



Neurodevelopmental psychiatry: an introduction for medical students

Edited by Simon Bonell, Tim McInerny and Jean O'Hara

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About Us

Educational opportunities for medical students, core trainees and higher psychiatric trainees in neurodevelopmental psychiatry are delivered through the Behavioural and Developmental Psychiatry Clinical Academic Group (B&D CAG) at the South London and Maudsley NHS Foundation Trust (SLaM). We provide mental health services for adults with neurodevelopmental disorders and for those who require enhanced risk management or secure inpatient services, working with people nationally and internationally.

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The artwork in this booklet was produced by people with neurodevelopmental disorders who required hospital treatment at the Bethlem Royal Hospital, South London and Maudsley NHS Foundation Trust. It has been reproduced with their permission. Art can be an important communicative and therapeutic tool for people who find verbal communication difficult.

All of the artists wished to remain anonymous except for Victor who produced the art on pages 2, 30, 36, 42, 46 and 52.

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Introduction

Welcome to *Neurodevelopmental psychiatry: an introduction for medical students*. This booklet is aimed at you, whether or not you have ever considered a career in this subspecialty!

Neurodevelopmental disorders cover a group of conditions that are evident early in development and include generalised learning disabilities, autism spectrum condition and attention deficit hyperactivity disorder (ADHD). The term learning disability is synonymous with intellectual disability or the outdated term, mental retardation. It is a state of incomplete or arrested development of the mind that arises during the developmental period and is characterised by a reduced level of intellectual functioning resulting in a diminished ability to adapt to the daily demands of the normal social environment (WHO 1992). This group of patients face considerable challenges and adversity. People with learning disabilities have higher rates of mental illnesses, shorter life expectancy and worse health outcomes than the general population. They face stigma, high rates of abuse and poor life chances.

All doctors will treat patients with autism, ADHD or learning disabilities at some point in their careers. They will often find consultations with these patients complex and challenging. Within these pages you will find insights that will help you approach this group of people with better understanding and confidence. We hope that you will find inspiration to think more about the needs of this vulnerable and often excluded group of people, and consider how you, as a doctor of the future, will ensure that you meet these needs. By doing this, it is hoped that you will realise that working with people with neurodevelopmental disorders is not only challenging but also very rewarding.

The psychiatric specialism of learning disability was one of the first to be formally recognised. We hope that by reading this booklet you will have a better understanding of why this specialisation is required. Training in learning disability psychiatry leads to a great variety of career opportunities. These include varied clinical roles, great research potential, teaching opportunities and managerial or leadership roles. The articles in this booklet will introduce you to some of this diversity.

Most importantly, we hope you find these articles interesting and relevant. You will find numerous case examples to help bring out the clinical issues. You will also find personal reflections from a range of professionals that go some way to explain why they have dedicated their careers to helping people with neurodevelopmental disorders. We hope that these reflections will be a source of inspiration and, for a select few, you will choose to follow a career in the field.

Reference

World Health Organisation (1992) The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines



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What should medical students know about the psychiatry of learning disability?

The answer to the question “what should a medical student know about the psychiatry of learning disability?” should, of course, be the same as “what should any doctor know about the psychiatry of learning disability?”

Of course, unlike doctors, medical students will also have the looming mountain of medical finals approaching. Whilst of course they wish to become good competent doctors (or should do!) they must also be acutely aware that in order to become doctors at all, they need to pass these exams, and will thus also be asking the question “what do I need to know on this subject to get more marks in my final exams?”

This chapter will attempt to address both questions, and in addition hopefully demystify the subject and even stimulate some interest in it.

Why, then, should a doctor need to know anything at all about the subject? Is it not too specialist? Psychiatry is a subject that, whilst interesting to some, can be sorely neglected or even scoffed at by others, struggling to shake off its (inaccurate) stereotyped image as unscientific beard stroking speculations of psychoanalysts barely more sane than the patients they treat. People with learning disabilities are rarely even portrayed in the media and have an inglorious history of being hidden from society at large, and hardly have a glamorous image even with mental health specialities (see examples of the portrayal of people with neurodevelopmental disorders in literature and film at the end of this booklet).

Fortunately, times are changing. The large psychiatric and learning disability institutions are closing, a series of legislations (such as the Disability Discrimination Act, Autism bill, Valuing People), change in government policy and public opinion mean that people with learning disabilities are more vocal, more visible, and more protected by law. And quite rightly, for they represent around 1 – 2% of the population.

Learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence) with
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development

This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient (e.g. an IQ below 70, is not, of itself, a sufficient reason to conclude that an individual has learning disabilities.

Adapted from: *Valuing People: a new strategy for learning disability for the 21st Century*, Department of Health, 2001.

That is a high enough statistic for any doctor not to ignore. But there is ample evidence that people with learning disabilities have significantly higher physical and mental health needs, which means that (with a few very rare exceptions) the medical practitioner is going to have a case load with a significant proportion of people having learning disabilities, and even more people with borderline intellectual functioning (IQ 70-85).

Exam spotters may wish to note the particular association of Down syndrome with dementia (of Alzheimer's type) and depression, and of autism with anxiety disorders.

The evasive-minded who feel uncomfortable about interacting with people with learning disabilities may, at this point, fantasise about imaginary specialist services for people with learning disabilities. Alas, there is no such solace for you. Whilst it is true that there are specialist local learning disability teams that organise social care, facilitate some primary care support, and even supply some specialist health care (psychiatric and behavioural), health services are required to treat people with learning disabilities without prejudice. Hence, it behoves every doctor to feel comfortable and competent in interacting with, assessing, and treating people with learning disabilities, irrespective of their speciality.

The first things to know about the psychiatry of learning disabilities, then, are that a significant proportion of the population has a learning disability and that learning disabilities are associated with an increased prevalence of a wide range of physical and mental health conditions and disability.

As far as mental health is concerned, nearly every condition occurs, and occurs more frequently in people with learning disability: schizophrenia, bipolar disorder, depression, dementia, and personality disorder to name but a few (and the more common). In addition, there is some emerging evidence that prognosis may be worse in people with learning disabilities for major mental illnesses.

In addition, the psychiatry of learning disability throws up a wide range of complex neuropsychiatry disorders that are often mentioned in textbooks as fascinating, but rarely seen in general psychiatry. This author, for instance, saw a grand total of one case of peri-ictal psychosis throughout his general psychiatric training, and has seen several since working in the field of learning disability psychiatry.

The next priority in knowledge for any medical student or doctor is to know how to interact with people with learning disabilities. The common lament of people with learning disabilities is that they are not listened to, and people talk "over" them, not involving them in decisions. Communication difficulties are, of course, common in people with learning disabilities (particularly as the learning disability becomes more severe), but this does not mean that communication can be circumvented, no matter how busy the doctor is. Even if an individual has no verbal communication, taking the time to make eye contact, take the person's hand, smile, and observe them is a worthwhile and essential non-verbal communication.

The normal advice on communication applies doubly so to people with learning disabilities: avoid jargon, take your time and check understanding. It is entirely reasonable to involve carers, family, and friends in facilitating communication, as long as this is done for the purpose of facilitation and not to avoid communication. And always ask, politely, if the person with a learning disability would mind such help.

If there is time (and you may well be legally obliged to make time) specialist help with communication involving speech and language therapy, or visual aids, may be required. The reason this may be legally obliged is the Mental Capacity Act: a piece of legislation that every doctor must be familiar with. The Mental Capacity Act defines the criteria for someone to have capacity to make a decision (the ability to understand, retain, and weigh the information needed to make a decision, and to communicate that decision) and the process for assessment of capacity and decision making if someone is found to lack capacity with regard to that decision.

The two most common errors this author has come across with regard to the Mental Capacity Act, and ones you should avoid are firstly that an individual either has or does not have capacity. This is not correct. An individual either has or does not have capacity for a specific decision. One cannot therefore paint "Does not have capacity" on the bottom of a patient's bed and assume he or she cannot make any decisions for himself.

The second error is that psychiatrists decide whether a person has capacity or not. Again, this is incorrect. They may well offer an opinion. However, the Mental Capacity Act explicitly states that it is the health professional who may (or may not) treat that is the ultimate decider of capacity (and if lacking capacity, Best Interests). This is quite right: a psychiatrist is in no place to offer up to date information on the risks and benefits of a hip replacement in comparison to the treating orthopaedic surgeon. For this reason, every doctor must be aware of the principles of the Mental Capacity Act.

The particular import this has for people with learning disabilities (aside from the fact that it very often comes into play) is that there is an obligation to maximise an individual's capacity before one can say they lack capacity with regards to a particular decision. There are of course some pragmatic boundaries to this: one will not wait for a speech and language therapist in an accident and emergency resuscitation room. However, for more routine

Exam spotters note that a good understanding of the Mental Capacity Act, the assessment of capacity and the process for best interest decisions are essential requirements for all doctors and guaranteed to feature in exams.

interventions, this means the doctor must make time to explain as carefully as possible, if necessary with specialist help, before he or she can satisfy himself or herself that the patient lacks capacity with regards to the decision.

What then of mental illness in people with learning disabilities? We have already mentioned that most, if not all, psychiatric conditions occur more frequently in people with learning disabilities. It is true to say that with more severe learning disabilities accuracy of diagnosis drops, and it becomes difficult or impossible to technically fulfil the diagnostic criteria for certain illnesses, although the same clusters of symptoms occur.

Firstly, remember that mental state examinations can always be performed, even in people who have no verbal communication skills. One can always comment on appearance and behaviour, and this author has yet to be unable to make some estimate on mood or affect.

Mental illness may well be harder to diagnose, or concealed by learning disability (termed diagnostic shadowing), but it must not be ignored. It is very treatable, with psychotropic medication, social interventions, and psychotherapy just as in people without learning disabilities. Under no circumstance must people with learning disabilities be excluded from treatment, or the choice of treatments, by virtue of their learning disability.

Psychotropic medication may need some particular consideration: many medications are proconvulsant (particularly antipsychotics) and thus care must be exercised in a population who are at increased risk of seizures and epilepsy. Polypharmacy is a problem, particularly when patients may be less able to communicate side effects (which may be subtle) of medication.

There is an ignoble history of using psychotropic medication for “challenging behaviour” (which is a social construct, not a medical diagnosis) which is out of licence, unproven, and not recommended under most circumstances. Short term use of these drugs may be justified for particular “hurdles” such as plane flights or medical procedures. Long term usage may occasionally be justified if there is clear evidence that there is long term benefit, using behavioural analysis over several weeks or months and correlating it with time. Be alert for indiscriminate use of these medications, which may be ineffective at best, and cause unneeded side effects (including challenging behaviour!) at worst.

Finally, a medical student or doctor should have an inkling about what a psychiatrist in learning disability does. The answer is surprisingly simple, and in the name. A psychiatrist in learning disability looks after psychiatric illness in people with learning disabilities. Who would have guessed?

It is perhaps remarkable then, that there are lingering misconceptions that psychiatrists in learning disabilities are specialists in learning disabilities. Whilst it is true that they may well have a good grasp of medical aspects of learning disabilities, this is not their remit. The occasional odd referral for orthopaedic, cardiac, gastroenterological and other reasons do occasionally (and mistakenly) end up in their inbox, all of which are politely declined.

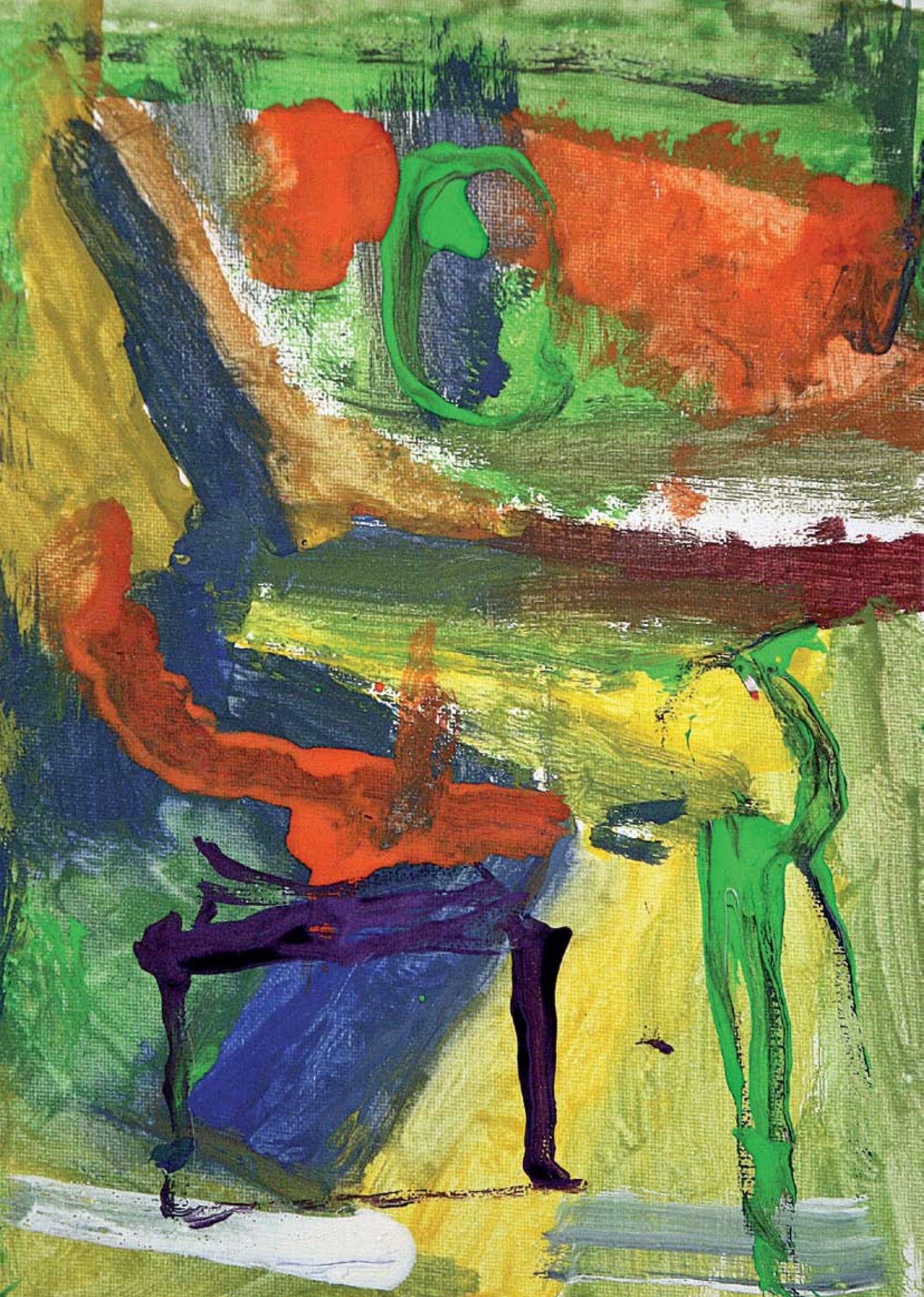
“Challenging behaviour” is a grey area in which there is much debate. National guidelines tend to accept that this is not a medical diagnosis, and medical treatment is based on scant, if any evidence. Normally, challenging behaviour in the absence of co-existing mental illness (such as that associated with autistic spectrum disorder or the learning disability itself) would be managed by specialist psychological and environmental treatments. The degree to which psychiatrists are involved varies with locality, but in general (and in keeping with national guidance) psychiatric involvement and the use of psychotropic medication is only considered as a “last resort” in serious cases.

