The Valued People Project: Views of parents and people with learning disabilities on learning disability nursing and a specialist health workforce for the future.

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ABSTRACT

Undoubtedly a well educated and trained workforce is crucial to the development of quality care for people with learning disabilities. Notwithstanding this and unsure as to the need to continue to commission educational programmes for one part of this workforce; pre-registration learning disability nursing, South Central Strategic Health Authority (SCSHA) commissioned the 'Valued People Project' (VPP) to undertake a detailed strategic review of educational commissioning, along with the specialist learning disability health workforce more generally. This project has recently been completed and provides a unique 'evidenced based' expert evaluation for the future strategic direction of education commissioning and leadership for workforce issues in specialist learning disability services, as well as the wider workforce of the NHS. This is the first in a series of papers that reports on one aspect of the project; the focus group work undertaken with parents and relatives of people with learning disabilities and people with learning disabilities themselves as to the need and type of health workforce needed to support them in the future. The paper concludes by identifying the 'key messages' of importance from parents and people with learning disabilities concerning the future specialist NHS workforce as well as the wider workforce in the NHS.

Key words focus groups, learning disabilities nursing, parents, people with learning disabilities and specialist learning disability health workforce.

INTRODUCT ION

It is now ten years since the government of the time stated as an objective that it wished, *'to ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce'* (DOH, 2001). And more recently that *'the workforce across public services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the Valuing People Now priorities'* (DOH, 2009). This paper based on finding from a regional review of educational commissioning and workforce issues argues that these statements have not been achieved. Further it is argued, in England at least , whereas recent workforce planning 'toolkits' meant for local workforce planning such as the 'Resource Pack for Learning Disabilities' (NWP, 2007) and the 'Best Practice Guidance for Learning Disability Partnership Boards' (DOH, 2009) are to be welcomed, that they will not sufficiently address the need for strategic influence for this future workforce. This is because local planning almost by definition is necessarily is deprived of any regional or national oversight, subsequently it is at the very least challenging and dare one say almost impossible to plan strategically. Also, no account, in either of these documents, is given to the interface between workforce planning and current arrangements for education commissioning in the health sector, the latter of which is extremely bureaucratic and often involves complex contractual negotiations with Higher Education providers, and which require a three to four year 'roll out' from the commissioning process to providing a professionally qualified practitioner. Neither is at all clear as to whether the Local Learning Disability Partnership Boards have sufficient expertise and or experience in any of these issues (Gates and Statham 2010). Workforce planning and education commissioning are further compounded by inadequate central policy direction for example, in the latest Valuing People Now policy document, although the social care workforce was specifically identified, the contribution of the specialist NHS learning disability workforce to the lives of people with learning disabilities and their families was notable by its absence. It is clear that strategic planning for a workforce for the future has to be able to accommodate the significance and implications of

both the personalisation agenda and personal budgets for health and social care (DOH, 2010) and this makes it imperative that such planning is undertaken as a collaborative enterprise designed to meet needs of people with learning disabilities and their families. This will necessarily involve local, regional and national stakeholders from the wider health and social care economies, crucially involving the third sector, as well as users and commissioners of services. The continuing and 'apparent oversight' and lack of clarity as to the future of a specialist NHS learning disability workforce was one of the original reasons, and part of the background to the 'Valued People Project' that commenced in May 2008. The project was undertaken in response to expressed concerns of regional key stakeholders regarding education commissioning specifically of pre-registration learning disability nursing, and the contribution of the specialist learning disability health workforce more generally. This work was also undertaken a consequence of the scale and cumulative effect of changes to education, workforce, professional regulation and central health and social care policy that has affected people with learning disabilities and the services and personnel that support them. The overarching aims of this strategic review were to;

- map the range and extent of services and service providers across South Central SHA,

- establish an evidence base that would support a strategic approach to future educational commissioning in learning disability,

- establish how specialist NHS learning disability staff were deployed [with the possibility of the development of a new learning disability practitioner for health and social care],

- articulate a flexible learning and development framework that would support the career framework for staff who work with individuals with learning disabilities,

- develop an educational model that would ensure that all education programmes commissioned by SCSHA will have incorporated key competencies related to caring for individuals with learning disabilities,

- develop a communication strategy to inform services and practitioners of ongoing work and outcomes.

