



# THE MENTAL MAZE

People with learning disabilities are more prone to experiencing mental ill health than the general population, but many struggle to access the help they need.  
Richard Shrubb reports

**F**or many people with learning disabilities, mental health issues are also a part of life. As the 2010 National Autistic Society (NAS) report *You Need to Know* suggested: "as many as 71% of children with autism have mental health problems, such as anxiety disorders, depression, and obsessive compulsive disorder (OCD), and 40% have two or more."

The NAS report also suggested that 33% of adults with autism have experienced serious mental health problems. Yet adults and children with learning disabilities and/or autism can have a tough time accessing mental health services. Psychiatrists and charities alike complain that mental health services provided to people with such conditions are at best patchy.

Two years earlier, the 2008 Independent Inquiry into Access to Healthcare by People with Learning

Disabilities, chaired by Sir Jonathan Michael – better known as the Michael Inquiry – strongly suggested that training be given to all health professionals in their core curriculum in dealing with people with learning disabilities. But this was never carried out and the result has been a postcode lottery for whether those with learning disabilities access the help they need.

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## Accessing services

For example, when south coast resident Emily (not her real name) who has attention deficit hyperactivity disorder (ADHD) and a number of specific learning difficulties, found it hard to get work due to her disability, she showed symptoms of acute depression and her OCD became problematic to the point her husband found it hard to live with her. Yet Emily's issues were all but ignored by her local mental health services.

Her husband complained several times about her difficulties in accessing services, saying that their marriage was in trouble, but even so the local community mental health team did not intervene. Eventually, unable to cope with the situation, Emily's husband left her and filed for divorce.

Tertiary learning disability services are not uniformly available across the UK, so families sometimes have to travel hundreds of miles to access appropriate

treatment. Emily had to get her unlicensed ADHD medication from her GP because there wasn't a specialist learning disability psychiatrist to prescribe it in the area.

Beverley Dawkins, a specialist advisor at learning disability charity Mencap, says that this is by no means an extreme case. "I know of one family with a child who self-harmed who had to travel 150 miles each way to access appropriate specialist learning disability services," she says.

Mental health services have long been known as a 'Cinderella service' with relatively poor funding compared to physical health, for example. Tom Madders, head of campaigns at the NAS, suggests that such limited access to tertiary learning disability services is down to funding issues: "It is not controversial to say that services as a whole are underfunded."

## Communication issues

But these are not the only problems. Sometimes when people with learning disabilities do access services staff have limited knowledge of the issues they face. Madders adds that this is often because of a lack of understanding of people with autism by their 'neurotypical' peers. "A lack of understanding from other people, including professionals often causes the mental health problems," he says.

As the Michael Inquiry suggested: "Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. They are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same. The health needs, communication problems, and cognitive impairment characteristic of learning disability in particular are poorly understood".

Indeed, while psychiatry primarily relies on verbal communication between professional and service user, many people with learning disabilities and/or autism have difficulty in communicating their issues and this can result in misdiagnosis.

The 2010 NAS report also suggested that many traits associated with autism can be misdiagnosed as independent mental health problems: "Professionals who do not have a good understanding

## there is no substitute for learning disability staff working into psychiatric teams

of autism can misdiagnose children as a result, leading to inappropriate discharge or unsuitable interventions. Without a sound working knowledge of autism, some of the behaviours that are common in children with autism can easily be interpreted as mental health problems."

It went on to show how these issues can manifest. "Autism-related personal obsessions, rituals and routines can lead to false diagnosis of OCD. Peculiarities and fads about what the child is willing to eat can come across as an eating disorder."

Yet, despite the Michael Inquiry's recommendation that all health professionals have training in dealing with people with learning disabilities, Dawkins says that such training isn't routinely given as part of the core curriculum: "Such training is patchy – whether training in learning disabilities is offered is down to training directors," she says.

There is also a paucity of specialists, as Dr Ian Hall, chair of the Faculty of the Psychiatry of Intellectual Disability at the Royal College of Psychiatrists, explains: "There are only 300 learning disability specialist psychiatrists in the UK. The majority of psychiatrists are not trained in this field.

"[Also] community learning disability and community psychiatric nursing is quite separate and there isn't much crossover training."

Autism too is not covered in the core curriculum for doctors, nurses and clinicians, Madders adds: "[Our research suggests that] less than half of parents felt that mental health professionals had adequate understanding of autism."

## Making progress

In response to the issues raised by charities and practitioners, Care and

Support Minister Norman Lamb says of progress since the Michael Inquiry: "We want to provide the best possible care, support and treatment to everyone with mental health problems – including people with learning disabilities. Since 2008, we have established organisations such as Health Education England which have a duty to make sure there is an education and training system fit to supply a skilled and high quality healthcare workforce."

Madders says that it is encouraging that resources are being developed that could help organisations make reasonable adjustments for people with autism, but warned: "If it's to make a difference, the Department of Health must ensure organisations are aware of the toolkit and supported in implementing it."

One key way to address the issue of limited knowledge of learning disabilities is to facilitate partnership working between teams. "There is no substitute for learning disability staff working into psychiatric teams," says Dr Hall. "I see a role in a community learning disability team supporting specialist mental health teams."

Such work can involve showing how someone is communicating their problems, and sometimes showing where a trait that might be considered a mental health issue is actually associated with a learning disability or autism. "If specialists work with non-specialists they can disseminate and share expertise among community mental health teams," suggests Madders.

Such good practice and expertise sharing may well be the answer to patchy learning disability provision in community mental health teams across the UK. For now, those experiencing mental health issues who have learning disabilities or autism often have a tough time in getting they help they need and, if they do, it is frequently down to where they live. ■

Madders T (2010) *You Need to Know*. London: National Autistic Society.

Michael J (2008) *Healthcare for all – report into the independent inquiry into access to healthcare for people with learning disabilities*. London: DH.

## About the author

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