

CONFERENCE REPORT

**Improving the Quality of Life for
People with Learning Disabilities**

Research into Practice

18th November 2005

Scottish Executive, Edinburgh 2006

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Services will strive to continually improve, using the latest research to provide the best treatment, care and support.

(HMSO 1993)

Foreword

This report summarises the presentations and discussions at a conference held at Heriot Watt University on 18th November 2005. The conference was jointly organised by the Association of Directors of Social Work, the Joint Improvement Team and the Mental Welfare Commission, to look at “what works in learning disability services”, i.e. what approaches have proven effectiveness in the planning, commissioning and provision of services for people with learning disabilities. We hope that you will find this report useful and informative. The Joint Improvement Team, in their role of supporting good practice in the context of partnership working, commissioned this report as the first stage of developing practice guidelines for health and social care services in this area.

The conference report was written by Dr Martin Campbell, School of Psychology, University of St Andrews.

Additional copies of this report can be obtained from the Joint Improvement Team and can also be viewed and downloaded, together with more details on presentations, on the JIT’s website:

www.jitscotland.org.uk

Other Websites

Association of Directors of Social Work: www.adsw.org.uk

Mental Welfare Commission for Scotland: www.mwccscot.org.uk

University of St Andrew’s School of Psychology: <http://psy.st-andrews.ac.uk>

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Introduction

This conference report provides an overview of key research findings presented by the main speakers at the conference. In addition, it summarises the discussions of the three parallel workshops, in which participants were asked to identify three current opportunities for getting research into practice more effectively, and three barriers which may prevent research influencing practice. The conference report is for the information of those who attended the conference and others who plan and provide services for people with a learning disability. The conference is the first of a series of events on the theme of learning disability research into practice.

The purpose of the conference was twofold:

- (i) to provide some up-to-date evidence based information relevant to health and social care services, and
- (ii) as a first step towards developing a framework to support implementation of this research based information.

Background

There has been limited opportunity to date in Scotland for health and social care services to examine research findings relevant to services for people with learning disabilities and to explicitly consider implications for practice across service commissioning and delivery. While there is a focus on research in some areas of practice, there is a need to raise awareness and develop approaches to support research into practice for health and social care services more generally, including the independent providers.

The Association of Directors of Social Work, with the Joint Improvement Team and Mental Welfare Commission, organised this conference to draw together some of the key research findings in the UK, with a particular focus on supporting people in community settings. This will be the first of a series of research focused events and seminars on specific topics.

Conducting empirical research to test the effectiveness of agreed principles of care planning has long been a challenge for researchers. It is notoriously difficult, both at service and at individual level, to obtain reliable evidence for what we believe (or hope) “works” in learning disability services. One of the difficulties is making quality concepts measurable. For example, at an individual level, “choice” and “empowerment” are terms widely used in services for people with learning disabilities, but there is little evidence to support the claims of publications and practices designed to successfully promote choice and empowerment.

Few of the protocols and instruments for promoting choice have been subjected to systematic evaluation regarding the quality of the choices which are finally made, and the extent to which any of these tools can make a difference to the involvement of people with learning disabilities in choice making or affect the quality of the choice made is uncertain (Harris 2001).

At a service level, specifying and measuring key outcomes for commissioning services is, at best, patchy across Scotland. No standard, research based measures exist, to guide how new services are developed, and in some areas research lessons about “what works” have only a minor role in planning.

Following the conference, the Joint Improvement Team will support the development of a set of guidelines to support practice and evaluation of health and social care services. Specifically, these guidelines will outline current and suggested opportunities to support research into practice in relation to (a) commissioning and (b) service provision in the context of partnership working with NHS Boards, Community Health Partnerships, local authorities, provider organisations, and users and carers. Initially, the guidelines will be specific to learning disability services, but it is hoped that they can later be developed to be more generic, and of use to other sectors of the care services. Similarly, in developing the guidelines, it will be possible to learn from the experience of other care groups and to inform ongoing work.

Policy and legislative context of the conference

It is important to consider policy and organisational developments across the NHS, local authorities and partner organisations in Scotland in relation to service improvements.

Recent policy developments have emphasised the need for joint working between health and social work, and other partners. The lead on developing joint working arrangements was taken by the Joint Future Group, which was set up by the Scottish Executive Health Department (SEHD) in December 1999.

The means of delivering services was outlined in *Partnership for Care, Scotland's Health White Paper (2003)*. This approach to joint working and well-being is reiterated in the *Community Care and Health (Scotland) Act (2002)*, and the new *Local Government (Scotland) Act (2003)*. These specify the roles of health, local authorities and others in improving and delivering health services, whilst *Improving Health in Scotland – The Challenge (2003)*, sets out the challenge of the health improvement agenda. The existing Partnership in Practice agreements, set out in *The same as you? (2000)* should inform, and be informed by local Community Plans and Joint Health Improvement Plans.

Extended Local Partnership Agreements (ELPA) also exist in all areas, and local improvement targets for local authority and NHS sector services are reported through the *Joint Performance Information and Assessment Framework (JPIAF)*.

Delivering for Health was published by the Scottish Executive in October 2005 and sets the national framework, change agenda and key priorities for health services in partnership with local authorities and other organisations.

Since September 2005, each health board is accountable for new local “Delivery Plans”, where performance against targets will be scrutinised by a Scottish Executive Health Delivery Group. This is an initiative to ensure that patients, including those with learning disabilities, benefit from the investment being made in staff and facilities.

