

INFORMATION SHEET



making a difference
to the lives of people with
severe learning disabilities

Health and Challenging Behaviour

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People with a learning disability, just like ourselves, will experience a range of health and medical conditions throughout their lives. In fact, they are more likely to develop health and medical problems than the general population.^{1,2} These include both physical and mental health problems and research shows a higher prevalence in mental health problems such as anxiety disorders and depression.³

There can be a number of reasons for this increased prevalence in people with a learning disability:⁴

- Certain syndromes can be associated with illnesses, e.g. people with Down's syndrome are more susceptible to respiratory infections and heart defects
- Communication difficulties which may make it difficult or impossible to inform others of feelings of ill health, or difficulty in following treatment recommendations
- Inability to complete daily living skills, e.g. personal hygiene tasks which may result in increased susceptibility to infections etc
- Lifestyle factors such as an unhealthy diet, limited exercise and congregate living
- Lack of both knowledge and experience amongst general and medical practitioners.

Unfortunately we can add to the above a lack of willingness amongst some care providers to give equal access to care and treatment for people with a learning disability, thereby denying them their right to a health service that meets their needs.

A document entitled 'Key Highlights of Research Evidence on the Health of People with Learning Disabilities' was produced by the Valuing People Support Team in 2002. Some of this evidence is reproduced below:

Respiratory Disease

Respiratory disease has a much higher incidence in people with a learning disability than with the general population, and is in fact the leading cause of death at 46 - 52%.^{5,6,7} This may be due to feeding, breathing and swallowing difficulties, regurgitation and gastroesophageal reflux, epilepsy, coughing and vomiting.

Coronary Heart Disease

Coronary heart disease is the second most common cause of mortality among people with a learning disability (14-20%).⁶ This is even higher in people with Down's syndrome, who are prone to congenital heart defects.^{8,9}

Cancer

The incidence of death from cancer amongst people with a learning disability is lower than the general population (11.5 -17.5% vs 26%).^{10,11,12} However this is increasing rapidly as people with a learning disability are living longer.

Despite the overall incidence being lower, there are differences in the type of cancer people with a learning disability are more likely to have. Rates of gastrointestinal cancer are 48-58.5% compared to 25% in the general population,^{10,11,12} and the incidence of breast cancer is lower,^{9,13} despite the lower incidence of breast examinations undertaken by women with a learning disability.¹⁴

Sensory Impairments

Around 30% of people with a learning disability experience significant impairment of vision and 40% have difficulties with hearing. These problems are often overlooked or poorly managed.^{15,16,17} Hearing problems may be due to impacted ear wax which can easily be treated.

Epilepsy

There is a marked difference in the prevalence of epilepsy in the general population (1%) compared to people with a learning disability (22%).^{18,19} This figure rises to 30% in people with profound and multiple disabilities. Multiple seizures are common and also often resistant to typical methods of treatment.²⁰

Mental Health

Understanding the importance of predisposing, precipitating and maintaining factors involved in mental health problems in people with a learning disabilities cannot be underestimated in the prevention or the provision of optimum care.²¹ Development of mental health problems can be due to a combination of biological, psychological, developmental and social factors.^{22,23,24}

It has been suggested by Emerson et al (1999)²⁵ that challenging behaviour may be caused or intensified by a coexisting mental health disorder. The findings of Moss (2000)²⁶ shows an increase in the severity of challenging behaviour associated with an increase in the prevalence of mental health symptoms, with depression showing the most marked association. In fact Meins (1995)²⁷ suggests that challenging behaviour can sometimes be an atypical expression of depression.

Reported prevalence rates of people with a learning disability who have mental health problems vary widely. They range from 10 - 39%, depending on the type of study and the methods used. Studies into specific psychiatric illnesses indicate that some conditions may be more prevalent than others in people with a learning disability, e.g. schizophrenia - between 1.3 and 3.7%,²⁸ affective disorders - between 1.2 and 6%, and anxiety related neurotic disorders around 16.4%.²⁹

Challenging Behaviour

We have established above that people with a learning disability suffer from the same medical and psychiatric conditions as the general population and in many conditions this can be at a higher rate of prevalence. We are all aware that how healthy we feel inevitably affects the quality of our lives, our mood and our level of participation in society. The question we need to ask is: "Do any health or medical conditions increase the risk of challenging behaviour?"