The project adopted a structured multi-method approach to systematically generate robust evidence based on a number of data sources to inform education commissioning and plan future workforce requirements. These data sources included; postal questionnaire survey of Local Learning Disability Partnership Boards, semi-structured interviews with commissioners of services, focus groups with a wide group of key stakeholders, along with analysis of relevant literature and policy documentation, and desk top research. The project was overseen by an expert strategic steering group, and the key stakeholders included, people with learning disabilities, parents and family carers, service managers from health and social care as well as third sector, learning disability practitioners, and academic staff from Higher Education Institutions, and students from Higher and Further Education Institutions; ensuring that there was the widest possible consultation with key stakeholders. This paper reports on one aspect of this project that is the focus group work undertaken with parents and relatives of people with learning disabilities and people with learning disabilities themselves. First some background information is provided concerning the use of focus group methodology. Next the methods used to undertake this component of the project is outlined along with approaches used to analyse the data. Findings from the focus groups are then presented and discussed before finally concluding by identifying the 'key messages' of importance from parents and people with learning disabilities concerning the future specialist NHS workforce as well as the wider workforce in the NHS.

METHODS

The VPP was conducted using a systematic and structured approach so that it was able to offer valid and reliable data to inform a consensual and strategic approach to achieving the overarching aims of the project. In general terms the project was conducted using the principles of *Prince 2* (Office of Government Commerce, 2009). And from a methodological perspective a

'multiple methods' approach (Creswell, 2003; Tashakkori and Teddlie, 2003) was adopted as it provided opportunity to;

- enhance the validity of the projects findings through providing corroboration from different methods (triangulation),
- illustrate, clarify and amplify the meaning of constructs or relationships in both specialist and mainstream health and social care settings,
- gain further understanding of the complexity of issues; in this context a complex arena of statutory, private and independent and voluntary sectors and an equally complex workforce and finally,
- enhance the practical and theoretical insights into the issues that this project sought to address.

This section now describes the background to focus groups as a methodological approach, and how they were used to collect data from parents and people with learning disabilities.

The concept of focus groups is perhaps most easily described as a group of people with a shared interest for example, gender, age, ethnicity, religion, life experience, expertise, being brought together (Bloor et al. 2001) in order to discuss or examine a particular issue and in some depth. For example, cars, (Puchta and Potter 2004, support for people with learning disabilities from the Asian community (Raghavan, Waseem, Small, Newell 2005), or assist in the development of accessible information Boyden et al. 2009). The theoretical literature around focus groups suggests that the group should be as representative of those parts of society who would be interested in the topic (Beyea et al 2000a, Bloor et al 2001, Puctha et al 2004). The number of people in the group should be determined by the nature of the topic being discussed for example, how personal it is, the more sensitive the subject the smaller the group; recommended group size is between six - eight people, (Beyea and Nicoll 2000a) but in practice it can range from between three to fourteen. It is suggested that recruitment can be achieved in a variety of ways

for example, though an advert, or word of mouth (Beyea and Nicoll 2000b) all aiming to produce a representative group. Groups can be formed from already established groups (Owen 2001), or brought together for a particular study (Webb 2002). Group members may be paid for their time (Cote-Arsenault and Morrison-Beedy 1999). The environment where the group is held should be carefully considered before conducting any focus groups (Beyea et al 2000b). The setting needs to encourage discussion that will enable participants to feel comfortable and able to talk freely. Individual's homes can be used (BBC 2005), as well as community centres, university rooms, schools and hospitals. There is now considerable support in the research literature concerning the use of focus groups as a legitimate research method for people with learning disabilities (Kaehne, 2010; Holburn *et al*, 2008; Gates and Waight, 2007; Fender, 2005; Mansell *et al* 2004; McCallion and McCarron 2004; Fraser, 2001; Kiernan, 1999; Prosser, 1998; Emerson, 1998; Stalker, 1998).

