

Learning Disability Evaluation

Part 2: Evaluation of the learning disability training
across the undergraduate health and wellbeing
programmes at Sheffield Hallam University

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Learning Disability Evaluation across the under-graduate programmes at the Faculty of Health and Wellbeing

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Introduction

The Strategic Health Authority funded an evaluation of learning disability training at the Faculty of Health and Wellbeing in March 2009. The evaluation has been undertaken by Speakup (a national Advocacy organisation run by and for people with a learning disability) and the Centre for Professional and Organisation Development www.shu.ac.uk/cpod at the Faculty of Health and Wellbeing at Sheffield Hallam University. The year long evaluation has been presented in two parts: Part 1 is An evaluation of the BA(Hons) Applied Nursing (Learning Disability) and Generic Social Work and was completed in January 2010. A copy of this report can be supplied by the author on request.

Part 2 of the evaluation is presented in seven sections and documents an evaluation of learning disability training across the under-graduate curricula in Health and Wellbeing at the Faculty of Health and Wellbeing at Sheffield Hallam University.

Section 1 sets out the aims and scope of the evaluation

Section 2 explores the background and context of support for people with a learning disability and summarises key findings from government reports.

Section 3 outlines the design, overall approach and methods used for the evaluation.

Section 4 details the key findings from the evaluation

Section 5 discusses and explores the key findings

Section 6 presents a summary of the design of on-line learning materials in learning disability produced from this evaluation study

Section 7 Presents a conclusion with recommendations.

The evaluation study aimed to respond positively to any gaps in the learning of undergraduate students in the area of supporting people with a learning disability in a wide range of mainstream placement areas. One of the outputs of the evaluation is the production of a series of six short videos which target the specific training needs of undergraduate students in the area of learning disability practice. Each video has a supplementary summary of further resources for students and guidance on how to reference these resources in their work. The videos are as follows:

- Accessible Information - Vicky Farnsworth
- Reasonable Adjustments - Russell Brynes
- Diagnostic Overshadowing - Judi Kyte
- Accessible Practitioners - Yvonne Ward
- Mental Capacity Act - James Wyatt
- Communication Workshop - James Gosling

All the videos, learning materials and copies of this report can be found at the following weblink: <http://www.friendlyinformation.org.uk/LDTKeySkills/index.html>

Section 1: Aims and scope of the Evaluation

This report specifically examines the extent to which learning disability training forms part of the undergraduate curricula of undergraduate courses taught at the Faculty of Health and Wellbeing. The undergraduate courses are defined as follows:

BA(Hons) Adult Nursing
BA(Hons) Mental Health Nursing
BA(Hons) Child Nursing
BA(Hons) Applied Nursing (learning disability) and Generic Social Work
Advanced Diploma in Nursing (Adult, Mental Health, Nursing)
BSc (Hons) Physiotherapy
BA(Hons) Social Work
BSc(Hons) Occupational Therapy
BSc(Hons) Vocational Rehabilitation
BSc(Hons) Diagnostic Radiography
BSc(Hons) Midwifery
BSc(Hons) Midwifery (shortened programme)
BSc Radiotherapy and Oncology
DipHE Radiotherapy and Oncology Practice
Dip HE Paramedic Practice
Dip HE Operating Department practice

Each of the above programmes has been designed to meet its own professional body's specific learning outcomes as well Sheffield Hallam University academic standards.

In addition to each individual programme's learning aims and objectives there will be some aspects of learning which will be considered to be universal across all the undergraduate programmes. These areas of joint learning across the undergraduate programmes are termed 'Interprofessional Learning' (IPL) or now more commonly Interprofessional Education (IPE).

Learning Disability Training is currently a theme within the IPE component of the undergraduate programme. It is not an aim of the evaluation to explore the IPE learning disability training as this is part of a broader IPE evaluation (King, 2010).

The aim of this evaluation study is to evaluate the learning disability training currently designed and delivered across the range of undergraduate programmes at the Faculty of Health and Wellbeing at Sheffield Hallam University to:

- Scope out the current learning disability content and assessment strategy within each undergraduate programme;
- Explore the level of knowledge and skills in the area of learning disability of current undergraduate students
- Identify areas for improving the content of learning disability training across the programmes

The outcomes of this evaluation are to work collaboratively with colleagues with learning disabilities to:

- generate a range of data that respond to the questions posed from the aims of the study
- produce a report with evidence of learning disability competence across the undergraduate programme and perceptions of managers on student abilities in this area
- produce on-line learning materials that support the learning currently being developed in learning disability across the undergraduate programmes

Section 2: Learning Disability - Health and Social Care - the context

There have been a number of significant reports which have documented poor quality healthcare experienced by people with a learning disability. These include:

- Disability Rights Commission (2006) *Equal treatment: Closing the Gap*
- Mencap (2007) *Death by Indifference*,

- Health Care Commission (2007) *A life like no other*
- Department of Health (2008) *Healthcare for All: An independent inquiry into access to healthcare for people with learning disabilities (Sir Michael Inquiry)*
- Department of Health (2009) *Valuing People Now: A New three year strategy for people with a learning disability*

The reports conclude with some disturbing findings:

- People with a learning disability die earlier than people without a learning disability.

"International evidence shows that people with learning disabilities or long-term mental health problems on average die 5 to 10 years younger than other citizens, often from preventable illnesses" (DRC, 2006:33)

- People with learning disabilities have higher rates of respiratory disease (at 19.8%) than the remaining population (15.5%) (DRC, 2006:39)
- People with learning disabilities are more likely to be obese. The rate of obesity in all those with recorded body mass index (BMI) was 28.3% in people with a learning disability, as compared to 20.4% for the remaining population (DRC, 2006:39)
- People with learning disabilities have more health needs than those without learning disabilities, yet are not as likely to have healthcare to respond to these needs (Department of Health, 2008)
- Accessing healthcare is problematic as very few services use "reasonable adjustments" (Disability Discrimination Act, 1995, 2003) to aid access to health and social care
- When people with learning disabilities do access healthcare they are more likely not to have an accurate diagnosis of their ill health than those without learning disabilities because of the occurrence of "diagnostic overshadowing". Diagnostic Overshadowing has have contributed to the deaths of people with a learning disability and is accounted for in the Mencap report (2007) and explained further in research findings (Mason and Scior, 2004)

Access to health care

The Disability Rights Commission undertook a formal investigation into the health inequalities experienced by people with a learning disability and or a mental health problem (Disability Rights Commission, 2006). It concluded that in spite of attempts through Disability Discrimination legislation to challenge inequalities in access to healthcare, people with a learning disability had increased health risks and health

problems particularly in the areas of obesity and respiratory disease. The report identified that in Primary Care, people with a learning disability are less likely to receive some of the expected evidence based checks and treatments than other patients and that efforts to target their needs are ad hoc (DRC, 2006). There is evidence of barriers in communication with staff at all levels of the service:

"Some staff do not speak directly to the person and make no attempt to use alternative ways of communicating where communication is difficult, and do not check if their understanding of symptoms is correct".(DRC, 2006: 69)

Reasonable adjustments

The Disability Discrimination legislation (1995) was amended (2003) to ensure that public sector services made '*reasonable adjustments*' to improve the way disabled people access services. For example a reasonable adjustment could be in the area of making appointments, which could be made by email or text message or telephone reminders. Information could be provided in different formats such as changing the font size, presenting information in an easy read format.

There is very little evidence of services making reasonable adjustments and a study in Wales of annual health checks of people with a learning disability found that the health of the sample worsened one year following the health check! (Nocon, 2004). In Wales they have been doing annual health checks through Direct Enhanced Services (DES) since 2006 and have found that when a person has a health check, one year later their health may have worsened suggesting a lack of health action in response to the annual health check. In England annual health checks commenced in 2009 and have been introduced as a Direct Enhanced Service that requires General Practitioners and Practice Nurses and Receptionists to undertake specific learning disability training to equip the staff with skills in learning disability to undertake the health checks.

We also found high levels of unmet health needs. Of 181 people with learning disabilities in Wales who received a health check, half (51%) had newly identified health needs and 9% had serious health problems; subsequent checks over a year later identified further new health needs among 68% of people, with serious problems in 11%. (DRC, 2006:48)

Valuing People Now: A new three year strategy for people with a learning disability (Department of Health, 2009) suggests that *health care is* a key priority. There is an acknowledgement of the evidence (Department of Health, 2008) that people with learning disabilities have poorer health than the rest of the population and are more likely to die at a younger age. One of the main problems centres on access to services which is documented as being poor and characterised by "problems that

undermine personalisation, dignity and safety' (Department of Health, 2008). The aim for the NHS is to "achieve full inclusion of people with learning disabilities and to ensure high quality specialist health services where they are needed" (Department of Health, 2009: 14).

However while people with a learning disability report the difficulties that they have in accessing services, these access issues are not usually acknowledged by health staff. Instead, staff are more likely to identify the difficulties encountered as being attributed to the person with a learning disability and the specific nature of their impairment :

"Whereas people with learning disabilities and/or mental health problems tended to identify service difficulties in terms of access barriers or 'diagnostic overshadowing', primary care practitioners were more likely to view the difficulties as intrinsic to the individual and their impairment. A cultural shift is needed, to embed the principle that services need to be adjusted to suit individual requirements and to raise expectations for improved health outcomes". (DRC, 2006:92)

Diagnosis of ill health

A significant problem in the diagnosis of ill health is the high occurrence of what is called 'diagnostic overshadowing'. This is a term that is used to describe the tendency for clinicians to overlook symptoms of mental and physical health in people with a learning disability and instead to attribute them to them being part of 'an intellectual disability' (Mason and Scior, 2004). The Disability Rights Commission (2006) identified that diagnostic overshadowing was occurring amongst people with a learning disability:

"people with learning disabilities and their families reported that when they told health professionals about changes in their physical well-being, they were sometimes explained as behavioural but turned out to be caused by pain or a significant physical illness" (DRC, 2006: 69)

Specific reference to pain relief has been cited in *Death by Indifference* (Mencap 2007) and "Health Care for All", Department of Health (2008). Several accounts of the consequences of a failure to provide appropriate pain relief were given to the Inquiry team by carers and by the families whose cases were described in the 'Death by Indifference' Report (Mencap, 2007). One parent explained vividly how symptoms of severe pain that she could see in her daughter were denied by staff because they mistakenly attributed them to her learning disability" (Mencap, 2007:17).

Developing capacity and capability within services to support people with a learning disability

The Valuing People Now strategy (Department of Health, 2009) believes that a key element of achieving change in *accessing* healthcare for people with a learning disability is in the development of *"capacity and capability at local levels to design and commission the support services that people need to enable them to live independently and close to families and friends"* (Department of Health, 2009: 18). This is essentially about the training and development of staff. Examples of how this is happening locally are:

- Sheffield Teaching Hospitals have produced on-line learning materials (produced by a service user group) for staff, and the leadership of learning disability staff training and the responsibility of the quality of patient experience of people with a learning disability is at Director level
- NHS Rotherham has taken a unique approach to learning disability led training being delivered to all practice staff, not just GPs, nurses and receptionists who have elected to undertake the health checks for people with a learning disability. This also included a cohort or trainee GPs with a view that this training will be on going.
- The Strategic Health Authority and Sheffield Hallam University have supported this evaluation of learning disability training led by Speakup, a national advocacy organisation providing employment for people with learning disabilities.