Research would suggest that certain conditions do contribute: seizure disorders,³⁰ sleep disturbance,³¹ psychiatric disorders,³² and infectious and pain related illness.³³ Despite this there is not enough research to give us a definitive answer, and also the research that has been done can sometimes leave us with more questions than answers.

This is especially so in regard to mental health problems: is the person's behaviour learned or part of a psychiatric illness; if the behaviour is part of the illness, then how much of it began with the illness but has now been learned? These questions are difficult to answer even with thorough assessment. Some studies indicate that factors other than just psychiatric problems, e.g. learning and environmental factors, are contributing to the challenging behaviour.^{22,34} Hillery (1999)³⁵ suggests three concepts regarding the relationship between challenging behaviour and psychiatric illness: primary, secondary and consequential:

- Primary is where the behaviour is as a direct result of the psychiatric illness, e.g. Jon uses aggression in response to hearing voices
- Secondary is where a behavioural response to a symptom of the illness creates challenging behaviour, e.g. Greg screams in response to a visual hallucination which commands a negative response from Tony his carer and Greg then uses aggression against Tony
- Consequential is where the behaviour begins as in primary but is reinforced by others and then becomes learned behaviour, e.g. Shaun had become aggressive as part of his psychiatric problems, and had noticed that he got a lot more attention when he did so. Despite the medication helping his psychiatric illness, he continued to use aggression as a way of attracting the attention he needed from others.

Difficulties with determining if challenging behaviour is due to mental health problems or learned behaviour can result in the inappropriate prescribing of psychotropic medication. Some of the difficulties which may arise include:

- Many and severe side effects, some of which are irreversible
- Some medications may have an opposite effect and actually increase or intensify challenging behaviour
- Unnecessary long term use as the effects for carers make them more desirable to administer
- Decreased participation in community and other activities due to sedating effects of drugs
- Suppression of adaptive behaviours
- Limited evidence to support the effectiveness of psychotropic drugs for the treatment of challenging behaviours in people with a learning disability⁴

Regarding medical illness causing challenging behaviour, Gunsett et al (1989)³³ reported conditions such as impacted bowel, compound fracture, and urinary tract infections in the main reduced challenging behaviour once treated. Bosch et al (1997)³⁶ showed significant decreases in challenging behaviour following treatment of conditions such as otitis media, rhinitis, duodenal ulcer and constipation.

When we feel anxious or in pain we may be more sensitive to our environment, e.g. criticism or demands, and may therefore react in ways that are generally out of character. It is no different for a person with a learning disability who may react with challenging behaviour. If this behaviour has then been effective in meeting the person's needs, e.g. by throwing an object at a person so that the person walked away, then they may be more likely to use the throwing behaviour the next time they want to be left alone.

Illness and pain may help to explain some of the behaviours that are totally unexpected or out of character. You may inform a person that their breakfast is ready and they come to the table on every occasion, then suddenly out of the blue they refuse, shout at you and throw something across the room. It is always worth considering health factors: do they have a headache, toothache, feel low, or feel anxious. It may just be that a request that would normally be followed may on this occasion act as a trigger for challenging behaviour.

In the same way as we discussed a psychiatric illness may result in consequential challenging behaviour, so can pain or illness. Challenging behaviour in response to pain or illness may trigger a favourable response from a caregiver, thereby increasing the likelihood of a quite neutral behaviour becoming persistent and quite challenging. To give an example of this a person may respond to an earache by gently rocking and banging their head on the wall. This behaviour may only last as long as the earache if it provides some relief. However, what could happen is a caregiver may respond to the head banging behaviour, which provides a pleasant time for the person. What do they learn – bang my head and I will get the attention I need. And so the behaviour begins: the person bangs their head, they get the desired response. For some people with little means of communication, this can be a very effective way of getting their needs met, so why not use it?

To illustrate with two brief case studies, meet Rob and Lisa whose stories are sadly not uncommon.