The focus groups reported on in this paper were conducted with parents and relatives of people with learning disabilities and people with learning disabilities between January and June 2009. The focus groups for people with learning disabilities comprised 23 people with a wide range of physical and intellectual (dis)abilities. They came from Oxford, Berkshire, Buckinghamshire and the Isle of Wight; although those on the Isle of Wight were met with separately. Members were contacted through a number of self advocacy groups. These groups were facilitated by the principal author of this paper, and Dr Steve McNally then from the Ridgeway Partnership NHS Trust - Oxfordshire. Typically each of the focus group meetings lasted two hours in duration, where a number of trigger questions relevant to the projects overall aims were discussed. The focus groups for parents comprised 16 people [mostly mothers] who had offspring [from children to mid fifties] with a wide range of physical and intellectual (dis)abilities. The parents came from Berkshire, Hampshire, Oxfordshire and the Isle of Wight. Members of these groups were obtained through contacts with a range of services across the region. These focus groups were undertaken as single events over a number of months; each event lasting from forty minutes to one and a half hours. At

each focus group the same trigger questions that were used for people with learning disabilities were discussed. At each of the focus groups for both for the parents and people with learning disabilities notes were taken and shared with the group at subsequent meetings where a post validity check was undertaken, however it should be noted that this was not possible for the last meeting of each of the groups.

This project was conducted within the general ethical conventions of social research (Haber, 1998) and at all times the project was conducted in a manner that respected the people who participated in the process, and was also concerned for their dignity and welfare. All participants consented to be involved in the project, and this was obtained in different ways. For people with learning disabilities an easy to read consent form was developed, and each member had this explained to them and signed or marked this form to acknowledge their agreement to participate (Insert consent form about here). At the initial, and each subsequent, meeting of people with learning disabilities the purpose of the project was explained and informed and consent was sought for involvement in the project, and participants were regularly reminded that they could withdraw from the project at any time.   Similarly for the parents the scope, remit and purpose of the project were explained and their informed verbal consent was sought, and once again participants were told that they could withdraw from the project at any time.   Both groups were assured of anonymity but it was explained that as the project was to be published on the web, and therefore made public and that a number of papers for publication would be sought it was not possible to offer confidentiality. Subsequently names and places and any other 'identifiers' have been deleted or changed in this paper to protect the anonymity of both groups of people. The methods used for analysis of data generated from each of the focus groups are presented next before moving to a presentation and discussion of the findings.

ANALYSIS

As focus groups produce 'rich data' by providing authentic accounts based on the breadth of knowledge, experience and views of people within the groups, they also provide a wide array of themes for analysis, and clearly this breadth of data needs to be systematically and clearly managed. Themes for analysis may vary from, for example, good or bad experiences of meeting particular health professionals, problems encountered in different health care settings, or training needs for the workforce identified. What ever themes emerge the aim of the analysis is to produce a valid and reliable record of what was said, and to understand the issues of importance to the members of focus groups. The process used in this project was that after all of the focus group meetings were completed, transcripts were read in full and then subjected to content analysis by categorising the statements and passages into themes, which in turn were further, divided and sub-divided. This eventually led to the development of a number, 11 in total, of 'theoretical categories' that are believed in part to describe the views of parents, relatives and people with learning disabilities themselves as to issues of importance for a future specialist health workforce as well as changes needed to the wider NHS health workforce. It is worth pointing out that other corroborative commentary that reinforces the points raised by focus group members were integrated into this process, and it is argued that this adds considerable weight to the validity of the findings. Text that appears in this paper in italic is that of focus group members, and represents verbatim script that has been compressed for the purpose of this paper. Reflection on the role of the project manager regarding areas of potential bias in his interpretation of the data was undertaken through out analysis and the writing up phase of this project. The next section moves to a presentation and discussion of the findings.

FINDINGS AND DISCUSSION

First, the findings from the focus groups conducted with people with learning disabilities are presented and discussed under five theoretical categories that include; the right kind of person, health staff, some things worry us, specialist NHS staff and making things better.

The right kind of person - 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 insisted that they had to have 'police checks'. They pointed to the personal characteristics of care staff as being very important, and these characteristics included; having a good personality, and good attitudes. 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 knowing about infections and food hygiene. Direct payments were discussed and people felt that employing their own support workers was a good thing, but they would be looking for someone who was caring and understanding. Participants talked about a need for a directory of support workers to look at, so that they could choose who would support or care for them. They also felt that in the future care staff should be able to assess their needs accurately. Finally, it was felt important that carers or supporters should have good communication skills, especially listening.

