

Involving Adult Service Users with Learning Disabilities in the Training of Speech and Language Therapy Students

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This article describes a pilot project carried out at City University London, Department of Language and Communication Science, where adult service users with learning disabilities trained first-year speech and language therapy students. The training involved presentations by the service users on their involvement in interviewing support staff, work experience, and daily routines. All service users employed their preferred communication mode when presenting. The purpose of this project was to evaluate the students' perceptions of the benefits of the training for them as future practitioners as well as developing their own disability awareness. Twenty-four students took part in the training, and 13 students completed an evaluation questionnaire. The feedback from students was generally positive with a range of comments around how they valued the experience in terms of developing knowledge and insight as well as challenging their own perceptions of disability. In addition, service users were asked to evaluate their own achievements in relation to the experience of teaching students.

Using service users, patients, and clients as teachers has been described as highly advantageous for student learning within the field of nursing (Costello & Horne, 2001). In addition, evaluations of such innovations in teaching have revealed dual benefits not just for the students, but for the service users themselves (Basset, 1999; Beresford, 1994; Glazier & May, 1995; Hanson & Mitchell, 2001; Rudman, 1996; Wood & Wilson-Barnett, 1999). Service users feel that they are experts regarding their needs, or their conditions, and feel strongly that they are giving something back to students and helping them to develop into effective practitioners. This paper explores the use of adult service users in the training of speech and language therapy students and the impact on the students' learning in relation to disability awareness and recognition of the diversity of communication styles used by this group. The main focus of this paper is on a questionnaire about the service user training received with discussion of the results and consideration for enhancing student learning further through this approach.

Involving Service Users in Training Practitioners

Patients, clients, and service users have been used in a variety of ways to teach students. Methods include using patients/ service users as advisors, gaining patient/service user views on what should be taught, evaluating what learning materials should be included, and providing actual face-to-face class teaching. Harrison and Beresford (1994) used a conference format to consult a range of user groups as a way of informing social work training. Participants felt that if students had access to service users, then a positive perception of service users would develop as well as increasing student knowledge. Ingham (2001) and

Sawley (2002) approached patient and voluntary service user groups to reflect on how the curriculum could be enhanced by user involvement. An important element to surface was that parents valued support and services more if rationales were explained clearly to them, and that information such as this would be useful for sharing with students as part of their teaching.

Within the field of mental health, service users have been approached on what specifically should be included in the curriculum (Forrest, Risk, Masters & Brown, 2000; Rudman, 1996). Rudman (1996) collected data from 20 mental health service users using a semi-structured interview forum. Service users reported that they felt that important clinical skills for nurses should include realising that an individual approach is needed, with an understanding of key issues rather than labelling behavior. In addition, participants felt that it was important for students to be aware of the importance of being aware of local resources and supports and the high level of relevance this had for service users. Forrest et al. (2000) had 5 focus groups involving 34 service users. A key theme that arose from these groups was that nursing courses did not cover clearly the specific clinical qualities important for clients.

Service users as teachers within the curriculum have been reported in a variety of studies where positive outcomes have been described. Stacy and Spencer (1992) interviewed 20 patients involved in a community medical project where over a 6 month period medical students visited patients. The students reported that they felt they learned to not treat the patient as a passive individual, but as an equal participant in the process. Coleman and Murray (2002) carried out a similar study and focused on patient views where they commented on how they had gained self-esteem and personal growth from participating in such a

project as well as gained more information about their illnesses. Rowley (1995), Soliman and Butterworth (1998), Costello and Horne (2001), and Wood and Wilson-Barrett (1999) all write about using patients/service users to actually “teach” students within a class-based forum. All of these studies comment on the value of how students changed their perspective of a patient’s needs, as well as how their reflective practice skills and insights into working with other people who are likely to be clients were developed. The Wood and Wilson-Barnett (1999) study raises the issue of service users feeling challenged when practitioners use terminology and jargon as well as the value of taking an individualised approach. Costello and Horne (2001) also raised similar points where students gained benefit from service user teaching mainly in the areas of developing a greater understanding of key issues, developing an empathy with the client, and reflecting on the wider issues relevant to the client and the impact of their condition on their lifestyle. In summary, service user/ patient/ client teaching is considered as being a valuable addition to the curriculum for health care and social work practitioners.

