South London and Maudsley
NHS Foundation Trust

Institute of Psychiatry

**Departments of Psychological
Medicine & Health Service Research**

*e*stia centre

Five Year Report
2004 - 2008

Estia Centre

Report on Activities 2004 - 2008

1.0   Introduction

The Estia Centre is a training, research and development resource for those who support adults with learning disabilities and additional mental health needs. The Estia Centre is based on the Guy's Hospital Campus and is an integral part of local services for people with learning disabilities provided by the South London & Maudsley NHS Foundation Trust. The Estia Centre is an Academic Section of the Institute of Psychiatry, the Health Service and Population Research Department, King's College London.

The Centre formally came into operation in September 1999. This report reflects on the Centre's work from September 2004 – August 2008. The Centre has built on its initial success and continues to develop its core areas of business, training, research and development.

This report describes the strengthening of the training department and the continual development of its local training programme offering staff a comprehensive package to support them in meeting the mental health needs of people using services. There has been a particular focus on supporting services with the implementation of the Mental Capacity Act (2005).   The success of the MSc Mental Health is described, with more students starting and successfully completing each academic year.

The research and development activities are reported in detail. The team has continued to produce high quality research in the mental health needs of people with learning disabilities.

Clinical Services

The Estia Centre is closely linked to clinical services for people with learning disabilities that are provided by the South London and Maudsley NHS Foundation Trust. These services include the Specialist Community Mental Health in Learning Disabilities Service, the Specialist Psychology Service and the Weston Unit.

The Specialist Community Mental Health in Learning Disabilities Service (MHiLD)

The MHiLD service consists of psychiatrists and community psychiatric nurses and provides services across Lambeth, Lewisham and Southwark. It also provides psychiatry services in Croydon borough. The service works closely with the local Community Teams for Adults with Learning Disabilities (CLDT), Social Services and local mental health services. The team provides two distinct but intertwined functions; clinical and service related.

On a clinical level the service offers highly specialised assessment, advice, treatment and prevention of mental health problems. Interventions may be home or outpatients based, depending on the needs of the individual. The MHiLD Service uses all the facilities of mainstream mental health services, including acute and medium-stay in-patient beds, and a variety of community resources.

On a service level advice, consultation and support is offered to other clinical services, such as mainstream community and inpatient services and organisations that provide direct support to service users. Training is often delivered in collaboration with the Estia Centre, focusing on educating carers and support staff about the mental health needs of the person.

Specialist Psychology Service

The Specialist Psychology Service consists of Clinical Psychologists, Assistant Psychologists, Behavioural Support Workers and Counsellors working as part of the Community Teams for Adults with Learning Disabilities in Lambeth, Lewisham and Southwark.

The main aim of the service is to work with its partners in ensuring that people with learning disabilities experience a good quality of life. This is achieved by working closely with service users directly and/or with parents, partners, carers or support staff. The service offers a variety of therapies such as cognitive behaviour therapy, counselling and positive behavioural interventions. The service offers a variety of training initiatives through the Estia Centre and tailored made packages for individual service users.

Other areas that the service has been focusing on is supporting people with learning disabilities in making decisions for themselves and ensuring that the rights of individuals who have difficulty giving consent are upheld.   The team also audits the implementation of good practice in services for people whose behaviour is challenging and is developing ways of enhancing user involvement in service and strategy development.

The Weston Unit

The Weston Unit is a specialist mental health unit for people with learning disabilities and additional mental health problems. The unit has a multi-disciplinary composition including nurses, occupational therapists and psychiatrists.

The overall aim of the unit is to provide a high quality specialist service to those who require a period of admission. This service includes assessment, a variety of therapeutic interventions and after care planning. The unit is able to provide an appropriate environment for those service users whose needs cannot be met on a mainstream unit. The unit focuses on maintaining close links with families and friends, staff in residential services, and other community agencies such as advocacy, CLDT and social services.

3.0   Training

Introduction

The Centre provides a comprehensive portfolio of training activities, aimed at a wide range of health and social care staff. The overall aim of the Centre's training programme is to support the development of a competent workforce who are able to meet the mental health needs of people with learning disabilities. The Centre's training programme is divided into the following categories:

1. Training for local service providers.
2. Training for statutory services.
3. Professional training
4. National conferences and seminars
4. A multi-disciplinary educational programme.

3.1   Training for local service providers

The Centre continued to develop and offer its rolling training programme to organisations who support people with learning disabilities in the London Boroughs of Lambeth, Southwark and Lewisham. These services are provided by a variety of charitable and private organisations. Their portfolio includes supported housing, outreach teams, day service and employment projects.

Training is developed and delivered by staff from the Estia Centre in close collaboration with clinical staff from South London and Maudsley NHS Foundation Trust, Southwark Primary Care NHS Trust and people who use services. The programme is developed in response to a bi-annual consultation with local providers, people who use services and changes/directions in policy.

The majority of the programme consists of a series of one or two day workshops, delivered locally in the three boroughs. These are attended by a range of staff from various organisations and are referred to as general workshops. Any of the general workshops can be delivered to individual teams, depending on the capacity of the clinicians/trainers involved. The Centre has also been involved in delivering user centred training, always in collaboration with a clinician involved in the person's care.

The range of general workshops offered by the Centre

Capacity to Consent

Workshops are delivered separately to support staff and managers. They seek to provide participants with the skills and knowledge to meet the requirements of the Mental Capacity Act (OPG, 2005).

Contribute to the Management of Substance Use and Abuse

This is a one-day workshop which aims to provide participants with the understanding and skills required to work with people who may use or abuse alcohol, tobacco or recreational drugs.

Activity and Skills Development

This workshop aims to increase participants understanding of the importance of a person centred approach to selecting activities and enabling people who use services to develop skills.

Introduction to People with Autism

A one-day workshop which aims to increase staff understanding of the needs of people with autism and to develop skills to improve their practice.

Introduction to Challenging Needs

A two-day workshop, which aims to provide staff with up to date non-aversive approaches to supporting people with challenging needs, including assessment,

Introduction to Mental Health of People with Learning Disabilities

A two-day workshop, which looks at how mental health problems can present in people with learning disabilities, a multi disciplinary approach to assessment and intervention, legal aspects and the important role that support staff have in promoting positive mental health.

Mental Health Needs of Older People with Learning Disabilities

A one-day workshop which examines the mental health needs of older people with learning disabilities, particularly Alzheimer's disease.

Risk Around an Individual

This one-day workshop provides information on how people with learning disabilities can be supported to take risks and the role that support staff play in risk assessment and management.

Risk Assessment

A one-day workshop for senior staff in assessing and managing risk in relation to service user behaviour.

Self Injurious Behaviour

To raise the awareness of self-injurious behaviour, it's detrimental effects on the individual and the services available to the individual/staff team.