Health Prevention programmes

Efforts and initiatives in specialist services have not had a significant impact on mainstream health programmes or primary care services. At government level, people with a learning disability have not been systematically targeted by programmes to reduce health inequalities which have mainly focused on socially deprived areas.

"There has effectively been no inclusion of the high risks to physical health amongst people with learning disabilities in mainstream targets or health policy". (DRC, 2006:31)

The report found that the health needs of people with learning disabilities were often 'off-loaded' onto specialist services rather than addressed through primary care (DRC 2006:32).

One of the conclusions of the Disability Rights Commission was to recommend that: *"all professionals and organisations with a role in the provision of primary care health services to people with a learning disability must act now to tackle the inequalities in physical health and primary healthcare services (DRC, 2006:34)*

Medical versus Social Model Approach

The medical model approach has defined the curricula for professions in health yet in social work the curricula has been defined from a social model perspective. The medical model defines disability as illness and essentially starts from a perspective of studying the impairments of the disabled person and identifying the medical condition/complaints of the person. The social model on the other hand takes the perspective that a person is disabled by their environment (including staff attitudes and prejudice, assumptions and lack of knowledge) as well as by buildings in the environment.

The conclusions from reports cited in this section suggest that the problems that people with a learning disability encounter is likely to be the social and physical barriers in the environment. These barriers can be in the lack of reasonable adjustments being made in terms of:

- accessible information;
- flexible appointment timings;
- the use of alternative or augmentative communication systems to communicate information;
- incorrect professional judgement and decision making caused by "diagnostic overshadowing"
- a lack of equality in accessing health promotion programmes.

Section 3: Evaluation Design, methodology and methods

The overall approach to this evaluation study was to measure the extent to which undergraduate programmes in health and wellbeing, include learning disability teaching in line with "Health Care for All" (Department of Health, 2008) recommendations.

Among several recommendations of "Health Care for All" (Department of Health, 2008) is the recommendation to ensure that the training of learning disabilities is mandatory within the under-graduate and post-graduate clinical training of health care professionals:

"Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training. RECOMMENDATION 1" (Department of Health, 2008)

Recommendation 1 from Health Care for All (Department of Health, 2008) shaped the approach to this evaluation. It was deemed appropriate and necessary to work in

partnership with people with a learning disability so as to establish a meaningful process of collaborative inquiry of learning disability training which would lead to the development of relevant and useful on-line learning materials.

Involving people with Learning Disabilities as co-evaluators

This evaluation was designed as a collaborative project between Speakup and the Centre for Professional and Organisation Development (CPOD) at Sheffield Hallam University. The collaboration meant that CPOD would support Speakup to develop the capacity of people with a learning disability who would develop inquiry based skills to undertake involvement in the project. Speakup established that individuals who had the skills and experience to be involved in Part 1 of the project (Evaluation of the BA(Hons) Applied Nursing (learning disability) and Generic Social Work)¹ might not necessarily be those with the same skills to be involved in Part 2. The skill set required for Part 2 of the project were those with experience and confidence in facilitating focus groups.

The aim of the focus groups was to determine the current skills of undergraduates in working with people with a learning disability. The focus groups intended to simulate real life situations where the student may be in a similar situation and to explore what they may or may not do in this situation. It was expected that having a person with a learning disability facilitating the workshops would engage the students more effectively and add value to the student's experience. The danger of an academic facilitating a focus group of this nature is the tendency to theorise an issue of real importance in every day practice.

The focus groups were based on the use of three real life stories drawn from the *Death by Indifference* Report (Mencap, 2007). The case studies were powerful and poignant in that all three of the individuals cited in the case studies died as a result of poor or inappropriate health care. The case study videos and the accompanying easy read Power Point is available at <http://www.friendlyinformation.org.uk/LDTKeySkills/index.html>.

The stories of Emma, Tom and Martin are presented here in this section of the report in full. Summaries of these stories were presented to the focus groups, with a planned time for discussion for each story of 15 minutes. The first 10 minutes of each focus group was spent exploring the participant information sheet, the consent form, payment details and setting up the recording equipment.

¹ Part 1 of the evaluation also collaborated with a Doncaster Advocacy Organisation CHAD and worked with people with a learning disability as interviewers. Part 1 report can be obtained from <http://www.friendlyinformation.org.uk/LDTKeySkills/index.html>

Emma

Emma's mother first took her to her GP because Emma had not eaten for eight days. Her GP suggested it might be a virus. Her mother was not satisfied, as Emma was very unwell and still not eating. She decided to find another GP. A month later, Emma was admitted to a surgical ward at the hospital with a swelling in her groin. She had an X-ray, and a scan culminating in a biopsy. While she was in hospital, Emma was distressed and in pain. She was not eating and couldn't take a painkiller orally. The hospital found Emma's behaviour very difficult to manage. Emma was discharged from the hospital on the grounds that there was nothing more they could do for her. She was sent home without any help to control her pain. Eleven days later Emma and her mother went back to the hospital to get the results of the biopsy. They were told that Emma had Lymphoma B1 type cancer and that, with treatment, she had a 50:50 chance of survival. But the doctors decided not to treat her, saying that she would not co-operate with the treatment. Emma and her mother were sent home with no advice about Emma's care needs and still no way of dealing with her pain. Emma was back in hospital again five days later, as by this time she had stopped drinking. Again, the doctor wanted to discharge her. Her mother refused to take her home. Emma received no treatment at the hospital for two more days, with the doctors again saying they could not treat her as she was unable to consent. So her mother instructed a solicitor to serve notice on the doctors to start treatment for pain relief by 9am the following day. Treatment did not start, so the solicitor started an action in the High Court and the hospital finally agreed to treat Emma. A second medical opinion was sought and this doctor said that as the cancer had advanced she now had only a 10% chance of survival with treatment. It was decided that palliative care was now the only course of action to take. A few days later Emma was moved to a hospice where she received excellent care for about a month. She started drinking again and her pain was well controlled until she died.

Tom

Tom had profound and multiple learning disabilities and complex health needs. He attended a residential special school. His parents raised concerns on numerous occasions about planning for Tom's future after he left school. However, social services took no action until very late on. There then began a frantic search to find a suitable placement for Tom. Prior to leaving the school, Tom was showing signs of distress. The school put this down to the fact that he was no longer happy there. Convinced that Tom was in pain, his parents had insisted that he was referred for medical investigations. Tom went to a hospice where the consultant recommended that further investigations were carried out to identify the underlying cause of the pain he was experiencing. The consultant suggested that the pain was likely to be related to Tom's digestive system. This advice concerning further investigations does not appear to have been acted on. Tom's GP decided that he should not have a PEG feeding tube inserted because of fears that Tom would not tolerate it. His

parents were not involved in the discussion about how best to ensure that Tom was receiving adequate nutrition. It soon became apparent that there was nowhere suitable for Tom to move to after leaving school, within the required timescale. Tom was eventually placed at an NHS psychiatric assessment unit. His parents were told that they would assess his needs, including his medical needs. However, no such assessment ever took place. During this period, Tom's health continued to deteriorate. He was steadily losing weight and exhibiting highly unusual behaviour – such as gouging his head. Tom's parents were sure he was expressing the pain he was in. Finally, a place became available at a social services residential home. The concerns raised by Tom's parents about his health were at last acted upon, and staff ensured that Tom was admitted to hospital. Following tests, they found that Tom had an ulcerated oesophagus. The hospital agreed to insert a PEG so that Tom could be fed by tube and the operation to do this was carried out. However, Tom died before receiving nutrition as by this time he was extremely weak.

Martin

Martin had a stroke and was sent to hospital. While there, he also contracted pneumonia. Martin had trouble swallowing after his stroke and so was visited by a speech and language specialist. But Martin's swallow reflex did not return. He could not take food or water orally and so was put on a drip. Martin did not tolerate this well and sometimes pulled the drip out. In the second week at the hospital Martin was still unable to eat and the drip was not providing him with adequate nutrition. He was visited and tested by the speech and language team several times. They recorded in their notes that he should remain 'nil by mouth' and that 'alternative feeding methods should be considered'. However, no action was taken. This situation continued into a third week. By this time, his veins had collapsed, which meant that the doctors couldn't get the glucose liquid from his drip into his body. So they decided they needed to insert a feeding tube into his stomach. This would have required a surgical procedure. However, by the time they had made this decision, Martin had been without nutrition for 21 days and his condition had deteriorated so much that he was in no state to undergo an operation. Five days later, Martin died. The hospital admit that they did not act on the information that Martin was assessed as being at 'high risk' on the Malnutrition Universal Screening Test (MUST) scale, and that they did not follow their own enteral feeding policy. This policy states that alternative feeding methods should be considered after seven days. The hospital carried out an internal investigation. This found that there had been a multidisciplinary communication failure, which resulted in the doctor being "under the impression" that the nurses had been feeding Martin via a naso-gastric tube when this was not the case. There had been a complete breakdown of communication, resulting in Martin being without food for 26 days before he died.

After publication of the Mencap (2007) report the families of the six people who died, called for an urgent investigation into their relatives death. The Health and Local Government Ombudsman report presented the findings from this investigation in a report called "Six Lives" (Health and Local Government Ombudsman, 2009). The report called for an urgent review of health and social care for people with a learning

disability. The Ombudsman report states that there were *"some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care"*. The report also found evidence of maladministration and service failure of some of the organisations involved: *"In some cases we concluded that there had been maladministration and service failure for disability related reasons. We also found in some cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality"*.

To prepare the Speakup facilitators to present the stories of Emma, Tom and Martin, a significant amount of lead time was used to enable people at Speakup to develop easy-read materials to facilitate the focus groups and to video record the three case study scenarios that were to be used. A lot of time was also spent practising their focus group facilitation skills and getting feedback from colleagues at Speakup.

The skills of a few key individuals from Speakup were drawn upon: Robert and Hayley designed the easy read materials through a power point presentation; Jonathon, Kirsty and Lona recorded the video case studies and Hayley, Jonathon, Robert, Alison, Richard, James and Annie practiced and rehearsed using the easy read materials to develop their skills to become facilitators of the focus groups. Eventually however Hayley and Jonathon took a lead role with support from James and Alison. Annie from Speakup took on a support role, with Malcolm and JA (the author) providing university room booking support, setting up the power point and projector and activating the audio equipment.

Evaluation Method

The methods used to undertake this evaluation have been:

1. A scoping exercise of the current curricula content of the undergraduate programmes

Each of the Programme Leaders were communicated with via email (MR) to inform them of the evaluation study and to ask for current teaching content, method of delivery and assessment strategy of learning disability training across each year of the undergraduate programmes. Some programme leaders responded immediately with the information required while others needed a reminder and in other areas we needed to communicate with another member of the subject team to help us complete the information for the scoping exercise. The data have been presented as a table in Appendix 1.

2. A series of focus groups with students in each of the undergraduate professional programmes

The focus groups set out to explore the level of knowledge and skills in the area of learning disability of current undergraduate students and to identify areas for

improving the content of learning disability training across the undergraduate programmes. The evaluation team sought advice as to how best to recruit students to the focus groups.

