



**THE  
ESTIA  
CENTRE**



**celebrating  
10  
years**



**An event to celebrate the 10th anniversary of the Estia Centre** was held on Friday 4 December 2009 at Guy's Hospital. There was a series of presentations about the work over the past decade and about plans for the future.

**South London and Maudsley NHS Foundation Trust's Mental Health in Learning Disability (MHILD) services** are now known as Mental Health and Learning Disabilities (MHL) services. This publication refers to MHILD services when talking about the past 10 years, and MHL when talking about the present.

Throughout this publication, South London and Maudsley NHS Foundation Trust is either referred to in full or as SLaM. The Institute of Psychiatry, King's College London, is referred to either in full or as the IoP.

**In 2009, the Estia Centre celebrates a decade of working towards making sure the mental health needs of people with learning disabilities are met – through specialist clinical services, research, and a programme of training and education for both support workers and mental health professionals.**

**Despite government efforts of recent years, people with learning disabilities are still marginalised. Those with mental health problems and more complex needs are even more socially excluded: they are much less likely to be given the chance to speak for themselves and much less likely to be given choices. Many people with learning disabilities and mental health problems are placed in residential or specialist treatment centres far from their local community: historical lack of state investment has led to a growth of independent providers of services and a dearth of specialist public sector alternatives.**

**Based on Guy's Hospital campus at London Bridge, the Estia Centre is part of South London and Maudsley NHS Foundation Trust (SLaM). Members of the Estia team work in SLaM's clinical services and at the Institute of Psychiatry (IoP), King's College London, SLaM's academic partner. There is also a dedicated team at the Centre responsible for organising a large portfolio of training, offered routinely to staff in social care and mental health services in south London, and also available on request to staff working in services around the UK and in other countries.**

**The work of the Estia Centre has been inspirational to clinicians and policy makers around the world. Over the years, the Estia team has shared skills and experience through long-standing collaborations and consultancy work, helping to shape and develop specialist mental health services for the benefit of people with learning disabilities and their families.**

# In the beginning...

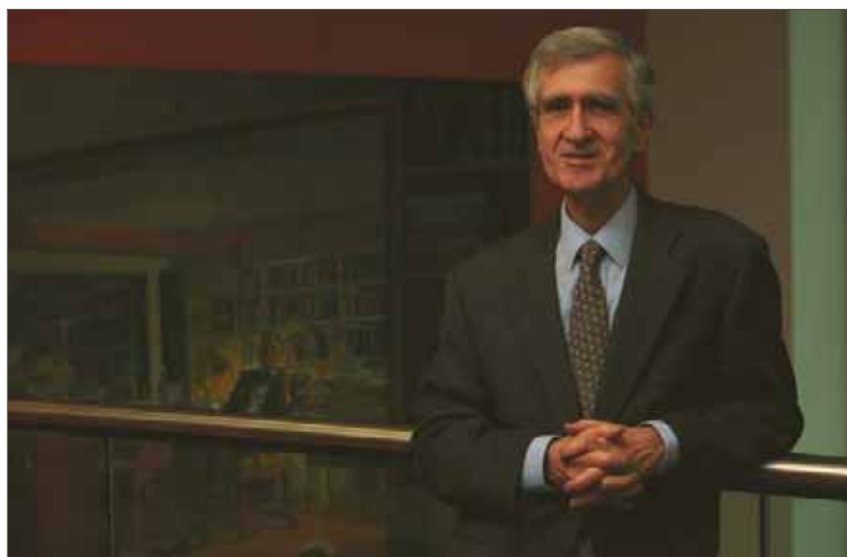
...A group of south London-based mental health professionals working in the community with people with learning disabilities proposed a strategy to develop specialist services, to carry out research to inform that development, and to create a training programme for frontline social care workers to help them support people with mental health problems on a day-to-day basis.

The multi-disciplinary team of staff was based at Guy's Hospital in London Bridge and was working with community teams in the south London boroughs of Lewisham, Southwark and Lambeth, set up in the

wake of the government's Care in the Community policies of the 1980s which had closed long-stay institutions and repatriated people with learning disabilities. The main job of the community teams was to settle people in their new homes and organise the support they needed. 'All the teams included a psychiatrist, but it became clear that that wasn't enough,' said Geraldine Holt, a founder member of the Estia Centre and psychiatrist who had joined the community-based team in Lewisham in 1986 after training in learning disabilities and mental health with Professor Nick Bouras at Guy's.

Professor Nick Bouras is one of the world's foremost researchers in the field of learning disabilities and mental health. As Director of the Estia Centre from its inception in 1999 to his retirement in 2007, Nick led on research and education while working as a psychiatrist in the MHILD services, championing the needs of the service users with whom he worked locally, nationally and internationally. When he retired, he had spent 25 years developing new and appropriate services to meet the mental health needs of people with learning disabilities who had been resettled from long-stay hospitals into the community since the 1980s.

After training in medicine and psychiatry in Greece, he had first come to Guy's Hospital to undertake a PhD. He joined a multi-disciplinary team working at the Mental Health Advice Centre or 'Yellow Door Centre' (as the project became known), one of the first community-based mental health centres in the country, which had opened in Lewisham in the late 1970s. GPs could refer there directly, and the team took self-referrals from anyone living in the borough. He went on to become part of a small team, set up to launch residential and community-based services in Lewisham and Southwark for people with learning disabilities who had previously lived in institutions, starting absolutely from scratch. Nick's involvement was to develop mental health support for people living in the community for the first time and thenceforward, he continued to work in community-based



services in south London while at the same time undertaking research to make those services more effective.

Bringing research, services and training together under the auspices of the Estia Centre was a logical step, he says. 'There had been no real investment in mental health research for people with learning disabilities and there was a huge need for evidence to inform the development of services.'

Services have improved tremendously over the past 25 years – but there are 'still challenges both now, and for the future,' he says. 'These challenges are about fulfilling people's expectations and respecting their choices, about improving services and delivering research that has a day-to-day impact. We need too to make sure service users and carers have a real voice and become meaningfully involved in our work.'

Nick is now Director of Maudsley International, set up by SLaM and the IoP to share expertise in mental health with research and teaching organisations, health care providers and governments around the world – including skills and knowledge in mental health and learning disabilities. He continues to be involved with the work of the Estia Centre and, together with Geraldine Holt, has edited *Mental Health Services for Adults with Intellectual Disability: Strategies and Solutions*, a new Maudsley Monograph published to mark the Estia Centre's 10th anniversary (see page 22). The publication, written by members of the Estia team and colleagues overseas, describes the development of mental health services for people with learning disabilities over the past quarter century.

‘We began to see there was a need for a dedicated psychiatric service for those with learning disabilities, for resources specifically for mental health problems, including specialist nurses,’ said Geraldine. One pivotal case was a person with moderate learning disabilities who was admitted to hospital because he refused to eat. ‘It was a tragic case because he had a tonsular abscess. The whole trauma of emergency surgery had caused him mental distress. When he was on the ward, all sorts of different professionals tried to treat him, to convince him to eat, but all were unsuccessful. He needed the specialist skills of nurses trained in behavioural support to help him get better.’

At the same time, it became apparent that many support staff working in the community had no knowledge or experience of mental health problems, of recognising them, of how people might be helped, or how they, as support workers, might be able to help, she said.

‘All of us were being asked to do quite a bit of training and we were getting referrals quite late because people weren’t spotting mental health problems. We also recognised that research in the field was very

sparse, and knew that good clinical services needed a good research evidence-base.’

Psychologist Theresa Joyce was also working in Lewisham at the time. ‘There was a real gap, a real need for research, education and leadership in learning disabilities and mental health,’ she said. ‘There had been an optimism in the wake of Care in the Community that moving people out of hospitals would solve all the problems, would make people’s lives better. But there were new difficulties: in the old institutions, everything was offered under one roof – accommodation, activities, social care and health care, including mental health care. Although we all wanted the institutions to close so that people with learning disabilities could have better lives, there hadn’t been enough detailed planning as to how we were going to deliver more specialist health care to people when they were living in the community. Under Care in the Community, all sorts of different organisations were offering different things, and it wasn’t easy for people with learning disabilities and mental health problems to access the care they needed.’

Geraldine Holt started working with people with learning disabilities just as Care in the Community policies were taking effect in the early 1980s. After finishing her medical training, she decided to specialise in psychiatry and worked for a while in child psychiatry. Then she took a job working with people with learning disabilities in Tower Hamlets while at the same time training with Nick Bouras, who was based at Guy’s Hospital.

In 1986, Geraldine joined the community team in Lewisham and stayed part of the MHILD service, working in different borough-based teams and on the specialist ward, until she retired in 2007, sometimes working part-time while undertaking fixed term policy jobs. She was Programme Co-ordinator for an NHS Executive London project scoping the possibility of a cross-capital research network

for learning disabilities, and also Senior Medical Policy Advisor to the Department of Health on learning disabilities. The latter, high profile job, liaising closely with the *Valuing People* team responsible for overseeing implementation of the government’s policies to improve services and quality of life for people with learning disabilities, was very useful for the Estia Centre, she says.

