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The People in Control Conference at City University, London: “We have opinions to share about our lives”

Abstract

Purpose: The purpose of this paper is to consider the benefits of service user teaching both for student speech and language therapists' learning and clinical development as well as for the service users themselves.

Design/methodology/approach: With reference to current policies and good practice guidelines, the experience of both the students and the service users is reflected on in relation to the literature and the events that led to the People in Control Consultancy Conference.

Findings: Students valued the experience in terms of developing knowledge and insight into different techniques to facilitate both receptive and expressive function. Students also had opportunities to think about their own perceptions of disability. Service users have gained in communication confidence and competence as well as gaining opportunities to have their voices heard.

Originality/value: Increased opportunities for service users have cultural and clinical benefits for all involved.

Keywords: *speech and language therapy students; service user – led teaching; service user communication competence; clinical values*

Paper type: View point

Speech and Language Therapy training and teaching Learning Disabilities

An essential part of teaching speech and language therapy (SLT) students is to highlight the challenges of providing communication support so that people with communication difficulties can be involved in the decisions that are in their best interests. When teaching students about a range of communication disabilities, Knowledge of augmentative and alternative communication (AAC) systems is necessary. This is important as AAC systems can be at risk of reduced use due to the perceptions of the people interacting with the person using the system, or lack of familiarity with the system in place (Hamm et al, 2008). Risk increases with less opportunity for independent use and a greater reliance on carer support (Harding et al, 2010). Students are taught that there may be a tendency to underestimate the abilities of the person using AAC, in particular, those with learning disabilities and therefore this could impact on communication opportunities appropriate to that person's skill level

SLT training involves teaching of a range of specific subjects linked to psychology, neurology, physiology, anatomy, linguistics, phonetics and elements of social science. This takes place alongside clinical placement learning as well as developing ways of linking theory to practice (Higgs & Tichen, 2001). Learning how to develop the professional skills essential for good practice is challenging, particularly within such a diverse field such as learning disability.

The role of the Speech and Language Therapist with people who have a learning disability

Speech and Language Therapy is a graduate profession which trains practitioners to assess and treat children and adults who have speech, language, communication and swallowing disorders. Many Speech and Language Therapists (SLTs) work with infants, children and adults who have a range of learning disabilities, across health, education and social care environments). Within the National Health Service, (NHS) there has been a drive to improve clinical competence and develop good practice within more vulnerable groups including learning disability (NHS

Executive, 2000). A recent HPC report (2011) focused specifically on Service User involvement in pre-registration courses both for direct teaching and for course curriculum content and course validation (HPC, 2011). The report recognised the “powerful insights” and “challenging opportunities for students” that could develop from service user teaching and learning as well as its undoubted contribution towards good practice (HPC 2011).

Figure 1: Clinical areas speech and language therapists provide support for.

<p>Clinical areas speech and language therapists work in:</p>	<p>Paediatric receptive language, expressive language and speech delay Paediatric learning disability (may include children with autism, global learning disabilities, etc) Paediatric specific language impairment Paediatric acquired disorders Stammering across the lifespan Eating, drinking and swallowing difficulties across the lifespan Adults with acquired disorders e.g. aphasia Adults with learning disabilities Adults with progressive neurological conditions (e.g. dementia, muscular dystrophy, etc)</p>
<p>Types of interventions speech and language therapists may facilitate:</p>	<p>Development of strategies to support understanding of language and understanding of new information Development of vocabulary, vocabulary knowledge and vocabulary resourcing Development of narrative skills Development of speech skills Use of augmentative and alternative strategies to support receptive and expressive skills</p>

Within learning disability, the wide range of communication styles used by this unique population makes developing a meaningful student learning experience essential. An estimated 50-90% of people with learning disabilities are likely to have some form of language and/or communication difficulty. About 80% of people with severe learning disabilities find it difficult to develop effective speech and/or language skills; 20% have no verbal skills, but demonstrate some level of communicative intent; around 20% have limited intentional communication skills, thus indicating that this is a wide-ranging and complex group (Emerson, 2001). Such communication difficulties and consequent mis-understanding of the nature of disability alongside negative cultural perceptions has led to serious acute care mis-management for people with learning disabilities as highlighted in the Mencap report, “Death by Indifference” (MENCAP 2007).

