Neurodevelopmental Disorders Service

A low-secure and open service for people with neurodevelopmental disorders (including intellectual disabilities), and complex mental health issues.
» For me, it was such a relief she had the chance to go to there and get a proper diagnosis and treatment. She was in prison when she was referred so that made it a double relief really. I’m 74 now so I was very grateful for the chance she had. Now we’re just taking things as they come. « Mary, carer
Contents

Service overview 4
Our philosophy 5
Who is our service for? 6
Interventions 8
Our care pathway 15
Outcomes 16
Research 18
Our facilities 19
Training and consultancy 20
Our team 22
Case studies 26
Referring to our service 30
Service overview

We offer an open and low-secure service for people with borderline to severe intellectual disabilities and additional complex mental health needs.

Our strengths include high quality care, agreed lengths of stay, regular outcome reporting, clear pathways and goal setting, and close liaison with commissioners and clinicians. Our neurodevelopmental inpatient pathway provides services for adults with neurodevelopmental disorders, including:

- Intellectual disabilities and co-morbid mental illness
- Autism spectrum conditions (with or without intellectual disabilities) and significant risk behaviours
- High functioning autism and co-morbid mental illness
- Complex attention deficit hyperactivity disorder (ADHD)
- All of the above presenting with forensic behaviours

King’s Health Partners

Our service is part of the Behavioural and Developmental Psychiatry Clinical Academic Group. SLaM has joined with King’s College London, Guy’s and St Thomas’ NHS Foundation Trust, and King’s College NHS Foundation Trust to establish King’s Health Partners, an Academic Health Sciences Centre. King’s Health Partners brings clinical care, research and education much more closely together. We aim to reduce the time it takes for research discoveries and medical breakthroughs to become routine clinical practice. This will lead to better care and treatment for those who use our services.

Visit www.kingshealthpartners.org for more information.
Our philosophy

We believe that the people who use our service have the right to keep their dignity, while improving their independence, physical health and mental well-being.

People who are treated by our service have a right to privacy, choice and autonomy, where these do not exceed the constraints imposed by wider society. Our duty is to provide the best physical, social and therapeutic environment to further our patients’ legitimate aims.

We believe that our duty is to deliver:

- Excellence in all aspects of care
- A holistic, recovery-oriented approach where we work with a person to achieve their aims
- A social environment that promotes a positive self-image, self-awareness, self-reliance and respect for others
- A wide range of stimulating and motivating therapeutic and occupational opportunities, both in the hospital and in the community
- Support and education for carers
- Support for referrers and commissioners

She had a lot of sessions with the psychologist, group meetings and sports sessions. She chose to take part in some things and not others. And there was occupational therapy, which was good... especially the cooking. « Mary, carer
Who is our service for?

Our service is for people with borderline to severe intellectual disabilities, requiring either a low-secure or open ward environment. They may have a co-morbid mental health disorder, though this might not be apparent prior to referral. People who are referred to our service may also have a history of challenging or forensic behaviour.

Eligibility
› 18+ years
› Male or female
› Borderline to severe intellectual disability
› Complex social and psychiatric needs that cannot be met by local services
› Diagnostic complexity
› Informal or subject to detention under the Mental Health Act (civil or forensic sections)
› Autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), mental illness or personality disorder
› Complex mental disorder, possibly associated with challenging behaviour or a forensic history
› Acute mental health problems that will benefit from brief treatment

Exclusion
› Profound intellectual disability
› People requiring a medium or high security setting

» I was so happy that they were interested in what was wrong with him – that there was a team of professionals who would take the time to look at him and help.« Margaret, carer
Interventions

Interventions are evidence-based and designed to address a range of mental health problems and improve our patients’ quality of life.