Further reading

[Valuing People: a new strategy for learning disability for the 21st Century](#), Department of Health, 2001.

[Mental Capacity Act \(2005\) and MCA Code of Practice \(2007\)](#)

[Intellectual Disability and Ill Health: a review of the evidence \(2010\)](#). Edited by O'Hara J, McCarthy J and Bouras N. Cambridge University Press.



GPs, community learning disability teams and the psychiatrist – how do they work together?

Patients with learning disabilities (LD) can pose a real challenge to a GP such as myself, working in an inner city practice.

In a practice with a list size of 20,000 patients like ours, there are likely to be around 200 patients with LD (ie very approximately 1%). Understanding these challenges and knowing when and how to get help are vitally important.

Patients with LD or “neurodevelopmental disorders” will have health needs like any other, but may be far more difficult to engage, consult with, or examine. This might be due to a number of reasons including cognitive or communication difficulties or a fear of clinical settings etc. It is very important to use the skills that you have learnt as a student to communicate effectively with these patients in order to ensure they are not compromised due to their disabilities. They will often be either living in the family home (with a variety of community support structures) or in residential homes with care support. It is important to listen to the patient themselves but also give the carer, who they might have come to clinic with, a chance to explain the problems. Spending time and understanding the problems is essential if we are to improve the poor health outcomes that this group currently experience.

Many health issues in people with learning disabilities will present to, and be handled by, the GP. However, at times the input of a community learning disability team (CLDT) is required. It is important to have good lines of communication between the various members of the teams and good referral pathways. It is important for a practice to have a register of all their patients with LD. This will allow approaches to be made to patients and their carers for preventative medicine such as immunisations and health checks.

Just recently a patient, supported by a carer, had a health check at the surgery carried out by a health care assistant and two problems became quite apparent. Firstly, at the age of 52, the patient had not been able to participate in the breast screening programme due to her difficulties with hospitals and machines. She therefore needed a breast check. The patient had also been exhibiting some quite challenging behaviour in the supported home, and the local LD psychiatrist had been involved because of this. The psychiatrist had followed up the patient and asked for a prescription of risperidone, which had helped the situation at home. The patient was calmer and happier and was now ready and able to have a breast examination by the GP. She attended with her carer and a breast examination was carried out. This was normal. Obviously, this is not a complete substitution for mammographic screening, but the patient was now better able to understand breast awareness. This case demonstrates the importance of good teamwork and the different roles that members of the team can fulfil to provide a better health outcome for patients with LD.

Patients on the autistic spectrum may have difficulties in communicating their needs and may become very anxious when coming to see a health professional. In our practice, we try and let the patient get to know one or two of the doctors well to gain their confidence. This is particularly important if they need procedures such as immunisation or venepuncture.

I remember during one flu epidemic, we were running extra immunisation clinics. Patients were being seen at 3 minute intervals to have their flu jabs, when a patient with LD arrived with her carer. The patient had a little ritual that she went through before being seen, and she always brought a camera down to have her picture taken with the doctor. This could take a bit of time as the patient recited 'doctor, picture' over and over. She would only allow this to happen when she was ready and had looked all around the room and at the equipment. Having settled her with this ritual she asked for her flu jab 'doctor, jab'. Unfortunately the patient also had a phobia of needles so when she was approached with the flu jab, she became distressed and said 'no needle'! She became quite agitated, as she wanted the flu jab but didn't like needles. After some gentle persuasion, we suggested she take a 'picture of the doctor with the flu jab' and after this she allowed us to immunise her!

Dealing with such problems requires patience, tolerance and sometimes improvisation and creativity! When the challenges faced become more complex, the CLDT can be of great assistance. The CLDT is a joint team of social care and health staff. The team is made up of social workers, community nurses, psychiatrists, psychologists and a range of therapists. They support people with learning disabilities to access mainstream services, provide specialist health services and fund and arrange social care.

Specialist health services include psychiatry, psychology, community nursing, speech and language therapy, occupational therapy and physiotherapy.

The team can help people with a learning disability gain access to a range of other specialist services such as health, education, day activities, respite care and employment opportunities. Services are provided in a way that suits the individual's needs (personalised care).

In our practice, we were often consulted by a single mother of two boys. She presented with a range of problems about herself, often ending the consultation in tears as she talked about the difficulties with her son. The eldest child had severe ADHD and was extremely difficult to cope with. His mother wanted him to remain at home if at all possible but, as he grew, he became more physically disruptive and almost impossible for her to handle. He had outbursts of hyperactivity and had been excluded from school because of his behaviour. At the age of 18 he was transferred from child to adult services and referred to the CLDT. It became clear that he could not remain at home and the idea of him moving away was gradually introduced. The social worker found him a supported home and he began to settle in to the structured and safe environment. He had input from the OT and psychologist to help him understand and deal with his feelings and outbursts and this helped a lot. Although no longer at home, he visited his mother and had a much better relationship with her. She now consults far less frequently about minor health issues, which were clearly a manifestation of her distress at not coping with her son.

Families can often be profoundly affected by patients with LD and it is the role of the GP to support and help them as they often struggle to fit in to so-called normal society.

In general practice these patients benefit from specialist knowledge of their conditions and may need proactive approaches to ensure their health care needs are met. The whole practice team will be involved from receptionists, who will get to know and understand the patients' communication issues, nursing staff, phlebotomists and talking therapists, to name but a few.

For example, contraception can be a very challenging issue for these patients and you will need to use all your skills to take accurate histories, promote understanding and gain consent. Carers and social workers are often extremely important in these situations to ensure that the patients are monitored and helped appropriately. Women's health is also very important and patients approaching the menopause often have difficulties with the hormone changes they experience.

In summary, patients with learning disabilities present a very specific challenge in primary care. As doctors, you will need to use all your skills and knowledge to provide excellent health care for these patients, but with good teamwork and a sensible approach, working with these patients can be extremely rewarding. Understanding how different patients communicate their needs, making reasonable adjustments, understanding the physical implications of their conditions and working together with carers and team members, will provide these patients with an opportunity to access the health care they require and deserve.

Recently a patient who was wheelchair bound and with severe autistic spectrum disorder, presented with possible post menopausal bleeding. It was important to first establish whether the history was correct and the carers were asked to monitor very closely any bleeding, site and frequency. As the patient was doubly incontinent, this proved very difficult, but it became clear that there was bleeding occurring and that this was not rectal. The patient was unable to give consent to be examined and she became distressed if approached by a health professional. It was decided to call a best interests meeting to establish whether it was appropriate for the patient to be investigated with a scan and possibly examination under anaesthetic (EUA). The GP, carers, case social worker and next of kin were invited to the meeting where all the pros and cons of investigation and treatment of the post menopausal bleeding were outlined and discussed so that all understood the possible outcomes and risks. The GP lead on this and a decision was made that it was in the patient's best interests to proceed with investigation. The patient subsequently had scans and an EUA and the bleeding was diagnosed as atrophic vaginitis. Appropriate treatment was instigated and the carers and next of kin were very happy. The leadership of the GP was very important in this instance and led to a diagnosis and good outcome. It was important for all team members to have their say and contribute to the care plan for the patient.

Useful websites

www.mencap.org.uk

www.rcpsych.ac.uk

www.learningdisabilities.org.uk

www.rcgp.org.uk – search for learning disabilities resources



Principles of assessing the mental health of people with learning disabilities

People with learning disabilities (LD) face a number of challenges in accessing healthcare, leading to inequalities in the standard of care they receive.

A recent report on the death of six people with LD who received sub-optimal care highlighted how they were let down by the healthcare system¹. Health care professionals are expected to provide people with LD the same level of care they would provide to anyone else. Given that mental health problems occur in people with LD at comparable or higher levels than the general population², assessing these needs is of paramount importance.

Assessing the mental health needs of someone with LD can seem daunting and challenging. This article is a brief introduction to help you see that with good communication skills, an understanding of the complexity of their needs and a structured approach, assessing people with LD should not be daunting and can be very rewarding.

People with LD should be treated with respect and be involved in decisions that are made about them. An explanation of the steps involved in the assessment can help ensure that they feel involved in the process and in clinical decisions. In situations when this is difficult (eg. due to communication difficulties), support from people who know the person well may help or alternative methods (eg. involving a speech and language therapist) should be considered. Where the person does not have capacity to make decisions about their care and treatment, the Mental Capacity Act should be followed.

Things to consider before the assessment

Background information regarding the person's childhood and education are valuable in ensuring that a thorough assessment is completed. Unfortunately in practice this information might not always be available due to the person not having any family member involved or the records being unavailable. In such circumstances, you could contact people who have known the person over many years, with the person's consent, to obtain further information. The communication abilities of people with LD can vary based on their ability level. People with mild or moderate LD can usually understand language and express themselves adequately. On the other hand, people with severe and profound LD might not be able to communicate verbally. Many people with LD know other forms of communication (eg. Makaton or sign language), which can be used to communicate with them through an interpreter. You will need to speak clearly in simple, short sentences and be mindful of any hearing impairment. The person may have a document summarising their communication needs (eg. a communication passport). These give valuable guidance on how best to communicate and should be referred to when they are available.

Many people with LD find it extremely difficult and anxiety provoking to be in situations that are unfamiliar to them. This can be avoided by either assessing them in situations that are familiar to them (home, day centre) or by ensuring that they have someone they trust with them during the assessment. If possible, the appointment should be arranged either at the beginning of the day or at less busy times to avoid the person waiting in a crowded and noisy area. Such environments can be distressing to people with LD or autism. It is equally important to allocate enough time for the assessment so that the person has enough time to express their concerns and not feel pressured.

During the assessment, professionals should make sure that the person is made to feel comfortable. People with LD can be suggestible and may answer positively to closed questions. Asking a range of question styles including open questions and frequently clarifying your understanding with them can help to avoid this. Sometimes the family or staff member who accompanies the patient will provide all the information, but professionals should make sure that the person's own perspective of any problems is understood. Letting the person know the structure of the interview before the assessment and showing patience throughout the meeting may make it easier for the person to feel less anxious.

The mental health assessment

People with LD can be affected by any psychiatric condition (e.g. depression, anxiety, schizophrenia) or present with aggressive and agitated behaviour. People with LD might deteriorate rapidly due to underlying psychiatric conditions due to their limited ability to cope with stressors and cognitive deficits. Identifying possible precipitants for the reported problems is important. The presentation of symptoms may be atypical depending on the severity of LD. People with mild LD may be able to clearly describe feeling sad, angry or report psychotic symptoms, which can lead to a psychiatric diagnosis. However, this might not be possible with someone who is non-verbal and has profound LD when changes in their behaviour might raise the suspicion of an underlying problem but not result in a definite psychiatric diagnosis. Behavioural disturbances can usually be explained if adequate information regarding the precedents is collected. Life events such as the loss of a loved one, moving homes, changing staff, change in daily routine or physical conditions such as constipation or those causing pain, can result in significant distress to people with LD. This could lead to aggression towards others or self-injurious behaviours, which need to be understood in context rather than attributed to a psychiatric condition. Loss of skills in people with LD (especially if they have Down syndrome) could indicate early signs of cognitive impairment (e.g. Alzheimer's dementia) and should trigger a specialist dementia assessment.

Appearance and behaviour	<ul style="list-style-type: none"> • of vital importance in people with limited verbal communication • dysmorphic features may suggest an underlying genetic syndrome • poor self care may reflect self neglect related to ability level or a mental illness. Good self care may be due to support from carers • stereotypical movements and mannerisms may be related to autism • an abnormal quality to the social interaction may suggest autism • increased agitation or hyperactivity should be noted
Speech	<ul style="list-style-type: none"> • if abnormal in character, carers should be asked if this is a change from their usual speech
Mood	<ul style="list-style-type: none"> • it can be very difficult for people with LD to describe their mood. Asking people to draw how they feel or point to pictorial diagrams may help • assess their interest and enjoyment in activities and energy levels • ask the patient and their carer about sleep and appetite changes • negative views of self are common in people with LD due to their life experiences / lack of role in society etc. • always ask about thoughts of self harm or suicide
Thoughts and perceptions	<ul style="list-style-type: none"> • formal thought disorder is difficult to recognise in someone with cognitive or communication impairments • hallucinations and delusions might present atypically • talking to self may represent normal behaviour for their developmental level or interacting with an imaginary friend • abnormal experiences more likely to be psychotic if accompanied by distress
Cognition	<ul style="list-style-type: none"> • any assessment of cognition should take into account their premorbid level of functioning • tools such as the Mini Mental State Examination (MMSE) might not be useful for people with LD
Insight	<ul style="list-style-type: none"> • assessment of insight should take into account the person's cognitive and communication abilities
Risk assessment	<ul style="list-style-type: none"> • risk to self and others should be evaluated • an in-depth enquiry into circumstances surrounding any past risk events should be made and documented • vulnerability and risk of exploitation and abuse from others should always be assessed

Having a structure to your assessment will ensure that you collect all of the relevant information required. The essential components of the history are listed below:

- Presenting complaints
- Psychiatric history
- Medical history and medication history
- Family history
- Personal and social history
 - to include developmental history, education (special or mainstream school), employment, interests and relationships, drug and alcohol use, current level of social support / support with activities of daily living, accommodation arrangements and financial situation. Vulnerability factors should also be considered and the potential for exploitation or abuse.
- Forensic history

A physical examination to rule out any underlying physical health issues is very important. Pain and constipation amongst many other physical health symptoms can present as behavioural disturbances in people with communication difficulties due to their inability to report the problem. It is also important to note the presence of sensory impairments, which occur more commonly in people with LD than the general population.

