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Mental Capacity Act (2005)

Enabling student learning through teaching provided by service users who use augmentative and alternative communication

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Introduction

Service users have been actively involved as visiting lecturers at City, University of London since 2005 (Harding, 2009; Harding, et al, 2012). Principally, speech and language therapy students (SLT) have been taught by service users with learning disabilities about their experiences interviewing support staff, work experiences, daily living activities, and accessing health care. All lectures have been presented by service users using multi-modal approaches to communication. Types of augmentative and alternative communication (AAC) used have involved use of Makaton (Walker, 1977), natural gesture, symbols and other pictorial methods of support, use of an iPad, voice output communication devices, use of Multi-Media Profiles and Objects of Reference (Park, 1987), as well as spoken language accompanied by natural gestures. Reflecting on the Mental Capacity Act (2005) is an important part of the service user led teaching.

Service user led teaching for speech and language therapy students

It is important that students are taught about the problems AAC users,

specifically those with learning disabilities, experience on a daily basis, especially when accessing healthcare. Students will be the healthcare practitioners of the future and these teaching and learning opportunities are essential in the development of clinical problem solving as well as understanding the communication styles and needs of service users

with learning disabilities, particularly in a healthcare context. Before meeting the service users, students receive lectures about AAC, including practical training, and the difficulties and challenges that may be experienced by both the students themselves, and when meeting the service users.

Table 1: The Advocacy Project

The Advocacy Project: www.advocacyproject.org.uk

This is a London based charity that supports marginalised communities to speak up, understand their rights and make choices, challenging stigma, isolation and inequality. The Advocacy Project works with people, including older adults, children and young people, who have learning disabilities, mental health problems, eating disorders and dementia.

Success of the teaching described encouraged university staff to discuss with the service users the development of other teaching topics, in particular, difficulties accessing healthcare and the relevance of the Mental Capacity Act (2005) for people with learning disabilities. Although SLT students have regular placement opportunities, they often experience difficulties linking theory to practice. One problem in particular is being able to be effective communicators when working with service users using AAC to support both their understanding as well as their expressive skills. Another problem is being able to use accessible information effectively when on placement to check that service users have understood what has been discussed during a consultation.

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Table 2: Student preparatory reading

- A short overview of the Mental Capacity Act 2005. (Mental Capacity Act, (2005). Mental; pub, TSO).
- A short summary of the Care Act 2014. (Care Act 2014; pub. TSO).
- The Mencap report about deaths of people with learning disabilities whilst in acute care (Mencap, (2012). Death by Indifference: 74 Deaths and Counting: A Progress Report 5 Years on. Pub. Mencap.
- An eight-page summary of the CIPOLD report. (Heslop, P., Blaire, P., & Flemming, P. (2013). Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD). University of Bristol: Norah Fry Research Centre. 10(1), 14.
- A fourteen-page summary report of the Winterbourne View scandal. (Flynn, M. (2012). Winterbourne View Hospital: a serious case review. South Gloucestershire Safeguarding Adults Board).
- A reappraisal of previous teaching notes and PowerPoint presentations about augmentative and alternative communication, and the relevance of this teaching to their interaction and learning with service users.

At City, University of London, the involvement of service users in teaching has become an important part of the curriculum. Traditionally, this teaching has involved service users communicating about work experience; living a healthy lifestyle; specific training opportunities for service users; being involved in interviewing support staff and everyday life experiences. All presentations have been given by service users who use a range of AAC. This project has been developed in collaboration with The Advocacy Project (Table 1).

What do students learn in the Mental Capacity Act (2005) teaching session?

Resources to develop an understanding of The Mental Capacity Act (2005) in relation to people with learning disabilities were developed. Education involved both direct teaching as well as self-directed learning in small groups before meeting the service users (see Table 2).

The aims of the direct teaching session for the SLT students by the service users about the Mental Capacity Act (2005) are as follows:

- To learn about and demonstrate an awareness of the Mental Capacity Act (2005) and its relevance to the SLT students themselves as developing healthcare practitioners and its importance when working with people who have learning disabilities
- To learn about and demonstrate an awareness of the difficulties that people with learning disabilities have in accessing healthcare, specifically in relation to examples such as Winterbourne View, and those highlighted in the Death by Indifference report (2012), and the CIPOLD Inquiry (2013)
- To reflect on how to check a service user has understood information shared during a consultation, and reflect on how healthcare practitioners should use AAC to enable service users to ask questions, check information and participate in the decision-making process relevant to their own healthcare
- Students to reflect on their own communication style when working with people with learning disabilities, and demonstrate an awareness of how to "jargon bust"
- To be aware of the Accessible

Table 3: Topics selected by service users on accessing health care for video materials

John (with Dave, his support worker)

Topics:

- Accessing the dentist;
- accessing speech and language therapy support

Methods used to support John:

Preparation, including role play; checking the sequence of what happens at the dentist; letting others know how to tell when John is in pain; how to gain a referral and therefore access to speech and language therapy, so John can sign and gain confidence with his spoken vocabulary as well as using pictorial materials.