Our interventions include:

› Clarification of diagnosis using standardised tools, including experimental withdrawal of medication
› Neuropsychological assessment
› Applied behavioural analysis
› Optimising physical health
› Risk assessment
› Pharmacological treatment
› CBT
› Occupational therapy
› Group therapy
› Social work support
› Learning from a pro-social environment
› Art psychotherapy
› Family therapy
› Needs assessment and discharge planning

Assessment

To support a person with an intellectual disability it is vital to identify each contributor to his or her difficulties, so the right treatment opportunities are made available. This is particularly important when a person behaves in a way that limits their social function or prevents community living.

A person with an intellectual disability may find it more difficult to get the help they need or manage their feelings and this can lead to inappropriate behaviour. Our staff are world leaders in the assessment of mental health disorders and challenging behaviour in the context of intellectual disabilities. The best available diagnostic techniques, including qualitative and quantitative psychiatric examinations, behavioural assessment, systemic analysis, imaging and genetics are used to identify a person’s problems.
We provide a detailed assessment and person-centred understanding of social, cognitive, emotional and psychiatric needs. We then work with each person to understand why they have experienced difficulties and to help them develop and achieve greater independence.

**Neuropsychological assessment**
Neuropsychological assessment involves the use of psychological tests, including tests of general intellectual function, memory and visuospatial abilities. Assessment of planning and organisational abilities is particularly important.

**Functional behavioural assessment**
Behavioural assessments form an important part of our understanding of a person’s difficulties and may inform a specific treatment.

In applied behavioural analysis, we analyse the circumstances that lead to and maintain a challenging behaviour. This often leads to specific behavioural treatments that can be used to improve social functioning.

Qualitative information from occupational, psychological and educational interventions will contribute to a behavioural formulation. This can be used to develop strategies to modify a person’s behaviour.

**Cognitive behavioural therapy**
We use adapted versions of CBT to suit the cognitive abilities of our patients. Our approach focuses on helping the person to discover for themselves the links between their thoughts, feelings and behaviours. Longer term treatment can address a person’s core beliefs and help them to develop a more positive view of themselves and the world around them. We also offer cognitive remediation therapy and mentalization-based therapy.

**Occupational therapy**
Each person is assessed by an occupational therapist who reviews their level of performance in vocational, leisure, communication and interaction skills. We then work with the patient to develop a graded skills improvement plan.

» She’d also made some good relationships with staff and other patients. «

Mary, carer
Social inclusion
We offer an environment where all patients’ rights to expression, choice and autonomy are respected by everyone. We support people in understanding that meeting everyone’s needs involves placing limits on their own behaviour and negotiating with others. This leads to the recovery of important social functions and prepares people for success in community living. Our nursing team promotes environmental safety and offers one-to-one support, often involving helping to understand other people’s points of view, and negotiating with others.

From as early as possible in their admission people are encouraged to access local community facilities to help develop and maintain their independence. These include local gyms, libraries, adult education, voluntary work, shops, cafés and work placements. Many of our patients participate in other activities that improve overall well-being like visiting places of particular interest, using a mixing-desk, music and riding lessons.

When independent community access is not possible, we accompany the person to activities. We use the principles of positive risk-taking to move as rapidly as possible to unaccompanied access to local community facilities.

Group treatments
Being in a group is central to learning to understand another person’s point of view. It leads to confidence in self-expression, decreases social anxiety and normalises the learning experience. People are encouraged to attend a wide variety of groups including community groups, where they share experiences and learn adaptive skills, sex education groups, social skills groups, current affairs groups, gender-specific groups and a daily patient-led group.

Promotion of physical health
We aim for people to achieve a healthy mind in a healthy body. We help patients access primary and secondary care services and offer smoking cessation and dietary advice, exercise instruction and support with sleep hygiene as part of our commitment to a person’s physical well-being.

Art psychotherapy
Art psychotherapy offers people a means of self-expression that helps them realise their potential by making sense of their experiences and developing insight and emotional intelligence.
Family therapy and support
We understand that it is a worrying time when a family member is experiencing psychological or behavioural difficulties, or when they are admitted to a unit that may be far from home. When someone is admitted we hold a meeting with family and carers to arrange support which we offer through regular phone calls, meetings with team members or in family therapy. We run a monthly carer support group to provide an opportunity for people to access information and discuss the experiences and challenges they face.

