

LASER SIG Newsletter

September 2019 Issue 1

Julie Blackaby and Noeleen Morritt give an insight into the role of learning disability nurse

Welcome to the LASER SIG

The LASER SIG is the Special Interest Group for Clinicians and Researchers working with Children and Young People with Learning Disabilities in the London and South East Region.

We are committed to supporting the professional development of those working with this client group. Uniquely this is the only multi-disciplinary forum for professionals (clinicians and academics) working with children and young people with learning disabilities. This is one of the aspects of the SIG that members value most! Membership of the SIG and presentations by researchers and academics who have active links with clinical practice are encouraged.

We meet three times a year on a Friday morning at Canada Water Library (SE16 7AR) with invited speakers presenting on best practice, research and service development. The talks often focus on how teams find ways to bridge the gaps between rigorous research and clinical practice. We actively encourage presentations from researchers with active links with clinical practice. There is always time for questions. The content of meetings includes discussion of complex cases brought by members, new service developments, policy initiatives and other items of relevance.

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10 Years on... Ealing Intensive Therapeutic & Short Breaks Service (ITSBS)



Dr Catherine Sholl Consultant Clinical Psychologist and Team Manager, Ealing CAMHS-LD

On the 28 June, Dr Catherine Sholl, Dr Heather Dilks-Hopper (Clinical Psychologists) and Daniel Brennan (Assistant Clinical Psychologist) presented the ITSBS model to LASER SIG members, describing their work, the challenges and outcomes over the last ten years, and their hopes for future work. These were illustrated by case examples.

Our journey and outcomes over the last 10 years aiming to prevent unnecessary residential care for young people with LD and challenging behaviour/mental health difficulties. The Ealing ITSB has been running since 2008, aiming to prevent unnecessary residential care (and more recently ATU admission) for children/young people with learning disabilities and challenging behavior/mental health difficulties.

Ealing ITBS has recently been mentioned as an example of good practice in the Transforming Care agenda good practice examples, the Lenehan Review into Residential Special Schools, NHS Ten year plan, and the recent Children's Commissioner for England report 'Far less than they deserve. Children with learning disabilities or autism living in mental health hospitals'.

For the full presentation email events@acamh.org

ProfileLearning Disability Nurse

In future newsletters we will focus on different professional roles. In this edition, Julie Blackaby and Noeleen Morritt give an insight into the role of learning disability nurse.

Julie Blackaby manages a Learning Disability Children's Emotional Wellbeing and Mental Health (EWMHS) Community Team in Essex. Her team works with children and young people aged between 4 – 18 years with a severe to profound learning disability and who have an additional emotional and/or mental health issue.



What does a learning disability nurse do?

Learning Disability Nurses will have completed training to support and enable people with a learning disability, in a wide variety of settings. We are lifelong learners, and I feel this means that it is hard to define what a Learning Disability (LD) Nurse does as we have such individual career pathways. Common for all is the training centred on understanding the impact of a learning disability on the individual and using that knowledge to make reasonable adjustments to support clients to reach their full potential. I worked with adults with challenging behaviours and then later became a Community Nurse. In 2001, I moved to CAMHS working with young people with LD and ADHD, young people without LD and with mental health issues. In 2006 I joined the team I now manage as a clinical nurse specialist. I was involved in developing and setting up the service.

What is a typical day for you?

As a clinical nurse specialist and manager there is no typical day. There are tasks and interventions that are a daily part of my job. In my role as a clinical nurse specialist I complete home visits, providing psycho-education and parent support. We assess and support a child's mental health issues. To aid understanding I might complete sensory profile and sleep assessments. We work with children's systems to improve understanding, developing plans to support children. I lead our six-session series of workshops for parents and provide training to other professionals on emotional wellbeing. I provided consultation to local "Children with Disability Teams", special schools, EWMHS Services and other professionals. I can be the key clinician attending psychiatry assessments and clinics liaising with psychiatrists about the children on our caseload. My role now also includes leading on developing the Team and our new members of staff as well as providing clinical supervision and guidance to my Team alongside the Team's Lead Clinician.

As a clinical nurse specialist and manager there is no typical day.

What is the challenge?

The challenges as with all working in the NHS and in Social Care is the balance of an increasing workload with providing a service to be proud of and that meets the needs of our client group. One difficulty is that our children and their families live in multi-layered systems of professionals and organisations, all providing a variety of packages.

Our children's emotional wellbeing is so reliant on their parents/carers having appropriate support, and children being able to access the right resources, that it can often be very hard to effect changes we feel are needed. As a health team we can influence a number of these issues but are not always in a place to effect change. It can be very frustrating when it means we cannot improve what we think is impacting on our child and family's emotional wellbeing, because they are so significantly interlinked.