Working with offenders who have learning disabilities

A one day workshop which provides information on supporting people with learning disabilities who are or who at risk of coming into contact with the criminal justice system or displaying offending behaviour

Total Amount of Training Delivered

Table 1: Total amount of training delivered 2004 – 2008

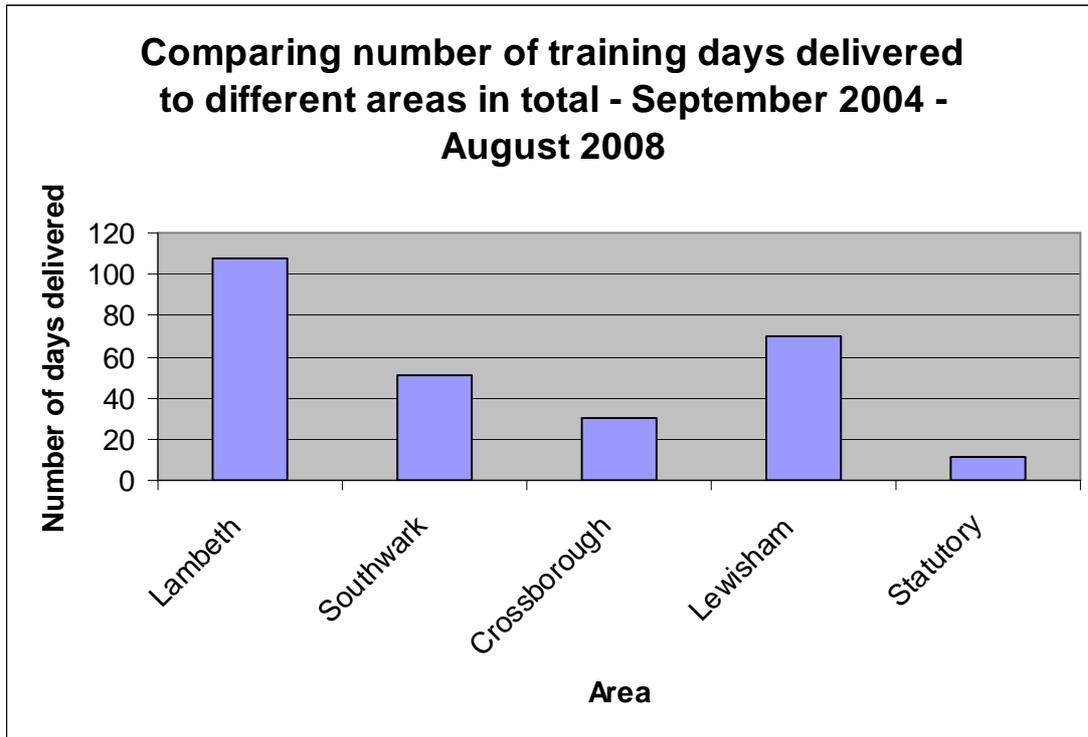| Study Days Delivered	Attendance
270	2709

From September 2004 to August 2008 the Centre delivered 270 study days in Lambeth, Lewisham and Southwark, which were attended by a total of 2709 staff. In comparison to the previous period there was a 16.8% reduction in attendance. The possible reasons for this being:

The previous reported period, detailed the Centre's first five years of operation. During this period we saw a surge of applications and trained an enormous number of staff, as many of our workshops had previously been unavailable. During this reported period, the training programme has mainly been attended by new staff and staff attending training on the Mental Capacity Act.
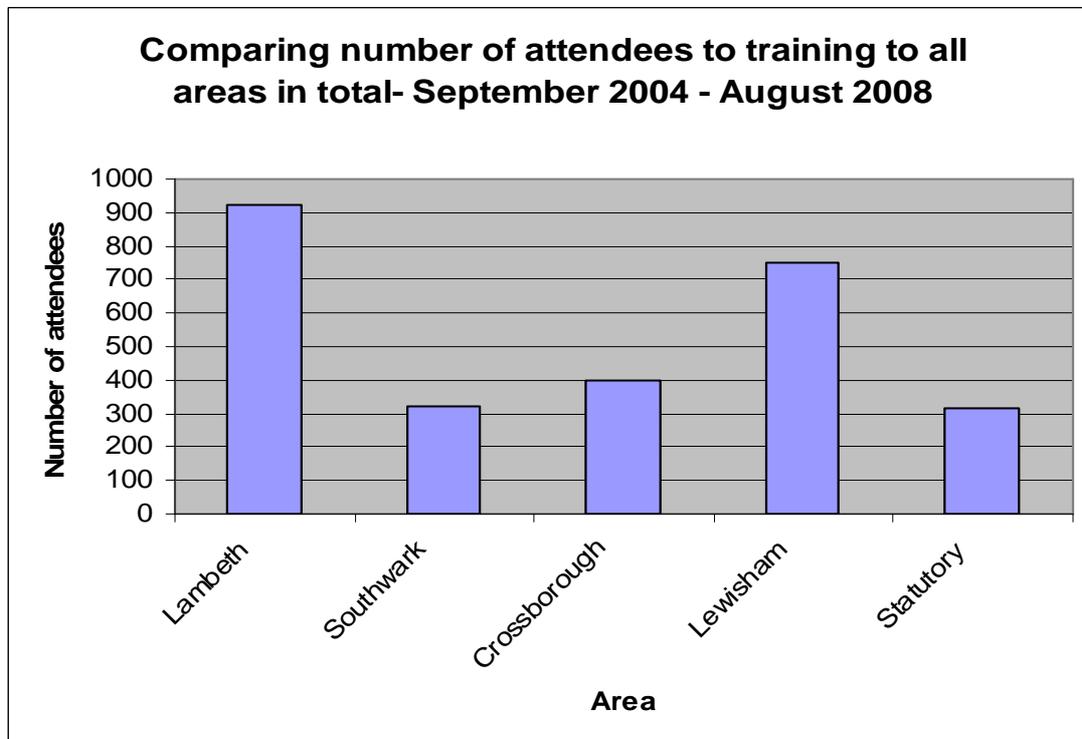
We have seen an increase in the amount of statutory training that social care staff are required to attend and this may have an affect on training such as mental health.

However the training attendance remains healthy and consistent and continues to play an important role in the development of local services and in promoting the mental health of the local population.

Graph 1. shows the number of training days delivered in each area over the reported period.

Comparing number of training days delivered to different areas in total - September 2004 - August 2008

Number of days delivered

Area	
Lambeth	~108
Southwark	~52
Crossborough	~30
Lewisham	~70
Statutory	~11

Graph 2 shows the number of staff attending workshops in each area.

Comparing number of attendees to training to all areas in total- September 2004 - August 2008

Number of attendees

Area	
Lambeth	~920
Southwark	~320
Crossborough	~400
Lewisham	~750
Statutory	~315

Training in the London Borough of Lambeth

The Centre delivers a larger portfolio of training in Lambeth, due to Occupational Therapy and Speech and Language Therapy clinicians being employed by the South London and Maudsley NHS Foundation Trust, who provide a number of specialist workshops. This reflected in the larger amount of workshops and attendance figures.

Table 2. Total amount of training delivered in Lambeth 2004 - 2008

Study Days Delivered	Attendance
108	922

Training in the London Borough of Lewisham

The Centre has continued to contribute to the comprehensive training programme that has been developed by Lewisham Partnership (the commissioning body for Lewisham).

Table 2. Total amount of training delivered in Lewisham 2004 - 2008

Study Days Delivered	Attendance
70	750

Training in the London Borough of Southwark

The training programme in Southwark has been steadily attended. Attendance when compared to the Lambeth and Lewisham may appear poor, this is due to larger organisations in the borough providing in-house training initiatives.