The Mental State Examination needs to be adapted to the particular communication and cognitive abilities of the person being assessed. Table 1 provides some examples of the types of adjustments required.

Completing the assessment

It might not be possible to complete the psychiatric assessment in a single session. This might be due to communication difficulties, the person requiring more time to respond to questions or the absence of someone who can provide reliable collateral information. Multiple assessments and contacting key people with the permission of the person being assessed may be required before making a diagnostic formulation and considering various interventions. The diagnostic formulation should be based on a holistic approach by taking the biological, psychological and social needs of the person into account.

Once the assessment is complete, feedback about what will follow the meeting is important so that the person and their carers know what to expect. If an intervention is planned following the assessment, it might be useful to supplement any verbal explanations with written information such as a leaflet, which explains the procedure. Easy read leaflets are available online from several resources³. The care plan should suggest possible interventions for each identified need and who will be responsible for delivering it.

People with LD may have difficulties in expressing their concerns and the symptoms might not conform to typical symptoms described by diagnostic classification systems such as ICD-10 and DSM-IV. A separate but complementary diagnostic system exists for diagnosing mental health conditions in people with LD (DC-LD).

References

1. Six Lives: the provision of public services to people with learning disabilities (2009) www.ombudsman.org.uk
2. Cooper SA. et al. (2007) Mental ill health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry* 190:27-35
3. <http://www.easyhealth.org.uk/>

Key points to remember

In summary, when assessing someone with LD, the points listed below should be kept in mind to make the assessment less stressful for the person and to make sure the right conclusions regarding interventions can be reached.

To make assessments of people with LD and mental health issues successful, you should

- Be respectful and involve them in decisions
- Make reasonable adjustments such as early appointments
- Acknowledge any communication difficulties and make arrangements to help them communicate through their preferred method
- Not attribute all their problems to simply having an LD
- Conduct a thorough assessment which includes collecting collateral information
- Screen for co-morbid healthcare issues

Further reading

Al-Sheikh A and O'Hara J (2008) Psychiatric and mental state assessment in learning disabilities. *Advances in Mental Health and Learning Disabilities*, Vol 2, Issue 4, pg 21–28

O'Hara J (2007) Inter-disciplinary multi-modal assessment for mental health problems in people with intellectual disabilities. In: *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities*, N. Bouras and G. Holt (eds), second edition, Cambridge University Press, chapter 3, pg 42–61



Learning disability, autism and mental illness

Autism as a model to understand human experience

When I was a student it was thought that about three quarters of people with an autism spectrum disorder (ASD) had a learning disability.

Now we know that this isn't true, and that the majority of people with an ASD are of normal intelligence. This has meant that the remit of neurodevelopmental psychiatrists has increased to cover people without a learning disability. In other words, we can 'poach' some of the most interesting patients from our general psychiatry colleagues! For example, as well as others, I look after inpatients with a learning disability and autism on one ward, inpatients with 'high-functioning' autism on another, and run a behavioural genetics clinic in which we assess across the entire range of the IQ spectrum.

This booklet speaks of 'neurodevelopmental psychiatry' at least as much as it does of the 'psychiatry of learning disability'. What this reflects is an acceptance that abnormal neurological development doesn't just lead to learning disability, but to a much wider range of behavioural phenotypes, only some of which include learning disability. Autism, in which people have difficulties in social interaction, communication, and interests and imagination, provides a good example.

Of course, given that by definition ASDs are 'developmental disorders' (this group of conditions is sometimes known as the 'pervasive developmental disorders') we need to be able to demonstrate that such abnormalities were present during the person's development. This is why we take a detailed developmental history as part of the diagnostic process. Perhaps the best way to do this is to use a semi-structured interview such as the Autism Diagnostic Interview – Revised to take a history from an informant. Sometimes, given that our patients are adults, and that their parents may be elderly (or dead), such a developmental history may be unreliable (or

absent), so there are also tests of present-state features of ASDs, though these are less diagnostically specific and may be confounded by current mental illness. They include the Autism Diagnosis Observation Schedule, which tests people's imagination, communication and social abilities in real time.

Aside from being a common cause of significant distress (ASD may affect as much as 1% of the population) the difficulties experienced by a person with an ASD go to the core of human experience and socialisation. What could be more fascinating than working in a field in which we can explore the genetics and neurobiology of human experience and how this relates to both healthy development and disease states?

Neurodevelopmental psychiatrists understand false dichotomies: disorder versus illness

Medicine is full of convenient ways of categorising things; these are often very helpful in the real world, but can lead us up the garden path if we don't remember that they are there just for convenience.

One obvious example is the false – but clinically useful – dichotomy between the 'organic' disorders, such as dementia, drug intoxication or a brain tumour, and the 'functional' disorders such as depression, anxiety or schizophrenia. Why is the dichotomy false? Because as scientists we acknowledge that everything, even the representation of our experience, is rooted in matter, and is therefore 'organic'. Why is the dichotomy useful? Because it prevents those of us in medical practice from missing reversible causes of distress, which might lead to unnecessary morbidity.

Another false opposition is that of 'disorder' versus 'illness'. Illnesses are usually labelled as such because they are discretely defined in time, imply a prior period of normality, have a relatively abrupt onset, and if only we could find the right cause (and therefore cure), stand a reasonable chance of going away. Thus, it might be said that abnormalities of development, which generally do not conform to this pattern, are in some way different. But what are we to make of the well-described developmental aspects of some illnesses such as schizophrenia, and the predisposition of some people with 'developmental' disorders to mental 'illness'? The answer is that this is another occasion on which we have to suspend our disbelief, because the distinction is useful in diagnostic and prognostic terms even though the opposition is false. Nowhere else in medicine is this issue – which is of real clinical import – so live as in the field of neurodevelopmental psychiatry. In our field, we juggle these concepts as needed for the benefit of the patient in a way that many of our colleagues struggle with. For example, people with autism are far more likely than those without to experience symptoms indistinguishable from those of obsessive-compulsive disorder. Our colleagues often see such symptoms as part of the ASD, rather than as features of an illness to which people with ASD are vulnerable. This is important, because if they are not labelled as illness, they are unlikely to be appropriately treated, and there is currently no evidence whatsoever that such symptoms respond to treatment less well when the patient has an ASD than when he does not. The reason we do not do this is because we have realised that the dichotomy between illness and disorder is false; this is something that is core to the neurodevelopmental psychiatrist's understanding of the world!

Top down, bottom up and endophenotypes!

We live in a time of great change in which we can participate in a radical reframing of a range of basic understandings about the origins of both normal behaviour and mental disorder.

If you read through chapter V of ICD-10 (I doubt you will), you will find that the vast majority of diagnostic descriptions are of groups of symptoms and clinical signs that tend to cluster together (broad 'behavioural phenotypes'). In other words, the disorders are described from a 'top down' perspective in which the diagnosis describes what you see or hear but rarely describe the aetiology of the problem.

So what about this aetiological 'bottom up' perspective? Perhaps more than in any other psychiatric specialty, neurodevelopmental psychiatrists are used to this. As medical students we learn about eponymous single gene disorders (the bottom) that give rise to abnormal phenotypes (the top). I remember being greatly surprised as a student by the idea that a defect in the enzyme HGPRT (which gives rise to Lesch Nyhan syndrome) gives rise to a phenotype so specifically 'behavioural' as repetitive self-harm. There is an enormous range of other genetic disorders that give rise to such cognitive and behavioural phenotypes (see chapter on genetics).

We are beginning to understand that the behavioural phenotypes described in ICD-10 are often the final result of a group of more or less specific genetic causes. In fact, the broader the phenotype, the greater the chance that there is no single cause, and this has scuppered many a researcher's hope to find, say, a single 'cause' of schizophrenia or autism. Recent advances in genetics include faster sequencing techniques, and 'array analysis', in which we can print 40,000 sequences of DNA onto a single slide to discover if a person has a variation in the numbers of copies of segments of DNA that may include multiple genes (copy number variations). As neurodevelopmental psychiatrists we use both bottom up and top down approaches together to diagnose and treat our patients. We are at the forefront of this aspect of medicine, which has such promise that it will radically affect the way you practice medicine and care for your own health within your lifetime.

Of course, the bits between the gene and social behaviour are (a) the physical structure of the brain, and (b) the neuropsychological components that when summed add up to the way a person behaves (note that this involves the superposition of two different models of the world). Recent advances in brain imaging have allowed researchers to make ever-finer distinctions between normal and abnormal brain anatomy and function. These 'mid-points' between the causes of a disorder and its manifestations are called endophenotypes, and they may be physical or neuropsychological in nature. It is truly extraordinary that in many cases we can now determine exactly what genetic material is abnormal, how this affects brain structure and function, and how this ultimately affects social behaviour. It is the first time in human history that we can do this. We are neurodevelopmental psychiatrists at a time of great discovery; we have the investigative tools, skills and imagination to use these resources both for our patients, and to explore important aspects of the nature of human existence.

Neurodevelopmental psychiatrists do complexity

As a rule, patients with developmental disorders are more complex diagnostically, socially and in treatment terms than those without. Reasons for this include:

- 1 Neurodevelopmental disorders such as ASDs or ADHD have high rates of co-morbidity with mental illness across the entire range of intellectual function;
- 2 Learning disability is associated with increased rates of other mental disorder;
- 3 People with a learning disability are more likely to be unable to report their thought contents, so the nature of the difficulty may have to be inferred from behaviour;
- 4 Specific behavioural phenotypes are often associated with complex physical phenotypes;
- 5 Physical illnesses (such as epilepsy) are more likely to be present;
- 6 People with developmental disorders have life-long difficulties interacting with their environment, and this often affects personality development;
- 7 People with developmental disorders may have difficulty making use of some forms of psychological treatment, or may be atypically sensitive to psychopharmacological agents;
- 8 On average, people with developmental disorders are more likely than others to originate from and live in difficult social circumstances.

This means that developmental psychiatrists, together with their colleagues, become experts in social, neuropsychological and scientific complexity. This leads to an interesting working life. For example, we have to negotiate complex areas of the law, understand neuropsychological perspectives with great nuance, and become as expert in measuring behaviour as we do in listening to our patients and their families. Often we have to set up a series of hypotheses and test them in the most parsimonious way possible, often across categories, and with time constraints –an exercise in true intellectual rigour.

It is not just the patients who suffer from neurodevelopmental disorder that keep us on our intellectual toes, but sometimes those who don't. For example, of the people who attend our behavioural genetics and autism assessment clinics, 40% leave without a diagnosis of developmental disorder. Their complex difficulties with social relationships might arise from a number of other reasons, including "organic" disorders, any functional disorder you can think of or as part of the range of "normal" human experience. In these cases, our function is to provide an explanation that makes sense to the patient, where possible, and support them to access the help that will alleviate their distress. Neurodevelopmental psychiatrists get to see a bit of everything and be expert in a lot!

Diagnostic complexity gives rise to great and varied needs; to meet these you require a team that is full of people with a wide range of expertise. We are enormously fortunate that in neurodevelopmental psychiatry we work with a fascinating set of colleagues, clinically and in research, some with similar perspectives, and some with different perspectives, all of whom will continue to challenge us and thereby provide us with the highest possible quality of working life.



What makes a good doctor? Views of people with learning disability

In 2001 the Government published 'The NHS Plan' which outlined the future direction of the NHS.

One of its main priorities was to ensure that people who use health services are included in all stages of planning, delivery and evaluation of services. Services for people with learning disabilities have been at the forefront of the patient involvement agenda and this is clearly embedded in learning disability policy over the last decade.

In 2001 the Department of Health published a white paper entitled 'Valuing People: A new strategy for learning disability for the 21st century'. It was based on four principles of choice, inclusion, independence and rights. From beginning to end, Valuing People embraced the principles of partnership working, not just between services but also with people with learning disabilities and their families. It stated that people with learning disabilities should be fully involved in the decision making processes that affect their lives and be seen as active partners. This concept was further reinforced by policy makers supporting people with learning disabilities to produce the policy document 'Nothing about us without us' (DH, 2001). As the title suggests, the focus of the report was the full inclusion and involvement of people with learning disabilities in every aspect of their lives. The report paid particular attention to health. Of those interviewed, many reported poor experiences, such as not being listened to and adjustments not being made in regards of their individual needs and disability. Examples of good practice were highlighted and from this recommendations were made such as support to stay healthy, the use of accessible technology and information and staff training on learning disabilities.

In specific relation to the mental health needs of people with learning disabilities, little attention had been given to the views and opinions of those using services until the early 2000's. In 2003 focus groups were held in south east London to engage with local people with learning disabilities as to what makes a good mental health service (Estia Centre, 2003). This example of good practice offers clinicians and managers insight into what people want from their mental health services and might be useful in other areas. Following the report a plan of action was implemented that included the development of accessible health promotion materials, training on learning disability issues for mental health staff and a mental health support group.