Benefits of Participating in Training for Adult Service Users

In addition to the student learning benefits, service users have reported increased self esteem as reported previously. However, the studies mentioned in the first section have focused on specific groups, learning disability not being one of these. This is despite there being many reported benefits for adults with learning disabilities when they are involved in training their peers. These benefits include the development of confidence with communication use (Hooper & Bowler, 1991; Osguthorpe & Custer, 1993; Raglan, Kerr, & Strain, 1978). Some studies have examined this concept, in particular, the use of more able peers with learning disabilities teaching, training, and supporting their less able peers. Makaton peer tutoring was initiated in 1996 (Hooper & Bowler 1991) as a pilot project. Eight adults with moderate learning disabilities were taught to develop strategies to support and enhance the communication attempts of less able peers. The main focus of the training focused on developing functional use of signing with support in everyday settings. The results indicated an increased use in vocabulary size and signed/spoken interaction attempts with the tutors. Hooper and Walker (2002) carried out an evaluation of Makaton peer tutoring through use of a detailed questionnaire sent to twenty-three establishments in England and Wales. Feedback indicated that the Makaton peer tutors developed an increase in self-confidence and self-esteem, and that

their own communication skills improved. Managers and facilitators also reported that the Makaton “tutees” who had received the support from the peer tutors developed increased attempts to make choices, improved attempts to make their needs known, and “more general enjoyment and interaction in communication sessions” (p. 40).

Ragland, Kerr, and Strain (1978) also explored the concept of using one able student to facilitate communication attempts with three less able peers. The intervention involved children with difficulties within the autistic spectrum, all of whom were classified as having low functioning autism and who were aged between 8 and 9. The peer trainer was aged 10 and was described as having milder features of autism. He was instructed to try to engage the other children in the playroom where the intervention took place. Findings from this study indicated that there were increased positive social initiations and social behavior noted with all the participants. The authors suggest that, with very careful instruction and precise programming, non-learning disabled, or those with lesser levels of disability, can be used in training programs to increase social opportunities for their less able and more socially withdrawn peers.

Michael Brady and colleagues (1984) examined the effects of training an adolescent with autism and a learning disability to develop his social communication by training non-disabled peers to use modelling and specific prompting and scaffolding techniques. The results of the study clearly indicated that the subject’s rate of unprompted initiations to his peers increased after the program had been instigated. Significant increases in the number of initiations and interaction attempts were noted. This is a study that highlights the significant benefits of developing appropriate communication strategies to enhance the potential of those with learning disabilities.

However, there are some studies that have examined the use of people with learning disabilities in the training of their non-disabled peers. Osguthorpe and Custer (1993) recognized that there was a paucity of studies undertaken to demonstrate the effectiveness of using students with disabilities as tutors. They focused on using 15 students with learning disabilities who had moderate learning needs and who they described as being in the fifth and sixth grade at school to train 15 non-learning disabled students from the same grade to use sign language. They also completed pre- and post-interaction observations on the students with learning disabilities during social settings such as the lunch hour. Outcomes from this study indicated that the students with learning disabilities developed what the authors describe as “a superior social advantage” as well as confidence in their communication skills. Additionally, the non-disabled peers developed a

respect, admiration, and an increased awareness of disability that they had not experienced before.

Summary

In conclusion, the literature appears to highlight strengths in projects that use service users in teaching, not just for the students themselves, but for the service users. Given the positive outcomes reported in these studies, it was decided to set up a pilot project at City University, London using adult service users with learning disabilities to teach speech and language therapy students about aspects of their lives important to them using a multi-modal communication approach.

Method

Participants

The participants involved in this study consisted of 24 students who were first years in a four-year Speech and Language Therapy degree course. The training was provided by a group of 6 adult service users from a Central London Partnership. The main training lectures provided by the service users included the following:

- Four service users employed a range of communication including speech, Makaton signs, symbols, and gesture to facilitate themselves and their peers and gave a training session on involving service users on interviewing staff to be key workers.
- One service user used Makaton, speech, and symbols to provide training to the students on his work experience.
- One service user who was non-verbal gave a video training presentation in collaboration with his support worker on the important aspects of his daily routine.