Table 4: Total amount of training delivered in Southwark 2004 - 2008

Study Days Delivered	Attendance
51	323

Cross Borough Training

Several workshops appeal to smaller groups of staff, due to their content and thus are run jointly across the three boroughs, these include:

Self Injurious Behaviour

Substance Misuse and People with Learning Disabilities

Working with Offenders who have Learning Disabilities

Table 5. Total amount of training delivered cross –borough 2004 - 2008

Study Days Delivered	Attendance
30	397

3.2   Training for Statutory Services

Since Valuing People (DH, 2001) was published there has been a drive to support people with learning disabilities to access mainstream mental health services. Though locally this was happening some years prior to a change in policy, the Centre saw this as an opportunity to offer their expertise and support to local adult mental health services. Initially this began with the offer of bespoke training to individual teams, which has been accessed by several in-patient services and various Community Mental Health Teams. Centre staff have also given presentations at Trust wide events held by the South London and Maudsley NHS Foundation Trust. This work also led to the publication of guidance on mental health nursing of adults with learning disabilities, produced by the Centre in collaboration with the Royal College of Nursing.

Table 6. Total amount of training delivered to statutory services

Study Days Delivered	Attendance
11	317

3.3   Professional Training

The Centre, in close collaboration with clinical services, offers excellent opportunities for those undertaking professional training programmes, including psychiatry, psychology and nursing. Students are offered ongoing supervision by experts in the field, have opportunities to partake in all of the Centre's training activities and are encouraged to contribute to the research and development programme. Staff from the centre have contributed to the pre and post registration courses offered by local Universities and also the MRCPsych course at King's College London.

3.4   National Conferences and Seminars

The Centre holds a number of national conferences and seminars each year, often in collaboration with other organisations. The themes of events are generally based around mental health and associated needs and improving the knowledge and skills of the workforce to meet these needs.

Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD)

Over the last four years the Centre in collaboration with Dr. Steve Moss has delivered numerous national seminars to equip clinicians to use the PAS-ADD instrument.

2008

Mental Health and People with Autistic Spectrum Disorders

Continuing from the success of the 2007 conference, this event explored developments in service design and delivery, psychological interventions and transitions.

Meeting the mental health needs of adults with learning disabilities: Working together

This conference explored how the mental health needs of people with learning disabilities could be best be met by a web of mainstream and specialist mental health services.

2007

Assessing Mental Health Problems in Children with Learning Disabilities

The overall aim of this event was to improve the assessment, diagnosis and formulation of mental health problems in children with learning disabilities. It took into account a variety of perspectives and elements that make up a child's life and how they should be incorporated into the assessment process.

Mental Health and People with Autistic Spectrum Disorders

This conference examined the mental health needs of people with Autistic Spectrum Disorders who fall across the spectrum of intellectual functioning. It specifically addressed issues of assessment, offending and the views of people of using services.

2006

Capacity to Consent: A practical approach to people with learning disabilities

Prior to the implementation of the Mental Capacity Act (2005) an event was held to highlight the importance of professionals in supporting people's rights to make decisions for themselves and promote good practice in decision making for those who lack capacity.

2005

Meeting the mental health needs of people with learning disabilities – Therapeutic interventions

This conference explored the range of therapeutic interventions available to people with learning disabilities who have mental health problems.

Primary Health Care for People with Learning Disabilities who have Mental Health Problems

Held in collaboration with The Judith Trust, the aim of this seminar was to provide evidence for the Disability Rights Commission formal investigation in the health inequalities experienced by people with learning disabilities and people with mental health problems.

3.5   Multi-Disciplinary Academic Programme

The Centre has continued to develop its Academic Programme. Each meeting takes the form of a case presentation, delivered by a number of clinicians from different disciplines and then a review of recent publications. Each meeting concludes with a presentation from an external speaker, some of which have included:

Assessment of Parenting Skills in People with Learning Disabilities
Dr. Sarah Bernard, Consultant Psychiatrist, South London & Maudsley NHS Foundation Trust

Civil compensation for victims of abuse. Special guidance for people with learning disabilities
Nicola Harney, Head of Abuse Litigation, Stewarts Solicitors

Behavioural phenotypes and the case of Fragile X syndrome
Dr. Jeremy Turk, Reader in Developmental Psychiatry, St. George's Hospital Medical School

Crisis management of challenging behaviour in people with learning disabilities
Peter Baker, Consultant Clinical Psychologist/Honorary Senior Lecturer, East Sussex County Healthcare NHS Trust/Tizard Centre, University of Kent at Canterbury

The Diagnostic Interview for Social and Communication Disorders (DISCO)
Dr. Judith Gould, Consultant Clinical Psychologist and Director of the Centre for Social and Communication Disorders

Bereavement, Loss and Ageing
Dr. Roger Banks, Honorary Secretary, Faculty of the Psychiatry of Learning Disabilities, Royal College of Psychiatry

Equal Treatment: Closing the Gap: A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems
Philippa Russell, CBE, Commissioner, Disability Rights Commission

Family Therapy and People with Learning Disabilities

Sandra Baum, Consultant Clinical Psychologist, Newham Primary Care Trust

Fetal Alcohol Syndrome – the single most preventable cause of learning disability?

Dr. Raja Mukherjee, Consultant Psychiatrist, Surrey Boarders Partnership Trust

4.0   Advances in Mental Health and Learning Disabilities

In 2007 the Centre in collaboration with Pavilion Publishing launched its journal 'Advances in Mental Health and Learning Disabilities'. The journal integrates current research with practice and keeps professionals up to date with a variety of different perspectives on developments in the field. It supports professionals in delivering high quality and evidence based practice and provides a forum for the debate of current issues and opinions. Each issue provides a range of papers, including;

Developments in service design and delivery

Policy and its implications for practice

Research reports

Clinical case studies

News and resources

Issues have been based on a particular theme, and themes for the first two volumes have included:

State of the Union

Therapeutic Interventions

Children and Adolescent Mental Health

People with Autistic Spectrum Disorders

Forensic

Diversity

Transitions

5.0   Key Publications

Staff at the Centre have continued to produce a wide range of publications, based on our research and development activities or producing training/guidance materials to improve practice. The majority of our publications are listed in Section 11. Some of the major publications are described below.

Best Interests: Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves – Theresa Joyce

Produced in collaboration with the British Psychological Association and the Department of Health, this guidance offers support and information to enable those who care for or support individuals who may lack capacity to meet the requirements of the Mental Capacity Act (2005)

Keeping It Together: A guide for support staff working with people whose behaviour is challenging – Peter Woodward, Steve Hardy and Theresa Joyce

A guide designed for support staff, provides practical and realistic information on how support staff can develop strategies to support people whose behaviour is challenging. It also provides information on the role of clinicians and the interventions they might offer.

Mental Health in Learning Disabilities: Training Resource and Reader – Geraldine Holt, Steve Hardy and Nick Bouras

The Training Resource (in its third edition) was developed to provide Trainer's with up to date information and a variety of training techniques to develop the skills and knowledge that support staff need to meet the mental health needs of people with learning disabilities. The Resource is suitable for staff supporting people with learning disabilities in a variety of settings, in the community or in-patient services and for staff working in either mainstream or specialist services.

