

## **A friend in need**

A project to consider the future specialist NHS workforce found that a 'hospital friend' for people with learning disabilities was a popular idea. Bob Gates and Mary Waight report.

The Valued People Project was launched in May 2008 as a response to concerns about education commissioning, particularly pre-registration learning disability nursing, as well to explore more generally the specialist learning disability health workforce.

It involved a postal survey of local learning disability partnership boards, semi-structured interviews with service commissioners, focus groups of individuals with learning disabilities and their carers, service managers from health and social care and the third sector, learning disability practitioners, and academic staff and students from higher and further education institutions and a detailed analysis of relevant literature and policy documentation.

The project was overseen by an expert steering group which included a person with learning disabilities, a parent, Skills for Care and Skills for Health, senior service managers, experts from workforce planning and education commissioners.

Based on our previous experience of using focus group methodology (Gates and Waight, 2007) this article reports on focus groups that were conducted between January and June 2009. These were conducted with 23 people with a range of learning disabilities from Oxford, Berkshire, Buckinghamshire and the Isle of Wight, as well 16 parents [mostly mothers] and relatives of people with learning disabilities.

### **What people with learning disabilities said....**

The people with learning disabilities in this project identified that it was important that they knew that they could trust the people who cared for and/or supported them, and they insisted that they had to have 'police checks'. They pointed to the personal characteristics of care staff as being very important, including 'a good personality and attitude'. Participants were clear that they wanted their carers to have nursing experience, and to be competent in moving and positioning. Also they thought it important that care staff understood the importance of food hygiene and infections. Direct payments

were discussed and people felt that employing their own support workers was a good thing. Participants talked about a need for a directory of support workers so that they could choose who would support or care for them. They also felt that in the future care staff should be better able to assess their needs accurately. Finally, it was felt important that carers or supporters should have good communication skills, especially listening. One area where they were clear about needing support was when they were attending hospitals. Participants talked of the need for a *'hospital friend'*, someone who would 'look out' for them whilst in hospital. They felt that all doctors and nurses should have training about learning disabilities. Participants discussed the importance of health care professionals understanding people with learning disabilities. This included occupational therapists, doctors, nurses, support staff, dentists, dieticians, chiropodists, speech therapists and physiotherapists. In particular focus group members felt that 'adult' nurses in district general hospitals would be more useful if they had more training in learning disability. All participants talked of the need to improve poor communication between health professionals and people with learning disabilities. And it was felt that at least one doctor in each surgery should have training in learning disability. These participants pointed to a number of things that caused them distress including forgetting things, medication, needles, consent forms and allergies. Participants also spoke about being very worried about pain. Everyone reported that casualty/accident and emergency departments were very frightening. Here more than anywhere they pointed to things being rushed and that they couldn't always read or understand information given to them. Often they felt that they didn't get the support they needed and staff didn't contact relatives. They were scared by ambulances and people noted that paramedics often talked to parents and carers and not to the individual. These focus groups suggested staff could engage in 'experiential' training in what it is like to use an 'Evac' chair, or to lay down in an ambulance when it is moving. Some participants felt that when people with learning disabilities make a '999' call they should state that they have special needs. Everyone referred to being very nervous about staying in hospital, and they also found it difficult to answer all of the questions asked of them - especially about medication. People with learning disabilities spoke of

the need for staff who *'really understood'* learning disabilities. It was felt that more learning disability nurses should specialise as sexual health advisors [male and female]. It was also felt that there was a definite need for more challenging behaviour specialist learning disability nurses. These participants pointed to the need for someone who could assess their needs accurately and who would specialise in injections and blood tests. Finally, these participants felt that to make things better in Accident and Emergency Departments there should be a separate waiting place for people with learning disabilities, and that staff should have available easy to read information, and use symbols and pictures for people who can't read. They also felt staff should not use so many abbreviations, and should call someone to support them if they don't understand a person with learning disabilities. These participants felt that other staff such as porters, care assistants, surgeons, doctors, chiropodists, dentists, opticians and receptionists should all have training in learning disability.

#### **What parents and carers said.....**

Parents and carers in these focus groups pointed to the general lack of support from services and health care professionals. Many pointed to a need for specialist services, and felt such staff had a *'better understanding and could accommodate'* their needs and that of siblings. Parents and carers were very clear about the need for improved education and training, especially for health care professionals who did not have a background in learning disabilities, but they also pointed to a need for specialist health staff to be, *'more tuned into their particular needs'*. And that parents pointed to their potential role in education and training; a role advocated by the Michael Report (2008).

As with individuals with learning disabilities, parents and carers reported numerous occasions of bad communication. One mother said;

*'My daughter has a phobia of hospitals. I phoned A&E and explained the situation and received an assurance that she would be taken into a side room*

*and seen right away. On arrival she was put into the main reception and had to wait two hours. The information is not being passed on.'*

The parent and carer group often spoke about poor services, and this should be a cause of real concern as the views expressed often mirrored parental accounts in Mencap's 'Treat me right' report in 2004. Comments included;

*'The doctor refused to give local anaesthetic for stitches - due to ..... having Aspergers - he said he couldn't feel pain.'*

*'We tried to pursue our complaint though PALs but they didn't understand'.*

*'They [health care staff in non specialist learning disability services] are frightened by people with learning disabilities'.*

A sense of frustration and of fighting for everything was felt acutely by some parents, though a few did point to examples of good practice, for example;

*'My GP was fantastic. If the hospital talked in jargon then ... he would explain.'*

*'When people listen things do work better not just for the person involved but everyone'*

*'The learning disability nurse was wonderful'.*

*'The wellbeing team at the sports centre is really helpful'.*

### **Key messages**

The key message from people with learning disabilities was that they wanted the right kind of person to support them and this included a range of health staff as well as social care staff. The importance of a learning disability nurse offering specialist support was identified by them on a number of occasions. They were also very clear as to the things that caused them concern and these could be addressed by further training, and the appointment of a hospital friend in acute health care settings. Finally, they were able to clearly

articulate the things that needed to be looked at to make things better including improved communication, training and an end to the continuing tendency of health care professionals to 'talk down' to them.

The central message from the parents was that they want to be listened to and supported. They want professionals to communicate effectively with them, and between each other, and they want these same health care professionals to value and treat their loved ones with respect and dignity. They were clear that all health care professionals still need educating about people with learning disabilities, and in addition a real change in their attitudes toward them and their loved ones was needed.

Specialist healthcare care professionals were valued, although it was often not individual professional groups that were identified, but the person that helped them the most, and in most instances this was a community learning disability nurse.

Taken collectively these two groups of people have identified that there is still strong support amongst these participants of a continuing need for a specialist NHS learning disability workforce, and that learning disability nurses were specifically identified as central to this.

However, what was clear is that educational preparation needs to be modernised, and more focussed to be of relevance to the parents and other family carers and people with learning disabilities, the NHS as well as the wider economy of health and social care provision.

#### **About the authors**

Bob Gates is Professional and Academic Lead for Learning Disability at the University of Hertfordshire, and until recently was Project Leader for Learning Disability Workforce Development at South Central Strategic Health Authority.

Mary Waight is a Clinical Specialist Occupational Therapist, Berkshire East PCT, and has specialised in working with adults with learning disabilities since 1997.

## References

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