Prior to the training session, students received a session on the range of communication needs expected, and a brain storming session to explore the types of questions that could be considered as appropriate for the service users. Additionally, levels of language complexity and supports such as natural gesture and Makaton signs were discussed. Students received a practical Makaton sign session to help facilitate their skills in this area. Students were also requested to fill in a questionnaire post the training session. Service users were also spoken to informally about their experiences post the event.

Results

Questionnaires were completed by 13 of the 24 participants. Results of Questions 1 and 2 – “What training have you had from adults with learning disabilities prior to this day”, and “What experiences have you had of working with adults with learning disabilities prior to this day?” – revealed that no students had any prior experience receiving training from adults with learning disabilities or experience of working with adults with learning disabilities.

Question 3 asked, “I have been helped to view the communications needs of this group differently today,” using a 5 point scale from *Strongly Agree* to *Strongly Disagree*. Of the 13 responses, 7 students responded *Strongly Agree* and 6 students responded *Agree*. All students agreed that their perceptions of adults with learning disabilities communication needs had been challenged. The service users were a clinical group that the students had not considered prior to coming onto the course. This is surprising given that one of the prerequisite requirements of the course indicates that potential speech and language therapy applicants should have had some clinical experience with people who have communication disabilities before coming for their interview. Many students had had experience of children with learning disabilities but not adults.

In addition, Question 4 stated, “I feel more confident about interacting with this group of service users,” with a rating scale from *Strongly Agree* to *Strongly Disagree*. Five students either answered *Agreed* or *Strongly Agreed*, while 4 students answered either *Disagreed* or *Strongly Disagreed*. The spread of ratings here indicates the range of feeling within the group about how to communicate with multi-modal communicators. One student did not record a response for this question. The students were given basic signing training, plus a session on how to use communication supports such as symbols, modification of language, time for language processing, and use of facial expression and gesture to support spoken language. The spread of responses indicates that whereas providing this training had benefits, it actually needs to be more pervasive to a context to allow students to gain confidence in using these strategies effectively.

Question 5 addressed students’ motivations: “I am motivated to seek a placement with adults with learning disabilities” (*Strongly Agree* to *Strongly Disagree*). Results from Question 5 revealed that 7 students replied *Agree* or *Strongly Agree*, while only 1 student replied *Disagree* or *Strongly Disagree*. The experience of being taught by adult service users had not convinced all students to consider requesting a placement with this group. The Learning Disability Partnership involved

with this project feels that an important part of this teaching and learning session should be about promoting an awareness and interest for the speech and language therapy students participating. They ensure that they leave contact information for those who wish to follow up any issues from the teaching. Also, this Partnership has an ongoing and strong commitment to having speech and language therapy students on placement. Issues around disability awareness could be explored further in future teaching at the university.

The next question, Question 6, asked students, "Describe how this day has been useful to you as a student practitioner." The student respondents' comments regarding this question were separated into seven key areas that were as follows:

1. Valuing having the opportunity to see how service users used the training session to maximise their own skills was an important issue for 1 respondent. Comments included, "allowing them to maximise the capabilities they have."
2. Six student respondents stressed that they gained much from hearing about key issues from the service users' point of view. Comments included, "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."
3. Opportunities available for adults with learning disabilities did strike two respondents as an issue that would have an influence on them as practitioners. Comments included, "It has been interesting to see what is on offer for adults with learning disabilities."
4. One respondent reflected on the necessary strategies needed to allow such a training session to take place. Comments included; "appreciating the repetition of things, e.g., watching videos or photos many times so the clients feel comfortable."
5. One respondent reported no view at all.
6. One respondent commented how much he/she appreciated gaining some insight into service users' everyday lives: "It has given me insight into what life is like for adults

with learning disabilities and what they like doing during their everyday lives."

7. One respondent reported that the session "taught me how much patience you need with working with learning disabilities," but there was no supporting statement as to why patience would be needed.