What makes the role worthwhile?

The times we do make a difference for a family, the systems around them and their child. This may be;

- expanding a family's understanding so they feel more able to support their child. We may not have actively changed behaviour, but the additional knowledge can be a powerful tool for change.
- Interventions that have made a difference.
- When families share that our support and understanding of their child and their issues, does make a difference to their lives and to the life of their child.

ProfileLearning Disability Nurse

We talked to Noeleen Morrit about her role.

What does an LD nurse do?

When asked to capture the typical day for me as a learning disability (LD) nurse, I wanted to creep into a dark corner and hide. Such a feeling is in itself interesting, and resulted in my asking, 'just what is the function of your behavior?' Clearly avoidance.

Avoidance of the question asked long before my professional career began, 'just what do LD nurses do?' Previous responses to my explanation of the role, were swiftly followed by the comment, 'ah, so you are not proper nurses then'. Despite the passing of years, I still occasionally hear this and am disheartened by it. A recent recruitment drive for LD nurses depicted us wearing uniforms and working in the acute sector. I suspect the vast majority working for the NHS are offering an outreach service in the community. LD nursing in the NHS has become incredibly diverse over recent years. We can be found in places traditionally unexpected, practicing in fields of medicine which would not have been considered possible at the start of my career.

As I near the end of my 34th year of LD nursing I have found myself reflecting on the diversity of my nursing experiences. The profession has struggled with identity over the decades. On more than one occasion I have been told 'the branch of nursing is dead'. However, as I approach the end of my career, I think it is probably the liveliest and most exciting it has been since the advent of the NHS. I am not sure if this perception is isolated to my area of work or if it's something other LD nurses are experiencing. I hope to be more informed on this following a pending event celebrating 100 years of LD nursing.

Where do you work?

I work in the London Borough of Croydon. I moved from the adult LD services to a new post in Children's Services. I was initially taken back by the completely different culture in service delivery. It was like learning a whole new language, moving away from the traditional focus of work in adult LD community nursing to defining a LD role in the trust for children, creating a service and seeking opportunities for development.



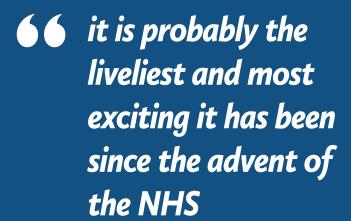
Initially I was placed in the safeguarding team for children. The team had followed the normal structure of named nurses who were from child and health visiting background. Joining as a LD nurse brought a whole new dynamic to the service.

The team readily made use of my knowledge on disability, mental health and laws about both, as well as my knowledge about behaviour, to contribute to consultations, investigations and teaching. It quickly became apparent that the skills of the LD nurse were transferable to areas previously deemed out of bounds. Importantly they were recognised as offering a unique perspective on safeguarding.

I found myself supporting risk assessments in maternity and participating in child death reviews, as well as, what I suppose could be referred to as the day-to -day work of an LD nurse. The safeguarding referrals we received for young people with LD often cited vulnerability surrounding sexual exploitation. While in the team and under the supervision of the FPA, I developed a teaching pack including sex education, consent etc.

In partnership with Croydon CAMHS we developed a 10 week behaviour programme for parents whose children have a learning disability. This has run for several years now, the outcomes and retention rates are positive. Many participants comment on the need for this at a younger age. Coupled with this and having good links with the community paediatricians I was rapidly becoming overwhelmed with referrals for children under the age of 5 requesting support with behaviour.

I adapted the behaviour programme for younger children with LD. This is now in its third year of running and I have recently secured funding for its on-going delivery.



Last year I accepted a job in Croydon CAMHS. The team had previously had a psychologist with dedicated LD time but had not had an LD nurse in the service before. As with my previous move, the LD nurse role has brought in a different dynamic and philosophy of care. The team is expanding, incorporating new initiatives such as CWPs and IAPT trainees. Presently the LD service within CAMHS consists of myself, 3 sessions of a psychiatrist along with an IAPT trainee who has 1.5 days for LD / ASD casework.

We are commissioned to provide tier 3 work. Given the limited provision the service is preserved for the children and young people with severe to moderate LD. However, recent negotiations with Croydon Health Services has resulted in them funding an additional 2 posts within CAMHS to develop a tier 2 provision.

The present LD nurse role in CAMHS is full time but is not fully ringfenced for learning disabilities. I complete ASD assessments, which include administering ADOS on children without learning disabilities. I had to adjust to this form of assessment, not only because it was a new tool to me but also children spoke in phrases and sentences when most of the children I have worked with throughout my career have had very limited communication.

What are the challenges?