Rob

Rob is twenty nine years of age and he lives in his own flat with 24- hour support. He has a moderate learning disability but has major difficulties with communication, e.g. he is unable to express himself verbally and can understand basic language only. He has managed to learn a few signs but unfortunately most of his carers are unable to understand them. Rob enjoys the company of others and participates well in his local community. He does not usually present with any challenging behaviour but on the odd occasion may show some aggression which his carers are at a loss to understand.

One Tuesday afternoon Rob's carer is getting ready to take him on his usual trip to the local college. Unfortunately and unbeknown to the carer Rob isn't feeling too good. The unfolding scene is as follows:

- Rob has a headache
- Rob does not have the communication skills to be able to tell his carer he has a headache
- Rob's carer asks him to get his coat on to go out
- Rob usually loves to go out – But Rob has a headache, he doesn't feel like going out
- Not only can Rob not tell his carer he has a headache, he also can't tell him he doesn't feel like going out because of the headache
- The carer persists in asking Rob to get his coat on, raising his voice a little
- Rob wants the carer to go away, he is getting anxious and his head is now throbbing
- The carer persists in asking Rob and then moves towards Rob
- Rob can't stand any more so he does the only thing left to him, he lashes out at the carer
- The carer shouts "No" and tells Rob in no uncertain terms that he is not going anywhere now
- Robs sits back to relax his aching head!

The incident report may look like this:

Antecedent	Behaviour	Consequence
Asked Rob to get his coat on	Rob shouted and hit me for no apparent reason	Left Rob sitting in the chair. Rob went to sleep

The next day Rob's headache had gone, he felt much better and wanted to go out. He got his coat and took it to his carer as this usually prompted the carer to take him out. The carer firmly informed Rob that he was not going anywhere and that he should go and watch television. Rob did not want to watch television, he wanted to go out. His coat was taken away from him and the carer left the room. Rob was annoyed, he felt it was unjust to stop him from going out. Rob ran after the carer to make him

understand and grabbed his coat from the carer, twisting the carer's arm. The carer, in pain, raises his voice to Rob and tells him to go to his room. Rob runs to his room, slams the door and proceeds to kick his wardrobe and throw everything from his dresser onto the floor.

The daily report read: "Rob is out of control, his behaviour is becoming violent. Telephone call to Dr Blake to put him on medication for his challenging behaviour. He will visit tomorrow at 2 pm."

The daily report may have read: "I am Rob's carer and within two days I have been very successful in teaching Rob how to use aggression to communicate. I have ignored his needs, made no attempt to find out the real reason for his behaviour. I am now going to give him chemicals so that he will find it even harder to communicate."

A pattern of challenging behaviour has begun, caused, shaped and maintained by the carer and all because Rob had a headache!

In reviewing the situation above it is easy to point the finger of blame at the carer. In fact, most of the time carers do their very best, often in the most difficult circumstances. We must therefore look to the organisation for answers. Often carers are employed to care for vulnerable people without sufficient training, support, or clear expectations of their roles and responsibilities, and with insufficient monitoring of the care they provide on a day-to-day basis.

Lisa

Lisa has a severe learning disability. She lives in a residential home with four other people who have similar needs. Lisa's parents have sadly both died in a car accident but Tanya, her godmother had promised to look after Lisa's welfare as best she could after their death. Lisa visits Tanya most weekends.

The staff had become concerned as a few days following each visit to Tanya, Lisa became very aggressive towards the staff at the residential home. They discussed this with Tanya and asked if anything had changed about the visits. Tanya assured them that they were doing the same things, activities that she knew Lisa enjoyed. Tanya could offer no reason for this change in Lisa's behaviour. After about three months, staff became suspicious and accompanied Lisa on a visit to

Tanya's. They found no evidence of anything which may be upsetting for Lisa. They were baffled but decided to stop Lisa going to Tanya's for a few weeks to see what happened. To their amazement the challenging behaviour stopped occurring, no more aggression, no more attacks towards staff. This confirmed their worst fears but they were at a loss to know what to do. Should they stop her visits to Tanya altogether, and if so how would they go about this?

It was at this time that staff noticed that Lisa appeared to be drinking more than usual. They decided to take her to the GP and request a blood test. The results showed diabetes. They discussed Lisa's behaviour with the GP who enquired what foods Lisa had been having at Tanya's. They said that when they visited she had bought in lots of sweets and cakes for her. The GP then explained that Lisa had probably had hypoglycaemia which can cause aggressive behaviour.