Specific developments relating to learning disabilities services include *The Same as You?* (2000), the National Nursing Review *Promoting Health, Supporting Inclusion* (2002) and *NHS Health Scotland Learning Disability Needs Assessment* (2004). Policy developments specific to other groups, such as *For Scotland's Children* (2001), *Adding Life to Years* (2002) and the *Right Time, Right Place* (2002), also have an impact on, and are relevant to learning disabilities services. The NHS Quality Improvement Scotland *Learning Disability Quality Indicators*, published in February 2004, provided the template for the recent national review of learning disability services cross Scotland. These indicators, along with the Care Commission Standards and the developing Social Work Improvement Framework, will provide the framework for integrated inspection.

In addition to the developments in policy, there have been significant changes in the legislative environment. These changes relate to people with learning disabilities, and are applicable across health, social and education settings. Of particular importance is the *Adults with Incapacity (Scotland) Act (2000)* which provides a legal framework for gaining consent or acting on a person's behalf when the person does not have capacity to give or withhold consent. More recently, the new *Mental Health (Care and Treatment) (Scotland) Act (2003)* came into force in October 2005. This places a range of duties on health and social care organisations.

Legislation regarding the prevention of discrimination is relevant to people with learning disabilities. The final part of the *Disability Discrimination Act (1995) (DDA)* was effective from October 2004. Other wider legislation, including the *Race Relations (Amendment) Act (2000)* and the overarching *Human Rights Act (2000)* provides a framework for the delivery of services that are culturally competent, free from discrimination and recognise individual rights.

Main points from speakers' presentations

Full details of all presentations can be seen on the Joint Improvement Team website: www.jitscotland.org.uk; further details about speakers are provided in Appendix 2 of this report.

Professor Eric Emerson: Supported Accommodation for People with Learning Disabilities

Areas covered

- Lessons from history
- The policy context
- Lessons from evaluation research
- Costs & benefits
- Lessons from epidemiology/demography
- Future need & demand

Key messages

- People with learning disabilities are still socially excluded, disempowered, lonely and have poor health, despite highly staffed resources. People with learning disabilities still have little real choice.
- There is a weak association between building design and purpose and life experiences of people with learning disabilities. Resources, costs, and staff ratio have little impact on the quality of outcomes with no relationship borne out in the research.
- In general services appear to be failing people with severe learning disabilities. People with more severe disabilities have poorer outcomes – further emphasising the endemic inequalities.
- There are moderate links between outcomes and participant ability, staff support & staff management practices.
- There is evidence of the impact of some structural characteristics. More dispersed (and smaller) services do tend to provide more positive life experiences (and cost less). Non congregate settings demonstrate better outcomes for people with challenging behaviour. The results from research reinforce government guidance in the UK that care should be taken to avoid congregating together people with challenging behaviour (Mansell Report 1993) when compared to congregate settings.
- The research on needs and supports for people with challenging behaviour shows that :
 - Deinstitutionalisation and the development of community based services for people with challenging behaviour are variable and preferable

- There is no consistent evidence that deinstitutionalisation leads to changes in severity of challenging behaviour.

Conclusions

There is a need to invest in:

- ✓ Dispersed (smaller scale) options
- ✓ Monitoring quality outcomes
- ✓ Effective support and therapeutic interventions for people with challenging behaviour
- ✓ Addressing social exclusion, choice & health as part of wider social justice agenda, address marginalisation and link to wider research on housing etc.
- ✓ Addressing systemic inequalities
- ✓ Expanding volume and range of provision
- ✓ Humility & good intentions
- ✓ Robust capacity planning based on informed needs assessment to take account of current and increasing demand

Professor David Felce: Community Living. How well does what staff do match people's needs?

Areas covered

- Staff input
- Staff performance
- Impact of staff input on staff performance
- Impact of resource or staff input on service user outcomes
- Impact of resource or staff input on service user outcomes

Key Messages

- There is limited availability and implementation of evidenced based effective treatment for people with learning disabilities.
- Variation in staff input: - A minority of variation in staffing per service user is related to service user characteristics with other aspects of the design of services influence staff input. High levels of staff turnover are due more to job security and lack of support than service user behaviour, characteristics.
- Staff performance: Studies examining staff performance across hospital and community settings demonstrate that levels of attention in the community are higher although still low levels of active assistance and encouragement (only 3 minutes per hour active assistance with about a third of the time related to residents). Staff performance does not relate to needs for support - people with lower skills (more severe learning disabilities) do not receive significantly more assistance or encouragement.
- Impact of staff input on staff performance: Evidence of a positive relationship (i.e., higher staff-to-service user ratios leading to service users receiving more attention) (Felce et al., 2002, 2003)

... but ...

- Evidence of a negative relationship between higher ratios and extent to which each member of staff attends to service users (i.e. diminishing marginal returns from adding staff) (Mansell et al., 1982; Felce et al., 2002)
- Impact of resource or staff input on service user outcomes: There were "no links between costs and outcomes" (Cambridge et al., 1994). There is no association between service costs and any indicator of quality (Hatton et al., 1996). The association between costs and outcome is weak (Emerson et al., 2004). Engagement in activity is associated with the extent of attention or assistance, but not directly related to staff-to-service user ratios (Felce et al., 2002; 2003; Perry & Felce, in press)

There is some evidence that more choice and greater involvement in household management are related to lower staff: service user ratios (Felce et al., 2000; 2002, Stancliffe & Keane, 2000) ... or independent of them (Perry & Felce, in press)

Some evidence that more frequent community activity is related to higher staff: resident ratios (Felce et al., 2002)

... but ...

