

Paul Ridd Foundation – Notes to support Mandatory Training Petition

First and foremost, people with Learning Disabilities (LD) are people. They are unique individuals with their own likes and dislikes, history and opinions and they have the same rights as anyone else (GAIN, June 2010).

'Learning disabilities (LD)' is an umbrella term for persons who have varying degrees of 'Impairment of intellectual and social functioning'. LD affects about 1.5 million people in the UK and are common, lifelong conditions which are neither illness nor disease. In Wales, there are some 15,000 adults with LD who are known to social services and in receipt of services. There are estimated to be at least a further 60,000 adults with milder learning disabilities who are not in receipt of services.

'Learning disability' commonly refers to a history of developmental delay, a delay in or failure to acquire a level of adaptive behaviour and/or social functioning expected for a certain age, and evidence of significant intellectual impairment. LD is nearly always present from birth, although some people do acquire a LD through trauma or infection. For them, their condition is the norm and it will always be there.

The nature of people's LD varies widely and will affect the kind of support that they may require. Many people with a learning disability will have a significantly reduced ability to cope independently in a variety of situations (including health services), to understand new or complex information, to learn new skills (whether practical things like tying shoelaces, or social skills such as holding a conversation or self-care), and they may have difficulty with generalising any learning to new situations. Some people with a LD may also have other physical and emotional conditions and this may lead to the person having more than one diagnosis

It is expected that by 2020 the number of people with LD in the UK will have grown by over 10 per cent as well as a growth in the complexities of LD (Michael, 2008). This is due to people with learning disabilities living longer and due to young people with complex disabilities surviving into adulthood.

Research evidence consistently suggests that people with a LD are at greater risk of physical and mental ill health than the general population. In 1998, Hollins et al reported that people with a LD are 58 times more likely to die aged under 50 than other people, and four times as many people with a LD die of preventable causes than do people in the general population. More recently, the Confidential Inquiry into Premature Deaths of People with LD (CIPOLD) Final Report (Heslop et al, 2013) found that, on average, men with LD die 13 years younger than the general male population and women with LD die 20 years younger than the general population. Many of these deaths are considered avoidable and/or premature.

Michael (2008) reported that the general standard of health of people with LD is lower than for the general population. They have a greater risk of poorer health because they experience greater variety, complexity and range of health problems compared with the general population.

People with LD can find it difficult to access services and often have a different experience of using services than do other patients, for a variety of reasons.

For example, if they have poor understanding, communication difficulties or sensory impairments, people will need to communicate with them in an appropriate and

accessible manner. However, professional barriers can inhibit this. **Professional barriers include:**

- Lack of awareness of LD.
- Lack of training in LD.
- Assumptions and biases about people with LD.
- Diagnostic overshadowing – attributing symptoms and behaviour associated with illness to the learning disability rather than any other cause, and consequently appropriate investigations and treatments may not be undertaken and illness can be overlooked.

In addition, organisational barriers can also impede effective communication.

Organisational barriers include:

- Rigid appointment systems.
- Reliance on written forms of communication.
- Poor signage, which people with low literacy skills and poor sensory abilities will find difficult to follow.
- Lack of awareness of the Mental Capacity Act, 2005.
- Inter-agency and inter-professional barriers.

People with LD prove to be one of the most challenging to Health Professionals and hospital staff as they all present differently. Learning disabilities can be mild, moderate, severe or profound and every individual has their own challenges. From our experience, some individuals react to loud noises, busy places, children, confined spaces, bright lights, a clinical environment, even people wearing ties. These are just a short list of examples.

A person with LD is twice as likely to access secondary care as an emergency as their health needs are often not picked up early enough. There are 12,000 people with LD in the UK dying an avoidable death whilst in secondary care which is to be known to be a conservative figure and is clearly not acceptable.

Figures show that at least 2% of the population in hospital at any one time has a learning disability so for example a hospital the size of Morriston which has 800 beds will have at least 16 people with LD at any one time. A person with LD will most definitely visit several departments whilst being treated in hospital and staff need to be equipped and educated to deliver the standard of care required. From our (The Paul Ridd Foundation) many hospital walkabouts, discussions with staff on the ground and supporting families in time of need, it has become apparent that most issues that arise and the shortfall in care comes from staff having a lack of awareness and not received any formal training. This maybe a receptionist, porter, nurse, support worker, radiologist, speech & language therapist or a Medic.

Paul Ridd died in 2009 and there was no awareness, tools or training available for hospital staff and as a result Paul died of neglect.

As the family of Paul our purpose since his death has been that another family would not have to go through the same experience, as we paid the ultimate price for the lack of training, ignorance and complacency which was proved by the Coroner and Ombudsman's investigation.

Since 2012 The Paul Ridd Foundation (PRF) has worked closely with the Welsh Government and Health boards across Wales to develop guidelines and tools for staff to deliver better health care, and in 2014 a care bundle for improving general hospital care for patients who have LD was launched by the health minister at the time, Mark Drakeford. He made it clear that each of the seven health boards where expected to implement the guidelines set out in the 1000 lives document and use the tools that have been developed.