Health staff - 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**.** Someone made the point, rather poignantly, that '*If you care for people you should care for all people properly no matter what'.* Participants discussed the importance of heath care professionals understanding of, and being able to, care for people with learning disabilities, and these included; occupational therapists, doctors, nurses, support staff, dentists, dietician, chiropodist, speech therapist and physiotherapist. In particular participants felt that 'adult' nurses in District General Hospitals would be more useful if they had more training in learning disability. All participants talked of poor communication between health professionals and people with learning disabilities, and that this should be improved. Concerning doctors, particularly General Practitioners, it was felt that at least one doctor in each surgery should have training in learning disability.

Some things worry us - Participants in this project pointed to a number of issues that caused them distress, and these included things like; forgetting

things, medication, needles, consent forms and allergies. All participants pointed out that 'Casualty' and 'Accident and Emergency Departments' were very frightening. Here more than anywhere they pointed to things being rushed, and that often they couldn't read or understand information given to them. Often they felt that staff didn't contact relatives or get the support they needed. Participants spoke about being very worried about pain. Also ambulances were reported to be very worrying, and people pointed out that paramedics often talked to parents and carers and not to the person with learning disabilities themselves. Participants talked of a need for staff to 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, as one person said, '*I didn't feel safe, very noisy and made me feel dizzy'*. Some participants felt that when people with learning disabilities make a '999' call they should say that they have special needs. All participants referred to being very nervous about staying in hospital, and also found it difficult to answer all of the questions asked of them - especially about medication.

People with learning disabilities feed back on their discussions from their groups

Specialist NHS staff - 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. Participants pointed to the need for someone who could assess their needs accurately and someone who would specialise in injections and blood tests. Participants felt that there should be a range of professionals and support staff to assist people with learning disabilities.

Making things better - Participants felt that to make things better in Casualty [Accident and Emergency] there should be a separate waiting place for people with learning disabilities, and that staff should have easy to read information, and use symbols and pictures for people who can't read, and that staff should stop using so many abbreviations, and that staff should call someone to support them if they don't understand someone with learning disabilities. It was felt that everybody should be valued, and this meant that other staff such as porters, care assistants, surgeons, doctors, chiropodists, dentists and opticians should all have training in learning disability for their everyday work. Participants also felt that occupational therapists, speech and language therapists, psychologists, and dieticians all need some awareness; it was also felt to be important to make sure that receptionists are also aware of their needs. It was said that everyone with learning disability should have an advocate if they want one and staff should not speak down to them and that carers should not take over.

Next, findings from the focus groups conducted with parents and other relatives of people with learning disabilities are presented and discussed. Here six theoretical categories are identified that include; It's hard being a parent, the need for specialists and special services, the need for education and training, poor communication, poor services and misplaced practice, some things are good and when they are they make all the difference.

It's hard being a parent - Parents in all groups consistently pointed to the difficulties of being a parent of a child with learning disabilities. Not because of the child [in some cases adults] with learning disabilities *per se,* but because of the lack of support from services and the inconsistent levels of support they received. Parents and carers reported;

'There is definitely a lack of support for parents'.

'NHS services are a bit hit and miss. Jane's daughter had a bad experience with the NHS dentist in …… and also ……. hospital; there was limited understanding and no dedicated support for learning disability. When she was in ……. hospital, the treatment was much better probably due to the dentist having a better understanding. Different hospitals/services have different levels of care by the people providing the services - how can this be addressed?

'Services are so fragmented it is difficult to imagine how it would be possible to create a seamless service'.

The need for specialists and special services - Many of the parents pointed to a need for specialist services, and felt that these staff had a *'better understanding and could accommodate'* their needs and that of their siblings, and that this enhanced their experience with the NHS - parents and carers reported;

'Elderly and learning disability should not be lumped together as they have varying needs. When learning disability clients get elderly they are often put in elderly care homes where staff are not trained for learning disability'.

'Independence can be whittled away through lack of support'.