Stancliffe & Keane (2000) found the opposite. (Note: May differ depending on ability of service users)

Conclusions

- ✓ Clearly, having sufficient staff is important...but there is limited evidence that there is a straightforward relationship between more resource intensive services and quality of outcome
- ✓ Certainly, resource input should not be viewed as a proxy for outcome, better to view it as getting the balance right between too few and too many staff
- ✓ 'Active Support' illustrates potential for improvement and better outcomes for service users
- ✓ Staff training is the 'missing link' between resource input and quality of outcome – train staff to provide active support
- ✓ There is a need to ensure effective approaches for people with greater support needs
- ✓ Need to address problem of under occupation of residents

Professor James Hogg: Adult Protection and People with Intellectual Disabilities: Exploring their Multiple Vulnerabilities

Areas covered

- The concept of the vulnerable adult and a model of abuse
- Scottish Executive Response to Adult Protection
- Scottish adult protection aims
- Ecological context
- Positive & negative abuse

Key Messages

- A model of abuse
Research evidence in relation to:
Characteristics of the individual and characteristics of the potential or actual perpetrator (*Nettlebeck, T., Wilson, C., Potter, R. & Perry, C. (2000)*)
- Scottish Executive Response to Adult Protection Pre-legislative consultation process and Adult Protection and Support Bill
 - New duties & powers conferred on public authorities
 - Establishment of Multi-agency Adult Protection Committees to manage adult protection policies, systems and procedures at local level
 - Investigate practice with respect to the protection of adults and
 - Development of an agreed protocol that reflects best practice.
- Case Study: Age Concern Scotland (2004) Interagency Procedures for the Protection of Vulnerable Adults. Edinburgh: Age Concern Scotland.

Positive & negative abuse

Systemic issues for intra- and interagency working:

Care staff in social and health settings need to be made more aware of risks, responses to signs and symptoms and monitoring of special incidents

Enhanced awareness of spectrum of positive and negative abuse among people with intellectual disabilities

Conclusions

Protection guidelines and procedures used to guide research in this area should:

- ✓ Be research-based
- ✓ Have been developed through an interagency, practitioners' working group
- ✓ Take account of failures in practice
- ✓ Take account of existing and future possible legislation and agency responsibilities

Professor Tony Holland: The Impact of Ageing on People with a learning disability

Areas covered

- Social and Health Changes over 20th Century
- Why is getting older a concern generally and for people with learning disabilities particularly?
- Life expectancy and aged related morbidity in people with learning disability
- Implications for policy and practice

Key Messages

- Social changes:
 - From institutional to community living
 - Segregation to integration
 - General to individual support
 - Respect for individual autonomy (choice etc)
- Health changes:
 - Better nutrition and advances in the prevention and treatment of major infectious and other diseases
 - Causes of learning disability identified
 - Increasing life expectancy for people with learning disability
- Why is getting older a concern?

Getting older is associated with:

- Changes in general cognitive and physical abilities (increasing frailty)
- Increased risk of mental and physical ill-health, sensory impairments, etc
- Changing family and social circumstances

Is this also true for people with learning disability?

What should the service response be?

- For people with learning disability:
 - Is the ageing process the same or different?
 - Do same factors predict outcomes in later life?
 - What is 'old age'?
 - Do age-related disorders cluster towards the end of life?
 - How should this inform planning?

- Life expectancy and aged related morbidity in people with learning disability:
 - Life expectancy influenced by additional factors than those in the general population (e.g., severity and cause of learning disability & associated illnesses)
 - Factors in the general population (people with mild learning disability) – illnesses undetected and help not sought
 - specific causes for learning disability associated with particular risks in later life (e.g. Downs Syndrome, Prader Willi Syndrome)

Conclusions

- ✓ The impact of ageing on people with learning disability has implications for policy and practice. Life expectancy will increase.
- ✓ A greater proportion of people with learning disability will live into old age and develop age-related illnesses;
- ✓ 'Ageing' and associated problems is not just related to chronological age (e.g., Downs Syndrome)
- ✓ Social care needs in retirement will increase
- ✓ There is a need for greater awareness of age-related health risks and specific risks associated with some causes of learning disability;
- ✓ There is a need for services that can adapt and respond to changing need;
- ✓ Improved links will be needed with local health and social care services and voluntary agencies

Workshop presentations and discussions

Workshop 1

Dr Keith Bowden: An overview of research evidence on vulnerability and abuse, and data on the use of current legislation (1)

Aim

To give delegates some examples of successful applications of research into practice and to gather delegates' views on what needs to be done to bridge the gap between academic research and professional practice.

Areas covered

- Physical, sexual, emotional abuse – main research findings
- Access to Justice - main research findings
- Health Vulnerability
- Service Design and Response
- Impact of Inquiries Individual cases
- The vulnerability of people with learning disabilities

What makes a difference?

Service based research?
Academic research?
Government led research?
Philosophy?
Inquiries?
Media reaction?
Champions?
Individuals?
Services?

Workshop 1

Dr Margaret Whoriskey & Margaret Anne Gilbert:

An overview of research evidence on vulnerability and abuse, and data on the use of current legislation (2)

Aim

Provide an overview of the use of mental health legislation for people with learning disability (recent study of 1984 Act) .

Areas covered

- Adults with Incapacity (Scotland) Act 2000
- The Mental Health (Scotland) Act 1984
- The Mental Health (Care & Treatment) 2003 Act
- Implications for new legislation, research and practice

Adults with Incapacity Act (2000) and The Mental Health (Care & Treatment) 2003 Act

New legislation provides a range of innovative rights and safeguards such as:

- Minimal intervention
- Named persons
- Access to Advocacy
- Advanced Statements
- Support for Carers
- Safeguards against conditions of Excessive Security

Implications for new mental health legislation

- The use of detention is different for people with learning disability - almost all are on long term detention and some for many, many years
- There is significant variation in the use of mental health legislation across Scotland. This could be due to risks being more difficult to assess/doctors more cautious and/or variations in clinical practice and availability of community and inpatient services. This requires further research to determine outcomes for individuals and the relationship with the provision and adequacy of community based services.
- Very few people with learning disability appeal against their detention although the new Mental Health Act provides an opportunity for regular reviews
- Some people are also on AWIA (part 6) – developing practice for people with ‘offending behaviour’

These findings have Implications for practice and research. In particular further research is required to focus on the experiences of service users and outcomes for individuals.