For the purpose of this publication eight people with learning disabilities were interviewed, asking a series of questions about their experiences and what makes a good doctor and psychiatrist. The hope is that their thoughts and opinions may support medical trainees to better understand the needs of people with learning disabilities and how they can adapt their practice. Direct quotes from individuals are included.

What makes a good doctor?

Participants had a range of ideas that focussed on two main themes; doctors' education and knowledge and their communication and interaction.

There was strong consensus that doctors should have knowledge about a wide range of treatments and be skilled in delivering treatment.

- » **A good doctor lets you know what your tablets are for, when to take them, and the side effects. They should give you a leaflet about your tablets. «**
- » **They should advise on things to stay healthy like exercise and eating healthy. «**

An important point raised by all participants was that all doctors should receive special training about the needs of people with learning disabilities. This included how to communicate with people, especially those with severe learning disabilities, understanding the health issues that individuals are more likely to have and about consent to treatment.

- » **They should know lots about epilepsy. «**
- » **They should respect your wishes, not force something on you. «**

In regards of communication there was much discussion around how doctors and other professionals interact with people with learning disabilities. Several individuals reported poor experiences and feeling that professionals did not respect them because they had learning disabilities. Some ideas were offered as to how this could be improved.

- » **Doctors should know about makaton (sign language). Using pictures can help you understand. «**
- » **A good doctor listens to you. They should be polite and respect you. «**
- » **A good doctor gives good eye contact, and talks to the patient first not their support worker or parent. «**

Experiences of how doctors have helped people with learning disabilities

Participants offered a range of good experiences, many of these were focused on communication and interaction, where the person felt valued and understood. When asked what had helped the most when seeing the doctor, all agreed being given the 'right advice and treatment'.

- » **The doctor was always friendly. He listened to me and asked me what I wanted. «**
- » **She gave me tablets and told me what I should and shouldn't do, like drinking alcohol. «**
- » **Took more time to help me understand things. «**

How have psychiatrists helped people with learning disabilities?

All participants had a broad understanding of what a psychiatrist was and all had seen one at some point. These had all specialised in learning disability psychiatry.

- » **The psychiatrist gave me tablets for my anxiety. They sent me to see a psychologist to learn relaxation exercises. «**
- » **I had voices in my head. The psychiatrist gave me tablets and they went away. The psychiatrist also talked to me about getting out and about, meeting new people. Not staying in doors and being bored. «**
- » **When I stayed in hospital I saw my psychiatrist once a week and at CPA meetings. He was very helpful. «**

What do doctors need to know about treating people with learning disabilities?

Interestingly the participants' answers reflected the four principles of Valuing People; choice, inclusion, rights and independence, areas which the group were very passionate about.

- » **People with learning disabilities have the same rights as everyone else and deserve the same respect. «**
- » **Know about how to communicate with people with learning disabilities. They need to pick up on things like behaviour and moods in people who can't speak. «**
- » **People with learning disabilities have the right to say yes or no to treatment. «**
- » **They need to give people with learning disabilities the same choices as everyone else. «**

'Challenging behaviour' is a term commonly used in learning disability services to describe behaviour such as aggression, self injury and anti-social behaviour. Though it can be associated with mental health problems, often it is due to communication and environmental issues. Participants thought that doctors should think carefully about challenging behaviour and always look for the reason why it happens.

- » **Doctors should know that challenging behaviour sometimes happens because the way people are treated. Staff can cause challenging behaviour. «**
- » **Staff can have challenging behaviour, like when they are rude to you or tell you off. «**

What bad things have doctors said or done?

Again a common theme was communication and interaction, where professionals had not taken into account the additional communication needs that people with learning disabilities may have.

- » **She talked to my keyworker, asked him how I was feeling. She didn't acknowledge me. «**
- » **Sometimes they read out the information about tablets too quick. «**
- » **In the waiting room your name comes up on the board. I can't read. «**

What makes a good psychiatrist?

The participants' remarks were insightful on this topic. This may be due to some of them having taken part in a mental health promotion course.

- » **A good psychiatrist knows about all the different types of mental health problems. «**
- » **Thinks about people's needs not just their illness. «**
- » **Gives time to people if they are having bad thoughts or thinking about suicide. «**
- » **Thinks about physical health as well as mental health. They should know about the body as well as the brain, the body is one, one bit affects another. «**

In conclusion people with learning disabilities can make valid and insightful contributions to all aspects of the health care experience and should be viewed as equal partners in this process. Medical staff as well as all other professionals may need to make reasonable adjustments to their practice and in particular their communication when working with people with learning disabilities.

Further resources

Department of Health (2001) Valuing People: A new strategy for learning disability for the 21st century. London, HMSO.

Department of Health (2001) Nothing about us without us. London, HMSO.

Michael J. Sir (2008) Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities. London, HMSO.

Estia Centre (2003) It's our mental health! London, Estia Centre. Visit www.estiacentre.org for further information

Clear Thoughts – a website offering information and resources to meet the mental health needs of people with learning disabilities: www.clearthoughts.info

Easy Health – a website offering a wide range of accessible resources on health issues: www.easyhealth.org.uk

People First – a national organisation run by and for people with learning difficulties to raise awareness of and campaign for the rights of people with learning difficulties and to support self advocacy groups across the country – www.peoplefirstltd.com



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Child and adolescent mental health services for children and adolescents with learning disabilities

Children and young people with learning disability are recognised as being at an increased risk of developing behavioural or mental health problems.

These problems impact on the child/young person, the family, the school and the wider community. Behavioural and mental health problems limit the child's access to education and leisure facilities, and ultimately, risk breakdown of family placement.

The development of the specialty of Mental Health of Child and Adolescent Learning Disability has lagged behind the development of mental health of adult learning disability services. More recently, there has been a flurry of interest in the provision of appropriate services for this group of children and young people. CAMHS now has an obligation to ensure that the mental health and behavioural needs of this group are met. Despite this, there continues to be deficiencies in service provision but, more positively, there are clear opportunities to develop highly skilled and excellent services in order to address the needs of this group.

As psychiatrists, the sub-speciality of mental health of child and adolescent learning disability is exciting. It combines expertise in childhood neurodevelopmental disorder, psychopathology, family functioning, risk management, and intervention. Children with rare genetic disorders and/or epilepsy comprise part of the patient group.

In general, services are multidisciplinary, and must be skilled in liaising with a wide, multi-agency group of professionals. Services are community and clinic based. It is rare for a child or young person with learning disability to require inpatient psychiatric assessment or management.

The role of the psychiatrist in mental health of child and adolescent learning disability

The psychiatrist in child and adolescent learning disability has a number of roles, which include:

- 1. Assessment** – this involves gaining current and background information from parents, carers, teachers and others who work or care for the child. The child is also interviewed/observed in the clinic, at home and at school. The child level of intellectual functioning might be assessed (psychometry) using standardised tools. Specific areas of assessment include the assessment of autism, attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), psychosis and mood disorders. Functional analysis of the behaviour is also offered. The detailed assessment enables a differential diagnosis to be reached. Some children will require further investigation (chromosomes, EEG, MRI)
- 2. Management** – behavioural psychotherapy, pharmacological, family work, group work, anger management
- 3. Risk assessment** – for every child. Particular areas of concern are severe aggression to self or others, fire setting, inappropriate sexualised behaviour, absconding, abuse and neglect.
- 4. Advice about safeguarding and child protection issues** – in liaison with social services
- 5. Advice about placement, including inpatient psychiatric assessment, educational placement and complex social care placements**
- 6. Advice about transition into adult services**
- 7. Medico legal work** – capacity, fitness to plead
- 8. Teaching and training** – to a range of disciplines/agencies
- 9. Research and service development**

Such a wide-ranging remit ensures that the speciality is stimulating. Currently, there is a lack of a clear evidence base for many interventions, thus there are opportunities for extensive research.

Case vignette

The following case vignette gives an example of how interesting the speciality can be.

Johnny is a child, aged 7, who is referred to the Mental Health of Child & Adolescent Learning Disability Service due to concerns of underachieving at school and behaviour placing himself and others at risk. He comes from an impoverished family. His father has committed sexual offences and is in prison. His mother is recognised as having a borderline level of functioning and accessed special educational provision as a child. Johnny also has three siblings, all of whom have developmental delay.

In discussion with Johnny's mother and class teacher, it is evident Johnny is not settled in class; he irritates the other children and is underachieving in his mainstream school. Johnny is unable to read and cannot carry out the most basic of numerical tasks. The school are concerned he is in an inappropriate educational placement and has requested advice.

Comprehensive assessment revealed that Johnny has a very poor level of concentration and is fidgety and impulsive. In addition to this, he has developed an interest in matches and has set a small number of fires. He dislikes change, has poor relationships with the other children in the class, and has a number of obsessions and rituals. Psychometric assessment indicates his IQ has an uneven profile, with his verbal IQ being at the top end of the moderate learning disability range (48) and his performance IQ being in the mild learning disability range (65). In addition to this, he has a poor working memory.

The team's initial opinion on Johnny was that he clearly has a learning disability, but his verbal IQ and performance IQ are discrepant. He has a number of features of Autistic Spectrum Disorder, and also has features of Attention Deficit Hyperactivity Disorder.

The team plan to offer further assessment, consider the role of behavioural intervention and the role of medication. Johnny's education placement is to be reviewed with the issue being whether he should be moved to a school for children with mild-moderate learning disability, or whether he requires a specialist Autistic provision. In addition to this, family support is to be discussed with the Social Services department because of the risks Johnny poses to himself and others.

From this case vignette, you will see that there are numerous issues to consider. The psychiatrist working in the field of child and adolescent learning disability is able to consider co-morbidities and the complex psychosocial issues. The psychiatrist has to work with a number of agencies, including education, Social Services and most importantly, the family, in order to plan further assessment and intervention. There is extensive communication and documentation.

Competencies

Those considering a career in mental health of child and adolescent learning disability must have an interest in working with children and, particularly, children with developmental difficulties. In addition to this, they need to be skilled communicators and be comfortable when working with a large number of professionals where roles are sometimes unclear. They need to be flexible in the way they work and be willing to work in the community, rather than being purely clinic-based.

There are ethical, philosophical and moral issues that arise in the field of child and adolescent learning disability, thus those working in the field must be receptive to seeking advice about any dilemmas they encounter.

It is important to understand developmental milestones, factors concerning aetiology, such as knowledge of genetic disorders and rare syndromes. A comprehensive knowledge of the psychopathology these children and young people present with is key to becoming a skilled psychiatrist in this speciality.

Training

In order to train in the speciality of mental health of child and adolescent learning disability, core training in psychiatry must be completed. This is followed by higher specialist training in child and adolescent mental health. The trainee will then specialise in the mental health of child and adolescent learning disability. There are opportunities to develop specific areas of interest, for example, rare genetic disorders, epilepsy or forensic aspects of the speciality

Background reading

Bernard, S. (2009). Mental health and behavioural problems in children and adolescents with learning disabilities. *Psychiatry*, 8, 387-390.
Bernard SH & Turk J (2009) *Developing Mental Health Services for Children and Adolescents with Learning Disabilities: A toolkit for clinicians*. Royal College of Psychiatrists, London
Emerson and Hatton (2007) *The Mental health needs of children and adolescents with learning disabilities in Britain Advances in Mental Health and Learning Disabilities 3: 62-63*.
Raghavan R., Bernard S.H., McCarthy J. (2010) *Mental Health Needs of Children and Young People with Learning Disabilities*. Pavillion.
Royal College of Psychiatrists (2004) *Psychiatric services for children & adolescents with learning disabilities*. Council Report CR123

Career satisfaction and challenges

This career is immensely satisfying for those who are interested in the field. There are ample opportunities to undertake complex clinical work, develop services and be involved in research and academia. There are also opportunities to work with voluntary organisations and parent groups and influence government policy.

There is involvement with paediatrics, neurodevelopmental paediatrics, paediatric neurology, community paediatrics and clinical genetics.

There are management opportunities and, in addition, opportunities to work at a national and international level.

The challenges associated with working in this field include having to work with families that are bereaved because of having a child with a complex developmental disability. Inevitably, some families feel angry and distressed about what they perceive as a lack of service provision for their children and it is important that professionals in the field are able to manage this with understanding and sensitivity.

At times, children present with very distressing situations and the psychiatrist might have to support the family and the team in managing instances of child neglect, abuse or bereavement. Other challenges include poorly resourced services, which compromise the high standards that you might aspire to achieve.

Conclusions

1. This speciality is an interesting and exciting speciality, which has ample opportunity for the development of clinical, managerial and academic interests.
2. This speciality demands a high level of communication skills.
3. This speciality can definitely improve the mental health and behaviour of children with learning disabilities. It is an opportunity to provide assessment and intervention at an early stage of a child's life in order to optimise prognosis and quality of life. This can be very rewarding.



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Understanding the impact of ADHD in adulthood

Clinical, psychological and social consequences of ADHD in adults

Attention Deficit and Hyperactivity Disorder (ADHD) is well known in childhood and has received extensive attention in the media. This is in part because ADHD has been surrounded by controversies, for example whether young children are medicated to 'cover up' bad parenting, or whether increasing prevalence of ADHD is a result of increasing demands of society. There have been concerns about over-diagnosing ADHD, in particular in the USA where the prevalence of ADHD tends to be higher than in the UK and Europe, and books have been written about this (for example "Ritalin Nation" written by Richard DeGrandpre in 1999).

In spite of these controversies, it has become apparent that ADHD is a valid and reliable syndrome that can be diagnosed in a repeatable way and that can be effectively and safely treated with medication. In children, ADHD is now one of the most prevalent psychiatric diagnoses. However, it is less known that a substantial part of the children with ADHD continue to have problems in adulthood. In fact, when ADHD is not recognized, children might be considered 'naughty' or 'lazy', and many of these children grow up to be adults that have not been able to complete secondary education and/or to find or keep a job, or worse, end up with an addiction or in prison. Most general adult psychiatrists and GPs know little about ADHD and this is the reason that there are still a lot of patients with ADHD without a diagnosis and appropriate treatment. The good news is that recognition of this disorder is increasing and that there are effective and well tolerated treatments.