Social work
We provide advocacy for all patients, as well as access to solicitors and mental health review tribunals. We provide guidance on matters relating to best interests, welfare benefits, safeguarding, the criminal justice system, the Mental Capacity Act, the deprivation of liberty safeguards and the care programme approach. Our social worker is involved in the multidisciplinary assessment and management of risk as well as in the liaison with referrers, community teams and other agencies.

Needs assessment and discharge planning
We use a range of tools to assess people’s individual needs. Needs assessments are regularly reviewed with the patient to measure progress and plan the next steps in treatment. This often improves patients’ self-esteem as they see their progress and acquire new skills.

We hold regular care programme approach meetings that are focused on recovery and decision-making with the patient, their advocates and home teams. As soon as the patient’s longer term needs can be identified, we prepare a placement profile and after-care plan with the patient and local services. Our approach maximises the person’s autonomy and minimises the risk of placement breakdown.

Risk assessment
We use structured assessment tools, including the HCR 20 and PCL-R to assess a person’s vulnerability and possible risk to themselves or others. We identify the support each person needs and monitor their environment, their behaviour and assist them with coping strategies for dealing with unexpected events. This enables our patients to access the least restrictive options available and maximise their independence.

Pharmacological treatment
Sometimes pharmacological treatment is necessary to treat a person’s mental illness. When drug treatment is required, we support our patients to understand the options available and help them to choose the treatment that is best for them. We hold regular medication education groups and continually monitor medication use and effects.
## Weekly programme

<table>
<thead>
<tr>
<th>Time</th>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
<th>SATURDAY</th>
<th>SUNDAY</th>
</tr>
</thead>
<tbody>
<tr>
<td>08.00 – 09.00</td>
<td>Breakfast group</td>
<td>Breakfast group</td>
<td>Breakfast group</td>
<td>Breakfast group</td>
<td>Breakfast group</td>
<td>Breakfast group</td>
<td>Breakfast group</td>
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<tr>
<td>09.30 – 10.00</td>
<td>Community meeting</td>
<td>Community meeting</td>
<td>Community meeting</td>
<td>Community meeting</td>
<td>Community meeting</td>
<td>Male and female group and individual occupational therapy sessions</td>
<td>Church coffee and newspaper group</td>
</tr>
<tr>
<td>10.00 – 12.00</td>
<td>Community centre 10.00 – 11.00</td>
<td>Swimming 10.30 – 11.30</td>
<td>Walking group 10.15 – 11.15</td>
<td>Feelings group 10.00 – 11.00</td>
<td>Cycling 10.30 – 11.30</td>
<td>Cooking 11.30 – 13.00</td>
<td>9.30 – 12.00</td>
</tr>
<tr>
<td>12.00 – 13.00</td>
<td>Lunch</td>
<td>Lunch</td>
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<tr>
<td>13.00 – 18.00</td>
<td>Ward round 14.15 – 17.00</td>
<td>Individual psychology 13.00 – 13.30</td>
<td>Group painting 13.00 – 15.00</td>
<td>Computing 15.00 – 16.00</td>
<td>Numeracy 14.00 – 14.45</td>
<td>Sports group 13.00 – 18.00</td>
<td>Cooking group 13.00 – 18.00</td>
</tr>
<tr>
<td>18.00 – 19.00</td>
<td>Dinner</td>
<td>Dinner</td>
<td>Dinner</td>
<td>Dinner</td>
<td>Dinner</td>
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</tr>
<tr>
<td>19.00 – 21.00</td>
<td>Art group</td>
<td>Film night</td>
<td>Social night</td>
<td>Individual psychology sessions</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

“I always felt it was a shame she didn’t want to do art therapy, but she really enjoyed the occupational therapy sessions and learnt quite a bit. One thing she also really loved to do was go to the chapel and sing.” — Mary, carer
Our care model