Saiful (with Azad, his brother)

Topics:

- Health checks with the nurse and doctor;
- Being healthy by exercising and eating the right foods

Methods used to support Saiful:

Using visual information to help Saiful remember appointments, and what will happen; using objects to help Saiful understand; using simplified language and repetition with the nurse and doctor.

Maryam (with Jane, her carer and Aisha her advocate)

Topic:

Accessing good, safe health care

Methods used to support Maryam:

It is important that Maryam sees a familiar doctor who knows her medical history, and knows how to communicate with her (she uses multi-modal methods of communication); she explains about a difficult experience where she saw a different doctor, and became unwell with medication prescribed which she would not usually have.

David (with Aisha, his advocate)

Topic:

Communication barriers when accessing the GP.

Methods used to support David:

David talks about non-accessible information; jargon and too much information; having to take his mother to appointments with him; difficulties processing information; unfamiliar vocabulary; David discusses his Health Action Plan and his Health Passport; his preferred vocabulary so he has understood; someone asking him to repeat back so he has understood; and use of traffic light cards.

Information Standard, (NHS England) and how it applies to people with learning disabilities

- To be aware of Health Action Plans, Communication Passports, Easy Read Crisis Card information and how this is relevant to people with learning disabilities

Service user visiting lecturers involved in the project

Four service users, Maryam, Saiful, David and John, were involved with creating videos of their experiences accessing healthcare (Table 3). All four service users are regular visiting lecturers at City, University of London. Maryam, Saiful, David and John have helped develop the curriculum in relation to understanding the importance of effective communication with people who use augmentative and alternative communication and they are diverse in the way they communicate. John uses some single Makaton (Walker, 1977) signs, single words, facial expression, pictures, symbols and Objects of Reference (Park, 1997). He has significant difficulties with his understanding of language, and is supported by use of simplified language, visual cues and prompts, e.g. signs, gestures, Objects of Reference (Park, 1997) and repetition. David is able to use spoken language, but his difficulties with language processing, as well as problems with comprehending less familiar vocabulary impact on his confidence, independence and ability to participate. Saiful uses some Makaton signs (Walker, 1977), some spoken words, Objects of Reference (Park, 1997), and visual / pictorial information. As with John, David has difficulties understanding language and therefore needs information presented in a way which allows him to participate. This includes use of repetition, familiar vocabulary, no jargon words and simplified language, i.e. use of shorter sentences, with pauses by the speaker to allow for processing time. The fourth service user is Maryam, who uses some natural gestures, facial expressions, pictures, symbols, Objects of Reference (Park, 1997), a voice output communication device and an iPad interchangeably.

Each service user spent time preparing a script to enable them to be video recorded discussing their own experiences of accessing health care (Table 3). It was important that Maryam, Saiful, David and John used a variety of AAC methods to communicate and to highlight the problems that would prevent them from accessing healthcare information and support. David wanted to share his view of confidentiality in that his mother has to attend appointments with him. Understanding language used by healthcare staff was something that all four service users raised. John needs visual AAC support such as signs, Objects of Reference (Park, 1987) and repetition to help him understand what is being said. He also benefits from role play related to the potential scenarios that he may experience and, in his video, he talks about going to the dentist. Saiful also needs the same AAC cues as John when he goes for his regular health check-up. The nurse asks him to repeat back what they have discussed so that she can check he has understood. Maryam reported that engaging with a familiar healthcare worker made a difference, as familiar people tended to show awareness about how much she understood, how she communicated and what her specific needs were. David commented that he is anxious about receiving too much information verbally, as well as not being literate. He finds simplification of language important. John, Maryam and Saiful all have unique communication styles supported by AAC. Their specific methods of communication are described in personal documents such as Communication Passports and Health Action plans.

Students view video materials created by Maryam, Saiful, David and John as part of their preparatory work. They consider what they would need to do if they were working with each service user both directly, and with the wider team (e.g. training about AAC approaches, for example). Part of the preparatory work encourages them to think about how to present information, and discuss it in an accessible way. Students identify what is challenging about using AAC, and what

they will need to develop to be effective when interacting with others who need support through use of augmentative and alternative methods. They are also asked to identify how they could be proactive in preventing any significant adverse health events. Finally, students meet Maryam, Saiful, David and John, to hear about their experiences live, and to have time to ask them questions linked to their previous teaching and self-directed study.

Conclusion

Although students have placement opportunities to develop the necessary skills to prepare them for being speech and language therapists, they still need education experiences that allow them to reflect on potential challenges. Service users with learning disabilities often find accessing healthcare difficult, and their personal experiences can be important in helping to shape students' understanding on capacity in relation to working with people who have different ways of communicating. Understanding how to engage with those who need and use AAC remains an important part of the curriculum for SLT students.

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Read all about the experiences of two parents who attended our CM2017 conference for the first time this year (their subsidised places were sponsored by AssistiveWare)

<http://www.assistiveware.com/communication-matters-our-experience>



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