 groups of n=3, matched abilities, vary order of 3 training conditions	Observations of participation & social interaction Baseline, intervention & follow up (staff run) Psychology technicians 10 item staff questionnaire	Inter-observer reliability Two-tailed correlated t-test on quanitative observational data. Content analysis of staff questionnaires
5 Anger Management mod-sev LD	One group Pretest-Posttest	6 adults with moderate to severe learning disabilities	Group feedback- participants, co-facilitators & staff supporters. Out of group feedback- staff	Collate and content analysis. Summary theme table participant feedback
6 Emotion management group 1	One group Pretest-Posttest	6 young people (16-18 years) with severe learning disabilities	Group feedback- participants, co-facilitators & staff. Co-facilitators' ratings of concentration, comprehension & participation	Qualitative description
7 Emotion Management group 2	One group Pretest-Posttest	8 young people (11-15 years) with severe learning disabilities	Group feedback- participants, co-facilitators & staff. Co-facilitators' ratings of concentration, comprehension & participation	Qualitative description

8 History of world of groups	Synthesis & reflections of studies and clinical experience- publications 1, 4, 5, 6 and six other clinical groups	See publications 1, 4, 5, 6	See publications 1, 4, 5, 6	See publications 1, 4, 5, 6
9 Access all areas – adapting CBT	Case series	N=3 (ages 14-66 years)	Self-report, family and staff report, behavioural observations, visual ratings for standardised measures, quizzes	Descriptive
10 Reducing harmful sexual behaviour in adolescents	One group Pretest-Posttest	N=4 (ages 14-16 years) Abilities- IQ range 50-70; 3 have diagnosis of ASD	Pre and post Knowledge & Attitude Scale; group feedback- participants, co-facilitators & staff. Co-facilitators' ratings of concentration, comprehension & participation	Descriptive, Content analysis of qualitative feedback