**ASSESSMENT**
- Mental disorder, including developmental disabilities, mental illness and personality disorder
- Behavioural disorder, including offending behaviour
- Neuropsychological functioning
- Physical health, including for genetic, metabolic and neurological conditions
- Social inclusion and daily living skills
- Communication abilities and needs
- Multidisciplinary formulations

**FAMILIES AND CARERS**
- Education about mental health difficulties
- Support in interactions with patients
- Family therapy
- Carers’ group with lectures and learning through shared experience

**EDUCATION, VOCATIONAL OPPORTUNITIES**
- On-ward, within hospital, community education
- Work-readiness training
- Support with voluntary work during admission
- Support to move to paid employment
- Liaison with charitable sector

**PATIENT**
- Freedom from distressing symptoms
- Improved physical health, personal function and self esteem
- Increased independence and involvement in decision making
- Improved social inclusion and social skills
- Contact with loved ones
- Decreased offending behaviour
- Fulfilled spiritual needs

**RISK MANAGEMENT**
- Comprehensive risk assessment
- Positive risk-taking
- Low-secure environment
- Step-down from medium secure units or prison
- Relational security
- Identification of future support needs
- Graded discharge
- Support for community services
- Appropriate use of MHA, MCA and DOLS legislation

**THERAPIES**
- Pharmacological treatment
- Cognitive and behavioural therapies
- Modelling in a pro-social milieu
- Cognitive remediation therapy
- Occupational therapy and social inclusion
- Life story work
- Psychoeducation
- Relapse prevention
- Art psychotherapy
- Mindfulness group
- Sex education
- Sensory integration and mentalization

**DISCHARGE PLANNING**
- Liaison with the tertiary panel, care-coordinator and referring agencies
- Early identification of future support needs
- Comprehensive placement profile
- Independent living where possible
- Support for commissioner in location of placement
Our care pathway

- Not suitable
- Not suitable for treatment
- Funding request for authorisation for 12 week assessment phase
- Week 10: assessment report with recommendations and placement profile provided to PCT and referrer
- Patient admitted, with monthly clinical update reports and review of legal status
- Week 10-12: CPA review with PCTs
- CPA discharge planning meeting
- CPA discharge planning meeting
- Discharged to referrer using planned placement profile and treatment recommendations
- Monthly clinical update reports and exit strategy review
- Treatment: non-forensic (3-6 months)
- Treatment: forensic (9-12 months)
- Length of stay agreed for treatment phase
- Referral received, review referral
- Discuss free assessment with PCT, to agree possible cost implications
- Free assessment at the person’s location
- Suitable for treatment, consider legal status
- Discharged to referrer using planned placement profile and treatment recommendations

Funding request for authorisation for 12 week assessment phase

Discuss free assessment with PCT, to agree possible cost implications

Free assessment at the person’s location

Suitable for treatment, consider legal status

Patient admitted, with monthly clinical update reports and review of legal status

Week 10-12: CPA review with PCTs

Length of stay agreed for treatment phase

Treatment: non-forensic (3-6 months)

Treatment: forensic (9-12 months)

Not suitable

Not suitable for treatment

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Treatment: forensic (9-12 months)
Outcomes

We aim to help people understand their difficulties, decrease their symptoms, improve their social abilities and gain control over their lives. This means that we tailor our outcomes to the requirements of each person.

Outcomes may include:

› Identification of intellectual disability and level of functioning
› Treatment for co-morbid disorders
› Decreased challenging and forensic behaviour
› Decreased risk to self and others
› Decreased vulnerability
› Optimum functioning and improved quality of life
› Future care needs identified in a placement profile
› Discharge planning with the referrer
› Person placed in a less restrictive environment
› Staff training and ongoing support via our outreach service
› Working relationships between local services, national services and families or carers

**Graph 1** shows that attendance at sessions over a 10 month period on the unit is positively linked with a reduction in violent incidents on the ward. All people have the opportunity to come to the groups. They are well attended and evaluated for their effectiveness.