'All hospitals need a dedicated person to oversee approaches/practices for learning disability'.

'Obviously we need a lot more of these people [learning disability nurses] *they are the people who understand the most'*

The need for education and training - Parents were very clear of the need for improved education and training, especially for health care professionals who did not have a back ground in learning disabilities. Although there was a view expressed that even those that did need to be more knowledgeable about children with profound learning disabilities and complex needs, and not just adults. Comments included;

'Professionals in all backgrounds need an understanding of learning disability.'

'There should be more feedback and communications with acute services to promote their knowledge of learning disabilities.'

'They might be trained in many things they might be well trained and well meaning but red tape keeps getting in their way.'

'Different hospitals have different standards. There appears no awareness of learning disability a lack of learning disability training, doctors under pressure to meet Accident and Emergency targets.'

'Learning disability nurses need to have knowledge of children's learning disability services'.

'Autistic Spectrum Disorder poses real challenges and we need to develop people with specialist knowledge and skills'.

Some parents reported that they would prefer to see practitioners with a university education, and that central to all roles was the need to be able to communicate effectively. Others pointed to their potential role in education and training a role advocated by the Michael Report (2008), and one that is now formally monitored by South Central SHA.

'Us as parents we could train people….who have experience… this is another area that could be looked into'.

Poor communication - As with people with learning disabilities - parents and carers reported on the numerous occasions when bad communication had a deleterious effect on their experience within the NHS. Some examples of this are exemplified by comments such as;

'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 2 hours. The information is not being passed on.'

'There should be more feedback and communication with acute services to promote their knowledge of learning disabilities'.

'Information is so inconsistent'

'Breaking the news about learning disabilities was awful they just told me that it was a translocation and basically said goodbye.'

Poor services and misplaced practice - The parent and carer group often spoke about poor services, and what would appear to have been misplaced and or poorly informed practice. This should be a cause of real concern as the views expressed mirror, in many respects, parental accounts expressed in Mencaps Report *'Treat me right'* published over five years ago (Mencap, 2004).

'The Dr refused to give local anaesthetic for stitches - due to …… having Aspergers - he said he couldn't feel pain. How can this be addressed'?

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

'If I am with Peter - when the Dr is asking me - I have to say he is here'!

'It all falls apart when they are out of the education system; I have to say the dental treatment was pretty awful until we got some one who specialised in dental work for people with learning disabilities'.

'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, and this has been articulated many times in the literature (see for example, Maxwell and Barr, 2003). Comments expressed included;

'You have to fight for everything – it's always us having to fight'.

'You keep meeting new people all the time but nothing changes'.

Some things are good and when they are they make all the difference -
Parents did point to some examples of good practice, but it has to be said that these were scarce, nonetheless examples included;

'My GP was fantastic if the hospital talked in jargon then he would tell me that 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'.

It is worth noting that a range of 'workers' including; specialist NHS learning disability staff, as well as some members of the wider NHS workforce, and social care staff were all singled out for good practice. This is why it is crucially important that all elements of the health and social care workforce for people with learning disabilities are planned for in a strategic way.

CONCLUSION

To conclude this paper it is worth reflecting on central messages. The central message from these 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. In addition they are clear that all health care professionals need not only educating about people with learning disabilities, but also help to change their attitudes toward them. Specialist healthcare care professionals were valued, although it has to be said, it was often not individual professional groups that were identified, rather it was the person that helped them the most, in most instances this was a community learning disability nurse. The central messages from people with learning disabilities were that they wanted the right kind of person to support them and this included arrange of health staff as well as social care staff. Learning disability nurse support was identified on a number of occasions. They were also very clear as to the things that caused them concern and these could be addressed by 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 such as better communication, training and the continuing tendency of health care professionals to 'talk down' to them.

Taken collectively these two groups of people have identified that there is strong support for a continuing need for a specialist NHS learning disability workforce, and learning disability nurses were specifically identified as central to this. Notwithstanding, it is clear that educational preparation needs to be modernised, and highly 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. Finally, it has between found that people with learning disabilities along with parents and carers still report many misgivings about the services they receive from the wider NHS. Evidently there is urgent need to align the ongoing modernisation of services with modernising elements of preparing and sustaining the learning disability

workforce and it is argued that this applies to the wider NHS workforce (Barr and Gates, 2008). To conclude, these focus groups point to some common concerns that need to be addressed urgently and these are summarized in the box below.