Workshop 1: Main points and comments from papers cited

Dunne & Power (1990) "Sexual abuse and mental handicap: Preliminary findings of a community-based study"

Ireland One of the early examples of studies of case series showing that this was a real issue for people in community settings and not "just" something institutionally based.

Beail & Warden (1995) "Sexual abuse of adults with learning disabilities"

England Importance of this study in identifying the extent to which the men they were seeing with severe challenging and sexually offensive behaviour had themselves been victims of sexual abuse

Cooke (1997) "Learning disability and abuse"

Reviews significant progress in approaches to managing sexual abuse, but highlights need for greater availability of therapeutic interventions

Dickman & Roux (2005) "Complainants with learning disabilities in sexual abuse cases: a 10 year review of a psycho-legal project in Cape Town, South Africa"

South Africa – project established in 1990 to assist l.d. victims of sexual abuse – complainants prepared for court & psychologists advise investigators and prosecutors. Review 100 cases – have a 28% conviction rate

Rusch et al. (1986) "Abuse-provoking characteristics of institutionalised mentally retarded individuals"

America – notion of abuse provoking – looked at 80 residents who had been victims of abuse within service - indicated for example that aggressive individuals were more likely to be victims of abuse as were those who were more socially disabled also younger more active people more likely to be abused

Cambridge (1999) "The First Hit: a case study of the physical abuse of people with learning disabilities and challenging behaviours in a residential service"

England - Powerful description of two case studies placed well within the context of systems and services.

Strand et al. (2004) "Violence in the care of adult persons with intellectual disabilities"

Swedish study – still frightening figures – community based (in country with good reputation for Id services) – survey of 164 staff members (122 responded) – 35% of respondents implicated in or had witnessed a violent incident and 14% admitted they had been the perpetrators!

Hawkins et al. (2005) "The use of physical interventions with people with intellectual disabilities and challenging behaviour – the experiences of service users and staff members"

Wales – nice example of the impact of physical interventions on the emotions of staff and service users.

Craft (1995) "Abuse including physical, emotional and sexual abuse"

Highlights range of types of abuse perpetrated against people with learning disability.

Jahoda & Markova (2004) "Coping with social stigma: people with intellectual disabilities moving from institutions and family home"
Scotland - Highlights awareness of discriminatory treatment

Sheard et al. (2001) "Bullying and people with severe intellectual disability"
Highlights experiences of bullying within specialist education and need for anti-bullying strategies

Hall (2005) "The entangled geographies of social exclusion/inclusion for people with learning disabilities"
Scotland – Strongly highlights the experiences of the difficulty some individuals with learning disabilities have in achieving real inclusion

Graham (2005) "Intellectual disabilities and socio-economic inequalities in health: an overview of research"
Highlights very significant impact of poor socio-economic status of many people with LD and the impact that this has on their health needs.

Cooper et al. (2004) "People with intellectual disabilities. Their health needs differ and need to be recognised and met"
Summary article based on the information in Health Needs Assessment (quick way of getting a summary – does point out difficulty about research caused by AWI limitations!

Sherrard et al. (2004) "Prevention of unintentional injury to people with intellectual disability: a review of the evidence"
Highlights need to recognise increased vulnerability to injury for people with LD – (suggests twice as likely as general population – therefore a key area to look at to reduce vulnerability) – highlights possibilities for improved safety design and improved staff awareness and monitoring

Levy & Packman (2004) "Sexual abuse prevention for individuals with mental retardation: Considerations for genetic counsellors"
USA Our objective is to educate genetic counselors and other health professionals about this vulnerable population in order to enhance the frequency and efficacy of inquiry into sexual education and sexual abuse prevention training for patients with mental retardation

Hogg, Campbell et al. (2001) "Evaluation of the effect of an open learning course on staff knowledge and attitudes towards the sexual abuse of adults with learning disabilities"
Go next door if you really want to know about this! (Martin) May have been a self selecting positive group but even for them awareness, confidence in identifying abuse and recognition of need for formal systems all improved

Cooke et al. (2002) "The virtual courtroom: a view of justice. Project to prepare victims or witnesses with learning disabilities to give evidence"
Follows English Youth Justice and Criminal Evidence Act which allows a range of supports in court (benefits to come in Scotland) – Computer based preparation – multi-media training to improve access to justice – develop with service users (have not seen outcome data yet).

Harper et al. (2002) "Protective behaviours: a useful approach in working with people with learning disabilities"

Large emphasis on helping people with Id learn importance of reporting things they are uncomfortable with and to understand how to make themselves safer.

Workshop 1 Discussions

Barriers to research impacting /influencing practice

- Information not easily accessible to practitioners
- Insufficient attention to relevance of research and evidence by commissioners, managers and practitioners
- Insufficient attention to the evidence base relevant to people with learning disabilities across generic planning and service delivery

Opportunities

- There is a need to build on the outcome agenda in areas such as assessment, care planning, care management etc. This should link to the JPIAF process and setting of local improvement targets.
- There is now an opportunity to incorporate evidence into standards, regulation, inspection and this is of particular relevance to Joint Inspection.
- It is timely to influence commissioning of services and policy implementation both more generally and learning disability specific. Community Health Partnerships provide a vehicle to influence this.