Shortly after the care bundle was launched we undertook hospital walkabouts in the four-main hospital in ABMU and visited all the health boards across Wales only to discover that

there was still little awareness and the care bundle was only being used in very small pockets. This quickly made us realise that we had a further mountain to climb being IMPLEMENTATION of the new system and supporting documents and tools.

The PRF is completely self-funded and has worked tirelessly to support each health board across Wales to promote the care bundle by offering training, developing and funding ward LOGO packs including the distribution to each health board delivered in person to key professionals. The LOGO now used across Wales was developed by PRF which is used as trigger for all staff to identify a person with LD and is proven to be effective when staff are aware of it and trained.

From the very outset, the Foundation set clear goals for all the health boards across Wales so there is a common standard and good practice is shared. The Goals set have never changed

- Care bundle resource file to be available on every ward and department
- Liaison Nurse service in each health board
- LOGO Pack to be available on every ward and department
- LD champions in every hospital
- IT Flagging System
- Mandatory Learning Disability Awareness Training for all Staff

Each health board is making slow progress on all the items on the above list other than the most important item Mandatory Awareness Training.

As a Family/ Foundation we have committed a significant amount of time to this campaign and are fearful that without Mandatory Training the care bundle, Logo Pack and supporting documents will not be implemented properly which will cause risk to the quality of the health care being delivered.

We strongly feel that creating a common standard is so important and the care provided will be consistent, so we proposed an All Wales group was formed which although in its infancy is the perfect vehicle to embed LD into the Health Service in Wales.

We lobbied for Liaison Nurse Services to be in operation as when a Liaison Nurse is involved in the health care of a person with LD on average they spend 45% less time in Hospital. The patient experience is less anxious, of a better quality and ultimately creates a more efficient service reducing bed time and saving on cost. Our support in champion training has created over 170 LD Champions in ABMU and most of the other health boards have started the process. Like the Liaison Service Champions make a huge difference on the ground and from personal feedback, for many it gives a considerable amount of Job satisfaction. But unfortunately, they don't reach everyone. The PRF also works closely with Swansea University and the University of South Wales, raising awareness of nurses just about to start their careers, but again it doesn't reach all.

As a charity, we also support other charities involved with LD, carers and families by giving advice on access to secondary care. Unfortunately, over the past few years we have learnt of many unacceptable incidents that have resulted in sub-standard care caused by a lack of staff training and some resulting in premature death in North Wales and three in Llandough Hospital all of which have been since Paul's death.

People with LD have the right to the same level of medical and nursing care as that provided to the general population. 'Reasonable adjustments' mean that services must anticipate and be responsive and flexible so that any diagnosis or treatment takes into full account the LD and needs of the person, so that the best possible

health outcome for that person can be achieved (NPHS, 2009). However, 'equality' for a patient with a learning disability does not necessarily mean receiving the same service as patients without LD, and may mean providing additional and alternative methods of support established with the patient and/or their families/carer to achieve a positive outcome (GAIN, June 2010).

Reasonable adjustments can be covered in Mandatory training by examples of good practise as they make the difference required. Individuals with LD have a lot of challenges in life and together we can make sure that the Health Service is not one of them.

LD is everyone's business and the feedback we have received from hospital staff is that they want to do a good job but need the awareness training and tools to do it. By not providing staff with Mandatory training we are letting them down.

From the great work produced since Paul's death we feel that Wales has a huge opportunity to lead the UK in Improving Lives of People with LD which is highlighted in the recently published document by the Welsh Government – Learning Disability Lives Programme June 2018.

Mandatory training is essential for an organisation to deliver safe and efficient services, designed to reduce organisational risks and comply with local or national policies and government guidelines. We passionately feel that Mandatory LD Training for Hospital Staff is essential and should act as a 'catch all' to cover both mandatory and statutory requirements, but most of all to deliver equal health care for people with a learning disability.

Wales has always led the way within the UK in terms of support for people with LD. The 1983 Mental Handicap Strategy was ground breaking and set a philosophy of more visibility and value placed on people with LD in their local communities. Wales was the first country to close all long stay hospitals and in 2006, the first country to introduce annual health checks. In 2014 we introduced the Care Pathways, the only country in the UK with a formal process for reasonable adjustments for patients with LD.

England now plans to introduce mandatory training for health professionals in LD. In 2013, Wales introduced a country wide training programme, delivered by Mencap Cymru to hospital staff which was evaluated by Bangor University and showed the importance of face to face training for health professionals and the impact on behaviour of understanding the dangers of Diagnostic Overshadowing - attributing symptoms and behaviour associated with illness to the learning disability rather than any other cause, and consequently appropriate investigations and treatments may not be undertaken and illness can be overlooked.

If the Welsh Government Support Mandatory training it will ensure that Learning Disability Awareness is embedded with our National Health Service and all the good work will continue to develop making the new service sustainable.