The diagnosis of ADHD in childhood is established by an interview with parents and examination of the child, and often a collateral history provided by the school teacher is incredibly informative. In children, diagnosing ADHD is sometimes difficult because hyperactivity and impulsivity are age appropriate in young children; in fact it is quite natural for a 4-5 year old child to be hyperactive and impulsive! A diagnosis of ADHD is made when impulsive and hyperactive behaviours are more pronounced or frequent than in most children of that age. Many children normally outgrow much of their hyperactivity and impulsivity and this also holds true for children with ADHD. This means that some of the hyperactivity and impulsivity symptoms will become less problematic when children grow older, and might be non-existent once they have reached adulthood. In contrast, symptoms of inattention tend to be much more perseverant and research has shown that ADHD related concentration problems are pretty stable over time.

In adults, ADHD is diagnosed by a psychiatric interview carried out by a psychiatrist and by applying the American DSM IV criteria. It is crucial to collect information regarding childhood behaviour, and patients are encouraged to bring a parent or to bring school reports to the assessment. Research has shown that adults tend to overestimate inattention and hyperactivity symptoms when they were children and it is extremely helpful to get 'objective' evidence of childhood behaviour. A patient who shows school reports stating 'excellent work' all through primary school is unlikely to have a diagnosis of ADHD! When people develop symptoms of inattention at a later stage in life, alternative diagnoses should be explored, such as depression, anxiety or organic causes.

There are two major groups of symptoms: the inattention symptoms, and the hyperactivity/impulsivity symptoms. In DSM-IV nine symptoms of inattention are described, and they include a range of behaviours that are a consequence of poor attention and concentration. These behaviours include: making careless mistakes, having a short attention span, not listening or 'being elsewhere' when people are talking, being unable to finish things or taking a long time to complete tasks, difficulties with organization, procrastinating and avoiding tasks that require mental effort, being easily distracted, losing things, and forgetfulness. There are an additional nine symptoms of hyperactivity and impulsivity. These include behaviours associated with over activity and carelessness, including: being fidgety, having trouble remaining seated, experiencing feelings of restlessness, being loud in situations when it's inappropriate, being overly energetic (or unable to relax!), being talkative, saying things without thinking, impatience, and being interruptive or intrusive.

For a diagnosis of ADHD at least six out of the nine criteria should be present. It is possible to have the 'inattentive subtype', with 6 or more of the 9 inattention criteria but not enough hyperactivity/impulsivity criteria. When individuals have 6 or more symptoms of both inattention and hyperactivity/impulsivity, they have the 'combined subtype'. Some people are diagnosed with ADHD, predominantly hyperactive/impulsive subtype, however it is quite rare to see patients who clearly struggle because of hyperactivity and impulsivity, but who are perfectly able to concentrate for hours! On the flipside, it is quite common for people with ADHD to 'hyperfocus' on a topic of interest, and to spend hours without needing a break and with poor tolerance for interruptions.

An illustration of how 'uncomplicated' ADHD can present in an adult is described in the following case vignette.

Case 1: Nicola

Nicola came to see us in a specialist Adult ADHD Service when she was 30 years old. She was referred to us by her GP who was keen to get some advice regarding the treatment and management of adult ADHD, as he was uncertain whether ADHD did even exist in adults. She told the following story that is quite illustrative for how ADHD can go unnoticed until adulthood.

"I grew up in Boston, America, with my parents and my brothers. I have always struggled with school. From the age of 6, when I went to elementary school, I found it incredibly difficult to sit still for a whole day, and to pay attention. The tiniest thing distracted me! If a child in class dropped a pen, I would get off my chair and pick it up. I was constantly talking to children next to me and my teachers had to keep reminding me to keep quiet. I never did my homework, as I could not get myself organized. I constantly forgot to bring things in to school that we needed and on numerous occasions I found myself in the toilet crying, because I was so embarrassed that I had forgotten something. Fortunately, I was bright, and I managed to get quite far without doing anything! However I have always felt quite 'stupid' and when I went to secondary school I started behaving as a 'giggly girl' because I felt that was what people were expecting from me. All throughout secondary school, I managed to get by with doing the least possible, I only did what was required and got average grades. I had stacks of energy and was very good at sports, and was a fanatic basketball player. I was known as 'the force' because of my drive and high energy levels! I managed to get a basketball scholarship to get into University.

Once in Uni, my problems started. For the first time in my life, I really had to work hard to get decent grades. And what was worse, I had lots of long-term assignments that required planning and organization! I could not get away anymore with doing everything last minute, like I used to. To make matters worse, my parents went through divorce when I was 19 and I became depressed. In the end of my second year of University my grades were very low and I was about to give up. At this time however, I was offered

an appointment with an educational psychologist and she suggested that I might have ADHD. I was referred to a psychiatrist and diagnosed with ADHD and commenced on Dexamphetamine. This made me feel agitated and nauseous and I did not like it at all. I was switched to Ritalin, the short-acting form of Methylphenidate, and the dose was gradually increased from 5mg to 20mg, which I took three times daily. I could tolerate this much better and I immediately noticed the effects! I was able to concentrate and sit still and actually remember what I was reading; it was amazing! From then on, I found it much easier to study and managed to complete my degree two years later. I was much happier and found it easier to socialize, as I was finally able to follow conversations with friends! It was around this time I met the great guy who is now my husband.

However, after completing university, I found myself without health insurance for a while and did not have access to Methylphenidate prescriptions. I had a job as a teaching assistant in preschool and although this was an easy job for me and basically below my potential, I struggled with the admin side of the job. I had a lovely colleague who ended up doing all the admin, she really compensated for my chaos! Around this time, I was organizing our wedding and this was a huge struggle for me. I forgot to organize essentials, for example I completely forgot that we had to buy wedding rings! We ended up borrowing the rings of the best man and his wife for the ceremony! I also forgot to make a seating plan, and to arrange transport, and I know I would have done a much better job if I had been on Ritalin then.

We went to the UK shortly after, and I was re-commenced on Ritalin and decided to start a PhD in child psychology. All throughout my PhD I was on Ritalin and I managed to finish within 3 years! I'm really pleased and am working in service development for children now. I'm still struggling at times, and my confidence is low. I still feel like the silly, giggly girl I was in high school, and I get in trouble with my friends when I blurt out stuff that is a bit inappropriate. Overall though I'm happy with my life and have found Ritalin incredibly helpful. We're thinking about having children and I'm already dreading having to stop using Ritalin when I get pregnant...."

As this case vignette illustrates, ADHD causes problems in study, in the workplace and in individuals' personal lives. The good news is that recognition of this disorder is increasing and that there are treatments which are effective and well tolerated. Where recognising, assessing and treating adult ADHD can get complicated is when there are co morbid disorders present and where the presence of ADHD in addition to other disorders leads to increased risks for the individual and those around him or her.

Up to 80% of adults who have ADHD also have other mental illness. Common co-morbid conditions include anxiety and depression, personality disorders and other neurodevelopmental disorders such as autism. In addition, ADHD is more common in individuals with intellectual disability.

Having ADHD can lead to a number of problems for young people. The educational and occupational disadvantage on its own has far reaching consequences. Problems with listening, concentrating and planning school work can start in primary school but it is in secondary school where students are expected to take more responsibility in the planning and organising of their work where individuals can really start to fall behind. Adults with ADHD often report high turnover of jobs, periods of unemployment and lower-ranking jobs than their siblings. Partly this is a consequence of educational underachievement and partly due to ongoing symptoms of ADHD.

We know that ADHD is associated with crime and several studies investigating mental health of prisoners found that up to half the prison population screened positive for ADHD in childhood (Young 2007). The reasons for this association are complex but include the co-morbidity with antisocial personality disorder, impulsivity and risk taking behaviour (that are core symptoms of ADHD), mood instability, difficulties managing anger and increased levels of substance abuse in adults with ADHD.

Case 2: Darren

Darren's case illustrates some of these complexities. He was referred to our specialist Adult ADHD Service at the age of 20 due to explosive temper and lack of concentration and motivation. Darren was born after a normal pregnancy. His mother reported normal developmental milestones but described Darren as a difficult baby, he never settled, never slept and as a toddler hit out at other children, he was into everything and had no sense of danger. Darren was educated in mainstream school but, from primary school, his behaviour was a problem. He was disruptive in the classroom, wandering about, talking all the time, and he was the 'class clown'. At the age of 8, his primary school suggested an assessment for ADHD and he was referred to the local child and adolescent mental health service. A diagnosis of ADHD was made on the basis of history from his mother and observing Darren in the clinic and at school. Because of the difficulties he was experiencing and concerns that he was getting further behind academically, treatment was started in the form of Concerta XL (a long acting form of methylphenidate). Darren's mother and his form teacher reported an immediate improvement; he was able to complete tasks, could concentrate on playing with one thing and seemed happier and calmer. Unfortunately he lost his appetite (which is a common side effect) and this limited the dose it was possible to prescribe.

Darren's behaviour was reasonably stable until he went into secondary school where he was bullied and teased because of having ADHD and he started refusing to take his tablets, his academic progress stalled and he got excluded from school several times due to fighting with children in his class and on one occasion he threw a chair at a teacher. Darren was permanently excluded from his school at the age of 15 and did not return to school after that.

Things escalated after Darren left school. He started to use cannabis regularly and was aggressive towards his family. Darren continued to get into fights, he started to get into trouble with the police and at the age of 16 he received a custodial sentence in a young offenders institution on a charge of actual bodily harm. Attempts by his mother to get medication restarted floundered as Darren refused to attend appointments.

At assessment at the age of 20, Darren was not working and was living with his mother, he was seeking help as his girlfriend was expecting a child and he was starting to see that he could not control his temper. Due to his poor concentration, he was unable to complete forms required for benefits and to apply for jobs. He struggled to follow even simple instructions, was disorganised and very easily distracted. He described angry outbursts and difficulty thinking before he acted however the overactivity described by his mother in his childhood was less evident. Darren felt frustrated and angry about his problems; he often felt miserable and thought about killing himself although he had not acting on this. He admitted to using cannabis on a daily basis as he felt it calmed him down although he acknowledged that it probably made him more forgetful. The outcome of the assessment was that Darren's primary diagnosis remained ADHD and he agreed to a trial of medication. Because of the previous side effects experienced on methylphenidate, a non stimulant, atomoxetine was prescribed. This led to an improvement in impulsivity and Darren's mother reported he was calmer and less volatile, he continued to have problems with concentration but the benefits seen with treatment allowed him to engage with an anger management course.

As this case vignette illustrates, ADHD that goes unrecognised (and untreated!) for years can cause huge setbacks and lead to having a criminal record rather than educational qualifications. It is therefore extremely important that ADHD is recognised and treated early. There is increasing awareness of ADHD in adults both in the general public, in the media, and also among the psychiatric profession. There remain few specialist services and debate about the validity of the diagnosis and appropriateness of treatment continues (Asherson 2010).

The mainstay of treatment remains stimulants but there is increasingly evidence that cognitive behavioural therapy (CBT) is helpful both with respect to core deficits but also associated symptoms including anxiety, mood instability and irritability. Medication (when tolerated) combined with psychoeducation and CBT to increase organizational skills, anger management skills and skills in dealing with negative thought patterns seems a promising treatment strategy and helps individuals with ADHD to overcome barriers and lead a fulfilling life.

Further reading

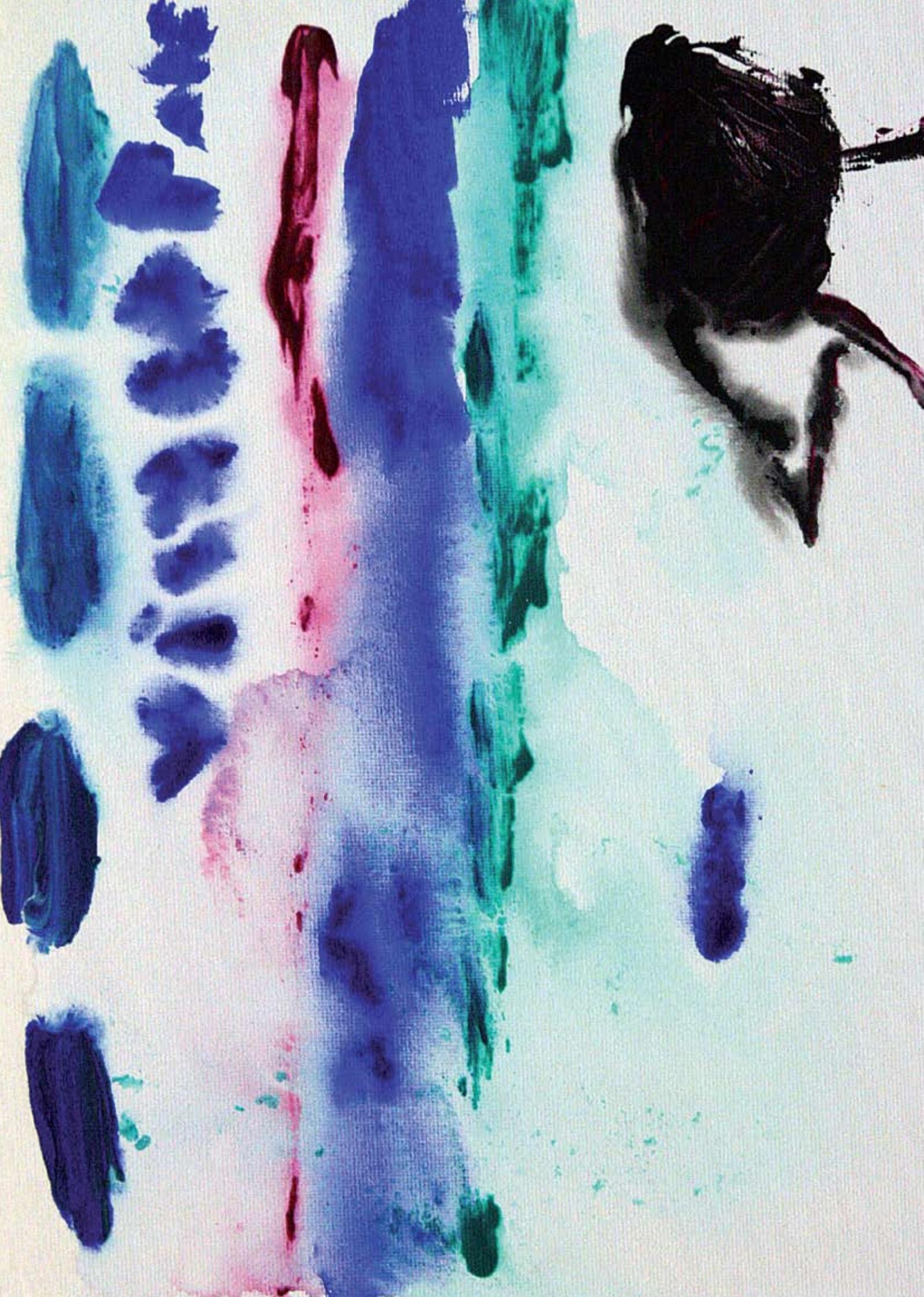
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Understanding the complex interaction between physical health, mental health and behavioural disturbances

This chapter briefly describes some of the issues of the interfaces between physical health, mental health and behavioural problems in people with learning disabilities.

Physical health

People with learning disabilities often have undiagnosed physical health problems e.g. thyroid dysfunction, infections, gastro-oesophageal reflux, symptoms of pain or discomfort, which can lead to behavioural disturbances or mood problems. The side effects of some medications can also cause mental health problems, e.g. beta-blockers causing depression and some anti-convulsants or anti depressants causing hypomania.

A holistic assessment of mental health and behavioural problems includes the consideration of physical health needs as an integral part. Routine health investigations in mental health practice are designed to look at both physical and mental health perspectives. Investigations commonly considered are MRI, EEG, chromosomal studies or genetic screening. As well as providing a health baseline assessment and assisting with diagnosis, results may also help explain certain behaviours (for example, frontal lobe damage is associated with violence, disengagement and disinhibition) or identify a condition with a behavioural phenotype (a behaviour associated with a particular genetic syndrome), such as Prader-Willi Syndrome, which is associated with excessive eating, or Lesch Nyhan Syndrome associated with self injurious behaviours.

Within primary care and general psychiatry settings, people with mental health problems may present initially with physical complaints that mask the disorder or underlying problems. This is not only in areas such as depression and anxiety, but other less common diagnoses e.g. personality disorders. Often those who have identifiable conditions will present atypically in some way. Physical symptoms can also mask the underlying mental health problem. They may manifest in behavioural problems; eg. someone who wants to avoid situations because they are anxious may become aggressive and hit out. Diagnosis is often made difficult due to poor communication or if the person is unable to explain their symptoms or label their mood. These behavioural symptoms can at times act as a marker for monitoring the effectiveness of treatment interventions.

Behavioural problems

These are often referred to as challenging behaviour especially if they are risky or difficult to manage. The cause of challenging behaviours is varied and includes mental illness, brain injury, organic conditions, physical health problems, environmental issues, communication difficulties or any combination of these. Understanding these factors and how they relate to one another will have implications for treatment. This is understood differently within different settings, but the challenge is to understand the persons' behaviour and the context in which it occurs. Perhaps the most common behaviours are aggression and self-harm; certainly they are the most common cause of presentation to psychiatric services. Challenging behaviour is more commonly associated with people with higher support needs, as causative and maintaining factors. There are many reasons why challenging behaviour occurs in individuals including, for example, poor environmental stimulation or too much environmental stimulation, in response to pain or distress (whether physical or mental) or as a communication strategy. In clinical practice it is often difficult to know immediately the reasons why a person may exhibit challenging behaviour. A physical health assessment to rule out common disorders and infections is an important first step. Psychological methods are often employed to see what precipitates, predisposes and perpetuates the behaviour with the aim of intervening at key points and rewarding prosocial behaviour.

CONSIDERATIONS DURING ASSESSMENT

Diagnostic and/or behaviour overshadowing

This is where presenting problems are put down to the person's learning disabilities and as a result an underlying cause may be missed. Examples include a person becoming aggressive due to pain but carers thinking that it is just a behaviour disorder or someone withdrawing from activities being labelled as "attention seeking" even where there may be other reasons for the behaviour eg. stress if moving placements, a person's day centre closing, finishing college, bereavements etc. The lack of awareness within society means that people often have little understanding of the importance of such events on the individual or have outdated ideas that this group have no or little feelings. Such attitudes often mean treatment will not be sought or considered. Within general psychiatry, many health professionals still feel poorly equipped to deal with individuals with learning disabilities and will dismiss problems as behavioural and not consider mental illness as a possible cause or contributor to the presenting behaviours.

Cognitive impairment

This can affect the presentation and reporting of symptoms and mean that major symptoms can be missed. A good example is delusional beliefs; delusions may present differently in that they may not be as complex and intricate as those often found in a general psychiatric presentation. This is often because of the persons' poverty of experiences compared to others in the wider society.

Communication

People may have problems comprehending and processing information. Sometimes enquiry is compromised as too many questions are asked at once. Poor communication may also be due to other factors e.g. poor sight and/or hearing. When communicating, it is useful to use short sentences and repeat what you have said often, to ensure the person has understood. It can be useful to check their understanding.

Biological markers

Often people will be poor reporters of biological symptoms such as changes in sleep pattern, or changes in appetite, sometimes because the individual may not even appreciate that there is a problem. Often these biological indicators can be missed. To monitor these areas measures such as sleep and weight charts are important to show problems or even to support a diagnosis, as they are observable over time.

Psychosocial masking

Determining symptoms can be hampered by poor and limited communication often found in those who are more dependent. Symptom presentation can often be bland in comparison to those presenting from the general population because of the persons' poverty of life experiences

CONSIDERATIONS DURING TREATMENT

Behavioural management

Detailed recording of behaviour and what precedes it is vitally important, as are the consequences the behaviour has for the individual and the function it plays. Central to an intervention plan is a consistent approach and manipulating and setting the environmental and communicative conditions. These can be difficult to achieve and often require a lot of staff/carer training and ongoing support.

Medication

Knowledge and experience of administration of treatment in this group is essential because of issues such as increased susceptibility to side effects and increased sensitivity to low doses of psychotropic drugs. Medication is used primarily to treat an identified or suspected underlying physical or mental illness that may be causing or contributing to the behavioural presentation. If this is absent, it is wise to delay starting psychotropic medications wherever possible so that a period of detailed assessment and observation can be conducted. This will assist with longer term management and prognosis of the individual. In cases of severe behavioural problems, where there are significant risks to the individual or others, medication may have a role to play. The doctor should always be aware why they are intending to prescribe medication, what the treatment goal is and how effectiveness of treatment might be measured. It is also important to consider and document capacity to consent to treatment.

Team working

The doctor often works as part of a multi-professional team. In specialist mental health learning disability services, the assessment and subsequent treatment plan, particularly for complex clinical presentations, is often carried out and developed from a team approach.

Below are two vignettes to consider in looking at the role of physical health and mental and behavioural disorders. Following these are tables of what to consider and how a treatment plan might be developed.

Vignette 1

Jo is a 23-year-old girl with severe intellectual disability and Prader Willi syndrome, who has been admitted to hospital for recent violent outbursts and oppositional behaviour.

Problems	Considerations possible causes	Assessment	Outcome	Plan
Violence Oppositional Behaviour	<ul style="list-style-type: none">• What is the context?• Is this normal in relation to food limiting?• Peer pressure• Irritability, behaviour associated with depression or anxiety• Change in circumstances• Rebellion	<ul style="list-style-type: none">• ABC (antecedents, behaviour and consequences) charts• Sleep charts and weight charts to look at physiological signs of depression• Look at recent events and reactions	<ul style="list-style-type: none">• Does not appear related to food• Sleep charts suggest early morning waking• Weight has decreased• Behaviours seem to occur when people do not do what she says at the day centre	<ul style="list-style-type: none">• Working diagnosis of an affective (mood) disorder• Consider medication• Consider specific psychological work• Consider environmental adaptation and training of day centre staff

Vignette 2

Mike is a 40-year-old man with Down syndrome. He has a history of depression, epilepsy and post-natal cerebral palsy. He is recently become increasingly confused and is spending long periods in bed. He is refusing food and staff are finding it difficult to engage him as he spits when they approach him. The table below outlines some of the considerations of the assessment.

Problems	Considerations possible causes	Assessment
Confusion	<ul style="list-style-type: none"> • How long has this been going on • Have there been changes in medication or increased doses • Early signs of dementia (increased risk in Downs Syndrome) 	<p>Assess for the following</p> <ul style="list-style-type: none"> • Delirium • Dementia • Specific neuro-psychiatric syndromes, including stroke and head injury • Mood disorder • Initially need to complete full history, mental state examination and physical examination • (Note that the Mini Mental State Examination will have little value due to his lifelong global intellectual impairment) • Assessment needs to rule out the following: <ul style="list-style-type: none"> ◦ Infection ◦ Metabolic disturbances ◦ Intra-cranial pathology ◦ Drug or alcohol withdrawal ◦ Medication side effects

Final thoughts

If you think that working with this group of people is for you, consider the following questions:

- Can you listen to other professionals, value what they have said but not give in to emotion, especially in difficult situations? People will over react but these are the times when a strategy is most important. This is particularly important in difficult to manage situations e.g. aggressive outbursts where the knee jerk reaction may be to keep increasing or adding medications
- Can you take time to remember the person you're treating, their preferences, and what supports they need to ensure recovery and well being and not to assume others are doing it?
- Can you work with outsiders by embracing advocacy and seeking second opinions as part of good clinical practice?
- Do you enjoy complexity?
- Do you enjoy gathering and piecing together bits of information to eventually form a hypothesis which you might test out in the treatment plan?

This career path might just be for you!

Reference

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Genetics and learning disability

This article is a brief introduction to some of the genetic syndromes associated with learning disabilities and a summary of why an understanding of genetic syndromes can be important in clinical practice.

It should be noted that in as many as 40% of people with learning disabilities, the underlying aetiology remains unknown. However, with improved technology and understanding this figure is gradually reducing. Both environmental and genetic causes lead to learning disabilities and they frequently coexist in an individual.

For many parents it is perplexing to be faced with a child suffering from learning disability. It can be reassuring to know that certain features of behaviour or clinical presentation are characteristic of the disorder; to know that they are not the only ones facing the daily challenges they encounter and to have some understanding of what to expect in the future.

From a purely scientific perspective, understanding genes and their relationship with learning disabilities, mental illness and behaviours may help us to understand the biology of specific human behaviour patterns. This may in time lead to the development of novel therapeutic possibilities.

Clinical presentations and behaviours are unlikely to be unique to a single genetic disorder. Similarly behaviours and clinical presentations are unlikely to be found in all instances of a particular disorder. Despite this, knowledge of the association between genetic disorders with peculiar conditions and behaviours is of prime importance. It helps clinicians to understand, diagnose and formulate patients' problems, develop care plans and make prognostic evaluations.

Behavioural measures such as hyperactivity, self injury, impulsiveness, clumsiness or personality characteristics like aloofness and anxiousness have low specificity and are seen in many genetic disorders. Aberrant behaviours like self injury are common in certain diagnoses also resulting in learning disability, such as Lesch-Nyhan syndrome or Smith-Magenis syndrome but could also indicate pain or discomfort. Head banging is quite a common presentation of dental pain, headache, ear infections, sinusitis or gastrointestinal reflux. The latter commonly occurs in Cornelia de Lange syndrome. Some conditions may present with distinct behaviours, making their identification easier eg. hyperphagia associated with Prader-Willi syndrome.

Anxiety, mood disorders and autism are a few examples of the psychiatric disorders frequently seen in genetic conditions that result in learning disability. Autism is most commonly seen in Fragile X syndrome and Tuberous Sclerosis. The co-occurrence of psychiatric disorders in those with genetic causes of learning disability has helped direct research towards genetic components of psychiatric conditions.

Genetic disorders are often associated with differences in physical appearance, such as short stature/accelerated growth, facial dysmorphism or delayed sexual development. Affected individuals can suffer from low self-esteem and this often precipitates secondary psychological or behavioural difficulties.

Severity in extent or frequency of aberrant behaviours such as self-injury could result in extreme distress for both affected individuals and their carers. Practitioners should offer support to both parties. Reassurance and support should also be offered to family members and carers, as they often perceive themselves to be the sole or contributing reason for the individual's behaviour.

Certain medical conditions are more common in people with learning disabilities. Their identification can be more difficult than in the general population due to atypical presentations, difficulties in communication and difficulties accessing health services. A good understanding of genetic conditions and their associated medical complications, along with their varied presentations will aid the diagnostic process. Early investigation or screening may help to prevent conditions presenting late or with secondary complications. For example, people with Down syndrome are more prone to develop hypothyroidism. If left unattended, this may result in medical complications as well as associated low mood.

Anatomical or physiological abnormalities of the cardiovascular system contribute towards the increased morbidity and mortality associated with a number of genetic syndromes with associated learning disabilities. Congenital heart defects are common and affect individuals with Fragile-X, Down syndrome and Rubenstein-Taybi syndrome. Also, secondary complications such as hypertension may occur in Williams and Turner syndromes.

Obesity is frequently associated with genetic causes of learning disabilities and can lead to serious and long term medical problems, like non-insulin-dependent diabetes mellitus, hypertension and cardiovascular disease. In Prader-Willi syndrome, the propensity for obesity is one of the cardinal features, and is potentially life threatening. Dietary intervention at an early stage can help counteract and minimise secondary medical complications. Intervention techniques such as limiting calorific intake are effective. Behavioural modification strategies with emphasis on self-monitoring and reinforcement, in combination with exercise programmes, can be effective in maintaining a healthy weight.

Epilepsy is commonly seen in people with learning disability and its presentation varies in various conditions. For example, in Rett syndrome seizure frequency reduces with age. In a number of syndromes, the presentation of epilepsy can act as a diagnostic marker, e.g. children with Aicardi and Angelman syndromes have diagnostically distinctive EEG patterns.

Epilepsy can also be an underlying cause of mental ill-health or behavioural disturbance in individuals with learning disabilities. Clinicians should consider offering screening for epilepsy particularly in the presence of deteriorating adaptive functioning.

In certain conditions our understanding of the disorder has led to the prevention of progressive decline and the prevention of learning disabilities developing. Examples include phenylketonuria and galactosaemia where dietary management can prevent medical deterioration eg. eliminating phenylalanine and lactose respectively. Clinicians should be aware of the nutritional implications of dietary restrictions and ensure that essential nutrients are substituted with supplements. This can prevent secondary complications such as osteoporosis.

With recent advances in diagnostic and intervention techniques, people with learning disabilities are living longer. It is therefore important that clinicians are able to anticipate future medical complications. The presentation of some of the key features of certain syndromes can change with age and so can the physical appearance, most notably coarsening of facial features occurs with age in Coffin-Lowry syndrome where as café'-au-lait spots of neurofibromatosis type I decrease after middle age.

Clinicians must offer information to the carers and family about the course of the syndrome, including knowledge of anticipated changes. The observations of those closest to the individual are valuable in alerting practitioners to any physical and behavioural changes. In a number of syndromes, such as Cornelia de Lange, early intervention and management of complications like cardiac anomalies, metabolic disorders or morbid obesity can significantly extend longevity. Severity of phenotypic expression can also determine mortality and morbidity.

The diagnosis of genetic conditions requires technical skills and specialist knowledge and expertise. A genetic diagnosis not only has an impact on the individual but also on the wider family. There can be consent issues in people with learning disabilities and, when a diagnosis is made, issues relating to confidentiality. All doctors should be familiar with these issues and understand when and how to refer people to genetic investigation / counselling services.

Conclusion

Advances in the clinical understanding of genetic conditions associated with learning disabilities and the mechanisms that determine the syndrome have resulted in improved quality of life and longer life expectancy for individuals with these conditions. Clinicians should be aware of the association between genetic conditions and mental and physical ill-health. This can allow targeted screening and monitoring for the development of associated conditions. Clinicians should also be aware that both the physical and behavioural profile of many syndromes changes with age, and should be prepared for this.

Further reading

<http://www.geneticseducation.nhs.uk/>



Forensic issues in the psychiatry of learning disability

Some people with learning disabilities engage in antisocial behaviour, defined as behaviour that violates the rights or safety of others.

Some of this antisocial behaviour is of a type or severity to result in conviction when brought before a court of law (Harding, Deeley & Robertson, 2009). Studies suggest that there is an association between learning disabilities (LD) and offending behaviour, with higher rates of offending in mild LD populations and less offending in populations of moderate and severe LD. However, it is difficult to know the true prevalence of offending amongst people with LD for several reasons. For example, rates of conviction may be artificially lowered amongst people with LD because they may not be considered responsible for their actions, and so be judged to lack the necessary mens rea (or the intent to commit harm) to justify conviction. Sometimes prosecution is dropped because the person is already detained in hospital under a civil section (eg. section 3), and their lawyers argue that they are already deprived of liberty and receiving treatment – so conviction makes no difference. Further, in institutional settings staff have historically been reluctant to contact the police to report offending behaviour, although these attitudes are changing, and in recent years staff have been encouraged to report offences whether patients have LD or not. Conversely, some factors may serve to increase the likelihood of offending and conviction in people with LD – for example, poverty and social deprivation increase risk of offending and are independently associated with LD. Also, people with LD may be less effective at evading arrest.

With these provisos in mind, epidemiological studies have reported that most recorded crimes in people with LD are acquisitive crimes such as shoplifting. However, though they are less common, more serious offences are committed by people with LD, including violent crime, arson and sexual offences. In general, offenders with LD are more likely to be convicted of arson or sexual offences compared to offenders with an average IQ. Very few people with severe LD are found within the criminal justice system

A 23 year old man with a mild learning disability, ADHD, autism, and an antisocial personality disorder (ASPD) was detained under section 3 on a specialist low secure inpatient unit after the breakdown of a community placement following an assault on care home staff. As an inpatient he frequently assaulted nurses but not other members of the multi-disciplinary team (MDT), and at times was even observed to be helpful towards some of his fellow patients. After assessment we concluded that his assaultive behaviour was likely to be influenced by: a) poor impulse control associated with ADHD; b) problems with perspective taking (seeing the point of view of others) associated with autism and learning disability, particularly under conditions of frustration; c) rigid expectations of others (eg. that nursing staff should meet his demands or needs), justifying aggression against them when he perceived his needs as not being met; d) a limited capacity to feel empathy for people whom he believes have 'wronged' him (rigid cognitions associated with autism); e) a strongly externalizing attributional style, believing others are responsible for whatever problems he displays (in keeping with his diagnosis of ASPD, reinforced by the cognitive rigidity that goes with his autism). This formulation allowed the MDT to design a suite of interventions to reduce his risk of aggression, including optimizing his ADHD medication; introducing antipsychotic medication to reduce the anxiety and irritability associated with his ASD; cognitive behavioural work to address his inflexible beliefs about nurses (including explaining their role); and designing behavioural care plans to help the nurses avoid 'flashpoints' that triggered aggression. He continues to have complex needs and will require long term support – but there has been a very significant reduction in his assaultive behaviour that starts to make it possible for him to move on.

Nevertheless, it remains the case that much 'forensic' or offending behaviour in people with LD does not result in convictions. Even in a low secure service for people with LD and mental disorders many patients will be detained under civil sections of the Mental Health Act (like section 3) for 'challenging behaviour', rather than forensic sections (such as section 37). This is not always to the patient's advantage, because a forensic section acts as a marker of risk in a way that a section 3 often does not, and can help to win the argument for higher levels of specialist support when the time comes (as it almost always does) to leave hospital and be discharged into the community. It should also be borne in mind that the victims of offences may want 'justice to be done' – even in cases where the perpetrator has a learning disability. Some forensic sections include a restriction order which means that the ministry of justice is involved in decisions about discharge and leave. This is imposed to reflect the seriousness of the offence and is designed to protect the public.

What makes working with learning disabled offenders so interesting and rewarding? Part of the answer lies in complexity: offenders with learning disability require careful assessment and formulation of the influences on their offending behaviour. Diagnostic co-morbidity, with multiple influences on risk of offending, is common. Formulating the contribution of different individual and contextual factors to risk of offending is essential as a basis for designing interventions (see box).

Understanding complexity allows us to help people, sometimes in ways that transform lives. This is particularly the case when co-morbid mental illness is effectively treated. One patient with a 'borderline' learning disability (on the lower end of the normal IQ range) and autism was detained in hospital for over 10 years because of 'challenging behaviour'. This included very risky impulsive aggression when frustrated (such as throwing anything that came to hand at people). His family was strongly opposed to medication because they believed that when given in previous settings (such as psychiatric intensive care) it hadn't worked and caused side effects. After a thorough medication review and time spent explaining the rationale for a careful trial of medication, aripiprazole was started (given increasing evidence of its effectiveness in reducing irritability in people with ASD). The patient's reckless, impulsive aggression virtually disappeared and he was able to visit the family home and go out with his mother for lunch for the first time in years. Yet he didn't feel better. His inability to describe his feelings (alexithymia – common in autism and compounded by his 'borderline' IQ) was such that it was difficult to work out if his disease was more akin to depression, generalized anxiety disorder, or some combination of the two. He was treated for depression in a careful trial of medication and after some weeks felt better. The change in his wellbeing was obvious to the eye, as he lost the tense and preoccupied expression that he had worn for years. After over a decade in locked wards, there is now a real prospect of him 'stepping down' to an open rehabilitation ward.

Often, risk reduction depends less on medication and more on changing a person's environment and support systems. One patient with a mild learning disability and autism longs to be more independent – but when he thinks about this his anxiety becomes unbearable, he starts to act on unrealistic plans and can behave extremely recklessly. His response to a whole range of anxiolytic medications has been limited. What has helped him the most is being surrounded by people who know what to say to him to 'de-escalate' him. When he starts to ruminate and lose control those around him 'become' his executive function, reminding him of important information that helps him to avoid destructive behaviour (just as someone else might 'talk themselves down' to avoid expressing anger and become calm). Transferring this method of support to new settings will be a key component of attempts to help him to become more independent. In this patient's case, as in forensic psychiatry more generally, risk reduction will be achieved with high levels of supervision, structure, and support and graduated transitions between services.

All of the above shows the importance of team working in learning disability, because no one professional carries all of the relevant knowledge and skills to assess, treat, and rehabilitate the complex individuals who come under our care. Yet the psychiatrist has a key leadership role in the MDT, because as Responsible Clinician (RC) the consultant psychiatrist has overall responsibility for the patient's care. Indeed, in a Mental Health Act review tribunal (when the detention of the patient under the Mental Health Act is scrutinized by an independent panel usually comprising a judge, a doctor, and a lay person), the consultant may find themselves spending more time explaining the provision of psychological, occupational therapy and nursing care of the detained patient than pharmacological management. The RC is indeed responsible and answerable in law, and the RC's leadership role in the MDT reflects that fact.

Part of the interest of forensic learning disability stems from the unprecedented rate of important new discoveries about what causes relevant disorders – not just learning disabilities, but associated problems of autism, personality disorder, psychosis, and other mental disorders (Deeley & Murphy, 2009; Sarkar, Clark & Deeley, 2011). Advances in genetics and neuroimaging, for example, have put us on the threshold of developing diagnostic tests for autism and other common mental disorders (Ecker, Marquand, Mourao-Miranda, et al, 2010). Yet as impressive and indeed potentially clinically relevant these advances are, there are powerful competing currents in ways of thinking about patients which mean that we are unlikely to forget that they are people, rather than 'just' biological systems with a penumbra of symptoms. For example, the Mental Capacity Act forms the legislative basis for a cultural shift in always presuming that our patients have capacity to make informed decisions about their care; and to formally consider their 'best interests' if a patient is deemed to lack capacity with respect to a given decision. 'Capacity' is a property of persons as agents, not brains (whatever the biological underpinnings that make the exercise of these competences possible).

Psychiatrists in forensic learning disability also find themselves in the midst of a revolution in health care provision. In the early 1990s John Major's government introduced the 'purchaser-provider' split, meaning that the purchaser of health care (such as primary care trusts) could choose which service provider to purchase care from. This has led to private health care providers and NHS foundation trusts competing to provide care for patients with chronic, high cost disorders, such as those found in secure services. Like the Red Queen in Alice in Wonderland, secure services now have to run in order to stay still. This has a number of important implications. For example, the psychiatrist as an expert in their field, may find themselves working closely with managers to identify how to adapt services to this new situation. This quasi-entrepreneurial role was largely foreign to psychiatrists as recently as a decade ago. This creates opportunities for medical management roles that were probably narrower in scope before the emergence of this more fluid environment. Equally, external regulatory agencies and processes (such as Mental Health Review tribunals and the Care Quality Commission) are more important than ever to ensure the robust protection of patient rights and care provision, given the temptation of less scrupulous services to inflate claims about what can be provided or achieved to win contracts. But you, as a psychiatrist, are also more important than ever to ensure that your patient comes first, and is your true 'customer'.

Key points

In forensic learning disability services:

- detailed symptom and trait description forms the basis for formulation and targeted interventions
- co-morbidity and atypical presentations of common disorders due to learning disability are common
- treatment of co-morbid mental illness can produce dramatic reductions in risk
- risk reduction is achieved via high levels of supervision, structure, and support; with graduated transitions between services

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Life as a higher trainee in the psychiatry of learning disabilities

Medicine is a career that offers many diverse fields and challenges. I have worked in many areas of medicine but none more remarkable than psychiatry and in particular the psychiatry of learning disabilities.

Working in this speciality has been the most challenging but the most rewarding job I have ever done.

Working with people with learning disabilities is fascinating because of how each individual's level of learning disability, social circumstances, physical and mental health issues can affect how that person presents when you meet them. There are no 'typical' patients in this group! For me this is why the jobs I have done in this field have been so interesting and appealing.

My current post as a higher trainee offers me an appealing mix of clinical work and allows me pursue my special interests too. My typical week at work starts with a referrals meeting which involves sitting down with members of the wider community learning disabilities team to discuss the referrals that we have received. These meetings and the cases we discuss have taught me that different professionals use a variety of approaches to tackle complex cases.

The team I work with also look after patients on an inpatient unit which offers its own challenges. Working to help patients with mental health problems who often have challenging behaviour isn't always easy but is always interesting. I have found that working as part of a team and thinking innovatively to help deal with the issues troubling our patients is stimulating and rewarding when we can make a positive difference for them.

During my week I also visit our patients who are in the local general hospital. Often this involves assisting medical and nursing teams to care for our patients effectively as well as supporting family members of those patients. I often find that I am advocating on behalf of my patients and their families with the medical and nursing teams. People with learning disabilities are amongst the most vulnerable people in our society and helping my patients access appropriate healthcare and services is very important.