Workshop 2

Dr Andrew Jahoda: Staff Training – Research into Practice (1)

Aims

- To explore some of the opportunities for getting research in staff training into practice
- To look at possible sources of evidence based research
- To explore opportunities afforded by changes in services

The provision of services: The role of evidence in commissioning

- How can we help people with a training role within organisations to interpret research findings and apply them in practice?
- Evidence should be a means of adding quality to staff training and practice, not a way of stifling innovation.

From hope to daily reality

New service models reflect the changing position of people with learning disabilities in society.

This has largely been achieved through campaigns.

The current challenge is to use evidence to help support staff to maintain progress that has been made, in areas such as employment and supported living.

Opportunities

- An emphasis on evidence based practice by statutory and non-statutory organisations.
- Greater access to research findings than ever before - even if not always very digestible.
- More databases and internet
- A greater commitment to putting evidence into the public domain in order to influence practice, supported by organisations such as the Scottish Consortium for Learning Disabilities.
- Possible sources of evidence based research such as BILD Current Awareness Service, Joseph Rowntree Foundation, Community Care Database, Journal subscriptions, others?
- A more dynamic service sector: It could be argued that newer services are more innovative and receptive to new ideas.

- A requirement for social care staff to have training (SVQ3) - an opportunity to inform the curriculum and a requirement across social work and health professionals to evidence continuing professional development.

Workshop 2

Dr Martin Campbell: Staff Training – Research into Practice (2)

Aims

- To explore some of the barriers to getting research in staff training into practice. Why is staff training by itself is not effective in improving staff performance?
- To look at other influences, including leadership, legislation, subculture, resources and public expectations of practice and training.
- To outline the complexities of measuring the effectiveness of staff training using different outcome measures

“Staff training alone is not an adequate solution to deficits in staff performance”

Ziarnik JP, Bernstein GS (1982)

“There is currently insufficient evidence to unequivocally establish the effectiveness of staff training alone in improving staff practice in managing challenging behaviour.”
Health Evidence Bulletin (1999)

Staff Training – Research into Practice

Some of the barriers

- Subculture
- “But we’ve always done it that way....”
- What/where is the evidence?
- Do we have enough evidence to justify changing training practices?
- *Perceived* quality, relevance and applicability of the training itself
- Researchers assuming that producing and disseminating research is sufficient
- Researchers producing research in inflexible formats
- Research that is not driven by “end user” needs (staff or service users)

How training effectiveness is measured

Various outcome measures to evaluate effectiveness of training:

Subjective outcome	- what staff report about the usefulness of the training
Cognitive outcome	- knowledge gain by staff
Behavioural outcome	- impact of training on staff behaviour
Client centred outcome	- the impact of the training on clients
Organisational outcome	- the impact on the work organisation

Workshop 2 Discussions

Opportunities for getting research findings into practice

- Individual's areas of specialist interest can lead to researching more evidence based practice
- People want to do the best job they can and provide training that makes a difference
- Legislative based training is easy to deliver, monitor and to see outcomes
- SVQs are an opportunity to incorporate up to date research findings in training. Managers are committed to this, it is changing workplace culture, and staff can see why they do what they do. New Workforce Development Strategy to invest in a different form of training for a new type of service, i.e. person centred, community based
- Team training and peer support encourages good practice
- Users and carers are a driver for change – they want better services. This is a driver to provide the “right” training to improve people's lives. Opportunities for training by carers and people with learning disabilities- this is a different form of evidence based training. Non tokenistic feedback from carers in evaluating training – taking account of what is effective training for carers
- A multi-agency approach with joint funding is the way forward, as it encourages evidence based, effective training

Barriers to getting research findings into practice

- Lack of investment in research into effective training – more is needed than “just what is required”
- Research doesn't necessarily tell you what to do to improve your service- it needs to be interpreted and you need to know the context
- Lack of ownership of research – it is often seen as distant, what academics do.
- We should all check out how our service is working; action research in real lives
- General wariness and lack of confidence about how to access research; how it is presented, easy format needed for presentation, e.g. bullet points and clear language
- Financial constraints – staff time, when service delivery is always the priority
- The Scottish Social Services Council identifies qualifications for registration purposes and organisations need to move and target resources towards achieving these qualifications

Workshop 3

Dr Craig Melville

Sarah Hamilton: Promoting Health Lifestyles

Aims

- To explore recommendations for healthy lifestyles for people with learning disabilities
- To identify barriers to change

Promoting Healthy Lifestyles

- People with learning disabilities experience health inequalities and have increased health needs and shorter life expectancy
- There are barriers to accessing services and current policies potentially “widening the gap”

Promoting Healthy Lifestyles - Lifestyle and health behaviours

- Wider determinants of health include: Disadvantage, Choice and autonomy, Employment, Relationships, Spirituality
- Healthy eating. Physical activity. Which types of physical activity? How much physical activity? Why promote a healthy lifestyle?

Barriers to change

- policy guidelines
- residential staffing and resourcing
- location, availability and accessibility of leisure services
- personal finance and budgeting
- lack of choice and autonomy
- work/life concerns
- weather
- safety
- transportation
- health concerns/injuries
- negative support from carers.

Case Study : Sam. The group has 30 minutes to reach agreement on 3 health-related lifestyle improvements that Sam is willing & able to implement.

Workshop discussion focussed on:

Choice and autonomy

Capacity to make informed decisions

The roles of family and paid carers in facilitating healthy lifestyles

Tackling barriers to change

The need for a multidisciplinary approach, with a shared task and good communication

Conclusion

Attempts to integrate research into the commissioning and management of care practices have had limited success to date. The cooperation and enthusiasm of at least five distinct groups of people is needed to improve this:

1. Organisations who commission research
2. Researchers who undertake research
3. Organisations who disseminate research
4. People who commission services
5. Practitioners who make use of research

There are gaps between those commissioning research, those doing the research and those who could make use of it, that is:

Policy makers commission research to make services better and better value for money. This research is more likely to be shorter term and smaller scale

GAP

Researchers want more time and more funding to carry out meaningful longer term research with more people

GAP

Researchers assume that publishing research in traditional ways is enough, but the research is not widely read by practitioners

GAP

Practice is influenced by many factors; research is just one of these

GAP

Even in services where policy is well developed, research based evidence is not implemented in services

OVERALL OUTCOME: Research does not inform practice to the extent that it should.

Key questions from the conference

- To identify the approaches required to support research into practice e.g. local networks, regional networks which builds on existing work exists in Scotland
- How does research evidence feed into policy implementation at a national and local level?
- How can evidence from research with other care groups be used to inform learning disability practice and vice versa? For example, research into abuse of older people.
- What are the key outcomes for commissioning services? How can these be specified in the context of stakeholder, cognitive, behavioural, organisational and subjective outcomes?
- How can services be measured at individual level, rather than the current research practice focus at service level?
- How can policy makers be convinced of the need for long term, rather than short term research to guide practice?
- How do we make commissioners responsible to evidence based research?

The Next Steps

- To identify the approaches required to support research into practice e.g. local networks, regional networks which builds on existing work exists in Scotland
- To develop a framework to support the commissioning process to take account of key research findings and support service evaluation
- To identify options for a potential JIT programme (with others) to support practice across health and social care partnerships
- To identify a programme for a series of research based seminars during 2006-07 and how best to support user and carer involvement
- To build up a knowledge base in association with commissioners and providers of services on "what works" for individualised and small group services

- To record the basis on which commissioners make their decisions for models of care and their experiences in a way that could be shared with others. The development of guidelines “What works and how do we do it?” (*Provisional title*)

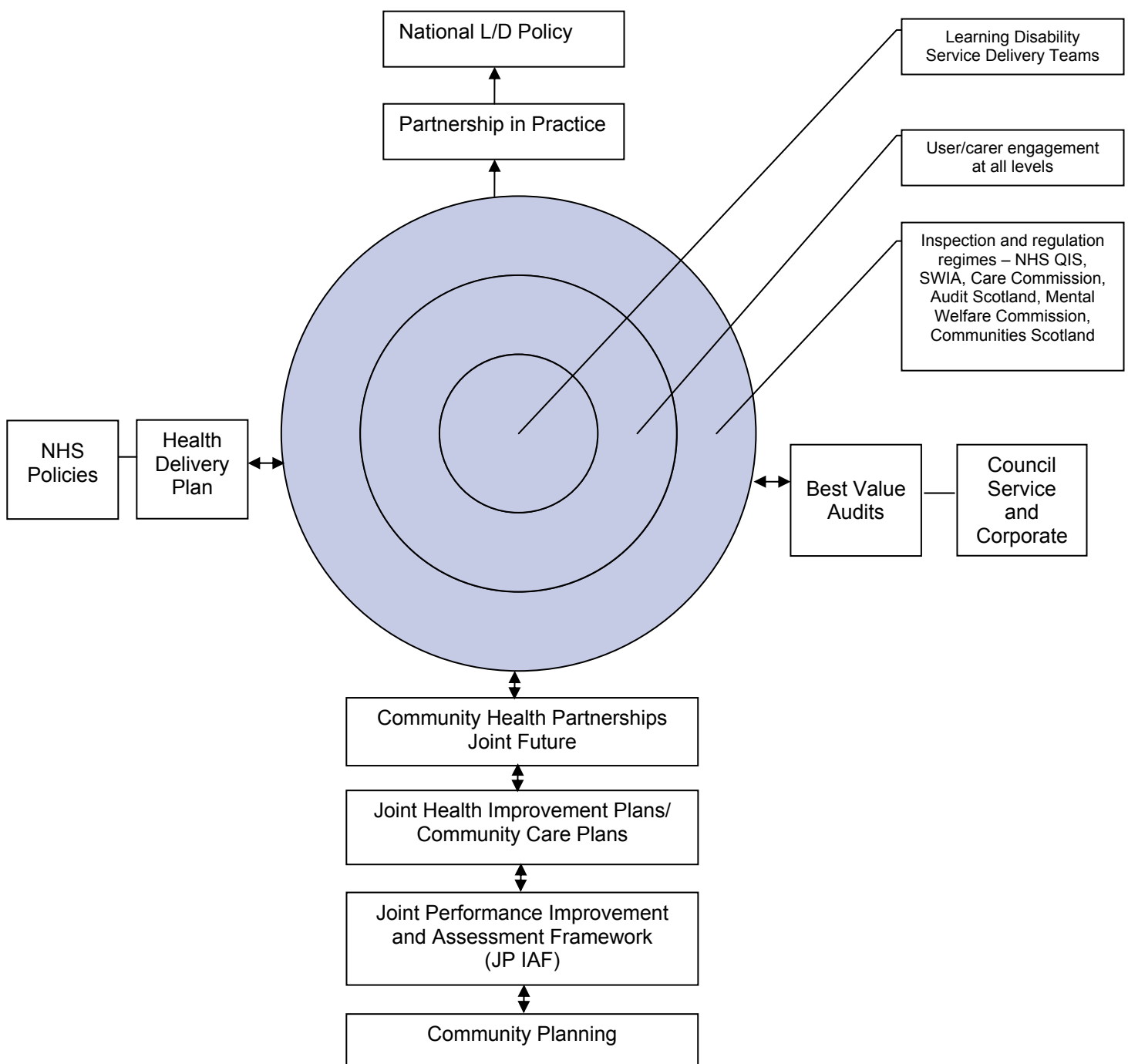
All of the above will be done in the context of continuous improvement of services to people with learning disability, but the recommendations produced will be applicable to other care groups.

Making Connections

Learning disability services sit within a policy context that requires both vertical and horizontal connections. Vertical connections within Learning Disability Services to ensure policy and strategy is reflected in operational practice and service delivery, and horizontal connections to ensure Learning Disability informs and is informed by wider personal services within an integrated public services framework.

Making the connections is a complex process particularly when seeking to balance the need to consult and collaborate with the need to make and implement decisions to ensure efficient delivery of services. This tension was a continuous strand throughout the conference. The diagram below seeks to indicate the range of connections required.

Diagram 1: Complex Connections



Final words/ Evidence Nuggets

1. “The key to the development of better services is management commitment. The knowledge and skills needed to develop effective local services are increasingly widely available; it is the extent to which policy-makers and senior management want to do this which may be the key limiting factor.” Mansell Report 1993

2. “*The greatest impact of research is to generate ideas and concepts for policy makers, rather than specific information on the effectiveness of treatment X, Y or Z*”

Eric Emerson, closing remarks.

3. *The same as you?* Is it really all about services and budgets and professionals and big meetings with fancy words and no-one who uses services sitting at the table? It is not, but sometimes it still feels that way despite all the hard work put in by so many people. What is it really all about? What really matters most?

- It's about my dream to grow up with the same choices as everyone else.
- It's about me being able to grow up with my family.
- It's about me having a home of my own.
- It's about me being treated as an adult.
- It's about getting a bit of support to do ordinary things.
- It's about living my life the way I want to.
- It's about me being able to see the world and all its glories.

For me it's about loving, sharing and laughter. The same as you.

Idem Lewis, SCLD trustee, Vice Convenor of the Learning Disability Alliance Scotland, member of the Scottish Executive's Users and Carers Group.2002 The same as you? Newsletter December 2002

4. In Europe socialisation emphasises individual autonomy and achievement; we live in an era where there is an emphasis on economic self-sufficiency, where we all have to earn our own way. In traditional African countries, by contrast, social responsibility as evidenced by co-operative activity is stressed; *'intelligence is obtained from one's neighbour like fire'*. (Serpell,1986).

Perhaps this is a better model for how we should be sharing research findings and getting these quickly into practice.

Appendix 1

Conference Programme

- 9.00 – 9.30 Registration and Coffee
- 9.30 – 9.40 Welcome – Chairman Professor Roy McConkey, University of Ulster
- 9.40 – 9.50 *Introduction*
Councillor Pat Watters: South Lanarkshire Council
President of COSLA
- 9.50 – 10.30 Supported Accommodation for People with Learning Disabilities
Professor Eric Emerson: Professor of Disability and Health Research,
Institute of Health Research at Lancaster University
- The session will focus on new results arising from the first national survey of the life experiences of adults with learning disabilities in England
 - Summarise the main themes and issues that have arisen from research on quality and cost issues
 - Draw out key implication for policy and practice.
- 10.30 – 11.05 Community Living. How well does what staff do match people's needs?
Professor David Felce, Welsh Centre for Learning Disabilities, Cardiff University
- How well is what staff do in today's community residences match the need of service users, and does staff performance meet service user outcomes.
 - What training better matches service user outcomes.
- 11.05 – 11.30 Tea and Coffee
- 11.30 – 12.05 Adult Protection and People with Intellectual Disabilities: Exploring their multiple vulnerabilities
Professor James Hogg, White Top Research Unit, University of Dundee.
- The concept of the vulnerable adult
 - Characteristics of abuse
 - Models of abuse
 - Scottish Executive Response to Adult Protection
- 12.05 – 12.20 Plenary Session

- 12.20 – 1.30 Lunch
- 1.30 – 2.05 The Impact of Ageing on People with an intellectual disability
 Tony Holland: Health Foundation Chair, University of Cambridge
 Editor: Journal of Intellectual Disability Research
 The challenge to develop services to support people with learning disabilities in later life that are of sufficiently high quality and to set standards for succeeding generations.
- 2.05 – 3.20 Parallel Workshops – Some Scottish experience
- Workshop 1 Protection and Legislation
- Dr Margaret Whoriskey - Assistant Director, Joint Improvement Team
 - Margaret Anne Gilbert - Social Work Officer, Mental Welfare Commission
 - Dr Keith Bowden - Consultant Clinical Psychologist, NHS Forth Valley
- An overview of research evidence on vulnerability and abuse, and data on the use of current legislation.
- Workshop 2 Practical Aspects of Research into Staff Training
- Dr Martin Campbell, Senior Teaching Fellow, School of Psychology, University of St Andrews
 - Dr Andrew Jahoda, Senior Lecturer (Learning Disability), Section of Psychological Medicine, University of Glasgow
- Workshop 3 Promoting Healthy Lifestyles
- Dr Craig Melville, Section of Psychological Medicine, University of Glasgow
 - Dr Sarah Hamilton, Section of Psychological Medicine, University of Glasgow
- 3.20 – 4.00 Plenary and Feedback

Appendix 2

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Appendix 3 Useful links

Recommended research into practice links

Research into practice: News from the Scottish Executive about research in social work and social care

<http://www.researchweb.org.uk/research.html>

Norah Fry Research Centre

This is one of the leading centres in the United Kingdom for research into services for people with learning difficulties. Rigorous research conducted at the Centre evaluates services highlighting good and innovative practice, identifying weaknesses and suggesting areas for development.