- There is need for a national agenda to oversee the appointment of a 'hospital friend' for people with learning disabilities, and the recent call for a learning disability nurse to be appointed to every district general hospital by the Royal College of Nursing might be one way of achieving this [See Taylor, A (2010) Still striving to get it right. *Learning Disability Today.* 11-12.]

- Even allowing for the personalisation agenda to evolve, there will always be need for a specialist NHS workforce. This needs to be strategically commissioned and is best achieved through stronger and transparent alliances between Learning Disability Partnership Boards and those charged with commissioning health educational programmes on behalf of the NHS.

- Much more training is required in the wider NHS workforce, not just in developing core competencies and skills in supporting people with learning disabilities, but there needs to be a sea change in both attitudes and knowledge about the needs of this group of people.

- Specialist NHS staff need to develop specialist skills and knowledge to support those with challenging behaviour, profound learning disabilities and complex needs [both children and adults, Autistic Spectrum Disorder, parents as well as to provide expert support to the wider health and social care economy.

- There is clearly a need to attend to communication issues both between health care professionals themselves and with people with learning disabilities their parents and other family carers.

- It is a source of great concern that parents and people with learning disabilities continue to report on misplaced practice. Such practice

needs to challenged, and the NHS must undertake to covenant that such practice has no place within contemporary health care.

- Given that good practice could be identified this needs to be celebrated and shared in a more systematic way so as to promote new ways that the health workforce can support people with learning disabilities and their parents and family carers.

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The Valued People Project

NHS
South Central

THE VALUED PEOPLE PROJECT CONSENT FORM

NAME:

I agree to take part in the Valued People Project.

I understand that anything I say may be recorded or written down.

If I decide that I do not want to continue being part of the project, I can stop at any time

I understand that anything I say will not be told to anyone else with my name attached to it.

This form has been explained to me by Bob and Steve.
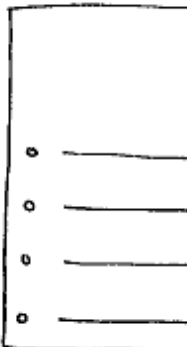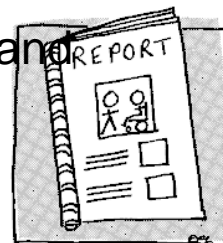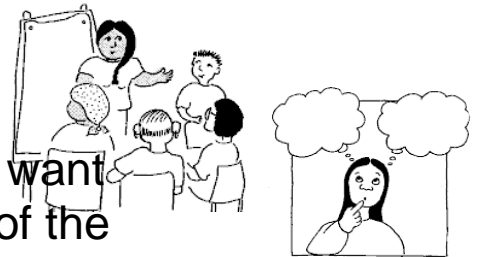
SIGNED

DATE

Biographies

Bob Gates - Professional Lead for Learning Disability at the University of Hertfordshire wrote this paper whilst working as Project Leader for Learning Disability Workforce Development at South Central Strategic Health Authority. Bob is Visiting Professor of Learning Disabilities at Thames Valley University - London and previously Senior Lecturer and Director of the East Yorkshire Learning Disability Institute at the University of Hull. He has spent the last thirty - eight years working in learning disability services and, or, management or education settings. He has worked in a number of geographical areas including; Hertfordshire, Gloucestershire, East Yorkshire, Lincolnshire and Surrey. He successfully established the East Yorkshire Learning Disability Institute at the University of Hull that brought together various professional and academic disciplines, parents, and members of parliament, as well as people with learning disabilities. He was Founding Editor in Chief of *Journal of Intellectual Disabilities* published by SAGE, now in its 14th Volume. He also serves on a number of editorial boards of international journals and is Consultant Editor to *Learning Disability Practice*. He has had published in excess of seventy papers along with numerous textbooks on issues concerned with learning disabilities. He has considerable experience of research, consultancy and project management in the field of learning disabilities. His main research interests are advocacy, challenging behaviour, families, people with profound and complex needs, and the education and training of carers.