Outpatient clinics are varied and always engaging. Working with people with learning disabilities has enhanced my communication and observational skills. I learnt quickly that speaking is not the only way my patients communicate with me. Gestures, grunts, smiles, pictures and most memorably for me, having a patient walk around in my size 4 shoes with his size 10 feet to show me that he trusted me, has demonstrated to me that my patients all have meaningful things to communicate. Showing patients, no matter how disabled they are, that they are the focus of consultations is crucial. I see a lady with severe learning disabilities in clinic, who vocalises and responds to touch. Over the course of our appointments she has become more relaxed and trusting enough for me to hold her hand when I introduce myself. Even those patients who find social interaction difficult, such as people with autism spectrum disorders, can demonstrate how building up a trusting therapeutic relationship can be achieved. I review a patient with severe autism in clinic, who did not look at me for the first 6 months I saw him. I found out that he liked to draw so for his next appointment I left paper and pens for him to draw with while I spoke to his carer. When he left that appointment, he briefly looked at me and said 'bye'. Although this might appear to be a small gesture to others, I understood how significant this was for him. Listening to patients and their carers to help understand their problems and together find the best way forward is a highlight of my job.

I also visit patients in their family homes, residential homes and schools. I find that seeing patients as part of a family and community has taught me to treat them in a more holistic manner because I am more aware of the challenges they face and roles they play.

Being a higher trainee also means having the time protected to look beyond my own clinical work at opportunities to conduct research and pursue special interests. There are many opportunities for research which higher trainees can have access to, both formally through doing postgraduate courses or informally by joining clinicians and academics in ongoing projects or developing new projects. Research in the psychiatry of learning disabilities brings up issues around people having capacity to give their consent to be involved. I feel this raises challenges about how to conduct research in an ethical and humane manner. I am currently completing online courses in psychopharmacology and learning to be a Deprivation of Liberty Safeguards assessor as well as attending specialist epilepsy clinics. I will also be starting an MSc in transcultural psychiatry in the near future.

One of the aspects I really enjoy about being a higher trainee is teaching junior doctors and medical students. When I was in medical school I noticed that certain clinicians were able to stimulate my interest in their subjects by the style of their teaching. I now enjoy the challenge of attempting to stimulate interest in those that I teach and of trying to help them to think about the issues for themselves. I have taught medical students at all stages of their careers, from 2nd year students about the place of medicine in society to final year students about communication skills. I am also involved with the local postgraduate teaching programme which means giving case presentations to colleagues and teaching junior doctors about various topics important to the psychiatry of learning disabilities.

Ultimately being a higher trainee means that I am aiming to one day become a consultant psychiatrist. One of the many skills that are needed to fulfil this role is leadership skills which is something I have found that I am acquiring as my training progresses. I have led ward rounds on the inpatient unit when my consultant has been away and supervised junior doctors in clinic and during their on call duties. Although initially daunting, I have found with the support and feedback of senior colleagues and nursing staff, I am growing in confidence in this aspect of my job.

I enjoy my job and the challenges it brings. My patients are fascinating individuals with a range of problems and issues. Being part of a team that helps empower them and tackle some of those problems is a real reward.

How many people are privileged enough to work with people, their families and their carers who inspire every single day with their determination, their strength, their humour and their kindness in the face of considerable challenges?

I am lucky enough to be someone who does.

Further reading

See the careers section and the training section on www.rcpsych.ac.uk for more information about training in psychiatry and the psychiatry of learning disabilities



Working as a consultant in the psychiatry of learning disabilities: challenges and opportunities

Working as a consultant in whatever specialty is challenging: the transition from a senior trainee to a consultant is a very substantial one.

Suddenly you are where the buck stops; your responsibilities extend beyond your own clinical practice; there are multi-disciplinary and multi-agency responsibilities, operational and strategic issues, local politics, supervision and educational responsibilities and the expectation that you are not only competent but an expert in your field, able and expected to work independently and to show clinical leadership (RCPsych 2010).

For me, I had the pleasure of returning as a consultant to my own medical school where some of the great doyens of psychiatry were still in the department; professors I had worked with as a medical student. I still remember their ward rounds, the patients I saw in their clinics and the long cases I presented to them. But I also remember my first exposure to the psychiatry of learning disabilities as a 4th year medical student. In those days learning disability was known as 'mental handicap', and more often than not families with an affected member were encouraged to leave them in the care of large 'mental handicap' hospitals. We had a full day visit to one such institution which has since closed down. Apart from touring the premises, visiting wards and the adult training centre, patients with chromosomal and genetic syndromes in particular, were paraded in front of us, their stories shared in detail and without any regard to consent. This was one of the first things I changed when I became a consultant: how this specialty was taught to students. I involved patients, parents and carers to speak about their experiences: how they were told of the diagnosis; what it meant to them; how it affected their everyday lives. Communication skills and breaking bad news were introduced earlier in the medical curriculum. Home visits with community nurses, social workers or other

members of the clinical teams were arranged; focussed visits to day centres, hospitals or special schools followed, and special study modules were introduced. This was the start of my interest in training and education; since then I have had the good fortune to not only supervise and mentor students, trainees and consultant colleagues but also to be part of national and international initiatives through visits to and lectures at other universities, a range of Deanery appointments and responsibilities, the Royal Society of Medicine and for 8 years being on the Board of Examiners for the Royal College of Psychiatrists, examining twice a year for the written and clinical Membership examinations. However, the most satisfying aspect for me is watching young doctors develop into excellent clinicians, educators and researchers and seeing them become leaders in their field. I am reminded of the Hippocratic Oath – the first being to share and teach the art of medicine.

In this climate of scientific evidence and randomised controlled trials, it is important to remember that whilst there is a scientific basis, the practice of psychiatry (and medicine) is also an art. To understand why someone with learning disabilities is presenting with a mental health problem at a particular time, requires the ability to pull together bio-psycho-social aspects of their history within the context of their personal, developmental and life experiences, to understand the human condition and the interplay between many facets, and to come up with a formulation that can then lead to investigations and interventions that can be measured and evaluated (O'Hara, 2007). This is one of the biggest challenges for this specialty: to show positive outcomes as a result of the individual's contact with services; outcomes that will ensure commissioners of healthcare in the future purchase the specialist mental health services we provide.

My training was broad and flexible, a situation that no longer exists post-MMC (Modernising Medical Careers). I was able to work in general and renal medicine, general surgery and accident and emergency medicine at district general hospitals and a regional trauma unit. I started in psychiatry as a GP trainee, but soon applied to join the psychiatric training rotation. My senior registrar years (now ST4-6) involved hospital and community placements, genetics, child psychiatry and child development clinics, autism assessment centres, paediatric neurology, family therapy and psychotherapy at the Tavistock Clinic. The clinical experience I had was immeasurable and formative and I had the good fortune of working with some excellent nurses, clinical psychologists and therapists (see box 1).

Box 1

I worked with a woman with moderate learning disabilities, Down Syndrome and an eating disorder. There were very complicated family dynamics and she required admission into hospital under the Mental Health Act. I worked with her as an inpatient and in the community and saw her through many life transitions. My most striking memory of her was when she came into my room one day wearing a t-shirt that read 'hug me'. She spoke then about her pain of knowing that there were antenatal tests available to prevent her birth, and that society routinely screened for this and offered terminations of pregnancy. She responded best to psychoanalytically informed music therapy (Heal and O'Hara, 1993).

My exposure to the case illustrated in Box 2 developed my interest in the significant vulnerability issues people with learning disabilities often face and led to my involvement with national bodies such as the Healthcare Commission and the Disability Rights Commission, intent on improving standards of healthcare for this marginalised group.

Box 2

As a senior registrar I was called to the ward of a large 'mental handicap' hospital to see a woman with severe learning disabilities, who was non-verbal, doubly incontinent, assaultative, refusing to let staff attend to her personal hygiene and pulling out clumps of her hair. Her behaviour was put down to her distress over missed contact with a family member. However, when I examined her she was 24 weeks pregnant, a condition that had been missed. There were many ethical dilemmas and legal ramifications to work through, and we did this in a multi-disciplinary, coordinated way not only within our hospital, but with the police, social services, the midwife and obstetrician. We worked with her through her pregnancy, prepared her for her child's adoption and worked with her in the years that followed.

Whilst I look back on my psychiatric training with a real sense of humility and personal growth, I am also disappointed by the attitudes of my seniors when I showed an interest in management. I remember one consultant warning me, 'remember who will be writing your references'. There was a real divide between senior clinicians and managers; a deep mistrust and each seemed to speak a different language. As a trainee I asked to be involved in the development of policies and protocols, to observe and take part in management meetings and spent time shadowing the chief executive.

Soon after taking up my first consultant post, I was appointed as head of service – a formal management role in which I was fully accountable for the service and its delivery. This was 1992, before general management really came into the NHS. I had almost 100 full time staff, £1.8 million, a large multi-disciplinary community team, community homes, some specialist community-based services and a respite unit. There was an operations manager, a senior nurse manager, a consultant clinical psychologist, and sessions from a management advisor and finance advisor to support the role. I was meeting with health commissioners on a quarterly basis, and involved in every aspect of the service. During this time I had the satisfaction of successfully transforming the service from a generic social care model into a specialist needs-led healthcare model, delivering integrated specialist health and social care through coordinated care pathways. I worked with the local community to understand the needs and ethnic diversity of its population; liaised with public health, local special needs schools, GPs, adult mental health colleagues and employed people with learning disabilities on our staff (as Makaton peer tutors and as admin support). However, it was not all as easy as it seems. From the first day as head of service, I became aware of poor practice in one area of the service; it led to police investigations, suspensions and dismissal of staff, the closure of the unit and the eventual re-opening of a new service following negative media publicity and many stakeholder consultation events. It was one of the most challenging experiences of my career, and a very steep learning curve. Despite the trauma of this experience, I also realised that poor practice had been going on for years but no one had done anything about it and that such practice can happen right under your nose. I have seen the same happen in services run by very reputable providers; it is incumbent on us all to act on our concerns.

Psychiatry of learning disabilities has a lot to offer as a career. There are many interfaces between physical health medicine, genetics, neuro-imaging and psychiatry; between children and family services, between social services, third sector providers and the NHS, between special schools, hospitals and secure units; and between doctors, other clinicians, commissioners and managers. There are complex dynamics within the family and their socio-cultural environment; families who often remain carers for their adult learning disabled child or within networks of paid carers and staff teams, as well as issues of stigma, discrimination and vulnerability. Career opportunities might lead to further specialisation into forensic aspects of the challenging needs spectrum, or to the science and biology of autistic spectrum disorder and adult ADHD, to an academic portfolio of research or education, or to work in the private sector, currently the largest provider of secure hospital services for this group.

You will have gathered by now that the role of the consultant is far more than just providing a good clinical service. Good time management is essential; learning how to delegate (but with delegation comes the responsibility of supervision); managing your own anxiety and those around you; dealing with uncertainty, managing risk; working in a collaborative multi-disciplinary way; providing clinical leadership and making decisions when it is appropriate to do so. Personal responsibility also means a life time of professional and personal development and learning. I have learnt an awful lot from my patients, many of whom have such courage and emotional intelligence; from my trainees who keep me up to date with the science and biology of the subject; from other clinicians who bring with them different perspectives to the assessment and management of a mental health problem, and from professional general managers who not only give me support but constantly stimulate and challenge me to develop my clinical leadership skills in an increasingly complex health economy.

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I have been a consultant for almost 20 years now; I have accumulated a wealth of clinical, academic and management experience along the way. I have always thought of myself as a doctor first, a psychiatrist second and a specialist in psychiatry of learning disabilities third. My approach has been very much one of inclusion and integration – bringing the issues people with learning disabilities and mental health problems have into mainstream services, through service design and care pathway provision, clinical governance as well as training and education. Instead of just looking at my own clinical practice, influencing the practice of clinicians working immediately around me and helping individual patients and their families, I am privileged in being able to effect change in a wider sense through my formal management responsibilities and through additional roles on national bodies. As one of the clinical directors in an academic health sciences centre, I have responsibility in partnership with our service director and academic director, to deliver on an integrated model of specialist mental healthcare which puts the patient and the patient experience at the heart of quality care, whilst ensuring that we have the right level of clinical engagement, that our workforce develop the skills and attitudes necessary to deliver care fit for the 21st century, and that our practice is not only evidence-based, but that through research and evaluation we provide the evidence base for the future.

Whilst this is all very exciting and immensely satisfying, I am also a woman, a wife and a mother. I have a professional life and a personal one, and I work hard at both. One of the greatest challenges is trying the balance the two. There have been times when this has not always been possible; I have made positive choices over the years sometimes to the relative detriment of my career (e.g. with a young family I did not accept any engagement that involved spending a night away; I worked part time until the youngest was 7, and that had its own challenges). The demands of work and family life are great, so it is important to also remember yourself in all of this. One of my true pleasures is sitting in front of the piano and playing classical music or show tunes. As a student sitting my 'O' levels I took to listening to favourite songs prior to an exam. I do so to this day – before any potentially stressful event.

**So if you see me singing to myself in my car
as I am driving to work, you will know why!**

Further reading

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Ryan J And Thoman F (1987) The politics of mental handicap. Free Association Books, London.



Neurodevelopmental disorders in literature and film

There follows a non-exhaustive list of books and films that portray neurodevelopmental disorders in various guises.

You might want to consider if the portrayal is accurate from a "medical" perspective, what it says about society's view of people with these disorders and how people with the disorder might feel in being portrayed in this way. Or you might want to just enjoy them!

Books

Animals in Translation by Temple Grandin
Barnaby Rudge by Charles Dickens
Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence by Luke Jackson
Of Mice and Men by John Steinbeck
The Curious Incident of the Dog in the Night-time by Mark Haddon
The Secret Agent by Joseph Conrad
The Sound and the Fury by William Faulkner
To Kill a Mocking Bird by Harper Lee
Such a Long Journey by Rohinton Mistry

Film

As it is in heaven (Kay Pollak) 2005
Girlfriend (Justin Lerner) 2010
I am Sam (Jessie Nelson) 2001
Introducing Dorothy Dandridge (Martha Coolidge) 1999
My name is Khan (Karan Johar) 2010
Praying with Lior (Ilana Trachtman) 2007
Pumpkin (Anthony Abrams and Adam Larson Broder) 2002
Rain Man (Barry Levinson) 1988
What's Eating Gilbert Grape (Lasse Hallstrom) 1993

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Notes

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