We were advised from the Interprofessional Education (IPE) Team at the Faculty of Health and Wellbeing team that they had successfully recruited student researchers for their evaluation study, so the team relooked at the budget to see if we could afford to recruit a 'student focus group recruiter' who would be paid a fee for recruiting up to 5 other students for a focus group at a pre-arranged time and venue.

Each of the other 5 participants would be paid £10 and given a £5 lunch voucher while the recruiter would be given £10 for each person they recruited and an additional £10 for themselves. In addition to the £5 lunch voucher the 'student focus group recruiter' could be paid up to £60. We identified that each focus group would have other fixed costs associated with it and that there would be other costs attributed to the project which were met outside of this project's budget. Details are provided as follows:

Student recruiter	£65
Student recruits	75
Facilitator x 2	60
Travel and expenses	20
Transcribing	65
Analysis ²	225
University support ³	0
Venue	0
Total	£510

We were able to undertake 14 focus groups which gave a total cost for this activity of £7,140. One of the hidden support costs of the above and for which we were most grateful is the support of the media and technology services at the Faculty of Health and Wellbeing. The media and technology services provided our facilitators (people with a learning disability) with an easy read instruction sheet on how to use the digital tape recorders. The media and technology team also gave support to Speakup on the occasions that MR and JA were unable to set up the audio recording equipment, they also liaised with Speakup's media and technology department to ensure compatibility of the video recorded case study scenarios. The presence of the

² Each focus group had a budget of £225 for data analysis, the analysis of each focus group took approximately 4 hours.

³ MR and JA gave their time to help the focus group facilitators book a room at the university, set up the room, lay out payment forms and participation information sheets and set up the audio equipment. We worked with facilitators by giving debriefings on their presentation styles and suggesting ways that this could be improved. The cost of this time was met outside of the costs of the project.

media and technology services has enabled this project to be successful with its use of technology 100% of the time.

MR and JA liaised with staff in the University to identify appropriate blackboard sites to advertise a series of dates in November 2009 and January 2010. This was an extremely successful way of recruiting the 'lead student recruiter' (11 out of the 14 focus groups were recruited in this way, please see Figure 1) who would either email MR or JA to suggest a date and a time slot that they and their colleagues could be available to attend a focus group. We would then book rooms, inform Speakup of the dates and times and prepare the paperwork for each of the focus groups.

The paper work consisted of a Participant Information Sheet and Consent Form (Appendix 2) a Focus Group Proforma (Appendix 3) and a SHU2 and P46 form for paying the student. JA or MR would normally set the group up. While in the first instance one of us would stay with the Speakup facilitators throughout the session, most of the sessions subsequently were conducted with our colleagues from Speakup undertaking this role independently. There were some difficulties recruiting some groups of students (for example Paramedic Practice and Operating Department Practice and Mental Health Nursing Students). Towards the end of the study JA made several attempts to liaise with course tutors, identify when the students would be in the university via searching the online timetable and seeking permission from course tutors to speak to the students at the end of a classroom session. This approach required me to be able to facilitate a focus group immediately rather than in a planned way which resulted in a lack of time to be able to book Speakup to facilitate these three focus groups.

The focus group recordings were downloaded onto a CD by our team of audio, media and technical colleagues and the CD was passed to JA There was time spent in listening to the audio recordings and providing feedback to the support people at Speakup to help refine and develop the focus group facilitation skills. The audio files were then sent off to an on-line digital transcribing service and returned within a week.

Analysis

The word files were imported into NVivo, qualitative data software for qualitative data analysis. The analysis was primarily a content analysis which has the advantage of enabling evaluators the ability to manage large volumes of data with relative ease in a systematic fashion. The content analysis was framed around each case study and each of the four questions that supported the case studies. Students were asked for additional ideas on ways to improve their learning about learning disability on their course and also for ideas in breaking the barriers for people with a learning disability in accessing health and social care.

Initially it was expected to have students from a mixture of the different professional programmes in the focus groups, however our recruitment strategy via the student's online blackboard site, ultimately resulted in the recruitment of single discipline focus groups. There were two mixed focus group (midwifery and social work and radiographers and Occupational Therapists), but the facilitator had to remind the students to say which course they were on before they gave their ideas in the focus group. Ultimately the singular discipline focus groups resulted in a more accurate process for content analysis.

The focus group sample is detailed in figure 1:

Figure 1: details of the focus group sample across the undergraduate programme

The undergraduate or pre-qualifying programme	Method of recruitment	Facilitator	Date of the focus group	numbers and mix in each group
BA(Hons) Adult Nursing (1st year)	notice on student blackboard	Hayley (Speakup)	12/02/2010	6 adult nursing students
BA(Hons) Adult Nursing (3rd year)	notice on student blackboard	Hayley (Speakup)	20/11/2010	6 adult nursing students
BA(Hons) Mental Health (3rd year)	direct recruitment after a class session	JA (SHU)	8/03/2010	6 mental health nursing students
BA(Hons) Child Nursing (2nd year)	notice on student blackboard	Jonno/Annie (Speakup)	17/02/2010	6 child branch students
BA(Hons) Applied Nursing (learning disability) and Generic Social Work	notice on student blackboard	James/Hayley (Speakup)	1/03/2010	6 joint Nursing and SW learning disability
Advanced Diploma in Nursing (Adult, mental health, Nursing)	No focus groups facilitated			
BSc (Hons) Physiotherapy (2nd year)	notice on student blackboard	Hayley /Jonno (speakup) MR and JA SHU	9/11/2009	12 physio students (2 groups)
BA(Hons) Social Work (3rd year)	notice on blackboard	Hayley/James (Speakup)	3/03/2010	6 social workers
BSc(Hons) Occupational Therapy (3rd year)	notice on blackboard	Hayley/Alison (Speakup)	11/02/2010	6 Occupational Therapists
BSc(Hons) Vocational Rehabilitation	No focus group facilitated			
BSc(Hons) Diagnostic Radiography (3rd year)	notice on blackboard	Jonno (Speakup) /MR, SHU	20/11/2009	4 radiographer plus 2 Occupational therapists
BSc(Hons) Midwifery (shortened programme)	No focus group facilitated			
BSc(Hons) Midwifery (3rd year)	notice on blackboard	Jonno/Hayley (Speakup)	11/02/2010	4 Midwifery students and 2 Masters in Social Work
BSc Radiotherapy and Oncology (3rd year)	notice on blackboard	Hayley/Robert (Speakup)/ MR	12/11/2009	6 Radiotherapy students
DipHE Radiotherapy and	No focus group facilitated			

Oncology Practice				
Dip HE Paramedic Practice	Direct recruitment from the cafeteria SHU	JA from SHU	1/03/2010	8 paramedic students
Dip HE Operating Department practice	Direct recruitment after class	JA from SHU	2/03/2010	6 ODP students
Total students participating in 14 focus groups				86 students

Section 4: Findings

A scoping exercise of the current curricula content of the undergraduate programmes

Details of the scoping exercise are presented in Appendix 1. A summary of the findings from the scoping exercise are presented as follows:

Year 1:

Nursing has a discreet workbook based on scenarios and constitutes 150 hours of self directed learning. The Joint Nursing and Social work course offers students a placement in the first year with people with a learning disability and their families. In addition to this it facilitates people with a learning disability coming into the classroom to facilitate student learning.

The remainder of the undergraduate programmes take an integrated approach to covering learning disability issues in year 1. Social work incorporates learning disability issues in the module 'The people we work with' (which also covers, mental health, older people, children). Physiotherapy also subsumes learning disability into other modules and Occupational Therapy and Radiography incorporates the issues into a discussion on anti-discriminatory practice. The remaining programmes Radiotherapy and Oncology explores learning disability in the module 'patient management in radiotherapy services; Paramedics explore learning disability in their module 'sensitive topics and special challenges' and Operation Department Practice covers learning disability in its clinical issues at level 4 and exploring a patient history.

Midwifery do not cover learning disability issues at all in year one of the programme.

Year 2:

In year 2 of the programme, adult nurses do a reflective piece on people with learning disability and other vulnerable client groups they have had contact with in practice. Mental health students do a module on caring for people with complex needs and explore scenarios about people with a learning disability who also have a mental health problem. Child branch students explore caring for the disabled child and examine the social model of care within the parameters of the social sciences.

Social workers cover learning disability in their module on anti-oppressive practice, while radiographers explore managing people with a learning disability while they have an x-ray. Radiotherapy have introduced some role play around specific examples of issues presented by people with a learning disability and paramedics also work with scenarios.

Occupational Therapy have an innovative optional module for up to 10 students where people with a learning disability facilitate the student's learning. They are assessed on the learning outcomes of this module. Unfortunately the module is quite intensive and costly and it has more students who want to study on the module than there are places available.

Midwifery covers congenital abnormality of the new born.

Year 3:

There is very little emphasis on learning disability in year 3 as it appears that the third year enables the students to develop some professional autonomy and management in practice of their specific professional discipline. Only the joint nursing and social work course in learning disability will continue to have placements and assessed work on learning disability.

Focus groups with each of the undergraduate professional programmes

The 14 focus groups were recorded and transcribed and the data analysed by each case study in turn. Nvivo, a qualitative data analysis software package enabled the analysis to be structured by grouping all responses together by case study and using this structure to generate key themes. The key themes generated from each case study formulated a matrix which was then subjected to a quantitative content analysis. The aim of the analysis was to:

- understand if there were any dominant themes emerging from across the 14 different student groups as a response to each of the case studies
- to use the generation of themes from each of the focus groups to inform a quantitative process of content analysis
- to use the content analysis to explore how the findings from this study reflect findings nationally (summarised in the earlier part of this report)

CASE STUDY 1 - EMMA

Emma died of cancer at the age of 26. She had a severe learning disability. This meant that she sometimes exhibited challenging behaviour and had difficulty communicating how she felt. Emma's parents were told Emma had a 50:50 chance of survival. but the doctors decided not to treat her saying that she would not co-operate with treatment. Emma and her mum were sent home without any advice on how to manage and no way of dealing with Emma's pain.

	assumptions	low expectations of emma	Discriminatory	Diagnostic overshadowing	Inadequate training in LD	A better assessment of need	Communicate with Emma	Other options might have worked	Disbelief about the case study	suggestions of reasonable adjustments
CASE STUDY 1- EMMA										
How did the Doctor decide not to treat Emma?										
BA(Hons) Adult Nursing (year 1)	•							•	•	•
BA(Hons) Adult Nursing (year 3)		•					•	•		
BA(Hons) Mental Health Nursing	•	•	•					•	•	•
BA(Hons) Child Nursing	•								•	•
BA(Hons) Nursing (learning disability) and Generic Social Work		•		•	•				•	•
BSc (Hons) Physiotherapy			•			•			•	•
Masters in Social Work			•					•		•
BA(Hons) Social Work		•			•		•			
BSc(Hons) Occupational Therapy	•	•							•	
BSc(Hons) Diagnostic Radiography					•	•			•	•
BSc(Hons) Midwifery	•	•								•
BSc Radiotherapy and Oncology	•	•				•	•	•	•	
Dip HE Paramedic Practice							•	•		
Dip HE Operating Department practice		•	•		•		•	•	•	•
total	6	7	4	1	4	3	5		9	9

1. How did the doctor decide not to treat Emma?

Most of the students in the focus groups (9 out of 14) could not believe that this case study was based on a real person. Many expressed their shock and disbelief:

"I'm a radiographer and I can't believe that the doctor would actually do that" (Radiography student focus group) *"I don't understand how that would ever happen"* (Physiotherapist student) *"it makes me feel angry"* (Joint nursing and social work student).