**Graph 2** shows improvement in the HoNOS LD and secure scores for patients on admission and following 12 months of treatment with our service.
» They’ve quickly got him into a routine and his social skills are really quite good now, whereas I wouldn’t have got anything out of him two years ago. «  Margaret, carer

1. Incidents and sessions attended for all patients in the unit over a 10 month period

2. HoNOS scores on admission and after 12 months’ treatment
Research

Our service works closely with the Institute of Psychiatry, King’s College London. Our research focuses on developing and improving our assessment and treatment methods.

Our ongoing research topics include:

› Pioneering applications of neuroimaging and genetics
› Understanding the relationship between genes, the brain, cognition, social environment and behaviour in normal and abnormal development
› Community-based research focusing on interpretations of illness, misfortune and distress in terms of religious beliefs and practices
› Psychological treatments for neurodevelopmental disorders

» I found she was so much easier to deal with. And, considering the way she was brought into the Bethlem, she was now being allowed into the grounds on her own. « Mary, carer
Our facilities

Our inpatient unit has 26 beds and is located on the grounds of the historic Bethlem Royal Hospital.

Our unit has recently undergone a major refurbishment, making it an ideal facility for recovery. It combines both low secure and open environments, enabling patients to move more freely depending on their changing needs.

Bethlem Royal Hospital has a long history of providing the highest quality care for people recovering from mental health issues. The hospital offers the perfect therapeutic environment for promoting recovery, set in 270 acres of green space, with woodland and meadows that are designated as a ‘site of importance for nature conservation’.

Facilities at the Bethlem include a swimming pool, art gallery, walled garden, a chapel, nature walks and an extensive occupational therapy programme, utilised by many of our patients. This programme provides a wide choice of creative activities, which gives people the opportunity to rekindle old skills, learn from new experiences and build their confidence on their path to recovery.

We offer:

› Separation living areas for male and female patients
› Private bedrooms with ensuite
› Therapy rooms
› Quiet rooms
› Laundry and linen rooms on either side of the ward
› Art and recreation rooms
› Library and IT rooms
› Kitchen
› Secure garden
Training and consultancy

Clinicians in our team are widely involved in undergraduate and postgraduate medical teaching, as well as teaching on MSc courses at the Institute of Psychiatry, King’s College London, including mental health in intellectual disabilities, forensic mental health research and mental health sciences. Our clinicians also supervise MSc and PhD students.

We would be happy to discuss training and consultancy with mental health professionals. For more information please email ndsreferrals@slam.nhs.uk

Estia Centre
An integral part of our work is our relationship with the Estia Centre, a training, research and development resource for those who support adults with intellectual disabilities and additional mental health needs. The Estia Centre is an integral part of our services for people with intellectual disabilities provided by the Trust.

The Estia Centre supports the development of a competent workforce, from support staff to experienced managers and from a variety of services. By working in close collaboration with clinical services, we aim to improve the care of people with intellectual disabilities, especially those with additional mental health needs, through evidence-based practice. To discuss our training packages further, please contact Steven Hardy on steve.hardy@kcl.ac.uk

For more information visit: www.estiacentre.org
Our team

Our team draws on expertise from a wide range of disciplines including nursing, psychiatry, occupational therapy, psychology, art psychotherapy, social work, pharmacy and administration.

Dr Dene Robertson  MRCGP, MRCPsych
Lead Clinician | Consultant Psychiatrist

Dr Robertson is a consultant psychiatrist and lead clinician for the Trust’s developmental disorders services. He also works in the Adult ADHD Service and the Autism Assessment and Behavioural Genetics Clinic.

He is the clinical lead in our service.

Other roles
Dr Robertson is a frequent speaker at engagements and conferences, specifically covering developmental disorders, forensic learning and disability psychiatry.

Background
Dr Robertson’s undergraduate training was completed at St Mary’s Hospital Medical School. His postgraduate training was completed at Hammersmith Hospital (GP training scheme).