What's being taught at City University, London?

SLT students are taught about the potential range of language difficulties that people with learning disabilities may experience. Clinical examples are given in relation to assessment and treatment of disorders across the lifespan. An important aspect of the teaching includes raising the profile of AAC i.e. use of gestures, Objects

of Reference (Park 1997), signing, symbols and photographic support that people with learning disabilities often access to support their understanding and communicative expression. Lectures introduce the concept that AAC for those who may not be able to use spoken language with ease is a form of empowerment and can provide communicative access to others. Lectures also highlight that regular training of significant others to support AAC use for the service user in their lives is a vital part of the client's management plan, (Newton et al, 2007).

Philosophical underpinning to learning disability teaching at City University, London

The philosophy underpinning intervention is rooted within the Social Model of Disability (Oliver, 1990). The clinical examples of children and adults are placed within the context of values that underpin the needs and rights of people with disabilities within our society. Teaching also includes consideration of the influence of values in our culture and the potential such values have to define how we develop as practitioners within a clinical area and ultimately how we view people within our practice communities (Tracey & Ianco, 2008). Students have an opportunity during self-directed learning to reflect on how a dehumanising experience can lead to a lack of engagement by those considered to be "outside" of society including people with disabilities and those perceived to be different, particularly people who use AAC. Students are also encouraged to think about the marginalisation of specific groups in society in relation to the lack of User Involvement in planning and delivery of these services with vulnerable groups (Barnes, 1991).

To strengthen this philosophy and to develop stronger learning pathways to link theory to practice, it was considered important that adults with learning disabilities who used a range of communication styles came to teach SLT students at the end of their first year. Part of this approach was to develop an interest in the clinical area and produce a more positive attitude (Kroll et al, 2007). Other researchers have noted an increased interest in disability from students when interacting with service users within a facilitated forum and where there are people familiar with the service users preferred style of communication who can model various AAC strategies used (Tracey et al, 2008).

Using Service Users to teach speech and language therapy students

Despite the range of teaching and clinical experience students would be able to access it was felt important that SLT students experienced cultural values within learning disability early on in the course. This would support their clinical integrity as well as developing a sense of having a cultural awareness within a clinical area. A positive attitude towards disability and the extensive potential service users have would also be fostered (Basnett, 2001).

Service user teaching

Service user teaching has long been recognised as an important method of developing a positive approach towards people from marginalised groups (Basnett, 2002). In recent years, using service users within tertiary education has been acknowledged as making an important contribution towards clinical learning (Le Var, 2002) and developing empathy with a specific client group (Costello & Horne, 2001). Methods include using service users as curriculum advisors, gaining patient/service user views on what should be taught, evaluating what learning materials should be included, and teaching an actual face-to-face class, (Basnett, 2001; Harding, 2009; Kroll et al, 2007; Ingham, 2001). People with learning disabilities gain considerable confidence and self-esteem with life skills and communication competence when placed in situations where they can use their skills. (Coleman & Murray, 2002; Harding, 2009; Hooper & Bowler, 1991; Osguthorpe & Custer, 1993).

Service user teaching contribution at City University, London

Service user contribution to teaching and learning at City University London comprises of; lecturing students about various aspects of their lives; giving a conference hosted by City University London, and provision of clinical placements for SLT student learning and practice. Service user teaching began in 2005 and service users taught twenty four students who were first years in a four-year Speech and Language Therapy degree course. The training was provided by a group of six adult service users from Westminster Learning Disability Partnership. The service users were supported by their key workers, including Kunden Patel, Speech and Language Therapist and Prue Nielsen, Service Manager, (Harding, Patel & Nielsen, 2007; Harding, 2009). The main training lectures provided by the service users included the following:

- Four service users employed a range of communication strategies including speech, Makaton Signs symbols, and gesture to lecture on their involvement in interviewing potential staff providing them with direct services.
- One service user used Makaton, speech, and symbols to lecture students on his work experience.
- One service user who was non-verbal gave a multi-media lecture in collaboration with his support worker on the important aspects of his daily routine.