Students expressed their emotions in the following ways: *"it stank .. everything was wrong"* (mental health nursing student); *"that's quite shocked me"* (1st year adult nursing student); *"I think its disgusting"* (Child branch nursing student) *"why would you not treat her? I think it is so frustrating"* (Operating Department Practice) *"because Emma has the right as much as everybody else to receive treatment"*(Occupational Therapy student)

The students appeared to agree that there were low expectations of Emma (8 out of the 14 focus groups) when considering why the doctors decided not to treat her.

"I think he looked at her disability and saw that she wouldn't be able to cope with it" (Radiotherapy and oncology). The low expectation of Emma having a learning disability appeared to be a common theme emerging from the focus groups:

"it seemed like he was basing his decision on the fact that Emma had got a learning disability and she wouldn't be able to cope with treatment" (3rd year Adult nursing students)

The students generated a wide range of ideas that could have been tried with Emma, to respond to the difficulties that were being presented. In fact students from 9 out of the 14 focus groups came up with ideas that could be classified as making "reasonable adjustments" for Emma:

Some of the students in the focus groups suggested that if Emma had received a more comprehensive assessment then this might have made a difference to the outcome:

"could have done a proper assessment and like put her in treatment position to see if she could manage them rather than just write her off" (Radiotherapy student)

"I'm guessing that he hadn't really assessed all aspects of her personality and the disorder before deciding and discussing with Emma whether she wanted the treatment or not" (Occupational Therapy student)

"unless the doctor did like a full psychological examination or assessment then its not really his place to just make one statement like that and to withhold all the treatment" (Physiotherapist student)

Others suggested that either improving or adapting the communication process between the doctor and Emma might be effective: *"he might have felt a bit uncomfortable like talking to her, because he might not have the communication to tell her"* (Social Worker student); *"probably failed using verbal communication and on that basis didn't treat"* (Paramedic student).

Some of the suggestions that the students came up with explored a range of options from giving a choice in the treatment *"there's also other options she could have tolerated chemotherapy, possibly surgery"* (Radiotherapy) *"he didn't even look at palliative care"* (3rd year adult nursing student); to pain relief *"just managing her pain, its better than nothing obviously"* (3rd year adult nursing student).

The students picked up on the 50:50 chance of survival and felt that Emma should have been given a positive response to her situation *"50/50 chance is a perfectly strong chance of living "* (Occupational Therapy student)

2. What would you do on a ward if a patient decided not to cooperate with treatment?

	Communicate with the person	Get help from another professional	Involve the family	consider the Mental Capacity Act	Make changes to the environment
CASE STUDY 1- EMMA					
2. What would you do on a ward if a patient decided not to co-operate with treatment?					
BA(Hons) Adult Nursing (year 1)	•		•		
BA(Hons) Adult Nursing (year 2)					
BA(Hons) Adult Nursing (year 3)	•		•		
BA(Hons) Mental Health Nursing		•	•		
BA(Hons) Child Nursing	•	•	•		
BA(Hons) Nursing (learning disability) and Generic Social Work	•	•	•	•	•
BSc (Hons) Physiotherapy	•	•		•	
Masters in Social Work	•		•		
BA(Hons) Social Work	•	•	•	•	
BSc(Hons) Occupational Therapy	•	•	•	•	
BSc(Hons) Diagnostic Radiography	•	•			
BSc(Hons) Midwifery	•			•	
BSc Radiotherapy and Oncology					
Dip HE Paramedic Practice	•			•	
Dip HE Operating Department practice			•		
Total	11	7	9	6	1

The overwhelming response from the focus groups (11 out of 14) was to suggest communicating with Emma: *"at first I'd speak to the patient, like in this case Emma, about why she's not co-operating with the treatment. See if there's anything upsetting her or if it might be she doesn't understand the treatment and explain to her what the treatments for, how long its going to help her and if it is still an issue maybe talk to her mother as well"* (Occupational Therapy student)

The students were keen to explore communication in terms of checking the patient's understanding

"You also got to make sure the patient understands what you want them to do, because they might not be cooperating because they don't understand. So if you can explain to them until they do understand they might actually be happy to do what you want them to do" (Physiotherapy student)

"yeah often its because like they don't understand why your doing it and that's why they wont co-operate, so I think that's important" (Physiotherapy student)

Some of the responses did suggest flexibility in approach and the idea of having a contingency plan if the person wasn't co-operative on the day: *"I wouldn't dismiss them straightaway, you would have to try and motivate them or talk them round or*

just talk to them or ... then if that didn't work, then maybe cancel it for the day and try again another day, on a better day" (Physiotherapy student)

"you maybe just have to leave it a while for them to think about it and then come back to them" (Radiotherapy student)

Others recognised the importance of family members (9 out of 14 of the focus groups) and in the absence of a family member an advocate:

"if she doesn't have those communication skills it may be that she's got an advocate who could talk to her" (Physiotherapy student)

Although there was a commitment to communicate with Emma and take a problem solving approach to Emma's case study there were some suggestions which indicated that some focus group participants might not necessarily understand what sort of communication challenges a person with a 'severe learning disability' may present with. Some of the suggestions to communicate with Emma were sometimes complicated and suggests that the students may not necessarily know the right language to use in these situations:

"you could just ask Emma what she wants to do, whether she wants to carry on with the treatment today or whether she, ... just get her opinion on it" (Physiotherapy student).

"or they might see it that it might restrict their lifestyle to some extent and they might not want that" (3rd year adult nurse)

"or they might know someone who's already gone through it and its not had a very good outcome, so they think oh that's just going to happen to me, but that might not be the case" (3rd year adult nurse)

"and perhaps they're worried about side effects or consequences of the treatment that aren't particularly probable but still likely to impact on their lives if they did happen" (3rd year adult nurse)

"I mean she could have said that she doesn't want to do this for a long period of time knowing full well what she was being asked to do" (Physiotherapy student)

There was some confusion about the Mental Capacity Act 2005 in terms of what people understand it to mean and how it will influence decisions made in practice by the health and social care practitioner: *"It also depends on where they fall under the mental capacity act, because if they're not compliant to treatment but they fail to meet the mental capacity act, so that they are not deemed as being able to make an informed decision, then an advocate would be able to make a decision for them" (Physiotherapy student).*

Uncooperative behaviour within a health care setting, can be misinterpreted as the person not wanting to have treatment: *"I would ask them why they didn't want to cooperate, if they'd got a reason, because everyone's got a choice whether they want*

treatment of not" (Social Worker student). "or maybe they decided that she could consent and she said she didn't want it because she can say that" (Paramedic student). "I think we have to support them in their decision. Once we've done as much as we possibly can to try and persuade them, if they're adamant that they don't want the treatment then that is up to us to then just deal with that and help them deal with this" (Occupational Therapy student). "And at the end of it all just to respect their decision about whether they want to have treatment of not yeah" (Midwifery student).

Without a clear means and method of communication it would not be possible for any practitioner to be able to conclude about choice of treatment from a person's behaviour.

There was a lack of clarity over who could consent for Emma: *"he decided that she couldn't consent as well, so he made that judgement for her and her parents. Instead of asking the parents for consent" (Paramedic student) . "yeah they should have spoken to her mum really and then she probably would have like given consent for her child to have the treatment" (Paramedic student).*

There was some confusion between the Mental Capacity Act and the Mental Health Act: *"under the mental health act as well its all about who can consent and why and if you cant consent then you (the paramedic) have to be the one who makes that decision, in our paramedic job anyway. You make the decision for them if they cant consent" (Paramedic student). In addition there was also confusion in terms of the Mental Capacity Act 2005 and terms that might have preceded this act: "and it is also about assessing whether they have the mental capacity to actually make a decision. its to do with the Gillett competence isn't it, whether they actually have the mental capacity to actually make a decision" (midwifery student)*

3. Would you argue with the doctor about not treating Emma?

	Yes I would	I would be careful in challenging the Doctor	It is an equality and human rights issue
CASE STUDY 1- EMMA			
3. Would you argue with the doctor about not treating Emma and if so what would you say?			
BA(Hons) Adult Nursing (year 1)		●	
BA(Hons) Adult Nursing (year 2)			
BA(Hons) Adult Nursing (year 3)		●	
BA(Hons) Mental Health Nursing	●		●
BA(Hons) Child Nursing	●		
BA(Hons) Nursing (learning disability) and Generic Social Work	●	●	
BSc (Hons) Physiotherapy		●	
Masters in Social Work			
BA(Hons) Social Work	●	●	
BSc(Hons) Occupational Therapy	●	●	●
BSc(Hons) Diagnostic Radiography	●		
BSc(Hons) Midwifery	●		
BSc Radiotherapy and Oncology			
Dip HE Paramedic Practice		●	
Dip HE Operating Department practice	●		
Total	8	7	2

One of the focus groups suggested that over time it has become easier to challenge professionals. This she argues is because *"people are getting more confident to say okay well just because you are the professional doesn't mean you are, the buck stops with you, there must be somebody else that can speak to"* (Physiotherapist student).

Approximately half of the students in the focus groups (8 out of 14) said they would argue with the doctor about his decision. Radiography students, Occupational Therapist students, social worker students, Joint Nursing and Social Work students, Midwifery students, ODP students, child branch and mental health students said they would argue with the doctors and referred to their advocacy role as a developing professional *"because nurses and midwives are meant to be advocates for the patients (Midwifery student); "I would definitely argue with them and tell him that she's a human being and she's every right to treatment"* (Child branch student).

The students suggested that they would challenge the decision not to give pain relief *"the fact that she didn't get anything for pain, that's just cruel really, especially with cancer"* (Physiotherapy student).

Others felt they would challenge the basis of the decision: *"you'd want to know how they came to that conclusion, would you, what information?"* (Physiotherapy student). *"If he cant deal with the patient does he not know anyone else that could communicate with the patient?"* (Radiography student) . Mental health student nurses and occupational therapy student nurses suggested they would argue from an Equality, Human Rights and ethical perspective: *"people with learning disabilities deserve exactly the right, they have the same rights as anyone else"* (Occupational Therapy student) *"but you are supposed to follow ethical guidelines and he isn't being ethical at all"* (mental health nursing student).

There were other students (7 out of the 14 focus groups) who suggested that they would need to be careful in 'arguing' with the doctor: *"we would challenge it but you would have to think about what you'd say and be very careful"* (3rd year adult nursing students); *"just ask them if they would like to consider another option"* (3rd year adult nursing student). *"I don't think I'd argue with him, I think I would just challenge what he decided to do"* (Social Worker), *"I would not argue as such but I would like to feel that there are channels or protocols that I need to follow to make sure that Emma's situation is actually addressed"* (Joint nursing and social work student, learning disability).