The moral of this particular story is that had Lisa not had the blood test and subsequent diagnosis, the staff may have stopped her visits to Tanya altogether thereby cutting off her only close support outside the residential home.

Luckily for Lisa this did not happen, but the staff learned some harsh lessons. Consequently they paid particular attention to Lisa's physical health, arranged for assessment and intervention from a Speech and Language Therapist to help Lisa communicate any difficulties she was experiencing, and ensured other significant people in her life were also aware of potential difficulties.

Recommendations

Taking into consideration all of the above, the following recommendations may be considered:

- Recognition that health and medical conditions can be a contributory cause to challenging behaviours
- Greater emphasis on all areas of health promotion for people with a learning disability
- Training for all people who work with people with a learning disability to recognise, understand and work proactively and in a person-centred way to respond effectively to triggers, signs and symptoms of challenging behaviour
- Regular health screening for people with a learning disability
- Equal access to treatment for diagnosed conditions, both medical and psychiatric
- Any behavioural support assessment must be preceded by a screening for health, medical and psychological issues
- More research into the contributory factors of health problems to challenging behaviours
- Training for general and medical practitioners
- Cautious prescribing of psychotropic medication for challenging behaviour
- Speech and language therapy interventions should include communication skills to help individuals identify pain and illness and communicate this to others
- Active involvement from organisations to ensure their care staff are valued, supported and adequately monitored to provide best practice at all times. This should start at the interview process to ensure candidates are clear about the requirements and expectations of the role and promote selection of staff who are truly committed to providing only the highest standards of care.

References

1. Evenhuis, H., Henderson, C. M., & Beange, H. (2001). Healthy aging adults with intellectual disabilities: physical health issues. *Journal of Applied Research in Intellectual Disabilities* 14: 174-194
2. Lennox, N., Diggins, J., & Ugoni, A. (2000) The general practice care of people with intellectual disability: barriers and solutions. *Journal of Intellectual and Developmental Disability* 25: 127-133
3. Tonge, B. J. & Enfield, S. L. (1991) Intellectual disability and psychopathology in Australian children. *Australia and New Zealand Journal of Developmental Disabilities* 17: 155-167
4. Sigafos, J., Arthur, M. & O'Reilly, M. (2003) *Challenging Behaviour & Developmental Disability* Whurr Publishers London and Philadelphia
5. Carter, G. & Jancer, J. (1983) Mortality in the mentally handicapped: a 50 year survey at the Stoke Park group of hospitals (1930-1980). *Journal of Mental Deficiency Research* 27: 143-156
6. Hollins, S., Attard, M. T., von Fraunhofer, N. & Sedgwick, P. (1998). Mortality in people with learning disability: risks, causes and death certification findings in London. *Developmental Medicine & Child Neurology* 40: 50-56
7. Puri, B. K., Lekh, S. K., Langa, A., Zaman, R. & Singh, I. (1995) Mortality in a hospitalized mentally handicapped population: a 10-year survey. *Journal of Intellectual Disability Research* 39:442-446
8. Brookes, M. E. & Albermon, E. (1996) Early mortality and morbidity in children with Down's syndrome diagnosed in two regional health authorities in 1988. *Journal of Medical Screening* 3: 7-11
9. Hermon, C., Alberman, E., Beral, V. & Swerdlow, A. J. (2001) Mortality and cancer incidence in persons with Down's syndrome, their parents and siblings. *Annals of Human Genetics* 65: 167-176
10. Cooke, L.B. (1997) Cancer and learning disability. *Journal of Intellectual Disability Research* 41: 312-316
11. Duff, M., Hoghton, M., Scheepers, M., Cooper, & Baddeley, P. (2001) Helicobacter pylori: has the killer escaped from the institution? A possible cause of increased stomach cancer in a population with intellectual disability. *Journal of Intellectual Disability Research*. 45:219-225