Prior to the lecture students received training on the range of communication styles to be expected, basic signing training and a session on how to use supports such as symbols, modification of language, time for language processing, and use of facial expression and gesture to support spoken language. Students were invited to reflect on the types of questions that could be considered as appropriate to ask service users. Levels of language complexity and supports such as natural gesture and Makaton signs were discussed as methods to support service user engagement. Students opinions were collected by use of a questionnaire, and service users were also spoken to informally about their experiences post the event. Thirteen students out of twenty four fully completed the questionnaire.

Student opinions about their experiences and what they learnt from the teaching was gained from questionnaire data. No students had any prior experience receiving training from adults with learning disabilities or experience of working with adults with learning disabilities. A strong message was that students had not had experiences within their lives or preparatory clinical experience prior to the course on learning disability, in particular of AAC users. All students agreed that their perceptions of adults who had learning disabilities had been challenged and changed; "Meeting the individuals made me realise that I have definitely chosen the right course and career" .

The question that stimulated the widest response, and was perhaps indicative of confidence in sustaining interaction with adult service users was: "I feel more confident about interacting with this group of service users," The benefits of this clinical learning opportunity were immense, in particular observing how service users maximised their skills to be effective communicators. Cultural , clinical and philosophical developments included comments such as; "Realisation how important feeling useful is for these adults and having choice" ; "To see the communication needs from the point of view of a person with a disability---also, what *they* want from a co-worker and employment" ; "I have learnt to see the needs of the service from a service user's point of view" ; "It's helped me to realise the range of people I may work with" ; and "It has given me a lot more confidence of how to react." A strong

message was that students valued learning about service users' life experiences and the impact of their learning disability on their daily lives. Students also increased their appreciation of the key worker/service user relationship and the immense importance of this to the support and confidence of service users. This was repeated frequently in feedback from students and helped them to see and understand the difference good communication made to this relationship.

Informal and unstructured interviews with service user teachers and key workers indicated improved self-esteem and improved communication competence. Service users also felt that teaching at the University was an important aspect of their work. Key workers remarked that service users appeared to use a greater range of communication skills more confidently and more independently. Figure 2: Case example

Name: Robin

Background information:

Robin is 32 years old and accesses the local services for people who have learning disabilities. He has opportunities to participate in a range of activities including work at the local ambulance station. Robin lives with his sister and her family.

Communication skills:

Robin enjoys meeting a wide range of people. He needs visual support such as use of signs and use of picture and photographic cues to support his understanding. He has a communication passport which states his need for receptive language support and which also has the key pictures and photographs that will support him throughout his working week. Robin uses a multi-modal approach to communication; he prefers to use some single signs supported by word approximations. He also uses objects and his communication book visual resources to support his expressive language. Robin needs time to process language and to consolidate information during conversations.

Involvement in teaching students:

Robin was one of the first Partnership participants to volunteer to come and teach. He was encouraged by his sister who felt that he would benefit from further opportunities to maximise his communicative confidence. Robin attended the first teaching session in 2005. He presented with two other peers on interviewing staff. He did not use any spoken language or word approximations. He used some single signs supported by PowerPoint presentation photographs and his key worker provided additional support using signing and his communication passport. His key worker needed to facilitate each point that Robin made during his presentation.

Conference presentation:

Robin gave a presentation at the conference about his work at the local ambulance station where he likes to use the jet spray to clean the ambulances. Robin had developed confidence with his presenting skills over the six years of teaching at City University combined with his work experience. Although his key-worker was present with him, Robin gave a lecture using spontaneous sign and speech to support a multi-media profile of his work. Robin required no prompting, and each comment he made was a combined sign and word output. Robin demonstrated the confidence he had gained from his experiences which was manifest in his increased communication competence.