Mental Health Nursing of Adults with Learning Disabilities – Steve Hardy, Eddie Chaplin and Peter Woodward

To support the 'inclusion' agenda this guide was produced in collaboration with the Royal College of Nursing. It was aimed at nurses and student nurses working in mainstream mental health services. It provides practical information on recognising, assessing and treating mental health problems in people with learning disabilities.

Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities – Edited by Nick Bouras and Geraldine Holt

The second edition of this publication provides essential reading for a range of professionals working in the field. Written by an international, multi-disciplinary team of

experts, it brings about a most relevant and useful resource on the mental health needs of people with intellectual and developmental disabilities.

Supporting Complex Needs: A practical guide for support staff working with people with a learning disability who have mental health needs – Steve Hardy, Richard Kramer, Geraldine Holt, Peter Woodward and Eddie Chaplin.

Produced in collaboration with Turning Point, Supporting Complex Needs offers practical guidance on recognising and assessing mental health problems. It provides the reader with an overview of how services are configured and ideas on how support staff can work with clinicians in improving the mental health of people with learning disabilities.

6.0   MSc in Mental Health in Learning Disabilities
Course Director: Dr Elias Tsakanikos

Programme Structure

The MSc in Mental Health Studies in Learning Disabilities (MHiLD) has been established significantly over the last years. Students undertaking the programme can gain direct access to the substantial and internationally credited facilities at the Institute of Psychiatry (IoP) as well as to the excellent informational and support services offered by King's College London. Furthermore, links have been made with active research groups at the IoP so a number of students can now undertake their dissertations with the support of experienced clinical/academic researchers.

The MSc programme has close working links with The Estia Centre and students benefit from this relationship in a number of ways. Students gain access to the monthly academic meeting offered by Estia Centre and attend lectures delivered by MHiLD experts who are also Estia members. Furthermore, a number of students have been involved as researchers in the R & D activities of the Estia Centre.

Programme Content

The MSc programme is organised in modular way with each module relating to subsequent modules. In this way, a cohesive and consistent academic programme has been achieved. Unit I provides the first year of the part-time MSc course. It is composed of three inter-related modules concerned with aetiology, psychopathology & assessment, and therapeutic management of the mental health needs of people with learning

disabilities. Unit II provides the basis for the application of the underpinning knowledge to direct client care and as such has marked a fundamental development within the programme. It provides the basis for the second year of the part-time MSc programme and is likewise composed of three modules: forensic issues & services; neuro-developmental aspects; pervasive developmental disorders. Students following other pathways of the MSc Mental Health Studies programme are able to choose a learning disability unit as one of their optional units.

Lecturers

The programme retains a diverse range of visiting lecturers - academic and clinical experts in MHiLD -   to compliment the core teaching staff in providing lectures for the programme. Cohesion and consistency between lecturers has been enhanced through the use of module curriculum development committees that focus on the content of each module. These then feed into the faculty committee.

Students

Recruitment

Recruitment onto the MSc programme remains robust with a gradual increase of full-timers over the last years (Figure 1).
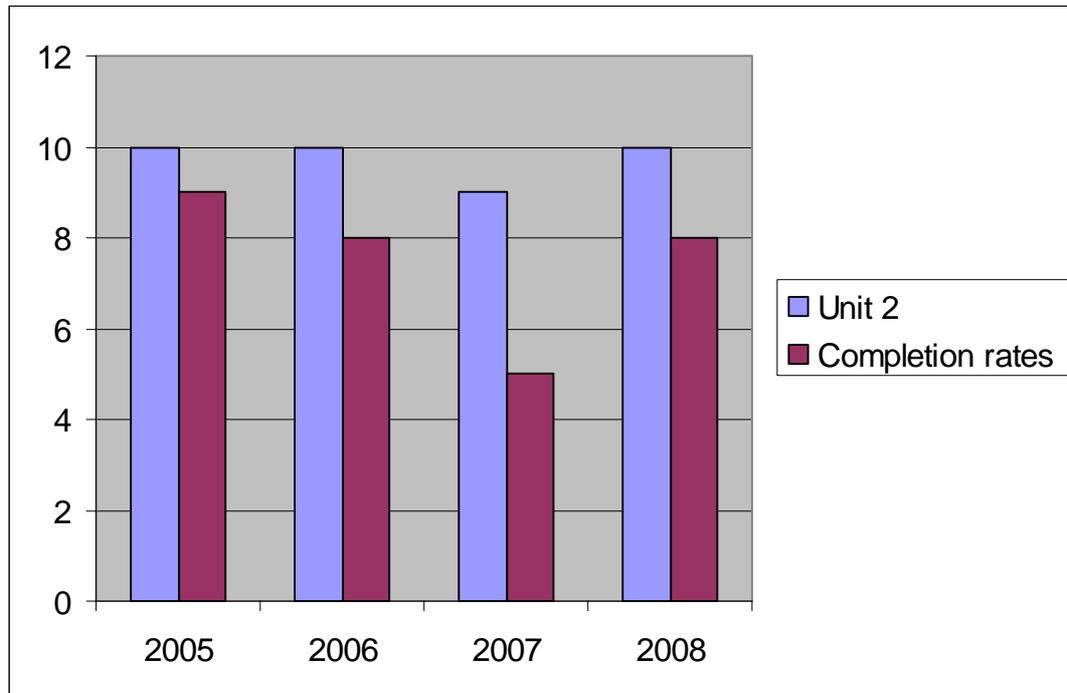
Figure1   **Student Numbers Entering Unit_I**
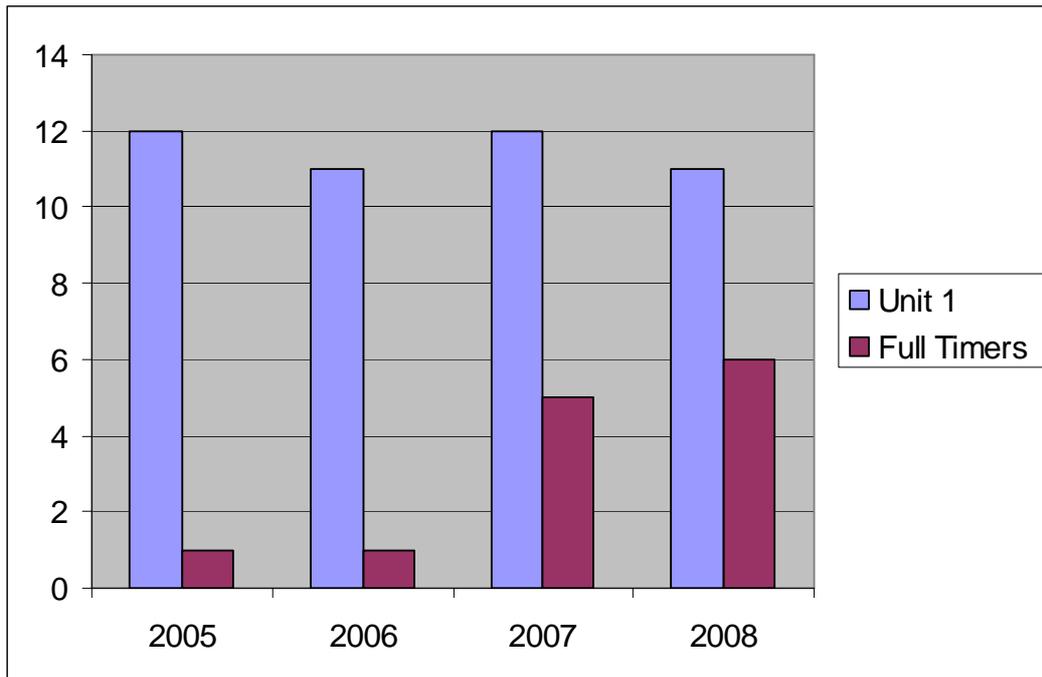
Retention Rates

Student retention rates have been maintained on the programme both in terms of students entering the second unit of the programme and students successfully completing the programme within the two year time period (Figure 2).

<u>Figure 2</u>   <u>Students Entering Unit II & Completion Numbers</u>

Academic Support

Students are allocated both an academic supervisor and a personal tutor. The role of the personal tutor is to provide students with a supportive listening environment to discuss concerns they may have regarding their course progress. Students are also provided with academic supervision focussing on the development and completion of their academic work, particularly their research project. This important aspect of the programme was formalised to enhance the equity of access to research supervision for students. During the last year all full-time students undertook research projects within the IoP Brain Maturation strengthening further the links between teaching and research within the Division.

Course Feedback

Student Feedback

The MSc in Mental Health Studies in Learning Disabilities is currently providing a curriculum of a high standard that receives very positive feed back from the students who attend. Anonymous feedback is sought via a feed back questionnaire following each lecture. The feedback questionnaire provides the students the opportunity to make comment regarding any part of the lecture or the course. This type of feedback provides information regarding specific lecture topics, lecture style and content. These have been useful in supporting lecturers to develop their individual lectures and also to remain responsive to the needs of each student group. End of term feedback is also obtained and as Figure 3 shows overall satisfaction has been relatively increased for both Units.

Figure 3   Student Feedback

Rating Key

1: Very Unsatisfactory
2: Unsatisfactory
3: Adequate
4: Good
5: Very Good
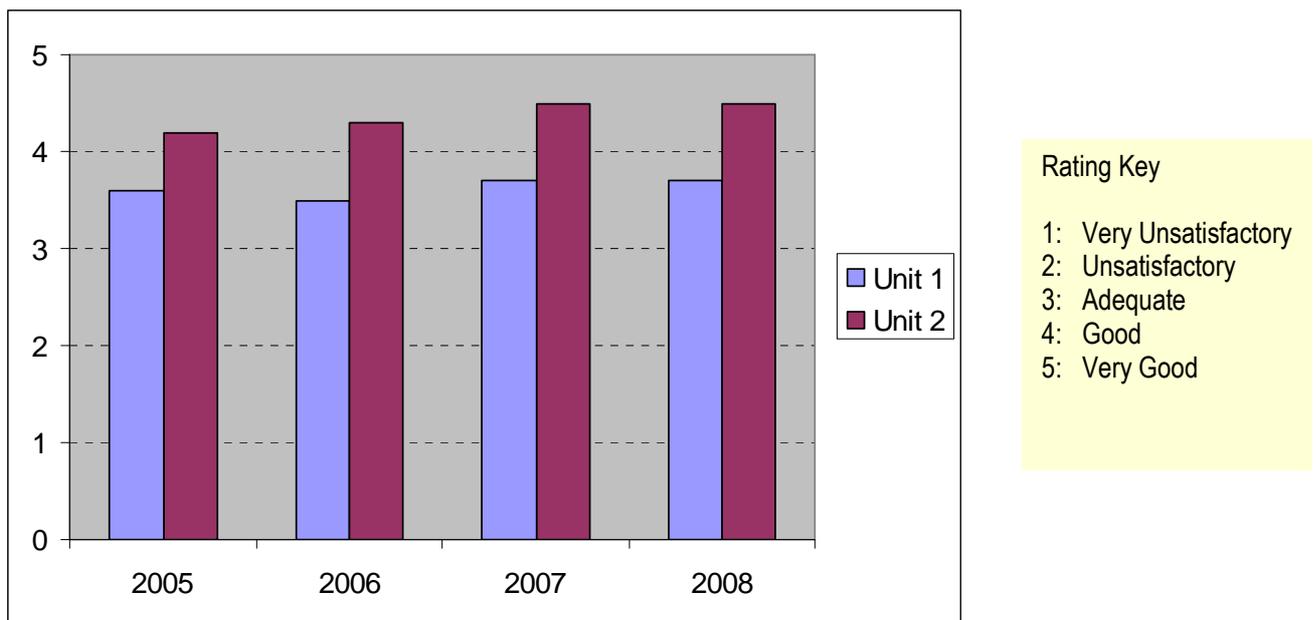
Summary

Overall, the MSc programme remains robust and viable. The programme has developed to more cohesive and relevant courses, both academically and clinically. There continues to be strong interest in the MSc programme which remains the foremost academic qualification within the specialty of mental health in learning disabilities.

7.0   Research and Development

The Estia Centre is an international centre for research specialising in the mental health of adults with learning disability. This section outlines the plan of for research and development over the next four years. This section describes the Estia's current research portfolio.

The Estia mission statement is to improve the quality of mental health care and services and other health related area for people with learning disabilities by promoting evidence based approach to local and national service provision.

About the Estia Centre Research and Development

The Estia Centre is an Academic Section of the Institute of Psychiatry of the Health Service and Population Research Department, King's College London.

The Health Service and Population Research Department (HSPR) seeks to find evidence-based ways to put innovatory treatments and services to the test – not only to improve people's mental health but also to enhance their quality of life. Researchers in HSPR are developing ways of tailoring effective services to the age, gender or culture of people in need of help, discovering what sort of services offer best value for money and establishing how to reduce stigma and discrimination against people with mental illness.

HSPR staff work collaboratively with service users, carers and mental heath charities as well as with researchers and organisations from across the world. Our priority is to find out what sort of care is most acceptable to service users and carers and to involve them in all aspects of research. Other collaborations include the Service User Research Group England (SURGE). (http://www.mhrn.info/), the Prison Health Research Network, a Department of Health funded initiative. Hosting the Cochrane Collaboration Depression, Anxiety and Neurosis Review Group (CC-DAN). For Estia specific collaborations see appendix 1.

HSPR works to make sure its research findings are widely available – not just to clinicians, scientists and policy-makers but also to service users and carers. www.mentalhealthcare.org.uk is a website for mental health carers created jointly by HSPR and South London and Maudsley NHS Foundation Trust (SLaM) in partnership with the charity Rethink (www.rethink.org).

Taken from http://www.iop.kcl.ac.uk/departments/?locator=4

The research activities of the Estia Centre are service-orientated and include the evaluation of service provision, clinical outcomes of adult psychopathology and training initiatives. These have included studies of clinical effectiveness, staffing and organisational issues, the detection and diagnosis of mental health problems and the use of psychological treatments. The over arching aim of the Estia centre is to forward practice and understanding of the issues faced by people with intellectual disabilities who have additional mental health problems, through research and development locally, nationally and internationally. The research has informed a number of evidence based academic and training publications world wide as well the dissemination of its research through peer review journals.

Since its development by Professor Bouras and Dr Holt as been one of the world research leaders in the field of mental health and learning disabilities and relies on a team of dedicated researchers and clinicians across disciplines. The current lead for research and development at Estia Centre is Dr Jane McCarthy.

There are regular research and development meetings and forums every 4 weeks at Estia Centre, which has regular representation from a number of local trusts and is also attended by research assistants and psychiatric trainees. The Chair for the Research and Development meetings is Dr Jane McCarthy.

UK Mental Health Research Network in Learning Disabilities.

The Estia is convenor of Mental Health Research Network (MHRN) clinical research group (Evaluation of Treatment Interventions in Adults with Learning Disability). http://www.mhrn.info/index/portfolio/research-and-scoping-groups/list-research-groups/evaluation-interventions.html

This is a multidisciplinary group comprising of a wide range of psychiatrists, clinical and research psychologists, nurses and academics in the fields of mental health economics, social anthropology, statistics and general practice. Dr Jane McCarthy & Dr Elias Tsakanikos are leading this group. Future research and development activity of the Estia

will capitalise on previous achievements with a focus on projects involving large multi-centre studies that evaluate treatments and interventions for people with learning disability within the aims and scope of UK MHRN. The next group meeting has been scheduled for Spring 2009.

Current Projects

The current projects are grouped under two themes each lead by Jane McCarthy and Colin Hemmings (Current projects in more detail see appendix 1)

A) Psychopathology (Clinical outcomes and training) – Lead is Dr Jane McCarthy

Effective treatments for people with neurodevelopmental disorders across the lifespan and intellectual ability. NIHR funded programme with Professor Declan Murphy as chief investigator. Estia centre to develop and evaluate training package in ADHD and Autism Spectrum Disorders for Adult Mental Health Services. Lead is Jane McCarthy

Mental Health in Adults with Autism and Learning Disability: Clinical outcome over Time. Funded by Baily Thomas Trust. Lead is Jane McCarthy & Elias Tsakanikos

B) Health Service Research – Lead is Dr Colin Hemmings

ESCAP-ID: Effectiveness of Services in the Community for Adults with Psychosis and Learning Disabilities. Lead is Colin Hemmings. The ESCAP-ID research programme aims to establish an evidence base for community services for adults with psychosis and LD.

People with Learning Disabilities and Mental Health Problems placed out of area. Funded by Guy's and St. Thomas Trust. Lead is Dr Colin Hemmings

Healthcare needs and experiences of care among adults with learning disability and mental health problems: the impact of ethnicity and gender. Funded by Judith Trust. Leads are Jane McCarthy & Colin Hemmings

Self Assessment / Risk Tool – Eddie Chaplin

Violence and threatening behaviour from patients with learning disabilities towards psychiatrists. Lead is Dr Alaa Al-Sheikh

Research Team

Honorary President:	Prof. Nick Bouras
Programme Director for Research and Development:	Dr. Jane McCarthy
Research Workers:	Lisa Underwood
Clinical Academics:	Eddie Chaplin, Dr. Colin Hemmings, Dr. Jean O'Hara, Dr. Dimitrios Paschos
Honorary Fellows	Dr. Geraldine Holt, Laurence Taggart, Dr. Kiriakos Xenitidis
Training and Development research:	Steve Hardy, Elias Tsakanikos

Research and development interfaces and philosophies

Estia, as the lead for the MHRN for MH-LD was invited to take part in the service users' forum of the Sainsbury's Centre commissioned by the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D. Their Report published in January 2007 included Learning Disability and Autistic Spectrum Disorders as a research priority with the following recommendations:

Research is needed to clarify the respective roles of mental health and learning disability services and under what circumstances people with learning disabilities should use each service.

Study the experiences of people with learning disabilities of mental health services.

Measuring met and unmet mental health needs.

Effectiveness of alternative models of service provision.

Capacity and willingness of mainstream mental health services to meet the needs of individuals with learning difficulties/ASD.

Improving detection of mental health problems, particularly within primary care rather than being "overshadowed" by learning difficulty/ASD.

Inappropriate prescription of anti-psychotics for people with learning difficulties/ASD.

How people with learning difficulties/ASD can be meaningfully involved in decisions about their care.

Generic vs. specialist inpatient units – experimental evaluation looking at differences in outcomes/ length of stay/ re-admissions.

Making therapies accessible for people with learning difficulties/ASD.

Carer support – effectiveness of informal carer interventions and role- modelling, and provision and uptake of respite services.

Short and Long term objectives of research & development at Estia Centre

Increase research output through

Seeking more external funding from DH, Charities

Develop multi centre projects with other academic organisations

Develop research projects in collaboration with the Institute of Psychiatry

Increase publications in high impact journals

Strengthen the infrastructure by ensuring diverse areas of activity including R and D and training and consultancy

Future R&D activity of the Estia will capitalise on previous achievements with focus on projects involving people with LD and mental health problems in large multi-centre typology studies and then RCTs. The questions to be addressed will be in keeping with those highlighted by the Sainsbury's Centre Report

Current Projects

ESCAP-ID: Effectiveness of Services in the Community for Adults with Psychosis and Learning Disabilities

There is currently a lack of evidence base for community services for adults with psychosis & LD and a wide range in the services & interventions provided. The few previous attempts to evaluate existing services & newer models of service delivery such as Assertive Community Treatment for people with LD have been unsuccessful. The ESCAP-ID research programme aims to establish an evidence base for community services for adults with psychosis and LD. In Phase 1 of the study researchers are using focus groups and a Delphi consultation to identify which staff, treatments or interventions, ways of working or styles of service organisation are considered (by carers, professionals and service users) to be essential or important for community services providing routine and intensive care for people with psychosis and LD. Phase 2 of the study will develop pilot studies to evaluate the effectiveness of a range of routine and intensive community-based service components. In Phases 3 and 4 evaluation will continue with multi-site randomised controlled trials and implementation in naturalistic settings.

Service Guidelines for Young Adults with Learning Disabilities and Mental Health Problems

This ongoing project is developing guidelines for the provision of a mental health services for young adults (14-25 years) with LD and mental health problems. The guidelines will utilise NICE guideline development criteria and will be based upon expert consensus, the best available evidence and the perspectives of service users and carers. It is anticipated that this guide will be broadly disseminated and used by a range of groups including clinicians, families and users in order to inform policy and practices and to improve the quality of mental health care received by young adults with LD.

Multi-centre Trial of Vitamin E in Aging Persons with Down syndrome

This ongoing multi-centre study is aimed at determining whether the administration of vitamin E, which has been shown to delay the progression of Alzheimer disease, will slow the rate of cognitive/functional decline in older individuals with Down syndrome. This is the first large-scale treatment study of Alzheimer disease complicating Down syndrome. It will serve as a model for future efforts at applying treatments developed for sporadic Alzheimer disease to the population of at-risk individuals with Down syndrome.

Neuroleptics in Challenging Behaviour and Learning Disability (NACHBID)

The use of antipsychotic medication is very high in people with LD. Yet, the vast majority of antipsychotic medication is used for management of behavioural problems. However, there is little published evidence regarding the efficacy of atypical antipsychotics to treat challenging behaviour. This is an RCT study, which aims to examine the effect of Neuroleptics in Challenging Behaviour and Learning Disability (NACHBID). It is a three-arm parallel design comparing the effectiveness of a typical neuroleptic drug (Haloperidol), an atypical neuroleptic drug (Risperidone) and a placebo in non-psychotic patients presenting at LD services with aggressive challenging behaviour. Comparisons will include short and long-term outcomes including reduction in aggressive challenging behaviour (primary outcome), improved quality of life, reduction in burden of carers, and cost of care (secondary outcomes). Any adverse effects of the three interventions will also be assessed.

The Relationship between Psychiatric Symptoms and Challenging Behaviour

Associations of problem behaviours and psychiatric symptoms are being explored in a cohort of adults with LD in SE London. Data from the first phase of the study has already been analysed (Hemmings et al., 2006). This large sample (n=214) cross-sectional study showed associations between specific affective symptoms and aggressive and self-

injurious behaviours. A follow-up study (data collected) will further examine these associations. Any changes in problem behaviours over time will be compared with any corresponding changes in psychiatric symptoms after the same time lapse in the second phase. Such a longitudinal study has not been previously reported in the literature and may provide stronger evidence for associations between problem behaviours and psychiatric symptoms than a single, cross-sectional study. Increasing our understanding of these relationships will help to improve the detection, and treatment, of mental disorders in individuals with problem behaviours.

Evaluation of a Specialist Community Mental Health Service (MHiLD)

This is a series of studies evaluating a specialist community mental health team which has been in operation for just under 25 years. Ongoing analysis has focused on trends in service referrals, predictors of psychopathology, predictors of admission, the manifestation of psychiatric disorders, the psychometric properties of assessment tools, gender differences, life events, ethnicity and individuals with PDD (Psychopathology, medication, referral trends, and behaviour problems). Key findings include: · A significant reduction in hospital admission & a significant increase in referrals for individuals with mild LD, with a psychiatric diagnosis, living independently and from Afro-Caribbean & Asian ethnic groups (Bouras et al, 2003). · Individuals with mild LD more likely to have a psychiatric disorder, in particular Schizophrenia Spectrum Disorders, Anxiety & Depressive Disorders Personality disorder. Predictors for admission: Schizophrenia Spectrum Disorders, mild LD & the presence of physical aggression (Cowley et al, 2005). · People with autism and LD no more likely to receive a psychiatric diagnosis than people with LD. People with autism were less likely to receive a diagnosis of personality disorder. Adults with PDD were more likely to be aggressive, destructive of furniture and clothing and overactive. Adults with PDD were also more likely to have problems with attention-seeking behaviours, self-injury, wandering/running away, screaming, temper tantrums/verbal abuse and disturbing others at night. Adults with PDD were more likely to receive anti-psychotics and to be admitted to an inpatient unit (Tsakanikos et al., In Press).

Evaluation of a Specialist Inpatient Mental Health Service

This is an ongoing evaluation of a specialist inpatient service for individuals with LD. Analyses include the comparison of outcomes for individuals with LD admitted to specialist and generic Adult Mental Health (AMH) wards, and ii) the comparison of

characteristics of individuals with LD admitted to specialist and generic services over a five year period. Key findings include: · Admission to a specialist unit was associated with significantly greater clinical improvements in the level of psychopathology, the severity of mental illness, the global level of functioning and the degree of behavioural impairment. Reflecting the special needs of individuals with LD, their average length of stay in AMH wards is longer than for those without LD (10 weeks compared to 3-4 weeks) and significantly less than for those in receipt of specialist services. Return to residential placement was more likely for individuals receiving specialist services compared with those admitted to AMH wards (Xenitidis et al, 2003). · Individuals admitted to the specialist unit were less likely to have a diagnosable disorders and less likely to have affective disorders. This highlights the highly complex mental health problems of individuals admitted to the specialist unit. Individuals admitted to the specialist unit were also significantly more likely to live with their families prior to admission whereas individuals admitted to AMH wards were more likely to come from "other" accommodation (Coster et al., In Preparation).

UK Mental Health Research Network in Learning Disabilities

The Estia centre is convenor of the recently formed Mental Health Research Network in LD. This is a multidisciplinary group comprising of a wide range of psychiatrists, clinical and research psychologists, nurses and academics in the fields of mental health economics, social anthropology, statistics and general practice. Acknowledging the critical contribution of carers, and given the urgent need to empower service users, these groups will also be represented. Jointly, the proposed group has extensive clinical expertise and experience in providing mental health services across a range of settings. Activities entail the design of multi-site projects focusing on care pathways and mental heath service outcomes. Research questions will focus on service utilisation and outcomes for subgroups within the LD population, as well as on the effectiveness of alternate models of treatment and service delivery.

The sensitivity and specificity of dementia screens

This is a case control comparing the sensitivity and specificity of the Oliver Crayton Scale and Dementia Questionnaire for Mental Retardation in individuals with LD. The findings from this study will provide novel evidence about the psychometric properties of 2 dementia screens when used for individuals with LD.

The Role of the White Paper 'Valuing People' (DoH, 2001) in Improving Access to Generic Mental Health Services by People with Learning Disabilities (EPIAMS)

Phase 1 of this study entailed qualitative interviews and focus groups with mental health professionals in community LD services and generic and specialist mental health services across three boroughs in South-East London. The results showed that i) generic community mental health teams had few plans to implement the proposals, ii) community LD teams were either in the process of implementation or had completed implementation, and iii) many professionals felt that the small number of people with LD using generic services did not justify the expense of making information accessible to them (Maitland et al, in preparation). Phase 2, for which data is currently being collected, is a quantitative postal and email questionnaire based study (n=100) of 50 staff from LD specialist services and 50 staff from general psychiatric services across several geographical locations across England. The study will assess i) the attitudes of staff in LD specialist and general psychiatric services towards the twelve proposals in VP, ii) the perceived level of implementation of the VP proposals among MH professionals, and iii) examine whether agreement/disagreement with the VP proposals predicts the perceived level of implementation.

Out-of-Area Placements for People with Learning Disabilities and Mental Health Problems

Reflecting a general local shortage of services for individuals with severely challenging behaviour and/or mental health needs, there are estimated to be several thousand people with LD and histories of psychiatric illness living in residential facilities out of their place of origin (OOA). However, due to the complex funding policies, it is often difficult to monitor how effective these services are. However, OOA have been linked with a number of negative outcomes for individuals with LD and for the areas in which they are placed. These include monitoring difficulties and an increased vulnerability to neglect and abuse. This quantitative and qualitative study comprises i) individuals in 'Out-of-Area Treatments' in independent mental health hospitals (OATs), ii) individuals in social care placements 'Residential Out-of-Area Placements' (ROAPs) and iii) Individuals in receipt of local mental health services. Direct comparisons of service-user profiles, service characteristics and service outcomes will be made to identify the factors determining the type of service received and to explore their relative effectiveness. In addition, this study will generate information about the function of OOA and the developments in local service provision necessary to meet these needs.

Clinical Governance Audit: Service User Satisfaction Survey

The study measured the satisfaction of people accessing LD services in two assessment units. It employed a specifically designed self-report questionnaire developed on the basis

of focus groups comprising service users. In general, service users were satisfied with the service received in respect of the welcome received, the level of participation in the care plan, living and recreation plans, advocacy and staff relations. Many service users used the study to vent frustrations, some real and some due to perceptual disturbance. The users reported problems relating to living with other users, some requested additional activities and some reported difficulties engaging with staff. Results of the study will be fed into clinical governance streams and used as feedback for the Green Light Toolkit. The findings will also be fed back to the participating units and measures will be taken to address any reasonable areas of discontent, with the aim of increasing the satisfaction of people using these services. One year after the initial interview, a further assessment will be conducted using the same questionnaire to see if there has been improvement in people's satisfaction levels.

Projects in Preparation

Risk Assessment Measures

This project will investigate the association between risk assessment instruments and subsequent behavioural outcomes in people with LD compared with those with mental disorder and examine whether the application of risk assessment instruments can predict different behavioural outcomes between people with LD and their Mental Health controls.

Clinical and Service Outcomes of Specialist Mental Health Services

A case note review at the Estia Centre identified that a relatively small proportion of service users (10%) consumed a large proportion (48%) of the service resources in terms of out-patient appointments, contacts with community psychiatric nurses and domestic visits by psychiatrists. Individuals with a diagnosis of schizophrenia spectrum disorder and those with a greater number of affective/neurotic symptoms were more likely to be heavy service users (Spiller et al., In Press). Based on the findings of the previous study, the Centre is currently planning a prospective study examining the utilisation and the outcomes of people with LD using specialist mental health services.

Ethnic Differences in Needs and Pathways into Mental Health Care

As people with LD are increasingly likely to require psychiatric attention and to make use of various care services, the presence of ethnic disparities must be a prominent issue when planning and providing services for this population. It is important to ascertain the causes of these disparities and to raise awareness among all those involved with the care of people with LD. A retrospective analysis of 806 new referrals to a specialist mental health service showed referrals from black and minority ethnic groups were more likely

than white referrals to have autistic spectrum disorders and schizophrenic spectrum disorders. Yet, white referrals were more likely than BME referrals to be living in supported housing (Maitland et al., in preparation). The current project aims to i) identify the differences in pathways of service users with LD into mental health care from different ethnic groups (White, Asian and African-Caribbean), ii) identify differences in the level of unmet need between service users of different ethnic groups with LD, and iii) study the predictors unmet need in ethnic minority service users with LD. Information from this study will enable planning and delivery of services for ethnic minority service users and facilitate future research into the specific needs of those who are currently in psychiatric services as well as culturally appropriate services for them.

Past Projects

1. Mental Health Guide for Families with Members with Learning Disabilities and Mental Health Needs.

2. Does Training improve Psychiatric Outcome for Individuals with LD?

3. Regional Audit of Low Secure Facilities for Patients with LD and Mental Disorder and very Complex Needs.

4. South Thames Regional Audit of the Care Programme Approach (CPA) & Risk Assessment/Management Implementation for Community Clients with LD and Mental Health Problems

5. The operational interface between inpatient generic and specialist mental health services

6. Measuring outcome in mental health services for adults with learning disability: the relationship between needs, functioning and quality of life: A pilot study.

7. Audit relating to the circulation of letters to services users & mental health professionals.

8. A naturalistic study of schizophrenia-spectrum disorders in people with and without learning disabilities.

9. Risperidone and Olanzapine in adults with learning disabilities: A clinical naturalistic study.

Collaborators in the Centre's research Programme

MENCAP

Foundation for People with Learning Disabilities

Judith Trust

Oxleas NHS Trust

Imperial College London

London School of Economics

University of New York

University of Canterbury

University of Birmingham

University of Wales

Royal College of Nursing

Royal College of Psychiatrists

London/National strategy Learning Disability working Groups

NHS Executive

Clinical Governance Support Service (College Research Unit)

Mental Health & Learning Disability Task Force

Private & independent Service providers

Turning Point

Current grants and applications

From 2007 onwards the activities of this research programme have focused on the priority areas identified by the national Mental Health Research Network (MHRN) in Evaluation of Treatment Intervention in Adults with Learning Disability of which Dr Jane McCarthy is the lead.

Research Funding grants

The Programme Grants of the National Institute for Health Research (NIHR) led by Professor Declan Murphy at Institute of Psychiatry. The project is titled "Crossing the divide. *Effective treatments for people with neurodevelopmental disorders across the lifespan and intellectual ability".* Dr Jane McCarthy is co-applicant in developing a training intervention for community services on autism spectrum disorders and attention deficit hyperactive disorders. 2008 for 3 years.

Difference in health care needs and experiences of care among adults with learning disability: a multi ethnic comparison. Dr Jane McCarthy is Lead applicant. Awarded

£10,500 from The Judith Trust to start the first stage of project. Project in collaboration with Dr Ghazala Mir, Senior Research Fellow, Director of Ethnicity Training Network, Centre for Health & Social Care, University of Leeds. Awarded 2007 for 12 months

Out area placement of people with learning disabilities and mental health problems. Dr Jane McCarthy is lead applicant. Guy's & St. Thomas' Charity awarded £20,000 from 2008 for 12 months.

Mental Health Outcomes in Adults with Autism and Learning Disabilities. Dr Jane McCarthy is lead applicant. Baily Thomas Charitable Fund awarded £70,895 awarded 2008 for 24 months

The following projects have been submitted for programme grant funding. Effectiveness of Services in the Community for Adults with Psychosis and Intellectual Disability (ESCAP-ID). Led by C. Hemmings & L. Underwood.

8.0   The Tuesday Group

The Tuesday Group is a mental health promotion group for people with learning disabilities living in the London Borough of Lewisham. The group began in 2000. They meet every two weeks and it is facilitated by staff from the Estia Centre. The overall aim of the group is to educate its members about mental health and the factors that can help people stay well. Some of the issues that the group have addressed over the last four years have included;

Advocacy
Accessing local mental health services
Alcohol and drugs
Assertiveness
Exercise
Getting a job
Health action plans
Healthy eating

The group are regularly asked to talk at conferences, including events held by the Royal College of Nursing and Pavilion Publishing. Their work has also been published in

Community Connecting and Living Well magazines. They have recently finished making a DVD, where they talk about important issues for the mental health of people with learning disabilities.

9.0   Consultancy

The Estia Centre offered advice and consulted to several service providers nationally and abroad. In England the Centre' consultancy work has mainly bee based around the implementation of the Green Light Toolkit (FPLD/VPST/NIMHE, 2004). The link of the clinical services with the Estia Centre and the expertise of its members in developing and running services for people with learning disabilities and mental health needs offers unique opportunities to share experience and knowledge with other services. Specially tailored packages taking into consideration the diverse local needs will be developed.

10.0 Visitors

The Centre often has visitors from the UK and internationally, to discuss our research, development and training activities and also visit clinical services. Programmes have been designed for individuals through to large groups of students or professionals and from a day visit through to a six month stay. Some of our international visitors have come from:

Centro de Investigacion en Minusvalias de Cadiz, Spain

Global Initative on Psychiatry, Lithuania

Latvian Centre for Human Rights and Ethnic Studies, Latvia

Kwai Chung Hospital, Hong Kong

Mental Disability Advocacy Centre, Budapest, Hungry

The Victorian Dual Disability Service, Australia

11.0 Publications by the Estia Centre Staff
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12.0 References

13.0 Members of the Estia Centre (2004 – 2008)

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Fay Coster   Research Assistant
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