12. Jancar, J. (1990) Cancer and mental handicap: A further study. *British Journal of Psychiatry* 156: 531-533
13. Hasle, H., Clemmensen, I. H., & Mikkelsen, M. (2000) Risks of leukaemia and solid tumours in individuals with Down's syndrome. *Lancet*, 355: 165-169
14. Davies, N. & Duff, M. (2001) Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research* 45:253-257
15. Lavis, D., Cullen, P. & Roy, A. (1997) Identification of hearing impairment in people with a learning disability: from questioning to testing. *British Journal of Learning Disabilities* 25: 100-105
16. McCulloch, D. L., Sludden, P. A., McKeown, K. & Kerr, A. (1996) Vision care requirements among intellectually disabled adults: a residence-based pilot study. *Journal of Intellectual Disability Research* 40: 140-150
17. Yeates, S. (1995) The incidence and importance of hearing loss in people with severe learning disability: the evolution of a service. *British Journal of Learning Disabilities* 23: 79-84
18. Chadwick, D. (1994) Epilepsy. *Journal of Neurology, Neurosurgery, and Psychiatry* 57: 264-277
19. Welsh Office (1996) *Welsh Health Survey, 1996*. Cardiff: Welsh Office
20. Branford, D. (1996) A study of the prescribing for people with learning disabilities living in the community and in National Health Service care. *Journal of Intellectual Disability Research* 38: 577-586
21. Taggart, L. & Slevin, E. (2006) In B. Gates. *Care Planning & Delivery in Intellectual Disability Nursing* Blackwell Publishing
22. Lowery, M. A. & Sovner, R. (1992) Severe behaviour problems associated with rapid cycling bipolar disorder in two adults with profound mental retardation. *American Journal on Mental Retardation* 36: 269-281
23. Gardner, W. I. & Sovner, R. (1994) *Self-Injurious Behaviours: A Functional Approach*. Willow St, P.A : Vida Press
24. International Association for the Scientific Study of Intellectual Disabilities (IASSID). (2001) *Mental health and intellectual disabilities: addressing the mental health needs of people with intellectual disabilities*. Report by the Mental Health Special Interest Research Group of IASSID to the World health Organisation
25. Emerson, E., Moss, S. C. & Kiernan, C. K. (1999) The relationship between challenging behaviour and psychiatric disorders in people with severe intellectual disabilities. In N Bouras (Ed.) *Psychiatric and Behavioural Disorders in Mental Retardation* Cambridge: Cambridge University Press.
26. Moss, S. (2000) Psychiatric symptoms in adults with learning disability and challenging behaviour *The British Journal of Psychiatry* 177: 452-456
27. Meins, W. (1995) Symptoms of major depression in mentally retarded adults. *Journal of Intellectual Disability Research*, 39: 41-45.
28. Turner, T. H. (1989) Schizophrenia and mental handicap: an historical review, with implications for further research. *Psychological Medicine* 19: 301-14
29. Hagnell, O., Öjesjö, L., Otterbeck, L., & Rorsman, B. (1993) Prevalence of mental disorders, personality traits and mental complaints in the Lundby study. *Scandinavian Journal of Social Medicine. Supplementum*. 21: 1-76
30. Gedye, A. (1989) Episodic rage and aggression attributed to frontal lobe seizures. *Journal of Mental Deficiency Research* 33: 369-379
31. Didden, R & Sigafoos, J. (2001) A review of the nature and treatment of sleep disorders in individuals with developmental disabilities. *Research in Developmental Disabilities* 22: 255-272
32. Matson, J. L. & Barrett, R. P. (1993) *Psychopathology in the Mentally Retarded* Boston: Allyn & Bacon
33. Gunsett, R. P., Mullick, J. A., Fernald, W. P. & Martin, J. L. (1989) Indications for medical screening prior to medical programming for severely and profoundly mentally retarded clients. *Journal of Autism and Developmental Disorders*. 19: 167-172
34. Matson, J. L. & Mayville, E. A. (2001) The relationship of functional variables and psychopathology to aggressive behaviour in persons with severe and profound mental retardation. *Journal of Psychopathology and Behavioural Assessment* 23: 3-9
35. Hillery, J. (1999) Self-injurious behaviour and people with developmental disability. In N Bouras (ed.), *Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation*. New York: Cambridge University Press
36. Bosch, J., Van Dyke, D. C., Smith, S. & Poulton, S. (1997) Role of medical conditions in the exacerbation of self-injurious behaviour: an exploratory study. *Mental Retardation* 35: 124-130

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