Beyond those we all face working in the NHS, I think the challenge which I feel I have never managed well is 'just what do LD nurses do'. I take some comfort in knowing that several reports have been produced over the years about our role and none have really impacted on other professionals' understanding. It appears to be direct involvement with us which informs opinions.

What is typical day?

I find it hard to capture a typical day for me as an LD nurse. One of the many joys about my job is the fact that no two days are the same. I expect the unexpected and enjoy it beyond any other job I can imagine. It is creative, flexible, fun and ever developing.

What makes it worthwhile?

There are some significant things such as being given money to develop a service before I retire from the NHS, to the tiniest things that make it worthwhile for me. The parent for example who says our intervention is 'family life changing', the little boy who recently told me, 'it can't rain cats and dogs, it can only rain water', the picture a 5 year old drew for me of his family and pointed me out. I am known in my office for telling stories from my 34 years as a LD nurse, sharing the unique world of learning disability and making people laugh. I have had the best career.

Many participants comment on the need for this at a younger age. Coupled with this and having good links with the community paediatricians I was rapidly becoming overwhelmed with referrals for children under the age of 5 requesting support with behaviour. I adapted the behaviour programme for younger children with LD. This is now in its third year of running and I have recently secured funding for its on-going delivery.

Good intentions, good enough?

Daniel Brennan, Assistant Psychologist at Ealing Intensive Therapeutic and Short Break Service (ITSBS) provides a summary of Lenehan, C. and Geraghty, M. (2017) "Good intentions, good enough?: a review of the experiences and outcomes of children and young people with learning disabilities in residential special schools and colleges", Department of Health.

The Lenehan review is a broad survey of the provision of residential school placements across the UK. Published in 2017, the review involved consultation with a wide range of stakeholders including parents and carers, 30 schools and colleges, and 20 Local Authorities, in addition to OFSTED, CQC, and the SEND Tribunal. The review took place in the first years of the implementation of the Children and Families Act 2014, which seeks to empower families of young people with SEND, by offering more choice of educational and health provisions and improving the assessment of special education needs. In this context, Dame Lenehan's focus on residential school placements is not so narrow as it might first appear; more than 6,000 children and young people spend much of their childhood in residential schools, many attending schools outside their local community. Moreover, residential school placements are estimated to cost the taxpayer approximately £500 million per annum. The Lenehan Review presents evidence from innovative projects across the country that show that outcomes for children and young people with SEND can be improved significantly, whilst reducing the cost of their education to Local Authorities.

It is clear from the report that the population of children and young people who attend residential school is heterogeneous and their pathways to residential schools are varied. More than 70% of children and young people who attend residential schools fall into one of two categories; those with diagnoses of ASD, communication difficulties, or severe learning disabilities, who display challenging behaviour, and those with Social, Emotional, and Mental Health diagnoses, who display challenging behaviour.

6 Some LAs have introduced their own PBS services, with one estimating a saving of £1.8M over 4 years by enabling children and young people to stay within their family homes and at local special schools.

For many of these young people, their mainstream school placements have been unable to support them adequately at earlier stages of development leading to an intensification of their needs. This tends to cause an increase in the severity and frequency of challenging behaviour over time and, in many cases, the eventual breakdown of the school placement. Children and young people with SEMH diagnoses are twenty times more likely, and those with ASD three times more likely, to be excluded from school than their peers without SEND. The remaining 30% of young people in residential schools are made up of those with Profound and Multiple Learning Disabilities, who require complex support from multiple agencies, and those with additional needs but without a learning disability, who usually have a physical disability. The former often seek residential school placement due to the complexity of their medical needs requiring additional care which would not be feasible in the home. The latter group are often young people who could be educated in local, non-residential schools if suitable accommodation was made for their disability.

However, Lenehan reports that these young people have usually sought residential placements after appalling (and sometimes multiple) experiences in local schools. The simple description of many young people's experiences offers some recommendations for reducing the use of residential placements.

The Lenehan review suggests there is a dire need for processes to identify those with additional needs early in order to maximise the impact of intervention. Secondly, there is a clear need for all mainstream and specialist schools to have a greater understanding of behaviour that challenges and to embed a Positive Behaviour Support approach to supporting these young people. Thirdly, there is a need for a more holistic approach to supporting young people with disabilities and complex needs which requires a multi-disciplinary, person-centred approach. Lenehan notes the work being carried out by the Gloucestershire Local Authority using a "whole system around the child" model as exemplary. The report also recommends that CCGs provide a greater range of mental health and short breaks services to reduce the pressure on families whilst also up-skilling parents to apply PBS strategies in the home.