Finally, Question 7 asked the students, "What other training would you like to receive from adults with learning disabilities?" The student respondents' comments regarding this question were separated into four key areas that were as follows:

1. Seven respondents felt that they would benefit from further training from service users to teach them how to communicate more effectively with this group. Comments included, "Showing us how they communicate and what helps them to get their message across"; "How to use communication effectively to communicate with adults with learning disabilities"; "I would like to learn more about communicating with adults with learning disabilities, e.g. more Makaton training"; and "how to respond naturally ...without any offence." One comment, however, was written in an inappropriate manner for this section. The quote being that, in terms of training, the student would like to know "how to control/handle them better." All forms were anonymous, but it was felt on discussion with other staff members that such issues should be taken forward more purposefully in clinical tutorials where there is opportunity to explore issues in a "safe" and confidential environment.
2. Two respondents felt it important to learn more about disabilities and their impact on everyday life from the service users themselves. Comments included, "more about their experiences in the community and within the services"; "I would like to know more about what adults with learning disabilities would like to gain from Speech and Language Therapy input."
3. Three respondents did not comment specifically in this section, but just wrote "Thank you."
4. One respondent commented on how he/she would like the opportunity to take part in a training context "where I can watch and see how the service users develop their communication skills and confidence over time."

Discussion

When adult service users with learning disabilities are speaking about topics that are meaningful for them and which they have been involved in planning or initiating themselves, they appear to convey a strong message. This was clearly reflected in some of the student comments:

- “I did not expect the service users to be able to pass on such a strong message to us as a group about what was important to them. Their level of skill really surprised me.”
- “I had no idea about what we were going to listen to today. I thought it would be basic. It wasn't, and I have been given a lot more to think about. I'd really like a placement with adults with learning disability.”
- “I thought the first presentation was great because not everyone could talk. The non-verbal group member was supported to put her view across by gesture and photo support. I was very impressed.”
- “I thought that having the Makaton training was a great support for us. I'd like to do more. I also found it good to have the talk about the kinds of questions we should try and ask. I hadn't thought of how I would make my language simpler. It was a real challenge for me.”

From such comments, it appears that these students are beginning to think about issues such as disability and identity. Given that none of the students reported having any sustained contact or work experience with adults with learning disabilities, it was felt that the training had provided some vital awakening linked to the learning outcomes required of them, such as the awareness of social and environmental implications of communication disability and the barriers to successful communication (Costello et al., 2001). It was perceived as being a valuable experience. From the questionnaire ratings, 7 students *strongly agreed* and 6 students *agreed* that they had been helped to view the needs of service users differently. No participants gave lower ratings.

All the students appreciated the benefit to them as developing practitioners of the training as reflected in the comments in the results section, and there were many statements about the desire to learn more about useful communication strategies to employ with service users as a training opportunity. Some had not really considered how they might modify their language to promote positive interaction and had found this a challenge. It would have been particularly useful for the students to discuss and explore some of the issues that

came up (e.g., how comments are phrased, such as the one which stated that training was need to ascertain “how to control/handle them better”). Such a session could have been an opportunity to explore in more depth some of the issues of disability awareness, language, and identity which had been touched on. Also, only 13 of the group filled out the evaluation forms, so the views stated in this paper are not necessarily representative of those of the whole group; it is acknowledged that a greater number of student feedback would have given a more substantial amount of data.

The informal discussions with service users revealed that providing training did actually have great benefits for themselves, not least to their self-esteem, confidence, pride, and a sense of ownership as to what was being delivered. It also represented a specific and meaningful role for all of the service users beyond their daily living experiences. It would have been useful to involve the service users in more formal evaluations to gain their own views on how the session went, if it enhanced their communications skills (and, if so, how), and their opinions on what future training should involve for the students.

Conclusion

It is clear that this trial teaching session had benefits for both the students and the service users in terms of raising awareness of disability and building confidence and skills for both groups. From informal debriefing discussions with the service users, they indicated clearly that they felt valued and that they developed increased confidence skills and heightened self-esteem. Two of the service users said that they felt it had given them a meaningful role that was beyond their usual daily experiences.

The benefits in terms of well being, confidence, and communication potential are still largely unexplored, although the studies mentioned in this paper have already highlighted that there are considerable advantages for people with learning disabilities being given the opportunity to lead and initiate training. It is felt, though, that service users appear to gain substantial benefits in terms of improving their communication confidence and skills in generalised settings.

The questionnaire and the training day raised a number of issues about disability awareness and how little the speech and language therapy students in this course knew. Given that none of the students had any previous sustained contact or work experience with people with learning disabilities, the training had provided an important trigger for their awareness of disability. In addition, issues around the social and environmental implications of communication disability

and the barriers to successful communication were an important learning goal for them.