‘It’s easy to become marginalised in a small sub-speciality, and we tried very hard to be seen and heard, to keep our work, and the needs of people with learning disabilities and mental health problems very visible,’ she says.

‘The job at the Department of Health was advising how mental health aspects might be incorporated into *Valuing People* ideology. I worked with civil servants and ministers on policies,

making sure they included the needs of people with learning disabilities, or at least acknowledged their needs, and indeed their mental health needs. I was able to bring real life scenarios to the policy making process.’

Geraldine was also involved in the Royal College of Psychiatrists’ Faculty of the Psychiatry of Learning Disability, both as a member of its Executive and Honorary Secretary.

Nowadays, she continues to be a trustee of The Judith Trust, a charity working to meet the needs of people with learning disabilities and a diagnosis of a mental illness. She also works as a volunteer support worker for Project London, an advocacy project run by Médecins du Monde UK that provides information, advice and practical assistance to vulnerable people to help them access NHS and other services.



**People with learning disabilities are more likely to experience mental illness:** research shows that as many as 40 per cent of people with learning disabilities also experience mental ill health, and that people's quality of life can be seriously impaired if a mental illness is not identified and treated.

**Valuing People**, published by the government in 2001, was the first White Paper about people with learning disabilities for 30 years. (Previously, the 1971 White Paper *Better Services for the Mentally Handicapped* had paved the way for an end to institutional care, the then norm for people with learning disabilities.) Covering only England, *Valuing People* talked about social inclusion, choice in daily life and independence. Very little was said, however, about the mental health needs of people with learning disabilities.

**Valuing People** said there were an estimated 210,000 people with severe and profound learning disabilities and about 1.2 million people with mild or moderate learning disabilities in England. The 2001 White Paper predicted the number of people with learning disabilities would increase by about one per cent a year for the next decade and a half.

**Estia** stands for Evaluation Services Training Intervention Assessment. 'We tried to find a name that was easy to use,' says Nick Bouras. '*Hestia* was in Ancient Greece the Goddess of Hearth and Home, and in modern Greek language means *focus*.'

Nick Bouras, Geraldine Holt, Theresa Joyce and colleagues Barley Oliver and Mark Allen decided it was time to address these issues: they drew up a proposal to develop and expand specialist Mental Health in Learning Disabilities (MHILD) services and bring them together with a programme of research and training by creating the Estia Centre. The proposal was implemented by South London and Maudsley NHS Trust (now South London and Maudsley NHS Foundation Trust), at the time the new Trust responsible for mental health services in the south London boroughs following an NHS re-organisation.

Thus, following several years of preparation and planning, the Estia Centre opened its doors in 1999. 'It was a unique project,' said Nick, a driving force in the creation of the Centre who became Director, a post he held until his retirement in 2007. 'There were other research centres around the country, but the difference was that the people involved in the Estia Centre's training and research activities were also the clinicians who were delivering services.'

The strategy also included a specialist inpatient facility for people with learning disabilities. This was originally at Guy's Hospital, later moved to the Maudsley, and is now based at the Bethlem Hospital (see page 6).

The training the Estia team began to develop was originally meant for frontline staff based locally, people who were working for relatively new services without any experience of mental health problems. 'But we found we were being asked to do training all over the country as well as overseas,' said Nick, 'and were being invited to conferences to talk about the materials we were developing. There was very little available about working with people with learning disabilities at the time, and virtually nothing about the mental health needs of those with learning disabilities.' The first edition of the package *Mental Health in Learning Disabilities: A Training Resource* had been commissioned by the Department of Health as part of its Care in the Community policies and came out in 1995, with a second edition in 1997 in a bid to meet some of those training requests. (The third edition was published in 2005 – see page 23).

The research that Nick, Geraldine and the team had already been undertaking to inform the development of services became more systematised, and the Estia Centre became affiliated with the then Department of Health Services Research (now Health Service and Population Research) at the Institute of Psychiatry, King's College London. There were also links created with the Division of Psychological Medicine there, which went on to house the MSc in Mental Health in Learning Disabilities (see page 13). This qualification was originally set up as a module of the MSc in Mental Health Studies run by Guy's, King's and St Thomas' School of Medicine (now King's College London School of Medicine). When the Estia Centre came into being, the module was expanded and became a separate degree.

Despite a constant battle to find funding, the research programme grew. 'The research started as part of our everyday clinical work,' said Geraldine. 'The bulk of the original research we did was assessment, finding out what the needs of our local service users were. There was a whole battery of questionnaires we used that were part and parcel of our everyday work. We needed to know, at the very least,

Theresa Joyce worked as both a nurse and a psychologist in old-style institutions for people with learning disabilities before joining community-based services in Lewisham in the early 1980s. She has stayed working with the learning disability services now run by SLaM ever since.

Now Head of Psychology Services for Adults with Learning Disabilities in the south London boroughs of Lambeth, Southwark and Lewisham (see page 6), she is also the Mental Capacity Lead for SLaM, charged with making sure health care professionals employed by the Trust support people in making decisions for themselves and that the rights of people who cannot give consent are upheld. The latter role brings together her clinical training and her legal training: while working as a psychologist she undertook a part-time LLM (a Master's Law degree) in Mental Health Law. She is the author of *Best Interests: Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves (England and Wales)*, published by the Professional Practice Board of the British Psychological Society and funded by the Department of Health under the programme for developing materials to support the implementation of the Mental Capacity Act 2005. The advice is for staff working

in health or social care such as doctors, nurses, psychologists, therapists, social workers, care home staff and managers, as well as for families and advocates. She also helped design the Estia Centre's workshops for support workers and managers about the Mental Capacity Act that came into force in 2007 (see page 11).

Theresa has a brother with learning disabilities and knows first hand about the difficulties people can face in everyday life because of misunderstanding, misinformation and lack of experience, often leading to prejudice and discrimination. 'People don't always realise institutional-style care isn't just a product of big buildings, it's also about attitudes and values,'

she says. 'But things have changed: family voices are heard more than they used to be, and I think service users' voices are also beginning to be heard. But people with severe learning disabilities are often still excluded and ignored, and there is still a lot of work to be done. Education is very important, and people with specialist skills must be willing to share them.'

Since April 2009, she has chaired the British Psychological Society's Faculty for Learning Disabilities, which provides a forum for psychologists who work with adults with learning disabilities. The Faculty works closely with the similar Faculty at the Royal College of Psychiatrists.



the needs of our local population. We built up our own database from collecting routine data, and as we went on, the information we collected became more refined.'

Some of the early research led by Nick resulted in a whole series of papers about the prevalence of mental health problems in people living in the community. 'This was very important work,' says Geraldine. 'It demonstrated specific mental health problems; that people who had been mentally ill when living in institutions often continued to have problems in the community. It also showed how difficult it is sometimes to recognise mental health problems, and how often they are missed.' More important evidence was produced by the Estia team, showing that people with learning disabilities and mental health problems have more complex needs than people with mental health problems who do not have learning disabilities.

Research in the early years also looked at the training needs of support staff working in the community and tested training packages being developed by the Estia team. There were collaborations on a number of multi-centre studies looking at the effectiveness of treatments, including psychological therapies like cognitive behaviour therapy and medication. Health and social care authorities

from all over the world began to call on the expertise of the Estia Centre to help them plan services and introduce training. 'We acquired wide-ranging experience in developing and delivering mental health services for people with learning disabilities,' said Nick.

International collaborations were launched: close links were forged, for example, with the National Association for Dual Diagnosis (NADD), Nebraska, Ohio and Rochester Universities in the USA. There were collaborations with Monash University and the University of Queensland in Australia, both home to research and education centres aiming to improve the health and well-being of adults with learning disabilities. In Spain, informal and formal collaborations led to the needs of people with learning disabilities and mental health problems being included for the first time in the Catalan Mental Health Plan (2006-2010). Links and working relationships were also developed with individuals and organisations in Ireland, The Netherlands, Austria, Italy, Hong Kong and Greece.

Today, the Estia Centre continues as one of the world leaders in the field of mental health and learning disabilities. This publication outlines current services, research and training activities, and looks forward to the next 10 years.

# Services

The Mental Health and Learning Disabilities (MHL) service at South London and Maudsley NHS Foundation Trust is quite unique, says Jean O'Hara, consultant psychiatrist and Clinical Director. 'Most people are treated in mainstream mental health services or community-based learning disability services, even though professionals there may not understand the specific mental health needs of someone with learning disabilities.'

When the Estia Centre was first set up, there was a tiny community-based service run in response to the closure of long-stay hospitals. 'Over the past decade, since the launch of the Estia Centre, the service has grown and developed along with research and teaching activities,' she says.

Nowadays, there are small teams of mental health professionals – including psychiatrists, psychologists, behavioural support specialists and nurses – working in the south London boroughs of Lambeth, Southwark, Lewisham and Croydon. Psychiatrists and community

psychiatric nurses have a caseload of about 150 in each borough, bar Croydon, which has about 300, and offer specialist mental health assessment and treatment in clinics based in the local community or at people's homes. Psychologists and behavioural support specialists are based in Lambeth, Southwark and Lewisham. They are employed by SLaM, but also work as part of the community teams for adults with learning disabilities run by primary care trusts and local authority social services departments in each borough, except for Lambeth, where the community team is also run by SLaM.

The psychology and behavioural support teams work with about 250 people across the three boroughs they serve, and have a particular expertise in working with people with challenging behaviour. 'Our work straddles both the MHL teams and the community teams,' says Theresa Joyce, Head of Psychology Services for Adults with Learning Disabilities. 'Our role is quite varied – we work with an individual with mental health problems, or with a group of people, or with a carer or a support worker to give them the skills they need to support an individual. Different skills are needed for each client and we offer a variety of therapies such as cognitive behaviour therapy, counselling, systemic work and positive behavioural interventions. We also train individual staff teams around how to support their individual clients.'

The professionals working in the MHL service see the spectrum of mental health problems, from anxiety and depression to severe psychosis. 'Sometimes we

The Mental Health and Learning Disabilities Unit offers a wide variety of treatments and therapies to people with learning disabilities and mental health problems who need to spend time in hospital. The newly opened ward at the Bethlem Hospital has been designed with the help of service users, and the specialist team of staff based there maintains close links with families, friends and support workers.

Previous research carried out by the Estia Centre team showed that people cared for in specialist wards like this fared much better than those cared for on a generic ward. People spent longer time in a specialist unit, but they were less likely to be discharged to an expensive out-of-area residential placement than those who had been on a mainstream ward. Clinical Director Jean O'Hara says general mental health wards are unable to cater for all people with a learning disability. 'People with a learning disability and mental health problems often have more complex needs, there are issues of vulnerability, and a need for more detailed or specialist assessment,' she says. 'The ward offers an appropriate environment for service users whose needs cannot be met on a mainstream

unit. After-discharge planning is also an important part of the service we offer there.'

Psychologists and challenging behaviour specialists based on the Unit are able to offer adapted cognitive behaviour therapy, systemic work, full functional assessment and analysis, and support to carers before, during and after admission, says Head of Psychology Services Theresa Joyce. 'There is specialist psychological assessment and intervention. The Unit uses the existing evidence base regarding effective intervention and also contributes to developing it, integrating clinical practice with development of knowledge and evidence about what works.'

The new 13-bed Unit caters for people living in Lambeth, Lewisham, Southwark and Croydon, and four of the beds are earmarked for referrals from anywhere in the UK. The opening of the ward in September 2009 marked an expansion in the inpatient service: the previous Weston Unit based at the Maudsley Hospital had only six beds.

The investment has been made 'as part of a whole package of work by SLaM to improve services for people with learning disabilities and raise

the profile of the specialism,' says Head of Neurodevelopment at SLaM, Lisa Seaburne-May. It's partly about thinking through some of the policy initiatives outlined in the independent inquiry report about NHS services *Healthcare for All* (which concentrated on physical health care), she says, and also about the contents of the *Green Light Toolkit*. The *Toolkit* was commissioned by the *Valuing People* support team and the National Institute for Mental Health in England, and written by the Foundation for People with Learning Disabilities. It paints a picture of how mental health services for people with learning disabilities should be run.

'The Unit is newly refurbished and massive,' says Lisa. 'There is a lovely garden space, a lounge, and an eating area. It's the nicest ward I've ever seen. There has been a lot of service user involvement in the way the ward has been set up to make sure people who are admitted are given choice during their stay.'

Before the ward opened, the newly recruited team of specialist staff took part in a two-week intensive training programme designed by Steve Hardy at the Estia Centre.





consult with or make referrals to other specialist services run by SLaM, like the National Psychosis Service,' says Jean, 'but if we refer, we keep in touch with service users and their families. We offer ongoing treatment and support, even if people are admitted to hospital for a period of time.'

The MHL D teams also offer advice and support to professionals working elsewhere in SLaM about the mental health needs of people with learning disabilities who are under the care of mainstream services. Their work involves ensuring effective links with other health and social care services to try to deliver a joined-up and efficient experience of care to service users.

All professionals working with people with learning disabilities and mental health problems meet regularly to make sure each service user is getting the right package of care. 'Referrals come primarily from community learning disability teams, from GPs and from adult mental health services,' says Jean. 'We have a referral hub that meets weekly and acts as a single point of entry and exit for the service. It also means everyone knows what everyone else is doing, who is working with whom, and where. When we discharge people, we report back to the GP through the hub, and advise on future treatment.'

The MHL D service includes a specialist inpatient facility for people who need time in hospital for assessment or treatment. A newly refurbished and specially designed unit opened at the Bethlem Hospital in September 2009, with a dedicated team of staff, including psychiatrists, psychologists, occupational therapists, creative therapists and nurses. The majority of beds are for people living in the four boroughs served by MHL D services, and there are also four beds for people referred from anywhere in the UK (see opposite page).

The new unit replaces the Weston Unit, the specialist ward previously based at the Maudsley Hospital. When the Estia Centre first opened, the Weston Unit was based at York Clinic on the Guy's Hospital campus.

The primary care trusts for each borough commission MHL D services from SLaM, and the package of care includes training for support staff working in the community that is provided by the Estia team.

**Mental health and learning disabilities services** are part of SLaM's Neurodevelopment and National Division. Neurodevelopment is headed by Lisa Seaburne-May and also includes the Behavioural Disorders Unit at the Bethlem Hospital (for adults who have autism, other mental health issues and challenging behaviour); Neuropsychiatry inpatient and outpatient services at St Thomas' Hospital, the Maudsley and King's College Hospital (for adults with memory disorders or other cognitive complaints – psychiatric complications of epilepsy or early onset dementia, for example); the Mental Impairment Evaluation and Treatment Service (MIETS) for adults with mild learning disabilities and challenging and/or offending behaviour; ADHD services for adults at the Maudsley Hospital; and the Behavioural Genetics Clinic at the Maudsley, for adults with cognitive abnormalities and behavioural disorders.

**The Royal College of Psychiatrists' Centre for Quality Improvement** has developed an accreditation programme for inpatient services for people with learning disabilities. All NHS and private sector wards are eligible to apply for accreditation if they provide assessment, treatment or rehabilitation services to adults with learning disabilities who have mental health needs. Jean O'Hara says the Mental Health and Learning Disabilities Unit will be applying for accreditation under AIMS-LD (*Accreditation for Inpatient Mental Health Services – Learning Disabilities*), developed by the RCPsych in response to high profile press coverage of poor quality care and the Healthcare Commission (now Care Quality Commission) subsequent review. Dr Shaun Gravestock, the newly appointed consultant on the Mental Health and Learning Disabilities Unit, has been involved in piloting the accreditation programme in his previous place of work.



Lisa Russell helps people with learning disabilities who behave in a way that is detrimental to their lives or threatens their safety, or affects the lives or safety of others. 'Challenging behaviour can be anything from rocking in a corner to severe aggression or screaming,' she says. 'It is behaviour that prevents people from using facilities and services and affects the quality of their lives, or behaviour that places their physical safety, or the physical safety of others in serious jeopardy.'

A Senior Behavioural Support Practitioner in the south London borough of Southwark, Lisa supports people according to their individual needs. 'I work with clients for a few months, or sometimes for a few years,' she says.

The first step in offering support is a long and thorough assessment process, which involves collecting and analysing information from family members, teachers, friends, support workers, health professionals and the individual themselves, if possible.

'There are many reasons for people behaving in a challenging way. We want to find out what triggers the behaviour, what an individual gains or prevents from happening by behaving in a certain way, and if possible, why the behaviour started in the first place. So, for example, someone may have

had an earache at some point in their life but had no way of communicating that their ear was hurting, so instead hit their head. They then learned that hitting their head brought them attention, so continued to behave in a self-injurious way.'

The assessment includes finding out about a person's background and history and takes into account the severity of their learning disability, their ability to communicate and other health issues they may have. Lisa also carries out a series of direct observations, typically amounting to eight hours, in different places at different times.

'It's often a very complex picture,' she says. 'Often people present with multiple behaviours, and the same behaviour may have a different function for an individual, depending on the setting they are in. Once the assessment is complete, we hypothesise as to what is going on, and then decide what we can do to help support that person.'

The two main ways of helping in the longer term are through skills teaching and environmental change. 'If someone is screaming as a way of saying stop, then we can teach them the sign for stop, for example,' says Lisa. 'Skills teaching is about offering

an alternative new skill that is easier to carry out than the behaviour but has the same effect.

'Behaviour doesn't occur in a vacuum, there is almost always a social context. It could be that the behaviour is a result of not having enough to do, or doing the wrong type of things, or because of lighting or noise levels, or the way people speak to an individual. So altering the environment – changing what is going on around someone in their life – can change behaviour.'

In the shorter term, strategies are put in place to bring the behaviour under rapid control, if need be, she says. 'Skills teaching and environmental change will affect change on a long-term basis and take variable amounts of time to become established and effective. We also put in place interventions that will help to support people when the behaviour occurs in the meantime. All interventions are designed to uphold the dignity of the individual and are non-aversive.'

Lisa offers training for support workers, family members and carers involved with an individual so they are able to offer support tailored to that individual's needs and based on the outcome of the assessment.

Behavioural support really does change people's lives, she says. 'I worked with one lady who had been excluded from almost all services from the age of four because of her behaviour and did not go out without her mother. After an assessment and behavioural support, she is now able to go out with support workers, it being no longer necessary for her mum to go.'

Lisa is employed by SLaM and works with both the community learning disabilities team and the mental health and learning disabilities team in Southwark.

### ***Keeping in Together, A guide for support staff working with people whose behaviour is challenging***

is produced by the Estia Centre team and published by Pavilion (see page 23). SLaM's Head of Psychology Services for Adults with Learning Disabilities Theresa Joyce and colleagues were also involved in the production of *Clinical and service guidelines for support for people with learning disabilities who are at risk of receiving abusive or*

*restrictive practices*, which spells out how best to work with people with a learning disability whose behaviour presents a challenge. The guidelines were published jointly by the British Psychological Society and the Royal College of Psychiatrists in consultation with the Royal College of Speech and Language Therapists. A new training pack on challenging behaviour from the Estia team is due to be published by OLM-Pavilion in 2010.

# Training and education

People with learning disabilities and mental health problems are among the most vulnerable people in our society. Training for the health professionals and support workers who offer them care is crucial to make sure staff have the skills and knowledge to meet people's often complex needs. The Estia Centre has designed a programme of training for support staff, and another for clinicians working in social care and NHS services with people with learning disabilities and mental health problems. Training has been an essential part of the Centre's remit from the beginning and many of the workshops developed by the Estia team have been translated into training packages available in CD-ROM and book format (see page 22).

Training and Consultancy Manager Steve Hardy has been responsible for the Estia's training activities since 1999: nowadays he and Training Officer Sarah Halls organise a large portfolio of workshops routinely offered to support staff in south London and available on request across the UK. There is an Estia programme of monthly seminars for clinicians and other mental health workers to discuss best practice, and two or three national conferences are organised each year to give professionals the opportunity to share expertise and discuss new developments.



## Workshops for support staff

Support staff play a significant role in the lives of many people with learning disabilities, particularly those who live independently or away from their families. Often the quality of people's lives can depend on the quality of the services that these frontline staff provide.

Support workers also play a crucial role in making sure people with learning disabilities who have mental health problems get the care they need. Because many people with learning disabilities have communication difficulties, they may not be able to describe symptoms or how they are feeling. Signs of mental ill health, like changes in behaviour, may be misinterpreted.

The Estia Centre has developed and delivers workshops specifically for support staff to give them the skills and knowledge they need to be able to promote good mental health, recognise a mental health problem, help the person they work with access appropriate services, and play a supporting role during assessment, treatment and recovery.

These workshops are offered all year round (bar August) to frontline staff who work in the statutory and voluntary organisations that provide services to an estimated 3,000 people with learning disabilities in the south London boroughs of Lambeth, Lewisham and Southwark.

A range of services are commissioned by primary care trusts and social services departments from more than 100 organisations offering supported housing, outreach services – where workers visit people in their homes for a few hours each day – day and community access services and employment services. On average, around 800 support staff working in these three boroughs attend the Estia's workshops each year. The workshops are led by members of the Estia Centre team, service users, health professionals working in SLAM's MHL services and staff from the primary care trusts.

There are about 80 workshops staged locally each year at a variety of venues. In addition, the Estia team can be commissioned to run training for support staff anywhere in the country – either leading a generic workshop or a session tailored to meet the specific needs of a particular staff team.

## The employer-led training authority Skills for Care is

responsible for vocational Learning Disability Qualifications for social care support staff, including an Induction Award and NVQs. However, mental ill health modules are only optional units within these qualifications.

New workshops are constantly being developed either in response to the needs of people working within learning disability services, or to topical and relevant issues. 'Since the new Mental Capacity Act came into force in 2007, for example, we have run eight to 10 workshops a year about the new law,' said Steve. New in 2009 was a two-day *Advanced mental health needs of people with learning disabilities* workshop, designed after people who attended the long-established *Introduction to mental health needs* workshop asked for a more detailed package of information.

The Estia team also offers bespoke client-centred training around the needs of an individual service user. They train support staff who are going to be working with an individual moving from hospital into supported housing, for example, and can work with a whole team on the needs of an individual with learning disabilities and a specific mental health problem, like bipolar disorder. This training is offered in collaboration with a clinician.

### Programme for clinicians and health practitioners

Psychiatrists, psychologists, mental health nurses and other clinicians working in a range of learning disability services

come from all over London and the Home Counties once a month to attend the Estia Centre's Multi-Disciplinary Academic Programme seminars.

Each of the seminars begins with a case presentation, where the individual's identity is protected. 'Usually this is about someone who has complex needs and everyone then discusses and contributes ideas on treatment and how the clinical team involved can support the person and help them get back to their normal self,' said Steve Hardy.

This is followed by a review and discussion of recent research results and policy. The latest research evidence helps ensure best practice, while the policy discussion helps keep professionals up to date with changes, new guidance, and their implications for practice. Each seminar concludes with an invited speaker working in the field of mental health and learning disabilities, highlighting a specific area – psychotherapy and people with learning disabilities, for example, or assessment of personality disorder.

The Multi-Disciplinary Academic Programme is open to all professionals who support people with learning disabilities. Seminars take place on a Tuesday, once a month, except April and August.



Patrick Dixon works in a supported living house, home to four people with learning disabilities and mental health problems. He is on a seven-day-a-week shift rota and enjoys his role: 'I get a good sense of well-being out of the job,' he says.

When he joined the house in Catford, south London, he had no experience of working with people with learning disabilities. That was in May 2008, and his employer, independent provider Access for Living, gave him two weeks' worth of inhouse training before he took up his post. Since then, he has attended many training days organised by Lewisham Partnership (the body responsible for buying services for people with learning disabilities who live in the Lewisham area), including

some of the workshops run by the Estia Centre - *Introduction to the Mental Capacity Act and people with learning disabilities for support workers*, for example.

'The workshop involved a lot of role play as well as discussion,' says Patrick. 'It was based on real life scenarios and examples, and gave me a lot of insight into what my role as an advocate for people I support, particularly a non-verbal person, should be. I haven't had to apply what I learned yet, but I can see there will be occasions when decisions have to be made on behalf of an individual, whether it is to do with finances or health care, for example, and the workshop helped me understand how best to do this.

'When I first started at the house, I went on the Estia Centre's two-day *Introduction to mental health needs of people with learning disabilities* and that was very good because it included people with learning disabilities as trainers who talked to us about the way they wanted to be treated. This first hand training was really direct and focused, and was very useful.

'Training is essential in this job, and I wouldn't be able to support the people who live in the house properly without it. People's individual needs are diverse and also change, so to be able to offer appropriate and good support, I need to keep learning and expanding my knowledge and experience.'

## Estia Centre workshops for support staff

If you would like to run any of these workshops for groups of support staff working in services for people with learning disabilities, contact Steve Hardy, Steven.Hardy@kcl.ac.uk or Sarah Halls, Sarah.Halls@slam.nhs.uk

### **Introduction to mental health needs of people with learning disabilities**

Helps support staff understand why people with learning disabilities are vulnerable to developing mental health problems, the assessment process and different interventions available. A two-day workshop.

### **Advanced mental health needs of people with learning disabilities**

Gives participants a more in-depth understanding of the mental health needs of people with learning disabilities, how best to support them, and how to work with both mainstream and specialist mental health services. A two-day workshop.

### **Listening skills for staff working with adults with learning disabilities**

Helps participants learn how to listen effectively to people with learning disabilities and provides an introduction to counselling. A one-day workshop.

### **Death and dying**

Enables participants to understand and support people with learning disabilities during terminal and/or prolonged illness. A one-day workshop.

### **Working with younger people in transition with learning disabilities**

Provides information about the transition process from children's to adult services and enables participants to support people with learning disabilities prior, during and after transition. A one-day workshop.

### **Introduction to autism and people with learning disabilities**

Increases understanding of autism and gives greater insight into the needs of people who have learning disabilities and autism. A one-day workshop.

### **Risk assessment and management of people with learning disabilities for support workers**

Helps support staff contribute to and understand their role in the assessment and management of risk in people with learning disabilities. A one-day workshop.

### **Risk assessment and management of people with learning disabilities for senior staff**

For senior staff working in learning disability services, to help them assess and manage risk in relation to the behaviour of service users. A one-day workshop.

### **Introduction to the Mental Capacity Act and people with learning disabilities for support workers**

Up-to-date information about the Mental Capacity Act 2005 and issues relating to the capacity of adults with learning disabilities to give consent. A one-day workshop.

### **The Mental Capacity Act and people with learning disabilities for managers**

Up-to-date information about the Mental Capacity Act 2005 and issues relating to the capacity of adults with learning disabilities to give consent. A one-day workshop.

### **Introduction to challenging needs and people with learning disabilities**

Gives participants information about causes of challenging behaviour, assessment and the most up-to-date approaches to people with challenging needs. A two-day workshop.

### **Self-injurious behaviour and people with learning disabilities**

Gives greater understanding of self-injurious behaviour, its detrimental effect on an individual and the services and interventions available. A one-day workshop for senior staff who have previously attended our *Challenging Needs* workshop.

### **Mental health needs of the older person with a learning disability**

Gives participants an understanding of the mental health needs of older people with learning disabilities, particularly focusing on Alzheimer's disease, including signs and symptoms. A one-day workshop.

### **Working with offenders who have learning disabilities**

Gives participants an understanding of why people with learning disabilities might be likely to offend, the role of professionals who can support them and skills staff may need to help people with learning disabilities and offending behaviour. A one-day workshop.

### **Contribute to the management of substance use and misuse in people with learning disabilities**

Helps develop skills to work with people with learning disabilities who use/abuse tobacco, recreational drugs or alcohol. It includes information about the law and specialist services. A one-day workshop.

### **Activity and skills development**

Gives participants an understanding of the importance of a person centred approach to selecting activities and enabling clients to develop skills. A one-and-a-half-day workshop.

### **Using objects, photos and symbols as aids to communication and independence for people with learning disabilities**

Gives participants an understanding of the importance of using objects, photos, symbols and gestures in environments which support adults with learning disabilities. A two-day workshop.

### **Health action planning and health facilitation for people with learning disabilities**

Explains how to support people to devise their own health action plan as recommended in *Valuing People*. A half-day workshop.

The Estia's *Introduction to mental health needs of people with learning disabilities* two-day workshop was different from other training that support worker Walter Musekiwa has had. 'It was the first training to involve a service user,' he says. 'The service user was there to inform us how services users are treated, and how they would like to be treated, and this was informative and enlightening, and challenged some of our thinking.'

Walter is key worker for five people living independently in Southwark and spends different amounts of time with each one every week, depending on their needs. His role is to help them in everyday life, and act as an advocate if necessary. He joined In Touch, a care, support and supported housing charity, at the end of 2008 but before then worked for six years as a support worker for another organisation.

'My job is very rewarding,' he says. 'Helping an individual is very satisfying.'

Walter had had previous training about the mental health needs of people with learning disabilities and the Estia workshop acted as a refresher course for him. 'Some of my clients do have mental health problems and the workshop taught me how to spot signs of deteriorating mental health. That means I can do something – refer them or discuss it with my team to make sure they get the help they need. In my role, training is very useful, especially as I work with different clients who all have different needs,' he said.



Rikki Wardally has been a support worker for people with learning disabilities all his working life. Since 2003, he has been based in a residential house in Stockwell, south London, home to five people, and run by not-for-profit independent provider Southside Partnership.

Even after 15 years of experience and studying for NVQ qualifications, he says training is still very important. 'Lots of concepts and ideas change, and there is new research coming out. Attending training courses also gives you a chance to share personal experiences and take stock of what you're doing with peers and colleagues working in similar roles. It's good to refresh skills and knowledge

as well as learn new things, or have the chance to step back and think differently.'

Rikki says the Estia's *Using objects, photos and symbols as aids to communication and independence for people with learning disabilities* workshop was 'fantastic', and prompted the creation of a visual staff rota at the house, with pictures of support workers on duty, as well as personal daily or weekly visual diaries for residents, designed according to their ability to understand information and communicate.

'Training can sometimes prompt you to do something different,' he says. 'I'd

already been on communication training, and I do a lot of creative things with the people in the house. But the course helped me think of new things – we talked about using fabrics as a way of communication, for example, to help people identify something through feel or touch, not words.'

In addition, says Rikki, a member of staff may feel they need some help in a particular area, or a weakness may come up during appraisal. 'It's very useful to look through the Estia Centre prospectus to see what's available on top of mandatory training organised by Southside Partnership head office.'

### National conferences

Since its creation in 1999, The Estia Centre has organised two or three national conferences a year to share research and best practice and discuss changing policy. People from all over the country come to the conferences to learn more about a specific subject in the field of mental health and learning disabilities – in 2009, for example, the June conference was about mental health and adults with autism. More than 100 people come to each conference: health and social care professionals – psychiatrists, psychologists, nurses, residential service managers, for example – as well as health and social care commissioners, researchers and sometimes family carers. The Estia Centre mostly works with other organisations, such as OLM-Pavilion, to stage the conferences.

### PAS-ADD training

The Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) is used to assess mental health problems in people with learning disabilities. It allows clinicians, health professionals, support staff and family members to collect information about symptoms to help make an accurate diagnosis. The development of the tool was led by Steve Moss, now an associate member of the Estia Centre. Since 1999, Steve has led regular workshops run by the Estia Centre to train people how to use PAS-ADD.

■ [www.pasadd.co.uk](http://www.pasadd.co.uk)

### Mental Health in Learning Disabilities MSc

The MSc in Mental Health in Learning Disabilities is part of the portfolio of postgraduate programmes at the Institute of Psychiatry, King's College London. Clinical staff who work in SLaM's MHLd services and academics who carry out research under the auspices of the Estia Centre contribute to both the development of the curriculum and the teaching programme. 'The course content is constantly updated as new research is published and new policy and guidelines come out,' said Course Director Dr Elias Tsakanikos. 'This MSc is the foremost academic qualification within the speciality of mental health in learning disabilities.'

The MSc is designed to offer both professional development to people already working in health and social care services and a good grounding of mental health issues to graduates with some clinical experience who are keen to forge a future career in the field. 'Our students are very diverse,' says Elias. 'We have people with a background in medicine, nursing or occupational health, social workers, GPs and psychology graduates. The course improves people's knowledge and skills if they are already working in mental health services for people with learning disabilities and can help them advance their careers. It also gives graduates an understanding of evidence-based approaches to specialist mental health care before embarking on a PhD or a clinical career.'



Photo: courtesy Elias Tsakanikos

The MSc is one of the three run under the umbrella of the Mental Health Studies Programme at the Institute of Psychiatry. Students undertake two modules common to all three (*Basic Mental Health and Research Methods*), and two specialist learning disability modules.

In addition, they carry out a piece of original empirical research about learning disabilities and mental health to be the subject of their dissertation. Often students are able to join an experienced team

**The Estia team** is working with students who have learning disabilities at Lewisham College in south east London. In 2009, the team developed a half-day workshop about mental health specifically for students. 'It covers mental health problems, staying well, what happens if you become unwell, what do to when you see a psychiatrist or mental health professional,' says Steve Hardy. Colleges who are interested in running this workshop should contact Steve, [Steven.Hardy@kcl.ac.uk](mailto:Steven.Hardy@kcl.ac.uk) or Sarah Halls, [Sarah.Halls@slam.nhs.uk](mailto:Sarah.Halls@slam.nhs.uk)

of researchers at the Institute of Psychiatry and complete a work stream of a larger project. 'This is very beneficial for students who can work with and learn from some of the most influential researchers, and build contacts for the future,' said Elias, who also carries out and supports research activity at the Estia Centre. Alternatively, students can design their own protocol with tutors' support.

The two specialist learning disability modules look in detail at the aetiology of specific mental health problems, the mental health needs of people with learning disabilities, assessment methods, treatments and interventions, and neurodevelopmental issues in mental health.

Students can opt for full-time study for a year, or part-time for two years. Most of the part-timers are sponsored by their employer – either the NHS or local authority social services departments. Launched 10 years ago at the same time as the Estia Centre, the MSc attracts students from abroad as well as from the UK.

Assessment of students takes place throughout the Programme and there are end-of-year exams. Each student has a personal tutor and a research supervisor to support their learning, and all students are able to attend the Estia Centre's monthly Multi-Disciplinary Academic Programme seminars.

■ [www.mentalhealthstudies.iop.kcl.ac.uk](http://www.mentalhealthstudies.iop.kcl.ac.uk)



Maggie Koliou was working with children who have autism at Jigsaw School in Guildford when she joined the MSc in Mental Health in Learning Disabilities programme in 2005. She continued to work while studying part-time at the school, one of five in the UK run by independent providers using Applied Behavioural Analysis (ABA), an intervention for young children with autism, designed to meet individual needs.

'There are very small classes in these schools, and the tutors work with one child at a time. The schools cater for the whole autism spectrum, and the majority of children have learning disabilities,' she says.

While studying Psychology at university, Maggie had trained in the ABA intervention during her placement year. When she graduated, she took a job in a London school working as an ABA tutor. During her time at Jigsaw, she decided to do an MSc to broaden her options.

'On the MSc, I learned about different mental illnesses and the symptoms of mental health problems. Sometimes these get masked in people with learning disabilities because they may not be able to describe how they are feeling. This was really helpful, and I also learned different approaches if someone does have mental health problems.

'The MSc is oriented towards adults so it wasn't very helpful in my work while I was studying. My research project however, was a case study with one of the children at my school: I carried out a mental state examination, made different diagnoses and recommended interventions.

'I was able to work four days a week and spend one day at university. The course is very interesting, and the lectures and small groups

are very interactive, so you pay a lot of attention when you are there.'

After the MSc, Maggie worked in Greece for two years as an ABA supervisor in a specialist school, working with both children with autism and their parents. Now back in England, she is a self-employed ABA supervisor, working with individual families in their homes. She is planning to sign up for a one-year course to obtain the Board Certified Behaviour Analyst (BCBA) certification, and then work as a consultant in ABA.

'The MSc was very interesting, and I enjoyed it. It gave me an insight into different mental health problems. The tutors were all very friendly and approachable. I think it's a very good course for people working with people with learning disabilities.'





### Issues in Forensic Intellectual Disability training

A three-month, one-day-a-week short course for professionals working with people with learning disabilities who are involved with the criminal justice system was launched in 2008 under the Estia Centre banner as one of a number of short courses offered by the Health Service and Population Research Department at the Institute of Psychiatry, King's College London. The course grew from a *Forensic Intellectual Disability* module of the MSc in Learning Disabilities: the module was first run in 2004.

'The course is not skills-based: it is grounded in theory, looking at the evidence base behind methods used in assessment and treatment, as well as policy developments and the criminal justice system. It also covers rights of individuals and issues of vulnerability and ethics. It's designed to extend knowledge and understanding,' said Programme Leader Eddie Chaplin who is based at the Estia Centre, and previously worked for 17 years as a ward manager at Bethlem Hospital on a low secure forensic unit for people with learning disabilities.

Eddie is one of the editors of a comprehensive new training pack, *Working with People with Learning Disabilities and Offending Behaviour*, published by OLM-Pavilion in 2009 (see page 22). Designed for professionals working in forensic services, the new resource is organised into modules, each supported by a chapter in a complementary reader. A national conference of the same name was organised by the Estia Centre in collaboration with OLM-Pavilion in September 2009, and included a DVD presentation made with Hertfordshire Partnership NHS Foundation Trust and featuring service users talking about their experience in forensic services.

'The training resource covers some of the same content as the short course,' said Eddie. 'The publication is more for people who are new to the field, whereas the course is for people who have been working in forensic services for some time.'

Eddie and his colleagues are currently considering developing the short course as a distance-learning package available on the internet to make it accessible to professionals throughout the UK.

■ [www.iop.kcl.ac.uk/courses/?id=58](http://www.iop.kcl.ac.uk/courses/?id=58)

**The Estia Centre runs an electronic network** for anyone interested in the mental health needs of people with learning disabilities. The Mental Health in Learning Disabilities Network is free to join: members share and disseminate resources and examples of good practice, and can use the Network as a forum to seek help.

■ [www.estiacentre.org](http://www.estiacentre.org)

# The Tuesday Group



**For the past 10 years, a group of people with learning disabilities has been meeting in Lewisham, south London, every other week on a Tuesday, to talk about staying mentally well and the services they use.**

Shortly after the Estia Centre opened, the team ran a workshop about mental health for people with learning disabilities at a conference organised by voluntary organisation Lewisham Voice. Those who attended the workshop said they would like a course about staying mentally well, which the Estia team then developed. The 12-week course evolved into the Tuesday Group: when it was over, people continued to meet on a more regular basis, and have been meeting ever since, with the support of Steve Hardy and colleagues from the Estia Centre.

Liam Peyton, Yolanda Zimock, Yvonne Montgomery and Peter Cronin are among the original members of the Tuesday Group, now much more than a place to talk and

**get support. Members of the Group take part in training and speak at conferences to tell professionals how they could better work with people with learning disabilities.**

'When I go to the doctor, he looks at the support worker and not at me. It upsets me. Most people don't look at us, they look at the support workers,' said Peter.

Over the years, members of the Group have also written articles about the needs of people with learning disabilities, about how to stay mentally well and about how staff can improve the way they treat people with learning disabilities. Members of the Tuesday Group are now regular contributors to the training workshops organised by the Estia team for support workers.

They have also helped train staff on courses run at the University of Greenwich and spoken at events organised by the Royal College of Nursing and Kingston University. Before the new Mental Health and Learning Disabilities Unit opened at the Bethlem Hospital, they



were involved in training organised for newly appointed staff there. 'We talk to people about support workers and doctors and counsellors being fair and listening to service users,' said Liam. 'We speak up for ourselves about mental health problems and what services are like,' said Yolanda, who has given a talk about what it's like to stay in hospital at a conference about autism.

The Tuesday Group has been invited to speak to people involved in running The Judith Trust (a learning disability charity) and each year interview service users and staff on wards for people with learning disabilities run by SLaM prior to an annual audit by the Care Quality Commission (previously Healthcare Commission). 'When we went to the Bethlem Hospital last year, most of the service users were happy, and some said how it could be improved. We wrote a report saying what they said, and saying how to make it better, and that report went to managers,' said Peter.

**As well as being in demand for training and conference events, the Group also enjoys socialising and continues to discuss strategies for staying well.**

'We talk about how to keep mentally well and how to keep physically well,' said Peter.

Day outings are organised: trips to seaside towns and London attractions like Battersea Zoo, for example.

'And at Christmas, we all go out for a meal,' said Liam.

When original members of the Tuesday Group have left – because they have secured work, for example – they have been replaced by newer members like Anne Onwuegbuzie who joined five years ago. The optimum number for the Group is 10, and when a space becomes available, Steve contacts local residential and support services to look for people who might be interested in becoming a member.

■ Contact the Tuesday Group via Steve Hardy, [Steven.Hardy@kcl.ac.uk](mailto:Steven.Hardy@kcl.ac.uk)

# Research



The results of the research carried out by the Estia team over the past 10 years have informed and influenced service development and clinical practice in south London, across the UK and across the world.

The work of the Estia team has highlighted the difficulties faced by people with learning disabilities and mental health problems, and continues to focus on research to make sure services meeting the mental health needs of people with learning disabilities are designed and delivered in the best and most cost-effective way.

Everyone who works in the MHL service can be involved with research carried out under the auspices of the Estia Centre. 'We are all clinicians with an interest in delivering services in the best way,' said Jane McCarthy, a consultant psychiatrist in the Southwark team who takes the lead on planning Estia-branded research alongside Dr Elias Tsakanikos, who also runs the MSc in Mental Health in Learning Disabilities (see page 13). All consultant psychiatrists working in the MHL service have 'research and development' in their job description.

Jane chairs a Research and Development meeting once a month where all professionals working within the service – psychiatrists, psychologists, nurses, junior doctors – or anyone working within other local learning disability services can

## **Online training for GPs and community mental health teams**

is being developed by the Estia team to help them make accurate diagnoses of autism and ADHD and thus make referrals to appropriate specialist services. This work is one strand of a large five-year National Institute for Health Research-funded programme focusing on the experiences of younger people with ADHD and/or autism, looking in particular at the transition from services for children to services for adults, with a view to developing better, cost-effective services and treatments. The study is being led by Professor Declan Murphy at the Institute of Psychiatry. 'Our core interest at the Estia is improving services,' says Jane McCarthy, 'but we do collaborate with other research teams who carry out genetic and biological projects, or studies looking at best treatments and improving diagnosis, such as this one.'

discuss current research, bring new ideas to the table and talk about future projects. MSc and PhD students are invited to attend these meetings.

The Estia Centre has a small number of dedicated research staff working on specifically-funded projects: Lisa Underwood, for example, is a PhD student working on a project funded by the Baily Thomas Charitable Fund which seeks to find out if people who have autism and also learning disabilities get the services they need (see page 20). 'Adults with autism and learning disabilities often have problems with communication, and mental health problems such as anxiety or depression. There is a concern that many drop out of services and go untreated. The aim of this study is ultimately to get the information that will allow us to design better services and improve the quality of life of adults with autism and learning disabilities,' said Jane.

Another current project is exploring the feasibility of providing services in south London for people who are currently cared for away from their local neighbourhood because as they stand, local services cannot cater for their needs. Over the past 30 years, an increasing number of independent health care facilities have been opened to meet the demand for alternative forms of accommodation for people with learning disabilities following the closure of long-stay institutions. People with mental health problems or complex needs are more likely to be placed in facilities like these, mostly outside their local area, despite government policy laid down in *Valuing People* to treat people locally, and against the wishes of service users and their families, often kept apart by the difficulties and cost of travelling.

'SLaM spends about £9 million a year to care for about 60 people from Southwark and Lambeth in health care facilities often miles away from their families,' said Jane. 'We want to find out if community-based and specialist residential services could be developed locally, be better for the individuals, and more cost-effective for the NHS.'

The Guy's and St Thomas' Charity-funded research is evaluating the needs of a sample of service users, looking at what of sort of services they need, their cost, and what impact out-of-area care has on their quality of life and their families' lives. The information yielded could help build the case for developing services locally, she said.

Many of the Estia Centre's research projects in recent years have been supported by the charitable sector. 'The mental health needs of people with learning disabilities is an under-funded and low priority area. In terms of research and evaluation of services, it doesn't fit neatly into any UK government funding programme. Learning disability programmes say it should be mental health, and mental health programmes say it should be learning disabilities. It's the same in most countries in the world, except in North America.'

Thus The Judith Trust, a learning disability charity, is funding another current study investigating whether a service user's ethnicity makes a difference to their experiences of health and social care. Junior doctors working within the MHL service have been collecting data for this research by interviewing service users, and the preliminary results highlight differences in the experiences of white people and black people. Everyone interviewed so far said staff don't say unkind things to people who are not white, but more black service users than white said staff sometimes made them angry or upset, that staff don't talk about what's wrong when they are worried or sad, and are more likely to offer them medication. The Estia team hopes to develop this research and compare the background and clinical needs of service users from different ethnic communities. In the longer term, the findings of this work will help create services that are more culturally sensitive, said Jane.

Early results of this study were presented to the 7th European Congress of Mental Health in Intellectual Disability, held in Amsterdam in September 2009. The Congress is organised by The European Association for Mental Health in Intellectual Disability (formerly the European Association for Mental Health in Mental Retardation), one of a handful of international organisations made up of professionals working in the field who share experience, knowledge, expertise and research results. The Estia Centre and MHL team are represented on all of them, including the World Psychiatry Association's Section on Psychiatry of Intellectual Disability and the International Association for the Scientific Study of Intellectual Disabilities' Challenging Behaviour and Mental Health Special Interest Research Group.

**The Estia Centre's initial research** concentrated on collecting information about locally-based people to inform the development of community-based mental health services in south London following the closure of long-stay institutions. The database that was set up has been used over the past decade in many studies – looking at referral patterns and characteristics of service users, for example. In future, it may help form the basis of a cross-England research database to be set up under the auspices of the National Institute for Health Research Mental Health Research Network (NIHR MHRN). The Estia Centre brings together researchers and clinicians across

England through the NIHR MHRN's Learning Disabilities Network. As convenor of the Network, the Estia Centre is taking the lead on designing and applying for funding for multi-centre projects that seek to inform the development of better services and treatments.

The Learning Disabilities Network (also known as Evaluation of Treatment Interventions in Adults with Learning Disabilities Clinical Research Group) is currently planning to set up a database of clinical records of people using collaborating services as a starting point for different studies focusing on mental health. 'This would be a national resource which could be

used for research to find out what is happening in services for people with learning disabilities and mental health problems across England,' says Jane McCarthy. The Estia team is now looking for funding for the project.

**Service users have been involved in the creation of 'the SAINT'** – a booklet designed to help people with learning disabilities recognise mental health problems and take action to help themselves. Eddie Chaplin, Strategy and Research Nurse at the Estia Centre, is developing the SAINT (Self-Assessment and Intervention Pack) for a part-time PhD.

Eddie is currently recruiting service users to test the effectiveness of the booklet, written in accessible language and devised with the help of expert clinicians and two mental health support groups for people with learning disabilities: the Tuesday Group (see page 16), facilitated by the Estia Centre, and the Beat the Blues Group, facilitated by staff from Oxleas NHS Foundation Trust.

The SAINT includes a list of feelings that could be symptoms or signs of a mental health problem – 'I am having problems sleeping'; 'I feel in a panic'; 'I feel down'; 'I find it difficult to do things', for example – and a calendar so people can record how they are feeling on particular days.

It also includes a list of coping strategies, many of them suggested by service users: 'think positive thoughts'; 'talk about how you are feeling'; 'exercise'; 'go out'; 'relax'; 'do things you enjoy,' for example. Use of a particular coping strategy can also be recorded in the calendar.

'The idea is that the booklet can help people to help themselves, but also act as a monitoring tool to help people remember how they have been feeling if they need to access professional help,' says Eddie. 'A record can also help a person order their thoughts when they are talking to carers or health professionals.'

### **Estia Research Lead Jane**

**McCarthy** attends meetings of the All Parliamentary Group on Learning Disability, a group of MPs and peers from all political parties who are interested in issues that affect people with learning disabilities and their families. The Group is chaired by Tom Clark MP and Lord Rix, Mencap's President, and it discusses relevant reports, proposals and policies, taking expert contributions from the floor.

Lisa Underwood is interviewing service users with a diagnosis of autism who are being cared for by MHL D teams in Southwark, Lewisham and Lambeth to find out about their mental health, their needs and their experience of care. She is also trying to track down people with autism who were referred to the service in the past decade to discover how they have fared, and whether their needs have continued to be met.

She is collecting a lot of information from the interviewees: what services people have accessed and used in the last year; what support they have had from unpaid carers; people's current mental health problems and behavioural problems; people's level of learning disability and communication ability; the interventions or treatment they have received. 'We are using a range of assessment tools to try to find out as much as we can about people, including looking at their medical records to get some sort of history, and find out what medication and therapy they have been offered,' says Lisa. 'It's a lot of information, but this data has not been collected before, and hopefully we can use it

as a starting point for a longitudinal study of those agreeing to participate.'

Lisa will be collecting the same information for a group of people who are on the MHL D caseload who do not have a diagnosis of autism in order to make comparisons. 'At the moment, we don't know whether there are differences in outcome or service use for people who have a learning disability with and without autism,' she says. 'We think people with autism and learning disabilities will be using more services, but will have more mental health problems, more behavioural problems and greater unmet needs. Testing these hypotheses and finding out exactly what the differences are, if any, will help commissioners and providers to plan services.'

She is carrying out interviews with people she recruits to the study with the help of a family member or support worker. The research has ethical approval to include people who lack capacity, so family members can decide about participation on behalf of an individual. 'This will ensure we include people with a full range of learning disabilities,' says Lisa.



# The future

In this, the Estia Centre's 10th anniversary year, times are beginning to change for its parent organisations, South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry, King's College London. Both are key players in the new Academic Health Sciences Centre (AHSC) called King's Health Partners, accredited by the Department of Health earlier in 2009. The other partners are Guy's and St Thomas' and King's College London NHS Foundation Trusts.

The creation of the AHSC heralds closer working links between the NHS partners and the university health schools, including the Institute of Psychiatry. The 'building blocks' of the AHSC will be Clinical Academic Groups (CAGs), new management structures bringing together services, research and teaching into speciality groupings – in the same way the Estia Centre has been doing for the past decade. 'The Estia exemplifies what CAGs should be,' says Clinical Director of MHL D services Jean O'Hara.

MHL D services are likely to be part of a Behaviour and Development CAG alongside Forensic Mental Health Services, services for adults with ADHD and Behavioural Genetics services. Research and teaching activities for each speciality will be housed within the same CAG – so will there be a need for the Estia to continue as a separate entity?

'It is important to keep the Estia brand, but how it fits in with the new structure is still up for debate,' says Lisa Seaburne-May, Head of Neurodevelopment at SLaM.

The new structure will allow the expertise of the Estia and MHL D service team to be shared not only with sister services within the CAG, but also with services based within other CAGs, she says.

'Most people with learning disabilities are treated in generic mental health services, therefore the skills of the professionals based at the Estia and in MHL D services are needed by all mental health professionals. It may be that the Estia could become a consultancy service – both internally within SLaM, and externally.'

The advent of King's Health Partners' new structures offers the opportunity to increase the profile of learning disabilities and mental health issues, particularly for research purposes, says Lisa. 'There is a commitment to continue and expand research about learning disability and mental health. Each CAG will need to be income generating, so there is the potential benefit to use some of that income to invest in research and provide more of an evidence base for services for people with learning disabilities and mental health problems.'

Since *Valuing People*, there have been various initiatives to keep the needs and rights of people with learning disabilities more centre stage, including government-appointed learning disability 'tsars' and recent moves to stamp out inconsistencies in services and funding in different parts of the country.

Despite this, investment in research about how best to meet the needs of people with learning disabilities and mental health problems remains low in the UK and around the world. 'Research to find out what works for this group of people is under-funded everywhere, and it may be because they are not outspoken and have few advocates,' says Jane McCarthy 'These are not influential people in our society, so they carry on being low priority and their needs are neglected.'

There are few centres in the UK carrying out research in learning disabilities and mental health, and Jane predicts that universities and health trusts are likely to be even less keen in the current financial climate to support work that finds it hard to attract government funding.

'We need to continue to flag up the needs of this vulnerable group of people and it needs to become a high priority area, with investment in research to get the evidence to show what services work best,' she says.

The Estia Centre has built an influential national and international profile within the 10 years of its existence. For the future, that profile needs to be sustained and expanded, says Jane, and its health service-oriented research activities need to be embedded into a place of importance within the new King's Health Partners to take the work of the Estia Centre forward for the next 10 years.

# Estia publications



## **Mental Health Services for Adults with Intellectual Disability: Strategies and Solutions**

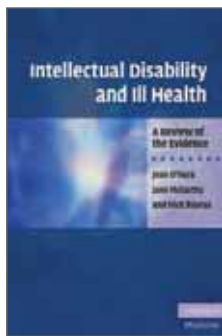
Editors: Nick Bouras and Geraldine Holt

A Maudsley Monograph

Published by Psychology Press, January 2010

■ [www.routledgejournalhealth.com/maudsley/series.asp](http://www.routledgejournalhealth.com/maudsley/series.asp)

The new Maudsley Monograph looks at the evolution of mental health services for people with intellectual disability over the past three decades.



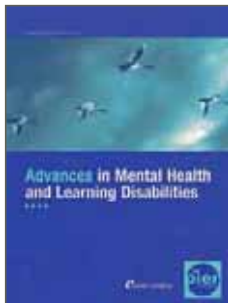
## **Intellectual Disability and Ill Health: A review of the evidence**

Editors: Jean O'Hara, Jane McCarthy and Nick Bouras

Published by Cambridge University Press, January 2010.

■ [www.cambridge.org/catalogue/catalogue.asp?isbn=9780521728898](http://www.cambridge.org/catalogue/catalogue.asp?isbn=9780521728898)

This book reviews the published literature on physical and mental health in people with an intellectual disability. People with intellectual disabilities often have health needs that go unrecognised and untreated – either because of difficulties in communication, discrimination or indifference. This evidence base can help shape public health policy, health care commissioning and the development of a more effective health care system, and can support better understanding and practice amongst clinicians.



## **Advances in Mental Health and Learning Disabilities**

Editors: Steve Hardy and Jane McCarthy

Published by Pier Professional

■ <http://pierprofessional.metapress.com/content/121395/>

The only UK journal specific to the mental health needs of people with learning disabilities, published four times a year and including articles about both research and practice in the field. *Advances in Mental Health and Learning Disabilities* aims to help professionals deliver high-quality and evidence-based practice to people with learning disabilities who have additional mental health needs, and to provide a forum for professionals, managers and academics to debate current issues and opinions.



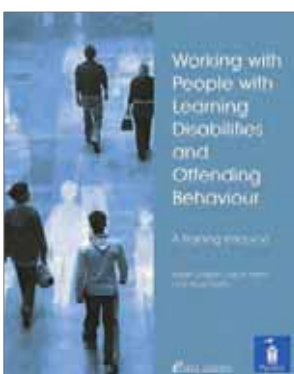
## **Mental Health Promotion for People with Learning Disabilities**

Steve Hardy, Peter Woodward, Sarah Halls and Ben Creet

Published by The Estia Centre and OLM-Pavilion, 2009

■ [www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=912](http://www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=912)

A training package that enables professionals to educate people with learning disabilities about mental health. Designed as a course of 12 sessions, the resource includes a CD-ROM, handouts and short training videos. It aims to help course participants improve their mental health by learning to recognise emotions and feelings; identify stressful situations; develop personal strategies to improve and/or maintain mental health; be more aware of mental health problems, particularly depression and anxiety; and have a better understanding of services and treatments that are available.



## **Working with People with Learning Disabilities and Offending Behaviour, A training resource**

### **Working with People with Learning Disabilities and Offending Behaviour, A handbook**

Eddie Chaplin, Jayne Henry and Steve Hardy

Published by OLM-Pavilion, 2009

■ [www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=948](http://www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=948)

■ [www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=947](http://www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=947)

A training resource and handbook for professionals working with offenders with learning disabilities, or people with learning disabilities who are at risk of offending. It offers a framework for delivering care and highlights current issues and legislation, and their relevance to practice. The training is presented in modules, each supported by a chapter in the complementary handbook (which can also be read independently): the modules can stand alone or be delivered as a comprehensive course. The package includes a CD-ROM containing PowerPoint presentations, case studies, report templates, an evaluation pack, and one copy of the handbook.





**Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities (Second Edition)**

Edited by Nick Bouras and Geraldine Holt  
Published by Cambridge University Press, 2007

■ [www.cambridge.org/catalogue/catalogue.asp?isbn=9780521608251](http://www.cambridge.org/catalogue/catalogue.asp?isbn=9780521608251)

Useful information about clinical practice and research findings, with hands-on, practical advice for psychiatrists, psychologists, nurses, therapists, social workers, managers and service providers to inform the planning and delivery of services to meet the mental health needs of people with intellectual, developmental and learning disabilities.



**Keeping it Together: A guide for support staff working with people whose behaviour is challenging**

Peter Woodward, Steve Hardy and Theresa Joyce  
Published by Pavilion Publishing, 2007

■ [www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=901](http://www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=901)

A self-help guide for support staff working with people with learning disabilities who are new to challenging behaviour, or facing it for the first time. The guide offers practical and realistic information on developing skills in the area and strategies for supporting people whose behaviour is challenging. It is written in plain English and includes a section on how people with learning disabilities view challenging behaviour.



**Mental Health in Learning Disabilities: A Training Resource**

Edited by Geraldine Holt, Steve Hardy and Nick Bouras  
Published by Pavilion Publishing, 2005

■ [www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=842](http://www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=842)

This training package offers information and a variety of training techniques to help support staff develop skills and knowledge to meet the mental health needs of people with learning disabilities. The package consists of 18 modules, each supported by a chapter in an accompanying handbook: the modules can stand alone or be part of a comprehensive course of learning. The package contains a CD-ROM, full trainer notes for each module, case studies, PowerPoint display slides and handouts as well as evaluation forms and handbook.



**Guide to Mental Health for Families and Carers of People with Intellectual Disabilities**

Edited by Geraldine Holt, Anastasia Gratsa, Nick Bouras, Theresa Joyce, Mary Jane Spiller and Steve Hardy

Published by Jessica Kingsley Publishers, 2004

■ [www.jkp.com/catalogue/book.php/isbn/9781843102779](http://www.jkp.com/catalogue/book.php/isbn/9781843102779)

This is a practical and comprehensive introduction for carers to mental health problems that can affect people with intellectual disabilities. The guide explains why mental health problems develop and advises on what can be done to help. There are chapters on treatments and interventions; getting the best services and understanding policy; legal issues; and carers' needs.



**CANDID: Camberwell Assessment of Need for Adults with Developmental Disabilities**

Kiriakos Xenitidis, Mike Slade, Graham Thornicroft and Nick Bouras  
Published by The Royal College of Psychiatrists, 2003

■ [www.rcpsych.ac.uk/publications/books/rcpp/1901242994.aspx](http://www.rcpsych.ac.uk/publications/books/rcpp/1901242994.aspx)

CANDID assesses the needs of people with learning disabilities and mental health problems and is a version of the Camberwell Assessment of Need, the most widely used needs assessment for people with severe mental health problems in the world. There are two versions: CANDID-R for research use and CANDID-S, a shorter version for both clinical and research use. CANDID is suitable for use with adults with all levels of learning disabilities.

The following publications can be downloaded from the Estia Centre website.

■ [www.estiacentre.org](http://www.estiacentre.org)



**Best Interests: Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves (England and Wales)**

Theresa Joyce

Published by the Professional Practice Board of the British Psychological Society, 2007  
The guidance was funded by the Department of Health under the programme for developing materials to support the implementation of the Mental Capacity Act 2005. The advice is aimed at staff working in health or social care such as doctors, nurses, psychologists, therapists, social workers, care home staff and managers, families and advocates.



**Mental Health Nursing of Adults with Learning Disabilities**

Steve Hardy, Eddie Chaplin and Peter Woodward

Published by the Royal College of Nursing, 2007  
RCN guidance for nurses published with the support and funding of South London and Maudsley NHS Foundation Trust.



**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  
Published by Turning Point, 2006

A practical guide for staff who provide day-to-day support to adults with learning disabilities in specialist or mainstream services in the voluntary, statutory and private sectors, such as supported housing, outreach, day services, employment and inpatient services. The guide, written in association with Turning Point, may also be helpful for student nurses, student social workers, family carers and professionals with little experience of the mental health needs of people with learning disabilities.



**Meeting the Health Needs of People with Learning Disabilities: Guidance for Nursing Staff**

Steve Hardy, Peter Woodward, Petrea Woolard and Tom Tait

Published by the Royal College of Nursing, 2006



**Autism and Related Disorders: The basic handbook for mental health, primary care and other professionals**

Edited by Geraldine Holt and Nick Bouras

Produced on behalf of the World Psychiatric Association by the Royal College of Psychiatrists, 2002



**Practice Guidelines for the Assessment and Diagnosis of Mental Health Problems in Adults with Intellectual Disability**

Shoumitro Deb, Tim Matthews, Geraldine Holt and Nick Bouras

Published by Pavilion for The European Association for Mental Health in Mental Retardation, 2001

Practice Guidelines for professionals working with people with intellectual disabilities to encourage and promote evidence-based practice.





*Estia* centre

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