Dame Lenehan notes the Intensive Therapeutic and Short Breaks Service in Ealing as a model for this kind of work. In addition to these recommendations, the Lenehan review suggests that the planning conducted by local authorities around the use of residential schools requires improvements. The report paints a picture of LAs that struggle to proactively fund services that will reduce the need for residential placements, such as intensive PBS teams, whilst also being reluctant to use residential placements due to high costs and the desire to keep children living locally.

Where LAs plan proactively to meet the needs of this population, such as in Essex and Hertfordshire, children and young people with additional needs have more positive experiences of schooling, are able to continue to live locally, and expensive, out-of-area residential placements can be avoided.

"Whether for a traumatised child supported to overcome their experiences, an autistic child struggling with anxiety but transformed by positive behaviour support, or a child with profound and multiple learning difficulties providing valuable skills to their community while on work experience, we know that the right support can be life-changing for these children and young people.



LASER SIG



LASER SIG - Intellectual Disability, Challenging Behaviour and the Role of Communication

Canada Water Library, 21 Surrey Quays Rd, Rotherhithe, London SE16 7AR

Friday 25 October 2019

Speaker: Dr Vicky Slonims

www.acamh.org

About the Speaker

Dr Vicky Slonims

Dr Vicky Slonims is Senior Consultant Speech and Language Therapist in the multi-disciplinary service for children with neurodevelopmental disorders at Evelina Children's Hospital (Guy's and St Thomas NHS Foundation Trust).

She is an Expert Adviser for the NICE Centre for Guidelines and a member of the Professional Practice and Policy committee for RCSLT. She is Chair of the Language and Communication Study Group; one of 4 themed groups in a national autism research network (Discover) established by the charity Autistica.

She is Visiting Reader in Complex Communication Disorders in the Child and Adolescent Psychiatry Division within the IoPPN, King's College London. Her research is closely aligned to her clinical interests in intervention for children with autism spectrum disorders and working with children with severe communication impairments and challenging behaviour.

Booking

This event is FREE for ACAMH Members, and £5 for Non-Members.

To attend you must book onto the event.

Ways to book:

- 1. Online www.acamh.org/event/laser-oct19
- Complete and booking form and email it to events@ acamh.org or post to ACAMH, St Saviour's House, 39-41 Union Street, London, SE1 1SD
- 3. Call the office Mon-Fri 08.30-17.00 on 020 7403 7458.

About the ACAMH LASER SIG

The LD-CAMHS special interest group LASER (London and South East Region) is run under the auspices of the Association for Child and Adolescent Mental Health. It hosts three meetings per year in London for professionals (clinicians and academics) with an interest in the mental health of children and young people with intellectual disabilities. In addition to learning events and skill sharing, the meetings provide a great networking opportunity. Tea/coffee and lunch are provided at each meeting.

Programme

09:30	Registration & coffee			
10:00	Dr Vicky Slonims - Intellectual Disability, Challenging Behaviour and the Role of Communication			
11:00	Case Discussion*			
12:00	Lunch			

^{*}Please bring any relevant clinical cases that you may wish to discuss



Intellectual Disability, Challenging Behaviour and the Role of Communication

LASER SIG

Friday 25 Oct / 09.00-12.00 / Canada Water Culture Space, 21 Surrey Quays Road, London, SE16 7AR

TO BOOK YOUR PLACE, PLEASE COMPLETE AND RETURN THIS FORM TO:

REF: 870

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Fees include conference materials, lunch and refreshments. Please note that ACAMH may record at this event.

To read more about this and future events visit www.acamh.org/events

Booking form

PERSON ATTENDING				PERSON MAKING	THE BOOKING (IF DIFFERENT FROM PERSON ATTENDING)
Title				Title	
Job title				Job title	
Name				Name	
Dietary					
requirements				Organisation	
Organisation				Contact Number	
CONTACT DETAILS OF P	ERSON ATTE	NDING			
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If you prefer, for security purposes, not to fill in your card details, and post or email, then we can contact you by phone for these.					
Name on card				Card number	
Expiry date			Issue No (if Maestro)		CCV (last three digits on back of card or four on front for AMEX)
Billing address					
Cardholder's signature					Date

Closing date: 23 October 2019

Confirmation will be emailed to all delegates, if you have not received confirmation at least one week before the event please contact the office on 020 7403 7458. Please do not turn up on the day without having received confirmation by email.

Cancellation policy: cancellations received 6 weeks in advance of the event will be refunded in full less a £10 administration charge; cancellations received after this date will receive no refund.

Data Protection: By signing this application you are entering into a contract with ACAMH to attend the above event. ACAMH will use the information provided to communicate details with you about the event. As part of the contract the email address provided will be added to our weekly newsletter, with details about CYP mental health topics, you can unsubscribe from this at any time.