Moving beyond teaching towards a conference for people with learning disabilities

Service user lecturing has become a vital and important part of student teaching and learning at City University, London. It continues to have an impact on developing student interest within the field of learning disability and student cultural value development. Indeed, the involvement of service users is being increasingly acknowledged at the level of statutory regulation of the training of health professionals by key stakeholders, including the NHS and professional regulatory bodies such as the Health Professions Council (HPC 2011). It seemed appropriate that as the teaching was continuing to be a success, service users should be given an opportunity to have a conference where they could present and discuss issues relevant to them as well as strengthening the notion of advocacy. As the teaching had been developed at City University London, the People in Control Conference took place there in July 2011.

The Conference saw the launch of People in Control presented by Westminster Learning Disability Partnership in collaboration with Saboohi Bukhari. The Conference served as a platform to launch **People In Control**, a group which specialises in providing user led teaching, training and consultancy on learning disability. City University, London hosted the event. Service users gave presentations on how People in Control evolved; training about disability awareness with the police; selecting staff and specific activities that service users participate in. Other presentations included action to facilitate supported employment and also University training for future health care and social care practitioners. The main keynote speaker was John Ladle who presented on using multimedia as a communication tool and as a means to promote inclusion for people with learning disabilities. A strong theme within this presentation was that local communities still need to recognise the importance of interaction and access for people who need to use other methods of communication instead of/in addition to speech such as signs, symbols and objects of reference.

Figure 3: The People in Control Conference

People in Control Conference Programme
<p>Introduction to the event</p> <p>Invited speaker: John Ladle – speaking on multi-media profiling</p> <p>Advocacy services for people with learning disabilities</p> <p>Developing housing support for people with learning disabilities</p> <p>Service user presentations included:</p> <ul style="list-style-type: none"> • Accessing support from the police • Work experience • Interviewing for staff • Daily life experiences when accessing day services

Why is setting up an organisation such as People in Control and launching it at a conference important?

Valuing People (DoH: 2001) underpins and guides the teaching ethos at City University London. The People in Control conference represented a unique opportunity to showcase the skills of people with learning disabilities which can enable them to achieve the aims laid out by Valuing People given the recognition and collaboration implicit in the organising and hosting of this event

Summary

The People in Control project is one opportunity that is moving towards providing employment and training to people with learning disabilities whilst recognising the individual communication methods of each person. It is a strength that presenters are valued for what they have to present and contribute rather than how they communicate it; all communication methods have equal value. The service user led philosophy is an important feature of the services provided by People in Control and the opportunity to be able to gain payment by being an employed member of this group is an essential aspect.

A major and important part of this collaboration is the clinical enrichment professional knowledge, and cultural awareness that students learn and can apply to their learning disability teaching and clinical experiences. The teaching and collaborations which exist between City University, London and Westminster Learning Disability Partnership are ongoing. Both partners recognise that more research is needed to analyse further the impact on student clinical development as well as how students are enabled to link theory to practice. Additionally and of equal importance is the need to ascertain and measure accurately the changes in communication competence of the service users providing the training as well as investigating changes in their initiation skills.

Key Learning Points

1. Speech and language therapy students gain considerable benefits both in relation to cultural awareness and development and also clinical ability to link theory to practice when taught by service users.
2. Service users feel validated and that they make a contribution to society by having the opportunity to help shape courses and teach students.
3. Service users gain confidence when presenting to students and this can enhance their communication competence.

Discussion Points

1. Service user teaching is not universal across courses allied to medicine; what can advocacy groups do to make this a reality?
2. How can teachers at tertiary level ensure that students maintain their cultural awareness within the competing demands of managing complex caseloads once they have graduated?
3. How can service users in collaboration with teaching staff effectively challenge the deep seated notion that augmentative and alternative communication means that someone does not have a valid contribution to make or can comment on their own needs and preferences?