For some people they were clear that they would not challenge such a decision: *"We would definitely get raised eyebrows if we started to tell a doctor how to treat"* (Paramedic student). *"and if the doctors are of that mindset where he's not going to treat somebody because of a learning disability then he's not going to be very approachable in the first place is he?"* (1st year adult nursing student)

4. What are the barriers to you providing care to someone with a learning disability?

CASE STUDY 1- EMMA					
4. What are the barriers to you providing care to someone with a learning disability?	Lack of training in LD	Communication barriers	A busy hospital environment	Time	Power/status barriers
BA(Hons) Adult Nursing (year 1)		•		•	
BA(Hons) Adult Nursing (year 2)		•			
BA(Hons) Adult Nursing (year 3)	•	•		•	
BA(Hons) Mental Health Nursing	•	•			•
BA(Hons) Child Nursing		•	•	•	
BA(Hons) Nursing (learning disability) and Generic Social Work	•	•	•	•	
BSc (Hons) Physiotherapy		•			
Masters in Social Work					
BA(Hons) Social Work	•	•			•
BSc(Hons) Occupational Therapy	•			•	
BSc(Hons) Diagnostic Radiography	•				
BSc(Hons) Midwifery			•	•	
BSc Radiotherapy and Oncology					
Dip HE Paramedic Practice		•			
Dip HE Operating Department practice		•			
Total	6	10	3	6	2

What are the barriers to you providing care to someone with a learning disability?

There was an overwhelming consensus from the focus groups (10 out of 14) that communication barriers were likely to be in existence. The students were very much driven from a person centred approach and suggested that the doctors should have talked to Emma: *"he should have asked her how she felt about it rather than assuming that she wouldn't be able to cope"*(Radiotherapy student).

While the students advocated for Emma to be involved as much as possible the students also recognised that communication barriers were prevalent in a number of ways.

There were the barriers that professionals put up sometimes unconsciously: *"communication barriers, they (the person with a learning disability) may not understand .. especially if the doctor just came up to you and speaking a load of jargon"* (3rd year adult nursing student). Other barriers included understanding non-verbal communication and understanding the communication function of behaviour.

There were solutions to breaking with these barriers:

"amend communication so that they do actually understand and use their preferred method of communication" (Joint Nursing and Social Work student)

"I think if someone is displaying behaviour they are doing it for a reason. You need to get to the root of that and then if it's the challenging behaviour that is making her not cooperate then that's something that you and all the other members of the team need to work on" (Radiography student)

"you could give them leaflets and things, perhaps explaining about the condition or treatment or things like that (3rd year adult nursing student). "and you're body language as well, making sure that you've got sort of your open when you go and meet them for the first time and smile and things like that" (3rd year adult nursing student). Paramedic students recognised that there might be limitations to the professional's own communication style: *"and also they might communicate using sign language and our communication is just like waving your hands about and pointing at things to try to get your message across"* (Paramedic student).

Some students recognised that a lack of training of Doctors and nurses might be a barrier and might have had a bearing on the decision that was made: *"maybe the doctor's been given inadequate training on how to deal with people with learning disabilities and not given the patient the time they have needed with the doctor"* (Radiographer student). *"it doesn't sound like the doctor properly understood her condition and the fact that they gave her no advice at all, not even to the mother, on how to deal with the situation is quite bad I think, yeah"* (Radiographer student). *"He (the doctor) might not be educated in communicating with people with learning disabilities, didn't know how to seek support with interaction perhaps"* (Social work student).

Another barrier is more the physical one of the environment in the hospital setting and the concept of 'time'. It was argued that the environment *"in terms of space might be difficult if you need to go somewhere quiet where the person can fully concentrate"* (Midwifery student) and that the environment might be a *"busy ward with lots of staff ... constant changeover and things can get missed or done differently"* (3rd year adult nursing student). Time was referred to in terms of its limited availability: *"how much time have you got to deal with them"* (Joint nursing and social work student learning disability) and that this might be difficult if *"the person might need one to one"* (Occupational Therapy student). *"if you wanted to sit with someone and explain to them about treatment and like was suggested use different methods of communication, you cant rush it, you need to have the time to sit with them for as long as they need you to explain it to them clearly"* (Midwifery student)

CASE STUDY 2 - TOM

	A lack of practitioner knowledge	The Doctor knows best	Not valuing the parent views	Not valuing a person with a learning disability	The hospital environment medicalising behaviour	They wanted hear from the patient
CASE STUDY 2 - Tom						
1. Why were Tom's parents not listened to?						
BA(Hons) Adult Nursing (year 1)	•	•	•			
BA(Hons) Adult Nursing (year 3)		•	•			
BA(Hons) Mental Health Nursing						
BA(Hons) Child Nursing	•	•		•		
BA(Hons) Nursing (learning disability) and Generic Social Work		•	•			
BSc (Hons) Physiotherapy			•			•
Masters in Social Work					•	
BA(Hons) Social Work		•	•			
BSc(Hons) Occupational Therapy			•			
BSc(Hons) Diagnostic Radiography	•		•	•		•
BSc(Hons) Midwifery		•				
BSc Radiotherapy and Oncology		•		•		
Dip HE Paramedic Practice			•	•		
Dip HE Operating Department practice	•	•	•	•		
Total	4	8	9	5	1	2

Why were Tom's parents not listened to?

People with a learning disability are not valued argued students in 9 out of the 14 focus groups. They argued: *"a lot of people see them as a low class citizen, which is obviously not the case I think the amount of effort that it would take to work with this person outweighed what the doctors and medical profession wanted to do"* (Paramedic student). There is sometimes misinformation about learning disability from a healthcare professional perspective: *"when I first started looking after people, some people actually thought that patients with learning disabilities don't feel pain. Because that's how ignorant they were"* (Mental Health student focus group). Others felt that it wasn't professional ignorance why Tom's parents were not listened to.

They felt that the Doctor valued what the patient had to say and if the patient has not been able to represent themselves then they may not believe the patient's representative: *"they (the doctors) probably thought they were being over protective .. doctors tend to prefer to hear it from the patient themselves rather than somebody else's second hand opinion"* (Physiotherapy focus group). This suggests a lack of knowledge in working with parents and carers to explore a more collaborative way of working for vulnerable patients.

There was some suggestion (8 out of the 14 focus groups) that the 'doctor knows best' and the explicit knowledge of the doctor is valued more highly than the tacit knowledge of parents: *"they probably thought that they knew best, they're the experts, so called experts; probably thought that they knew better than his parents because they work with people"* (Child branch student).

It may also be that health professionals lack insight into how the people most closest to them may know the most about them: *"parents know that they can interpret his behaviour better than what the health professionals can"* (Social Worker student). Knowledge domains were explored by some focus groups suggesting that the carer might have greater knowledge than the healthcare professional in some situations: *"but even through healthcare training you might come across certain learning disabilities but you don't come across, they're not the same in every person. So obviously the carer's got better knowledge"* (ODP student). *"Because family and relatives can know a patient a lot better than anybody else can. Like when they were saying that Tom changes his behaviour because he was in pain, they knew him and they knew that that's why he was doing it"* (3rd year adult nursing students).

Not all students believed this to be the case suggesting that the views of carers/parents might not be reliable knowledge: *"they might think the parents are exaggerating caring for the, like disability, like they're more overprotective of him and increasing the symptoms and things like that"* (Radiotherapy and Oncology),

There was some suggestion of a 'knowledge hierarchy' where carers are placed at the bottom and the consultant at the top. However in the ODP focus group they could draw upon examples where this hierarchy wasn't always fixed but it was dependent on individual medical practitioners: *"yeah I mean I have seen the surgeon and the anaesthetist ask for the carer to be brought into theatre, but I have also seen the opposite of that, through the carer being asked to leave. It is down to individual medics at the end of the day sometimes"* (ODP focus group). This view was supported by another focus group who said: *"its very much been down to medical staff and what they think"* (3rd year adult nursing students).

The issue of power emerges as a theme from the focus groups: *"Like you say it's the power and they don't want to appreciate that the people closest to them have got all this knowledge about them"* (Social Worker student). 'Power' was not just explored in relation to the doctor/relative dynamic but it was also considered to exist amongst all

professionally trained groups: "sometimes there is a mentality between some health professionals where they think I know best because I've done such and such a training, but in most cases with children with learning disabilities the parents will know what is going on" (Occupational Therapy). "And I think sometimes maybe health professionals feel they know better. So the parents are saying that they feel that this is his way of expressing pain, but maybe the health professionals are just kind of dismissing it and saying well no that's just normal behaviour not appreciating his parents knowing best" (Midwife).

<p>Tom was just 20 years old when he died. He had profound and multiple learning disabilities and died of aspiration pneumonia and reflux oesophagitis. While he was still at school his parents insisted that Tom was in pain and that he be referred for medical investigation. Further investigations were not made and he continued to lose weight and engage in unusual behaviours such as gouging his head. Tom's parents felt he was expressing pain through the behaviours. Tom had an ulcerated oesophagus but died before receiving nutrition as he was so weak.</p>	Negative behaviour seen as part of the learning disability	A hospital environment which medicalises conditions	Parents views are viewed negatively and not valued	Needed further assessments/specialists	Is it what Tom normally does?	A lack of knowledge of learning disability	A lack of time in the hospital environment
CASE STUDY 2 - Tom							
2. Why were the strange behaviours not seen as something wrong with Tom?							
BA(Hons) Adult Nursing (year 1)	•						
BA(Hons) Adult Nursing (year 3)	•	•				•	
BA(Hons) Mental Health Nursing	•						
BA(Hons) Child Nursing	•					•	•
BA(Hons) Nursing (learning disability) and Generic Social Work	•		•				
BSc (Hons) Physiotherapy	•				•		
Masters in Social Work	•						
BA(Hons) Social Work	•				•		
BSc(Hons) Occupational Therapy	•				•		
BSc(Hons) Diagnostic Radiography	•		•				
BSc(Hons) Midwifery	•			•	•	•	
BSc Radiotherapy and Oncology	•			•			
Dip HE Paramedic Practice	•		•		•		
Dip HE Operating Department practice	•						
Total	14	1	3	2	5	3	1

Why were the behaviours not seen as something wrong with Tom?

All the focus groups responded saying that Tom's behaviour was seen as part of his learning disability and not symptoms of ill health. "Because of stereotypes they felt it was just something that people with learning disabilities do, so they didn't challenge it or try to explore it" (Social Worker student). We now know that the tendency of explaining symptoms of ill health as part of a person's learning disability is called

"diagnostic overshadowing" (Mason and Scior, 2004). The Physiotherapy focus group felt that this problem occurs because there is insufficient information (or a baseline) of how the person is when they are well: *"I think if you don't know what normal is for a person with a learning disability you haven't got a baseline. Whereas if someone who doesn't have a learning disability .. and then being ill is their abnormality, so that's how you know that they're ill and maybe that's what's different"* (Physiotherapy focus group)

	Try and stop them	Talk to them and ask them why	Is it what the person normally does	Try to understand why	Undertake assessments/observations and check for triggers	Check the care plan	Talk to the relatives	Think of our own safety	Seek out help and guidance from other professionals	this is the wrong question, why arnt the doctors doing more about it?	try other methods of communication
CASE STUDY 2 - Tom											
3. What would you do if you saw a patient hurting themselves?											
BA(Hons) Adult Nursing (year 1)			●				●		●		
BA(Hons) Adult Nursing (year 3)		●	●								
BA(Hons) Mental Health Nursing											
BA(Hons) Child Nursing		●	●	●			●				
BA(Hons) Nursing (learning disability) and Generic Social Work		●	●	●	●		●				
BSc (Hons) Physiotherapy	●		●	●				●		●	
Masters in Social Work											
BA(Hons) Social Work		●					●				
BSc(Hons) Occupational Therapy	●	●	●				●	●	●		
BSc(Hons) Diagnostic Radiography											●
BSc(Hons) Midwifery		●					●		●		
BSc Radiotherapy and Oncology	●	●	●								
Dip HE Paramedic Practice			●				●				
Dip HE Operating Department practice	●		●	●							
Total	4	7	4	9	1		7	2	3	1	1

What would you do if you saw a patient hurting themselves?