<http://www.bris.ac.uk/Depts/NorahFry/>

British Institute of Learning Disabilities

BILD carries out applied research in the field of learning disabilities, and is committed to actively disseminating research findings to ensure the adoption of best practice

http://www.bild.org.uk/policy_research/

Development of the National Electronic Library for Learning Disability In collaboration with the NHS Information Authority. The National electronic Library for Health (NeLH) has as its aim the delivery of best current knowledge, using web based browser technology. NeLH has core collections, and will also have a network of virtual branch libraries. The Pilot site is now live at

<http://www.minervation.com/ld/>

The Scottish Consortium for Learning Disabilities

The Network is for people who are interested in research into things that most concern people with learning disabilities and their families. This research happens in many places across Scotland, including universities. Interest in such research is also shared by many people with learning disabilities, their families, and those who provide services.

<http://www.sclld.org.uk/research/default.asp?p=hc>

Appendix 4 List of Delegates

<i>NAME</i>	<i>ORGANISATION</i>
Antoni Anderson	West Dunbartonshire Council
Edith McRoberts	West Dunbartonshire Council
Sally Lakeman	Leonard Cheshire
Ian Quigley	West Lothian Council
Joyce Ormiston	West Lothian Council
Scott Crawford	Leonard Cheshire
Gregor Robertson	NHS Highland
George McLachlan	Scottish Executive Health Department
Jim Dean	Perth & Kinross Council
Carole Bellshaw	Gowrie Care Centre
Marjory Gibbon	Gowrie Care Centre
Fiona Raffaelli	South Lanarkshire Council
James Thomson	Cornerstone Community Care
Sharon McGee	East Renfrewshire Council
Darren Gracie	Castlebeck Care
Katroina Hendry	Renfrewshire Council SW Department
Brian Lithgow	Renfrewshire Council SW Department
Charmain Ledsham	Brothers of Charity Services
Linda Tuthill	The Action Group
Robin Hamilton	The Action Group
Billy Henderson	East Dunbartonshire Council
Janice Sweeney	NHS Dunfermline
Dr Tracy Sanderson	NHS Lothian
Rona Laskowski	City of Edinburgh Council
Mark Grierson	City of Edinburgh Council
Catroina Barr	East Ayrshire Council
Maria Brown	Inverclyde Council
Joyce Jackson	Inverclyde Council
Connie Johnstone	North Lanarkshire Council
Morag Dendy	North Lanarkshire Council
David Formstone	East Dunbartonshire Council
Jennifer Baillie	Barony Housing Association Ltd
Lesley Malone	Neighbourhood Networks
Marion Shillinghaw	East Dunbartonshire Council
Josephine Barrett	Unity Enterprise
Maria Dawson	NHS Grampian
Margaret Bates	South Ayrshire Council
Kirsty McPherson	Scottish Executive
Julie Murray	East Renfrewshire Council
Innes Turner	East Renfrewshire Council
Heather Harscote	Dumfries and Galloway Council
Mr William Reekie	Dundee City Council, SW Dept
Gail Ferguson	Care Solutions
Dawn Sherwood	Community Social Services
Kirstie McLaden	Community Social Resources
David Hughes	Key Housing Association

Teri McKeand	The Salvation Army
Gavin Steven	The Salvation Army
Andrew Reid	Scottish Consortium for Learning Disability
Gwen Gillespie	Aberdeenshire Council, Social Worker
Duncan MacNaughton	Perth and Kinross Council
Karen Redpath	Angus Council
Judith Proctor	Dumfries & Galloway Council
Helen McNeil	Aberdeen City Council
Suzanne Davies	Perth & Kinross Council
Sharon Reid	William Fraser Centre
Anita Young	NHS Grampian
Lindsay McNair	Glasgow Learning Disability Partnership
Anne-Louise Hayden	Falkirk Council
Gayle Mackie	Falkirk Council
Colin Anderson	Midlothian Council, Social Work
Karen Indoo	Scottish Consortium for Learning Disability
Andrew Miller	Scottish Consortium for Learning Disability
Lisa Curtice	Scottish Consortium for Learning Disability
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Joseph Woods	NHS Forth Valley
Lynsay Mowatt	Orkney Islands Council
Anna Cooper	University of Glasgow
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Jean Butterly	East Ayrshire Action Forum
Caroline Silkowski	Oban, Lorn & Isles
David Ramsay	Key Housing
Paul MacArthur	Key Housing
Claire Leslie	Kirklands Hospital
Susan Cotterill	Kirklands Hospital
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Chris Laidlaw	South Lanarkshire Council
Stuart Storie	NHS Tayside
Moira Healey	Mental Welfare Commission
Douglas Whyte	Mental Welfare Commission
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Martin Cawley	Quarriers
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Harold Boddy	Lothian Primary Care NHS
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Ian McFayden	Argyle & Bute Council
Rajen Mawjee	Transition Service (Complex Health Needs)
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Kathleen McIntyre	Loretto Housing Association
Bernadette Craig	Loretto Housing Association
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Diane Brisbane	Glasgow Learning Disability Partnership
Maria McCluskey	Glasgow Learning Disability Partnership
Jeff Morgan	East Lothian Council
Jean McLellan	Scottish Executive
Bette Francis	Scottish Executive

Staff from South Lanarkshire Council who helped to organise the conference and provided support on the day were:

Anne Marie Smith (Secretary)

Kerry Quinn (Admin. Assistant)

Sally Dunsmuir (Clerical Assistant)

Lynda Stark (Clerical Assistant)

Claire Park (Clerical Assistant)

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Janis Stevenson (Residential and Day Care Officer)

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Annette Bonar - East Renfrewshire Council / ADSW

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