Rising to the **Challenge**

The number of private sector Learning Disability Hospitals has grown significantly over the last few years. Adrian Roper argues that the recently amended (13th July 2009) 2002 Regulations for Private Hospitals (Wales) and the proposed consultation on new statutory guidance to replace the Welsh Office Circular 1/91 gives us hope to change this situation … If we are willing to 'Rise to the Challenge' that is.

Since the early 1980s, Welsh policy for the accommodation and support of people with learning disabilities (LD), including people with challenging behaviour, has been clearly directed towards the development of small-scale, community-based, non-hospital models. Consequently, the old large LD hospitals within the NHS have been steadily closing and will shortly all be closed. But unfortunately, this does not mean that there has been steady progress towards community-based patterns of service for people with LD in Wales, and especially not for people who may challenge services from time to time. In recent years there has even been a surge of new LD hospitals opening in Wales but this time within the private sector.

Flaws with the hospital model

What is wrong with this situation? Well, the first thing to say is that there are fundamental design flaws in the hospital model of service for people with learning disabilities. One basic flaw is best summed up by the words "people with learning disabilities are not ill". The second flaw lies in the fact that hospitals (particularly hospitals larger than a family-sized dwelling) are poor environments for long-term accommodation – and given the problems with finding anything to cure and the shortage of community-based places to which people can be discharged, long-term accommodation is what they tend to become. The second thing to say is that research has highlighted that people with learning disabilities who are congregated together on the basis of their potential for challenging behaviour receive higher levels of sedation and physical restraint and have lower levels of therapeutic support including contact with family and familiarities. The third thing that's wrong is that these hospitals are too large to meet the needs of only local people so they rely on a flow of people being sent "out of county", and all too often across the border with England. This helps to explain why residents have lower levels of contact with families, but it also leads to low levels of quality monitoring by the

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commissioning authority. Fourthly, these hospital placements are typically expensive, and not unusually extremely expensive, extracting money from the public purse which surely could be better spent on local alternatives.

Challenges and Responses

How has this situation come about? Well, the story probably begins with a 1992 Welsh Office report called “Challenges and Responses”. This flagged up that the ten year All Wales Strategy (1983-93) had not yet given enough attention to the needs of people who may challenge and that they were at risk of having no adequate service response. Sadly, this report was quickly followed by the then Secretary of State, John Redwood, effectively terminating the All Wales Strategy. The introduction of the Community Care Act 1990 led to an unhelpful emphasis on competition rather than collaboration between providers and commissioners. And in 1995/6, we had the chaos of Local Government Reorganisation and the dismantling of joint LD planning structures. In the absence of leadership at all levels of the public sector, the only people who responded to the challenge were private companies who spotted a market opportunity. Rumps of a local infrastructure of collaborative LD services enabled some areas to maintain the confidence and commitment needed to find local solutions for people who challenge, but this was very patchy. In many areas, provision went soft, and too easily gave up on people at the first hurdle. Cost constraints on local authorities also led to a tendency to try and label people as “continuing healthcare” and pass all responsibility over to the NHS, despite the fact that people with LD who challenge have, at most, a fluctuating need for specialist health support, as against an unceasing need for the social and environmental supports and opportunities of an ordinary life. To make matters worse, the people commissioning “continuing healthcare” within Welsh Local Health Boards have all too often had little or no expertise in the LD field.

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Moving things forward

So what is being done about it? Well, the good news is that a number of people have been trying to move things forward in Wales, and some real progress is being made. Following the announcement of a new LD hospital in Cardiff in 2007, letters were written to the Welsh Health Minister asking her to look into the matter, and this led to a review of the 2002 Regulations for Private Hospitals (Wales). On 13th July, the Minister accepted amendments to the Regulations which mean that any new private hospital for people with learning disabilities in Wales must have no more than ten beds, ideally spread across two or more units, and it can not be in close proximity to any other similar facility. This change should promote a more person-centred service within the facilities, and hopefully will also prove to be a disincentive to private investors motivated primarily by the profit to be made from large-scale facilities.

Partnership and Collaboration

In August, the Learning Disability Implementation Advisory Group announced the launch of a new Self Assessment Checklist for Monitoring Services for People with Learning Disabilities & Challenging Behaviour. This is the outcome of much labour and perseverance by a partnership comprising of commissioners, social care providers and health specialists. It is exactly this sort of collaboration which Wales needs, but replicated in each region and county. Working together on the implementation of this checklist will help to raise the profile of the issues to be faced, and encourage local solutions to be found. After all, if we restrict hospital-type solutions in Wales but fail to develop better alternatives, we will simply increase the exporting of people across the border. It is in this spirit of collaborative solution-finding that voluntary sector provider agencies are re-

committing to the principles of ordinary living and community inclusion for all people with LD. Working in partnership with health specialists, we aim to be fully competent, robust and resilient. Working in partnership with housing providers and other relevant stakeholders, we aim to build the required infrastructure of ordinary homes and short term respite or "step up" facilities.

Coming soon will be consultation on new statutory guidance to replace the Welsh Office Circular 1/91, and all the indications to date suggest that this document will also reinforce the appropriateness of small-scale, local accommodation options for people with LD, including people who may challenge.

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What next?

Well, further work is required on the development of an agreed infrastructure for Wales and its regions. The LDIAG work on quality monitoring needs to be followed through. More work needs to be done to consider the implications of the Bradley Report into the prevalence and experiences of people with LD in the judicial system. We need to identify allies in each of the new Health regions and in all counties too. And we mustn't ignore the fact that the private hospitals that exist in Wales already are not likely to disappear in any great hurry.

Some have already put advocacy systems in place, but there is scope for further collaboration in areas such as community access and social activities. Despite some regret that we haven't moved on as much as we might have wanted these past thirty years, the voluntary sector shouldn't lose sight of what matters most, and that's to set aside the boundaries of sector and organization and to do right by people with LD, wherever they live.

Adrian Roper

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