When asked about what they would do if they saw someone hurting themselves, there were different perspectives from the students, while some said they would try to stop the behaviour, one person said they would not try and stop the behaviour as this might have severe consequences for the person: *"you can do more harm if you stop them sometimes, because if you restrain them, obviously you are not allowed to do that anymore but .. I remember one case where they restrained him and he was using that much force with his arms to hit himself he broke his arm. He actually physically broke his arm from the restraints"* (Mental Health focus group)

Others came up with using different forms of communication to try to understand why the person was hurting themselves: *"If they're having difficulty in telling you in speech how they're feeling, see if they can write it down or draw a picture of it"* (Radiotherapy student focus group). The same group of students wanted to get further help in this communication process and suggested identifying calling in services to help: *"or get just someone more socialised who understands what's going on to like try and help interpret why, like if you don't have the skills to do it yourself then there must be someone you can call on to help interpret what the patient is trying to say, so its like calling in extra services"* (Radiotherapy student focus group). Unfortunately these students did not identify who this might be, what sort of extra services they might be and from which organisation. It is possible that an Independent Mental Capacity Advocate may be appropriate to step in here but (only available if no friends and family are around).

There was a suggestion that community facilities would be more geared up to understanding and managing behaviour as opposed to a hospital environment: *"I haven't seen it (patients hurting themselves) on a ward but in a community its definitely dealt with better than in sort of an acute hospital setting"* (3rd year adult nursing students) Another student from the same focus group suggested that she had seen a patient hurting themselves on a ward: *"I've seen it on a ward but it wasn't dealt with very well because this lady had challenging behaviours so was quite aggressive anyway and she was in a lot of pain. But we couldn't distinguish between whether it was just her behaviour or whether the pain was causing her to act in that way. So I think it was dealt with quite badly really because the medical staff, especially the doctors, couldn't really, didn't understand as much as they should do"* (3rd year adult nursing).

	Talk to them	Calm them down	Establish if the behaviour was normal for the person	Try to understand why the behaviour was occurring	Listen to people who know the patient	Get help from other professionals	Try to communicate using a range of methods	unless you know the person you cant do anything about it create a safe space
CASE STUDY 2 - Tom								
4. What would you do if you saw someone showing challenging behaviour?								
BA(Hons) Adult Nursing (year 1)			•					•
BA(Hons) Adult Nursing (year 3)			•	•				
BA(Hons) Mental Health Nursing								
BA(Hons) Child Nursing			•				•	
BA(Hons) Nursing (learning disability) and Generic Social Work			•	•				
BSc (Hons) Physiotherapy			•	•				•
Masters in Social Work			•					
BA(Hons) Social Work			•	•	•			
BSc(Hons) Occupational Therapy	•	•						
BSc(Hons) Diagnostic Radiography			•					
BSc(Hons) Midwifery			•				•	
BSc Radiotherapy and Oncology		•						
Dip HE Paramedic Practice			•					
Dip HE Operating Department practice	•						•	
total	2	2	1	4	1	3	1	1

What would you do if you saw someone showing challenging behaviour?

The one area of consistency in responding to this question was a clear commitment from students to understand why the behaviour was occurring (11 out of 14 focus groups). It is not clear from the student's responses as to how they were going to understand the function of challenging behaviour and there was no reference to a range of specific assessment and observation instruments that are helpful when trying to understand the purpose and function of difficult behaviour. None of the best practice in this area was cited by students although they did all explore a process of enquiry they would go through to try to determine the cause of challenging behaviour: *"I've seen children where they have banged their heads against the door it is for a reason. So if you understand that behaviour you might be able to do something without it getting to that stage"* (Social Worker student). *"I have noticed sometimes when i have been out on placement, things they do are in a way like wanting your attention, they're trying to tell you something. So I believe that they're doing it for a reason"* (Occupational Therapy). *"Trying to get other professionals together and find a pattern in that behaviour"* (Social Worker). There was also a lack of evidence base

knowledge informing the understanding of behaviour. One person talked of behaviour more likely to be seen in mental illness than with people with a severe learning disability *"If they're like cutting their wrists, if we were to approach them theres nothing to say that they're not going to lash out on us for like interfering"* (Occupational Therapy).

One mental health student cited an example of a form of restraint that had been observed as a behavioural management strategy on a hospital ward. The example illustrates that there are particular problems of managing behaviour of people with a learning disability in a hospital setting and perhaps a lack of networking with skilled leaders in learning disability practice or learning disability advocacy services:

I looked after a patient before Christmas who had Downs syndrome. He was 65 and came in with query swine flu. He ended up having pneumonia. I was the second nurse to look after this patient at my handover it was reported that he was aggressive, he'd had five lots of haloperidol and boxing gloves were on him to stop him from pulling the leads out. The first thing I did was to take the boxing gloves off because i cant stand them. He wasnt aggressive; he just wanted to get out of bed. he couldnt understand why he had to stay in bed because in the nursing home he walked around with a frame. That is the attitude of a lot of nurses, mental health, haloperidol, knock them out and keep them in bed. It just frustrates me so much

CASE STUDY 3 - MARTIN

Martin died of a stroke at age 43. He had a severe learning disability and no speech. In the 26 days that he spent in hospital before he died he went without food. The hospital failed to use a nasal feeding tube to prevent his condition from deteriorating. This left him feeling too weak to undergo surgery. The hospital admitted it did not act on information that Martin was assessed as being at high risk in relation to a malnutrition assessment.

CASE STUDY 3 - Martin

1. If someone has no speech how would you communicate?	use alternative methods to communicate	A lack of time	a failure to record key information about a patient	There's alternative methods of giving someone food	feeding is part of human rights	nutrition chart	Other assessments should be done through their carers	lack of evaluation	behaviour can be used as communication	afraid of learning disability	acquiescence
BA(Hons) Adult Nursing (year 1)	●	●	●	●	●	●					
BA(Hons) Adult Nursing (year 3)	●					●					
BA(Hons) Mental Health Nursing	●		●				●				
BA(Hons) Child Nursing	●										
BA(Hons) Nursing (learning disability) and Generic Social Work	●									●	
BSc (Hons) Physiotherapy	●						●				
Masters in Social Work	●						●	●	●	●	
BA(Hons) Social Work	●						●				
BSc(Hons) Occupational Therapy	●						●				
BSc(Hons) Diagnostic Radiography	●						●	●			
BSc(Hons) Midwifery	●		●			●	●	●		●	●
BSc Radiotherapy and Oncology	●						●			●	
Dip HE Paramedic Practice	●	●				●				●	
Dip HE Operating Department practice	●					●		●		●	
Total	14	2	3	1	1	5	2	7	3	1	6

Alternative Communication

All students in the 14 focus groups identified that they would use alternative ways of communicating with Martin as he had no speech. Students came up with a number of solutions which were either completely intuitive: *"there are all kinds of ways to communicate; you just kind of do it. It sounds obvious but you just kind of find a way to do it"* (Paramedic student) or based on a more formal process of inquiry: *"well it doesn't mean they can't understand you, it just means that they can't talk back, so you've got to, again it's all about what's in the care plan and what their family and friends and support workers and whoever else are involved with them normally, how they'd normally communicate with them. So it's about finding out from the how you*

can do your job basically. So its using their expertise again isn't it? And then obviously he may display behaviours when he wants something or when he doesn't want something, and you just need to learn what those are" (Masters Social Work student).

For others there seemed to be a lot of support for using sign language, yet it was not evident that this was the communication method of choice from the case study:

"even I'm doing a sign language course and like its just common sense, like a sign for eating, a sign for drinking, its simple your don't need to speak through that" (1st year adult nursing student)

"sign language, or picture cards" (ODP student)

"signs, pictures" (Midwifery student)

"sign language, you can use pictures and diagrams" (OT student)

"signs and symbols" (Physiotherapy student)

"reading, sign language, picture charts, makaton, picture banks" (child branch student)

"like you can do sign language; get him to do sign language" (Radiotherapy and Oncology)

While sign language might have been appropriate it might have also been completely inappropriate as the students themselves were not proficient in the use of this medium of communication. An assumption can sometimes be made that all people with a learning disability use sign language, which is an incorrect assumption to make:

"I mean surely he'd sign if he couldn't speak" (mental health nursing student)

It would have been preferable to hear more about talking to people who know Martin and identifying his preferred method of communication. The following are suggestions along this line of inquiry:

"you can use the parents because of course they know the patient or the main carer, they know the patient best. They know the best ways that the patient can communicate and also become the best translators" (Radiotherapy student)

"talk to the relatives and some wards have the little white boards patients can write on" (3rd year adult nursing students)

"consult the carer" (physiotherapy student)

"Communicate through the carer" (OT student)

Fear of Learning Disability

Just under half of the focus groups (6 out of 14) suggested that people might be afraid of people with a learning disability: *"yeah maybe it is like nurses are, I don't know not saying, I don't know just like scared really because of their own lack of understanding they don't know where to start from, they don't know, its just like if you didn't have any training for anything, you cant just you know, your afraid of making mistakes as well"* (Joint nursing and social work student)

"no at the end of the day I think it comes down to training again ... i think there is a fear factor as well" (ODP student)

"I think some people have a fear of people with learning disabilities, like severe, I mean you know they'd be, because they're probably different like. I know some people that would be scared of them. Its not right. More training we need, yeah more training" (Radiotherapy and Oncology)

The consequence of being afraid of people with a learning disability is that people do not provide the care and support that is expected from health and social care services:

"I think maybe as well, it is ignorance but I think a lot of people are quite afraid of learning difficulties, they don't know how to deal with it and so if they go into a ward and see .. It wouldn't surprise me if they're quite kind of avoided, do you know what I mean, kind of well the next person on shift will sort that out, do you know what I mean and it will get left and left. Because people don't know how to deal with it and so they'll be scared of it" (Masters social work student)

"I mean having worked on a ward, I can totally see what you mean about somebody on the next shift will do that. it comes to like 12 o'clock and you think you know what, I've been here all morning, I'm run ragged and I actually cant be bothered to deal with this .. and that's how this man has been left for 26 days because nobody has actually taken the bull by the horns and said do you know what I'm ringing a dietician, I'm going to get him a nasal gastric tube" (Midwifery student)

"I think sometimes because some people find it difficult to communicate or like spend time with people with learning disabilities because they don't know how to communicate with them, that they like avoid it and spend less time with them" (Paramedic student)

	organisational failure	no structure to care	nobody taking responsibility	failed to use a nasal feeding tube	didn't monitor care	didn't write in down in his notes	no food charts	food given out and taken away	staff are overworked and overstretched	no one acting on the change in condition	he didnt have speech to ask for food	no one communicating with each other	probably in pain	fear of learning disabilities	no training in learning disability	didn't like the food
CASE STUDY 3 - Martin																
2. Why did Martin not have nutrition for 26 days?																
BA(Hons) Adult Nursing (year 1)	•		•		•	•				•						
BA(Hons) Adult Nursing (year 3)					•		•					•				
BA(Hons) Mental Health Nursing	•	•	•													
BA(Hons) Child Nursing	•		•	•	•	•	•	•								
BA(Hons) Nursing (learning disability) and Generic Social Work	•				•	•	•	•			•					
BSc (Hons) Physiotherapy				•	•	•	•	•			•	•				
Masters in Social Work					•							•				•
BA(Hons) Social Work	•		•		•	•				•	•	•				
BSc(Hons) Occupational Therapy				•							•	•				
BSc(Hons) Diagnostic Radiography					•											
BSc(Hons) Midwifery			•										•			
BSc Radiotherapy and Oncology					•			•		•	•	•	•	•	•	•
Dip HE Paramedic Practice	•			•	•			•								•
Dip HE Operating Department practice			•		•							•				
Totals	6	1	5	4	11	5	3	2	5	2	5	8	1	1	2	1

Why did Martin not have nutrition for 26 days?