It was acknowledged that issues around disability awareness and communication barriers needed further work and exploration within the context of the course. All the students appreciated the benefit of the training to them as developing practitioners. Many wanted to learn more about useful communication strategies. Some had not really considered how they might need to modify their language (e.g., what words to use and how comments are phrased) and had found this a challenge. It was felt that such issues should be taken forward more purposefully in clinical tutorials where there is an opportunity to explore issues in a safe environment.

This project is now in its next phase. It has included pre- and post-student measures as well as more specific service user measures. Besides people with learning disabilities, the project has included a person with a tracheostomy, a person with aphasia, parents of children with complex learning and communication needs, and an adult with a chronic stammer. Their feelings around participation in such a project have been sought through focus groups and the data is currently being collated and analyzed. Methods of analyzing the impact of service user teaching on students learning still requires further exploration. The suggestion is that the participative role of service users in class-based teaching has a positive role in promoting awareness of client needs as well as developing clinical interests. Further work within this project will seek to explore learning and communication competence measures for both groups involved.

References

- Basset, T. (1999). Involving service users in training. *The Journal of Practice and Development*, 7(2), 5-11.
- Beresford, P. (1994). *Changing the culture: Involving service users in social work education*. London: Central Council for Education and Training in Social Work.
- Brady, M., Shores, S. R., Gunter, P., McEvoy, M. A., Fox, J. J., & White, C. (1984). Generalization of an adolescent's social interaction behaviour via multiple peers in a classroom setting. *Journal of the Association of the Severely Handicapped*, 9, 278-286.
- 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.
- Forrest, S., Risk, I., Masters, H., & Brown, N. (2000). Mental health service user involvement in nurse education: Exploring the issues. *Journal of Psychiatric and Mental Health Nursing*, 7, 51-57.
- Glazier, S., & May, P. (1995). Changing cultural norms. *The IHSM Network*, 2(25), 6.
- Hanson, B., & Mitchell, D. (2001). Involving mental health service users in the classroom: A course of preparation. *Nurse Education in Practice*, 1, 120-126.
- Hooper, H., & Bowler, D. (1991). Peer tutoring of manual signs by adults with mental handicaps. *Mental Handicap Research*, 4, 207-215.
- Hooper, H., & Walker, M. (2002). Makaton peer tutoring evaluation: 10 years on. *British Journal of Learning Disabilities*, 30, 38-42.
- Ingham, M. (2001). How patients can contribute to nurses' education. *Nursing Times*, 95, 42-43.
- 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.
- Raglan, E. V., Kerr, M. M., & Strain, P. S. (1978). Behaviour of withdrawn autistic children. *Behaviour Modification*, 2(4), 565-578.
- Rowley, D. (1995, January). Tapping into experience. *Community Care*, 20-21.
- Rudman, M. J. (1996). User involvement in mental health nursing practice: Rhetoric or reality? *Journal of Psychiatric and Mental Health Nursing*, 3, 385-390.
- Sawley, L. (2002). Consumer groups: Shaping education and developing practice. *Paediatric Nursing*, 14(3), 18-21.
- Soliman, A., & Butterworth, M. (1998). Why carers need to educate professionals. *Journal of Dementia Care*, 6, 26-27.
- Stacy, R., & Spencer, J. (1999). Patients as teachers: A qualitative study of the patients' views on their role in a community-based undergraduate project. *Medical Education*, 33, 688-694.
- Wood, J., & Wilson-Barnett, J. (1999). The influence of user involvement on the learning of mental health student nurses. *NT Research*, 4(4), 257-270.

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children with complex special needs including autism. These interests are still maintained clinically for one day a week. In addition, the author has a strong interest in disability, particularly children and adults who were premature infants. Current teaching involves the areas of learning disability, augmentative and alternative communication, and eating and drinking disorders. It is felt that using adult service users in teaching also enhances their own skills and confidence in terms of their communication development and this is an area currently being researched further in collaboration with colleagues in the NHS.

Author Acknowledgements

I would like to express my gratitude and thanks to the Central London service users and their support workers for their work and presentations. I would also like to thank Kunden Patel, Speech and Language Therapist, and Prue Nielsen, Services Manager, for the tremendous amount of work they put into developing this project with the service users and support workers to allow it to come into fruition. I would also like to thank Tina Arnold, Speech and Language Therapist, who provided Makaton training for the students.