References

Barnes C. (1991) Disabled people in Britain and discrimination: a case for anti-discrimination legislation. *BCODP*

Basnett I. (2001) Health care professionals and their attitudes towards and decisions affecting disabled people. In G.Albrecht, K.Seelman & M. Bury (Eds) Handbook of disability studies (pp 450-464).Thousand Oaks, CA: Sage

Coleman, K., & Murray, E. (2002). Patients' views and feelings on the community-based teaching of undergraduate medical students: a qualitative study. *Family Practice*, 19(2), 183-188

Costello J., Horne M. (2001). Patients as teachers? An evaluative study of patients' involvement in classroom teaching. *Nurse Education in Practice*, 1, 94-102

Department of Health (2000) *The Government's expenditure plans, 2000 -2001: NHS Executive* London: Department of Health

Department of Health (2001) *Valuing people: a new strategy for learning disability in the 21st century*. London: Department of Health Publications

Emerson et al (2001) Learning disabilities; the fundamental facts. London: The Foundation for People with learning Disabilities

Hamm B., Mirenda P. (2006) Post-school quality of life for individuals with developmental disabilities who use AAC. *Augmentative and Alternative Communication Vol. 22(2)*, p 134-141

Harding C. (2009) Involving adult service users with learning disabilities in the training of speech and language therapy students. *International Journal of Teaching and Learning in Higher Education*, 20(2), 205-211

Harding C., Lindsay G., O'Brien A., Dipper L. & Wright J. (2010). The challenges of implementing AAC to children with profound and multiple learning disabilities: A study in rationale underpinning intervention. *Journal of Research in Special Educational Needs* p 1 – 10 ; doi: 10.1111/j.1471 – 3802.201001184

Harding C., Patel K., & Nielsen P. (2007) People with learning disabilities teaching others. *Learning Disabilities Today*, 7(4), 30-32

Health Professions Council (2007) *Standards of Proficiency: Speech and Language Therapists*. London: HPC

Health Professions Council (2011) *Education and Training Committee, 10.3.11: Service User involvement in the design and delivery of education and training programmes*. London: HPC

Higgs J and Titchen A (Eds.) 2001, *Practice knowledge and expertise in the health professions*. Oxford: Butterworth Heinemann

Hooper, H. & Bowler, D. (1991). Peer tutoring of manual signs by adults with mental handicaps. *Mental Handicap Research*, 4, 207-215

Ingham, M. (2001). How patients can contribute to nurses' education. *Nursing Times*, 95, 42-43.

Kroll T; Groah S; Gilmore B; Neri M;Elrod MW; Libin A.(2007) Involving people with spinal cord injuries in the education of rehabilitation professionals. *International Journal of Therapy and Rehabilitation* 14; 299-305

Le Var RMH. (2002) Patient involvement in education for enhanced quality of care. *International Nursing Review* 49,219 -225

MENCAP (2007) *Death by Indifference*. Pub: Mencap

Newton C.,Clarke M.,Donlan C.,Wright J.,Lister C.,Cherguit J.(2007) Parents' expectations and perceptions concerning the provision of communication aids by the Communication Aids Project.(CAP).*Child Language Teaching and Therapy*, 23(1), pp 47-65

O'Brien, J. (1981). *The principle of normalisation: a foundation for effective services*, adapted by Tyne, A. (London: Values into Action)

Oliver M. (1990). *The Politics of Disablement*. Palgrave – MacMillan

Osguthorpe, R. T., & Custer J. D. (1983). Improving social acceptance by training handicapped students to tutor their non-handicapped peers.*Exceptional Children*, 50(2), 173-174

Park K. (1997) How do objects become objects of reference? A review of the literature on objects of reference and a proposed model for the use of objects in communication. *British Journal of Special Education*, 24, 3

Tracey J; Ianco T. (2008) People with developmental disabilities teaching medical students: Does it make a difference? *Journal of Intellectual and Developmental Disabilities* 33, 345 -348

Walker, M. (1977) 'Teaching sign to deaf mentally handicapped adults.' *Language and Mentally Handicapped*, 3, pp. 3–25