The students in the focus groups came up with a range of reasons why Martin didn't have nutrition for 26 days. The two most common suggestions were that staff 'didn't monitor the care' (11 out of 14 focus groups) and that 'staff were not communicating with each other (8 out of 14 focus groups).

Students within the focus groups believed that staff should have been writing down and monitoring the care provided. They should have been recording fluid intake and urinary outputs and having some sense of how much was being eaten. *"if he was high risk they should have been writing it down"* (Paramedic)

"you should always document like what you do as well and always like the handovers just say ,... just cant believe like you get somebody going 26 days .." (Physiotherapy student)

"obviously didn't monitor him. There is no evidence of it is there? You're supposed to have these monitor sheets that they do every day so that they could have kept an eye on him" (Child branch student)

There was some debate across the focus groups about whose responsibility it is to check that the person has eaten their meals. There was discussion about the use of

outside caterers and how reliable this service was to ensure that the relevant observations were being made about meeting dietary and nutrition requirements.

A lack of observations would lead to fewer reporting opportunities and a breakdown of communication:

"that's probably down to a lack of communication because you always think that somebody else is going to follow something up ... but that should be done when he was admitted.... yeah .. they should have been reading the notes" (Child branch student)

"lack of communication maybe between the staff" (Physiotherapy)

"I think it's the sort of thing where they could have been told but they're so busy they hadn't written it down and you forget, the person forgets and then nobody knows" (1st year adult nursing student)

	named nurse	keyworker	enforce the policy	fill out the referral and refer him	follow it up	follow policy	monitor through observations	communicate	document it	bring in a specialised LD nurse	get a multi agency meeting going	talk to martin	reassessed Martin	staf need training	speech and language involved	dietician involved	bring in the family	look back at his risk assessment
CASE STUDY 3 - Martin																		
3. What would you do to make sure martin got nutrition?																		
BA(Hons) Adult Nursing (year 1)																		
BA(Hons) Adult Nursing (year 3)								•	•									
BA(Hons) Mental Health Nursing	•	•	•															
BA(Hons) Child Nursing				•	•	•	•											
BA(Hons) Nursing (learning disability) and Generic Social Work		•	•		•	•	•	•	•	•								
BSc (Hons) Physiotherapy							•		•	•								
Masters in Social Work									•	•				•			•	•
BA(Hons) Social Work							•		•		•	•						
BSc(Hons) Occupational Therapy				•			•	•	•						•	•		
BSc(Hons) Diagnostic Radiography							•											
BSc(Hons) Midwifery			•			•	•	•						•		•		•
BSc Radiotherapy and Oncology							•						•	•	•			
Dip HE Paramedic Practice							•		•									
Dip HE Operating Department practice								•				•						
Totals	1	2	3	2	2	3	8	7	7	2	1	2	1	3	2	2	1	2

What would you do to make sure Martin got nutrition?

There is the likelihood that people with a learning disability will 'acquiesce' which is the tendency for the person to say what they think the enquirer want s to hear. Simply asking a question such as 'have you eaten your meal today' may prompt a response: 'yes I have', when they in fact have not.

"When you ask them if they've passed urine or had their bowels open, you don't go and watch them, they'll say yes I have ... and yes you take their word"(Midwife student)

Whose responsibility to feed a patient?

There is a need to establish who is doing what in terms of roles, responsibilities and accountability. Checking levels of nutrition should be a standard feature of care particularly with vulnerable adults in hospital settings.

"in my placement area we have catering staff and the nurses don't actually go in and deliver the food, it's the catering staff who go in and just drop it off and I think that sometimes when they come back and if they see its not been eaten then its not been eaten, fair enough, they've not got any sort of knowledge about the patient" (ODP student)

"and I mean whether its an outside company that delivers this food and feeds this patient and takes it away, everyone has a duty, surely that person eventually would say well they haven't eaten anything, they haven't touched a meal for four days" (Paramedic)

"a lot of qualified nurses still think that's its not their job to feed patients; they'll say its support workers job to do it, so they'd turn a blind eye to it. Do you know what I mean, so its easy to pass the buck ain't it?" (mental health nursing student)

There needs to be a realisation that people with a learning disability in hospital do have increased vulnerabilities and will need extra systems in place to enable accurate communication between professionals and family members:

"we had a lesson yesterday where they're saying like you go on your food round sometimes and people just put trays in front of patients and then just take it away after a certain amount of time". (3rd year adult nursing student)

"it depends on if they're on a food diary or anything, but a lot of the time its not nursing staff that take the trays and things away; its domestic staff who don't pass it on" (3rd year adult nursing student)

	food diary	fluid balance chart	stool chart	proper care	Better communication	could have picked up on the nutrition	staff training	food/nutrition	valuing him	co-operation	planning	Time	Better documentation	interprofessional working	reduce the fear of LD
CASE STUDY 3 - Martin															
4. What could have stopped martin's death?															
BA(Hons) Adult Nursing (year 1)															
BA(Hons) Adult Nursing (year 3)					•		•			•					
BA(Hons) Mental Health Nursing	•	•	•												
BA(Hons) Child Nursing				•	•	•	•								
BA(Hons) Nursing (learning disability) and Generic Social Work				•	•			•	•						
BSc (Hons) Physiotherapy				•	•				•	•				•	
Masters in Social Work					•		•								•
BA(Hons) Social Work					•					•	•	•	•		
BSc(Hons) Occupational Therapy	•	•			•								•		
BSc(Hons) Diagnostic Radiography				•	•		•						•		
BSc(Hons) Midwifery	•	•		•	•		•	•					•		
BSc Radiotherapy and Oncology					•	•					•			•	
Dip HE Paramedic Practice		•					•					•			
Dip HE Operating Department practice					•		•			•					
Total	3	4	1	5	#	2	4	5	2	4	2	2	4	2	1

The majority of students in the focus groups (11 out of 14) agreed that better communication could have stopped Martin's death:

"communicate, got to be fundamental hasn't it for everybody to know so your on, your documenting it, its recorded properly where it is needed to be recorded" (Joint nursing and social work student)

"better communication with the staff on the ward where he was" (Radiotherapy and Oncology)

Better communication can only be in place if staff stop making assumptions about the person and check the details with people who know the person. If people continue to interpret signs of ill health as part of the characteristics of a person's learning disability then communication between professionals will not improve. There has to be some fundamental shifts in attitudes towards people with a learning disability

"and i think some people have made the assumption that he's got a severe learning disability and that's what came into their heads first - that's the way he is normally" (ODP student)

Increased awareness of the vulnerabilities of people with a learning disability will ensure more attention to systems and processes that may not be in place for those

without a learning disability. Such a system can be increased communication between the ward staff and the catering staff:

"ask people who are handing out the meals and things like that if he's actually eaten anything, or like communicate with family and relatives to see if they know if he's eaten anything or not" (3rd year adult nursing students)

A lack of attention and responsibility for Martin from each member of staff led to the inadequate service response in Martin's case:

"maybe they just didn't work together, they didn't communicate. If they didn't feed back to each other saying he hasn't had any nutrition today so obviously the next person needs to try. But they didn't, its that lack of communicating, lack of skill being able to work together to be able to provide that care he needed" (social worker)

Monitoring and evaluation of care requires attention to the policies that alert staff to levels of vulnerability. This midwifery student suggested that it was remiss of staff not to revisit risk assessments and review them on a regular basis:

"and no one seems to have gone back through the case notes and looked at his risk assessment or any assessments or looked at whether he's had anything to eat, or like its like everyone's gone into the notes, written their bit and put them away, they haven't bothered to kind of flick back and see" (Midwife student)

Section 5: Discussion

Several themes were generated from the content analysis of the focus group data. These themes were mapped alongside the current core content of 'learning disability' embedded in the curricula of the undergraduates (Scoping exercise, Appendix 1). What is apparent is the students views were that this content does not currently prepare them to work with people with a learning disability when working across a range of placements in health and social care. Students recognised that they would most benefit from a placement with people with a learning disability but if this was not possible other options might work.

The students expressed a level of dissatisfaction with how learning disability issues had been covered currently in their course:

"nothing, we haven't had any training .. and I think sometimes you are just thrown into that situation and you are expected to know what to do" (ODP student)

"I don't know that I have learnt anything on my course, but I think it is my age and my experience that has helped me" (Mental health nursing student)

The students had suggestions on what would be useful with some asking for a placement: *"we should have a placement for a week"* (Mental Health student) *"or a placement for a couple of days"* (Radiotherapy student) and others suggesting some

training from *"signposting what's available in terms of information that might help the person"* (Physiotherapy student) or *"a module or at least part of a module"* (1st year Adult nursing students). Others suggested *"even a few seminars as well like giving us scenarios a bit like this .. but helping us to know what to do in these situations"*(3rd year adult nursing students).

The discussion in the focus groups that centred around the case studies identified that there are clearly communication barriers in place which will have an impact on people with a learning disability accessing health and social care services. The students themselves have generated a lot of ideas and material for extensive examples of "reasonable adjustments". From dropping the visiting hours to enable parents and carers to support people with a learning disability at meal times, to enabling carers to support their relative in theatre.

The students identified examples of "diagnostic overshadowing" but were just not calling it that! It is clear that more of an awareness of this will help professionals to give greater scrutiny to the assessment process when working with people with a learning disability. There will need to be more attention paid to the assessment of pain for people with a learning disability particularly when some individuals present with complex needs and challenging behaviours.

Understanding and managing complex behavioural difficulties is an area that students consistently demonstrated a lack of skills in. At the same time however, their commitment to want to understand the meaning and function of behaviour was consistently voiced.

There is more of a need to develop basic concepts of alternative and augmentative communication skills so that students can see that there is a clear process to undertake the use of such communication methods with individuals.