He worked at St George’s Hospital in Tooting, London, before becoming a clinical lecturer at the Institute of Psychiatry, King’s College London. He took his consultant post in the Trust in 1999.

Research
His main research interests include developmental forensic psychiatry, the neurobiology of developmental disorders including chromosomal, single gene and polygenic disorders, as well as sex steroids and brain development.
Dr Shaun Michael Gravestock MBBS, FRCPsych
Consultant Psychiatrist

Dr Shaun Michael Gravestock is a consultant psychiatrist who specialises in the mental health of intellectual disabilities.

He is also an editorial board member of the *Advances in Mental Health and Intellectual Disabilities* journal.

Dr Gravestock is a member of the Royal College of Psychiatrist’s learning disability faculty and executive and project lead for the family carer strategy working group.

Research
Dr Gravestock is a co-author of the *Diagnostic Criteria for Learning Disabilities (DC-LD 2001)*, published by the Royal College of Psychiatrists. He is also responsible for writing diagnostic criteria for eating disorders, personality disorders and problem behaviours.
Our team continued

**Dr Kiriakos Xenitidis** MSc, MD, MRCPsych
Consultant Psychiatrist | Visiting Senior Lecturer

Dr Kiriakos Xenitidis is a consultant psychiatrist at our unit and also works with the Trust’s Adult Attention Deficit Hyperactivity Disorder Service.

He is a visiting senior lecturer at the Institute of Psychiatry, King’s College London.

**Other roles**
He is a member of the General Medical Council, the Royal College of Psychiatrists, the Association of Family Therapy UK, the British Association of Sexual and Marital Therapists and the Institute of Group Analysis.

**Background**
Dr Xenitidis sat his medical degree, ‘Ptychio Iatrikes’, at the University of Athens’ Medical School in 1984. Moving to the UK, he became a member of the Royal College of Psychiatrists in 1993 and went on to complete a masters degree at St George’s Medical School, University of London, in 1996.

In 1998, he finished a certificate of completion of specialist training with the General Medical Council and completed a doctor of medicine degree at the University of London in 2003.

**Research**
His current research interests include ADHD, the forensic aspects of intellectual disabilities and health services research.
Lynette Kennedy
Clinical Services Manager

Lynette Kennedy is the Clinical Services Manager for the Neurodevelopmental Disorders Service. She is responsible for the effective daily running of the service, including the operational management of team leaders and professional heads.

Background
Lynette studied at Stoke Mandeville Hospital in Buckinghamshire and became qualified as a registered nurse for people with learning disabilities in 1996. She then moved to Leeds to work in a low secure mental health facility, before starting work for the Trust in 1997. Lynette first worked for the Mental Impairment Evaluation and Treatment Service, before she moved to the Mental Health of Learning Disabilities Unit. After five years, Lynette became the team manager, before being appointed to her current position of service line manager.

Other role
Lynette was part of the Royal College of Nursing’s mental health nursing of adults with learning disabilities guide steering group. She co-authored the Improving services through partnership and consultation: a case example article, published in Advances in Mental Health and Intellectual Disabilities, March 2011 and presented at the 5th and 7th European Congress of Mental Health in Intellectual Disability conferences in Barcelona (2007) and Amsterdam (2009).
“My brother has autism and learning difficulties.”

There was a breakdown in residential care. He’d been living somewhere for 18 years and had to be moved to a private clinic in Waterloo, which then closed down, so they were frantic to find him somewhere else.

To be honest, I was concerned when they suggested the Bethlem. I wasn’t sure it was the right placement for him because I only knew it as a mental hospital. What learning difficulties support did they have? I was worried he was being sent to the Bethlem just because they didn’t know what else to do. But, they told us that this was a specialist unit for learning difficulties and assured us he would be okay, so he moved there in May.

“They have built a good rapport with him.”

It can be difficult to get a sense of his inner world, because although he has some language skills, he can’t really process and express his feelings. I do think he felt a bit frightened about the move – and sad initially – autistic people like structure and this was a big change. He got on with it though.

The staff are definitely fond of him. And, although he doesn’t have the ability to connect with the other residents, they seem to be quite protective towards him. He has the lowest ability on the ward when it comes to looking after himself physically, so he could be vulnerable, but he hasn’t been, and the others have looked after him.

My mum, my dad and myself like to visit him two or three times a week, and what I really liked was that we were included in things from the very beginning – with all his processes and much of his care. He doesn’t like people taking his blood, for instance, so they asked me to come in to be with him.

“The staff have been really supportive and respectful.”

They are really caring and it’s been a really transparent process. We have always been made aware of any wobbles and, in these cases, the team has considered the triggers, looked at what they can perhaps do better for him and what we, as his family, can also do to help. He challenged the medication a bit at the start, but they were able to get support from the old placement.

We’ve always been invited to his care programme approach meetings and feel we have a voice. Though there are a variety of professionals in these meetings, our opinion seems to carry an equal weight and our suggestions are taken on board. As a family taking part in these kinds of processes, you sometimes wonder whether you’re heard, but they seem to think we have a lot to contribute, which is nice. It’s been a really empowering process.

“They’ve helped us to understand his autism better.”

We may have lived with him for his whole life, but the team has helped us to understand his autism better. They’ve been wonderful.
His autism diagnosis has always felt a bit vague actually and one thing they’ve done is explain to us more clearly what his condition looks like day-to-day, and how it relates to his learning disability. He can sometimes stand too close to people and they have helped us unpack behaviour like that – to realise that he doesn’t really have the usual awareness of space and social rules.

The staff have a lot of empathy too. At one stage, he didn’t look well when he started on new medication and we told them how worried we were. They took the time to tell us what was happening and explained that the side-effects would wear off. We’ve always felt comfortable to ask and they have always given clear explanations. We could even go home, do our own research and come back to them with questions if we wanted.

“They’ve helped us through the daunting processes too.”

He had a tribunal as part of the sectioning process and that felt a little daunting because of the cross-examination and panel. But the staff explained what was going to happen and it felt like we were respected at every stage. He had a solicitor in the tribunal and she was also very good.

I think they admire the support we give him actually. I feel we’ve been held in high regard in a way. They seem happy he has somebody – that his family is behind him.

So, this has been eye-opening for me because, like I said, I started from a place where I wasn’t sure if the Bethlem would be right for him. I wanted to get him in and out as quickly as possible, but the team hasn’t rushed the process, which is really good. They have wanted to be thorough so he won’t need to be re-admitted.

“The team has invested a lot of time in his diagnosis.”

They’ve been able to shed a different light on things and it’s good to be able to link behaviour to the diagnosis rather than to him. He has had enough labels thrust upon him and words like ‘difficult’ or ‘challenging behaviour’ can have consequences in the future.

At the end of the month, he’s actually moving out of hospital and into somewhere else, and it seems like a good time for him to settle. Before that happens, the staff from the new place are coming to the Bethlem to work with him for a couple of days. So, the care planning process is a thorough one.

It’s felt like a long year, but there’s light at the end of the tunnel. What I really hope is that the good work will carry on and stand him in good stead for the future.
Mary, carer

“I knew early on that things were difficult for my daughter.”

She was the second of my four children. When I sent to see the headmistress of the primary school about her admission there, I mentioned I had some concerns about her development. It was quite a small school so the headmistress had my daughter seen by an educational psychologist who diagnosed her with minor learning difficulties – or, as they referred to it then, ESN... educationally subnormal.

Consequently her proper schooling started when she was ten in another primary school where they put her into a special opportunities class with nine others. She did quite well in that setting actually, learning to read and write. Afterwards though, she joined a special school and things changed. She got really fed up because she knew her brothers and sister were going to a different school and wondered why she couldn’t do the same.

“One of the difficulties is that her abilities are quite uneven. She can express herself quite well, for instance.”

When she was 15 she went to a regular school, but that didn’t really work out. So, when she left school at 16 it was a question of where she could go. Unfortunately there were quite a few simple things that she couldn’t do. She got some work experience in a local clothing store, but we found out that she couldn’t fold clothes. In fact, what she really wanted to do was to work with children in a nursery, but the competition for that kind of work was just too high. Also, she was very good with the children most of the time, but sometimes she wanted the attention from other staff members.

“She moved into lots of different places and it was quite difficult to cope, I must admit.”

When she went into one of those old ‘sub-normality’ hospitals for a while, she was one of the brightest there. She then moved into a temporary home on the hospital grounds, but came home from that. And there were various day centres too, but she didn’t like them either. Actually, there was a good period around the age of 24 when she was in a scheme for housing adults with learning difficulties. At the time I thought ‘wonderful, wonderful’, and they said never again would we have to worry. But she became difficult there, so they arranged a flat for her. There was a lot of help at first, but it fizzled out. Help was fading away.

“It finished up with her in prison on a hospital ward.”

When she moved into another house, she got scared because the local boys would tap on the window. She became really paranoid and thought they were stealing from the house... which they weren’t. She went into care with the local mental health team for three days, but then refused help when she was out again.

That’s when things went really haywire. She was going to the local high street every day and stealing from shops – fizzy drinks and sweets – even though she had money in her bank account. The police were involved a lot, and eventually they got fed up with her and put her in prison... on a hospital ward there.
One thing that was good at that time was that her sister kept in close touch with her. So, from prison it was arranged she would go to the Bethlem Royal Hospital’s Mental Impairment and Evaluation Treatment Service.

“She was diagnosed with borderline personality disorder.”

When she arrived at the Bethlem the first time, they needed three staff members to escort her, but at last she could be assessed and treated properly.

She was diagnosed with a borderline personality disorder and that was a relief really. I’d had a child for so many years and, although I knew things were difficult, I never really knew why. Her psychologist explained the diagnosis to me and gave me some information so that I could see how things fitted together a bit better.

I have to say though, the term ‘borderline personality disorder’ does seem like a bit of a misnomer. Something that’s borderline doesn’t sound real... is it or isn’t it, kind of thing? It makes the experience sound trivial, but that’s certainly not true in our case.

“At the Bethlem, she really enjoyed occupational therapy.”

She had a lot of sessions with the psychologist, group meetings and sports sessions. She chose to take part in some things and not others. And there was occupational therapy, which was good... especially the cooking.

I always felt it was a shame she didn’t want to do art therapy, but she really enjoyed the occupational therapy sessions and learnt quite a bit. I wish she had a chance to use those cooking skills where she lives now. One thing she also really loved to do was go to the chapel and sing.

“After a while it was obvious she had made progress.”

I found she was so much easier to deal with. And, considering the way she was brought into the Bethlem, she was now being allowed into the grounds on her own.

She’d also made some good relationships with staff and other patients. She became good friends with someone who self-harmed, and she found she could help this girl because she always knew when she was going to self-harm... which meant she could warn members of staff.

After nearly two years, she was discharged when they found her a suitable group home. The move took quite a while because the local social worker had to find the appropriate place and social services had to agree funding. But, since the move, it’s mostly gone well.

“It was such a relief she had the chance to go to the Bethlem.”

Perhaps there are stigmas around places like the Bethlem – and maybe it’s difficult for some people to get past the stigma of mental illness itself – but I’d say those things are mainly a thing of the past now, aren’t they?

For me, it was such a relief she had the chance to go to there and get a proper diagnosis and treatment. She was in prison when she was referred so that made it a double relief really. I’m 74 now so I was very grateful for the chances she had. Now we’re just taking things as they come.
Referring to our service

Referrals are accepted from consultants, NHS hospitals, CMHTs, prisons and GP consortia.

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Denis Hill Unit
Monks Orchard House
Bethlem Royal Hospital
Monks Orchard Road
Beckenham BR3 3BX

T: 020 3228 4183
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Dr Dene Robertson