Students identified that there needs to be clear communication between professionals and a greater responsibility for writing down and documenting processes for vulnerable patients including people with a learning disability. It cannot just be left to chance that people will eat their meals and drink appropriate levels of fluid.

Students do need clarity on how the Mental Capacity Act 2005 works in practice, perhaps scenarios can be developed to explore the learning from the videos that have been produced.

Reflection on the method of evaluation

The case studies had a powerful impact on the students and were made even more powerful when the focus groups were facilitated by people with a learning disability and who themselves used video clips of others with a learning disability reading out the case study:

"I think this is really, this has raised an awareness hasn't it? It has flagged up that there are other things as well as just the basic guidelines" (Child branch students)

"but it's not such a big thing to address is that we've sat here for an hour in a focus group being spoon fed a bit of information and we're all going oh have we done that, have we done this, and we've got ideas, that's an hour of just six people " (Child branch student)

"Thank you .. we don't usually get the chance to sit down and talk about stuff like this" (1st year adult nursing students)

"I think if you made everyone watch this and made people more aware of it, I think that would be a really, because I got a strong message from watching this, its like quite upsetting. I think if you made everyone watch it because its only like a session, even its during the whole year, at least then it makes people more aware when they're on placement to like make sure everyone's being treated equally and just place a bit more emphasis on it" (Physiotherapy)

"i think its just raising awareness really that you need to think about like, just watching these clips has really shocked me and made me realise how much you need to consider it really. I suppose I've been quite narrow minded and not really seen anything or had experience with patients with learning disabilities. I think the Uni needs to sort that out" (Radiographer)

We would recommend this partnership approach to other aspects of evaluation of education.

Section 6: The design of learning materials

There are six short videos (produced by Speakup) which have been developed in response to the data analysis. The videos are as follows:

1. Reasonable Adjustments and the practitioner
2. Accessible communication
3. Consent, Capacity and Decision Making
4. Diagnostic Overshadowing

5. Methods of communication

6. Reasonable Adjustments and Access to services

These videos and all the resources that accompany this evaluation can be found at <http://www.friendlyinformation.org.uk/LDTKeySkills/index.html>:

Section 7: Conclusions and Recommendations

Conclusions

This evaluation study has attempted to engage positively a number of stakeholders to review learning disability training in the undergraduate programme at Sheffield Hallam University. It has been a complex process as we were committed to working with Speakup to enable them to take leadership with this project. We hope that the work produced here can help to generate an action plan to develop a more coherent training strategy in learning disability across the under graduate curriculum at Sheffield Hallam University.

Recommendations

1. A need to have information about the person prior to admission to hospital. The information could be a video diary, an audio diary, a communication profile, a photograph album with significant milestones and achievements. This helps to establish a baseline for professionals to understand that the person has some level of accomplishment before they become ill.

2. One of the ideas from one of the focus groups was to develop a model of involving parents and carers which should develop good practice in this area. The suggestion was about engagement and about supplying information about access to different medical services: "I think they need to be involved in the decision making right from the start and be fully informed about what the options are. And I think possibly more information about how to access different medical services so that you can use them if you need them" (3rd year adult nursing students)

3. To make sure all students are knowledgeable about the mental capacity act and how this can be applied to a range of scenarios (case studies). Currently students might be aware of the act as a piece of legislation but not be aware of how it could be used in practice (A video has been developed as part of this project to enable undergraduate learning).

4. Undergraduate students are not likely to come across patients and clients who present with challenging/difficult behaviour. Most of the incidents of behaviour explored by students in this study were reflections on previous posts working with people with a learning disability. The key skills in understanding and managing

behaviour are not currently covered in the undergraduate programmes but this would be a positive module for staff from all areas of practice to develop as part of a post-graduate programme.

5. While this evaluation has engaged all programmes within the Faculty of Health and Wellbeing for health and social care, medical training has been excluded due to current provision being based at Sheffield University. The Commission for Equality and Human Rights does however recommend that 'diagnostic overshadowing' and unequal treatment training, should not only be available for all health and social care practitioners but Doctors also. The DRC suggest incentivising training through the GP appraisal system.

6. The DRC also suggests that receptionists should hold specific competencies, and that training providers should work with The Association of Medical Secretaries, Practice Managers Administrators and Receptionists (AMSPAR) and the British Medical Association (BMA) (DRC 2006:92)

7. People with a learning disability should be engaged across the Faculty of Health and Wellbeing and an annual service user led conference could be hosted where all undergraduate students are invited to participate. There is currently a Partners forum made up with people with a learning disability from a range of user organisations in south Yorkshire. This partners meeting might be a useful forum to expand and to ensure all undergraduates are exposed to people with a learning disability as 'partners in education' at the university. This is in line with the DRC recommendations that the participation of people with learning disabilities as leaders in health care organisations should improve (DRC 2006:96).

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Appendix 1 - Scoping Exercise of learning disability training across the undergraduate programmes

Discipline	Year 1	Year 2
Nursing	A 20 minute introduction to a learning disability work book 'Learning Disabilities and the social model'. Students are directed to scenarios and outcomes from 'Death by Indifference' report (mencap, 2007). A total of 150 hours work.	Adult Branch - A piece of work to reflect upon their experiences of working with children, people with mental health needs, people with a learning disability and mother and child experience
Mental Health nursing		Caring for people with complex needs and multiple diagnoses such as physical and mental health problems, learning disability and mental health problems.
Child branch nursing	Learning disability workbook introduction. Some content integrated into foundation studies when exploring holistic care and activities of daily living.	Learning disability and social model explored in sociology, conduct disorders and learning disability integrated into psychology. Caring for a child with disability (learning, physical or complex needs) a focus in sociology and also part of applied studies, caring for children with complex needs in acute setting, and palliative care.
Applied Nursing learning disability and Social Work	Learning Disability is the specialism of this joint nursing and social work qualification and content is applied from a health and social care perspective	Learning Disability is the specialism of this joint nursing and social work qualification and content is applied from a health and social care perspective
Social Work	A module called 'the people we work with' explores different client groupings, and learning disability is introduced here	Our module on anti-oppressive practice and our specialist children's module has content about learning disability. There is no specific assessment relating to assessing skills in working with people with a learning disability.

Discipline	Year 1	Year 2
Physiotherapy	We have very little in our course relating to learning disability. It is subsumed into the modules and is not as a separate entity in itself.	
Occupational Therapy		An optional 10 credit module for some students with specific learning outcomes and facilitated by people with a learning disability. Not all students will be able to study this module.
Diagnostic Radiography	No discreet delivery of learning disability issues but will be incorporated into discussion surrounding anti-discriminatory practice and social inclusion/exclusion.	An exploration of how we as professionals manage their [people with a learning disability] experience within the x-ray department.
Midwifery	We don't have very much at all around learning disability for the women.	Scenarios and taught session total 5 hours of related material - not all directly about learning disability - more generally about congenital abnormality and acquired disability
Radiotherapy and Oncology	Learning disability is addressed in year 1 as part of an overall topic on 'patient management in radiotherapy' where a number of scenarios are explored including learning disability.	Psychosocial issues are addressed in year 2 - in terms of sexuality, relationships and body image. For the first time this year we did role play with a patient (undergoing radiotherapy to the cervix) with learning disabilities and an activity for students to discuss the different ways we could meet this patients' needs.
Paramedic practice	Patient assessment lecture on confusing behaviours/histories; limited intelligence or education; developmentally challenged; language barriers; visual impairment; hearing problems. Comes under the banner of sensitive topics or special challenges.	Assessment for learning in scenarios - consolidated at Level 5 in scenario work and on placement practice assessment document. Assessment for Grading - "assess the patient's ability to understand and appreciate matters affecting their health and wellbeing", "obtain informed consent" and "identify vulnerable individuals".
Operating Department Practice	This is covered in the clinical modules, at level 4 communication and gaining a history.	Level 5 is professional issues and clinical modules a number of areas are covered including safeguarding children and vulnerable adults, care for the elderly and dealing with altered mental status.

Appendix 2



Sheffield Hallam University

PARTICIPANT INFORMATION SHEET

Evaluation of Learning Disability Training in the undergraduate curriculum
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You are being invited to participate in an evaluation of learning disability training in the undergraduate courses in the Faculty of Health and Wellbeing. Before you decide, it is important for you to understand why the evaluation is being carried out and what it will involve. Please take time to read the following information carefully.

Ask the investigator (either Jill Aylott or Malcolm Richardson) if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

“ Why have I been asked to take part in this evaluation?”

The evaluation is being supported by the Strategic Health Authority and by Sheffield Hallam University and will take the form of a series of focus groups which will be set up in semester 1 and 2 in the 2009/10 academic year. We would like to know how prepared you feel you are, to work with a person with a learning disability when out on your placements.

What if I do not wish to take part?”

It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You will be given a £10 payment to participate in the focus group.

What will happen to me if I take part?

You will be recruited by another student to participate in the focus group. Before the focus groups start you will be given a 'Focus Group Proforma' where you will be asked some basic questions for example about your age, year of study and programme of study. You will not need to insert your name on this form. Once you have completed this form, the student focus group recruiter will look after these forms

to insert into a self addressed envelope which will be sealed and returned to the evaluator.

There will be a facilitator of the focus group who will enable you to watch 3 short videos, explaining some real life experiences of people with a learning disability (cited from the 'Death by Indifference, Mencap Report) who tragically died from poor medical care . You will then be invited to share in a structured discussion with up to 5 other students and respond to 4 short discussion questions for each of the videos. There are no difficult questions and it is not a test, people can say what they want to say in response to the discussion. The focus group will be recorded and we will analyse the data from the focus group transcript.

All the information you give will be treated anonymously and confidentially and after the material has been used it will be destroyed.

How long will the evaluation last?

The evaluation will be completed in March 2010. You will be involved for one hour on one occasion.

What if I change my mind during the evaluation?

You are free to withdraw from the evaluation at any time without needing to explain your decision for doing so. If you decide to withdraw your consent your data can be removed and not included in the analysis. You will need to be present for the whole hour of the focus group to be paid £10.

Are there possible disadvantages and risks of taking part?

None

“What will happen to the information from the evaluation?”

All information will be kept entirely confidential. Interview transcripts will be destroyed 5 years after the evaluation. No individual will be identifiable in the report. You will also have the chance to pilot some newly designed learning materials on learning disability.

You will be informed of the results of the evaluation if you wish. Articles for various journals conference presentations and other will be prepared about the evaluation once it is completed.

“What if I have further questions”

Contact: j.aylott@shu.ac.uk

Appendix 3



Sheffield Hallam University

CONSENT FORM

Learning Disability Training Evaluation in the undergraduate curriculum

Please give your consent to participating in the evaluation by answering the following questions

Have you read the information sheet about this evaluation?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Have you been able to ask questions about this evaluation?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Have you received answers to all your questions?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Have you received enough information about this evaluation?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Do you understand that you are free to withdraw from this evaluation:

<ul style="list-style-type: none">• At any time?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<ul style="list-style-type: none">• Without giving a reason for withdrawing?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Do you agree to take part in this evaluation?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
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Your signature will certify that you have had adequate opportunity to discuss the evaluation with the investigator and have voluntarily decided to take part in this evaluation. Please keep your copy of this form and the information sheet together.

Signature of participant:

Date:

Name (*Block Letters*):

Signature of investigator:

