

# Preparing social work students for practice by involving young people with profound and multiple learning disabilities in teaching and learning

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Service user engagement has been promoted in England by policy and legislation since the 2001 Valuing People Paper and is a fundamental requirement in social work education in England, as well as internationally (Ward *et al.*, 2016). There are some good examples of engagement of service users with lived experiences in social work education and practice which involve those with profound and multiple learning disabilities (PMLD) (*ibid.*); it is, however, limited. This paper focuses on the partnership between the RIX Research Centre at the University of East London (UEL) and the Charlton Park Academy (CPA), a special secondary school in south-east London. We present our model of an Advocacy Pathway as part of social work readiness for practice. The engagement of young people with lived experience of PMLD helps social work students to consider their attitudes and assumptions, while learning new communication skills from the young people.

## INTRODUCTION

The Advocacy Pathway is a 12-week programme during which social work (SW) students are paired with a young person who has lived experience of profound and multiple learning disabilities (PMLD). The main aim of the pathway is to address initial attitudes, promote the value of all people and equip SW trainees with the following skills: communication, person-centred practice (PCP), advocacy and technical

skills. All these skills are important for SW practitioners to support people with lived experience of PMLD.

In this paper, we will first introduce the history of the Advocacy Pathway and the partnership between the RIX Research Centre at the University of East London (UEL) and the Charlton Park Academy (CPA). We will highlight the importance of the pathway and its aims. Through examining the

## KEYWORDS

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ADVOCACY

INCLUSIVE DIGITAL TOOLS

SERVICE USER ENGAGEMENT

PERSON-CENTRED PRACTICE

PMLD.

procedure and methodology applied in this programme, we will consider the outcomes of the Advocacy Pathway for both the SW students and the young people as inclusive partners. Finally, we will analyse and discuss the findings within a wider context of SW skills, that can be acquired in practice-based learning, while also being applicable in the education of other professionals.

## BACKGROUND

PCP is a cornerstone of social work practice. It requires social workers to work with individuals with lived experiences in a supportive way that is empowering and capacity-building. Communication is one of the most important skills that social workers need to develop to support a range of clients. According to the British Association of Social Work (BASW) England, there is a long-standing gap as regards the skills needed to support people with learning disabilities. To address this gap, in 2018 a new Capabilities Statement was produced by the BASW, which highlights the need for social workers to develop robust advocacy skills based on values, ethics, personal behaviours, knowledge, skills and interventions, through critical reflection (see Figure 1). To support people with lived experiences, social workers need to:

- ‘Get to know people with lived experience as individuals
- listen and know how to communicate effectively
- support their family and friends
- help them lead the lives they choose
- show respect and treat them as equal citizens.’ (BASW, 2018: 6)

There are 1.2 million people with learning disabilities living in England, and the number is growing, with a predicted 16% rise by 2030, meaning that the number of people with learning disabilities is going to expand to 1.6 million (Care England, 2016). Social workers and other education, health and social care professionals will encounter people with learning disabilities more than ever before. To address this increase and the deficit in skills, we need to ensure that student trainees who are going to qualify as teachers, social workers or health professionals have the basic skills which will enable them to provide student-centred education, care and support that promotes independence and inclusion.

An ongoing theme which is addressed within our Advocacy Pathway is the acknowledgement and awareness of the impact of various labels and definitions of people with disabilities, especially those with PMLD; how preconceptions and the personal history of such definitions can affect initial interactions and the ongoing relationships between individuals. There are various levels to which a person can be disabled: mild, moderate, severe and profound. The group of people with a learning disability who face the most barriers to inclusion are non-verbal

individuals who will fall within the PMLD category.

According to Colley and his colleagues, people with PMLD have a range of additional needs, namely very severe learning difficulties, sensory impairment, physical disabilities, complex medical conditions, and behaviour which sometimes challenges those around them (Colley *et al.*, 2022: 2). People with PMLD use unconventional ways to communicate; they use body language, facial expressions, vocalisations, gestures, touch, eye-pointing and other idiosyncratic means. The wide range of additional needs (and the associated diverse ways of communicating) means that there is no single definition of PMLD (Nind & Strnadova, 2020; Colley *et al.*, 2022). Due to having such different needs and unique characteristics, this group of people are the most disadvantaged and most difficult to engage in a person-centred way (Ware, 2004; Nind and Strnadova, 2020; Colley *et al.*, 2022). Despite these challenges, research shows that it is possible to engage and work with people with PMLD and enable them to share their wishes, preferences and viewpoints (Ware, 2004).

## HISTORY OF THE PROJECT

The Advocacy Pathway involves a partnership and way of working which has been developed through a decade-long relationship between the RIX at UEL and CPA, a special secondary school in London. Following 20 years of research and development, RIX have established a new way of working with people with lived experience of learning disability using multimedia, called Multimedia Advocacy. As part of their approach, they have also developed an online, easy-to-build secure platform called RIX Wiki, which enables people with additional needs to use multimedia to communicate their viewpoints, wishes and preferences. The Multimedia Advocacy approach is based on the values and principles of



Figure 1. BASW (2018) Professional Capabilities Framework – social work level capabilities: [www.basw.co.uk/pcf/PCF05SocialWorkLevelCapabilities.pdf](http://www.basw.co.uk/pcf/PCF05SocialWorkLevelCapabilities.pdf) (accessed 29 December 2021).

person-centred practice, and it supports collaboration between the person with the lived experience, their family, and education, health and social care professionals (Kwiatkowska *et al.*, 2012).

The use of assistive, accessible and innovative technologies at CPA is an integral aspect of the academy environment. The implementation of the Education Health & Care Plan (EHCP) in 2014 and a stronger focus on PCP and multidisciplinary working led to the implementation of RIX Wikis for every pupil as their tool for self-advocacy. The partnership between RIX and CPA brings together the experience of RIX in using multimedia self-advocacy throughout education and the social care sector with the opportunity to engage with the pupils at CPA and to model communication systems and strategies for engagement, participation and independence.

What concerned us as educational practitioners, both within school and higher education, was that PCP was much used and talked about, but without the reality of meaningful involvement for those with the most complex needs. The lack of knowledge and skills of current professionals when it comes to related communication systems and digital skills helped inspire this Advocacy Pathway. Perhaps even more important were the inappropriate attitudes and beliefs which impede participation by people with PMLD in decision-making processes. Research on involvement demonstrates that there are many whose voices are seldom heard and who are more likely to be excluded from processes of involvement (Ward *et al.*, 2016).

Ward *et al.* (2016) conducted a systematic literature review using the following keywords: learning disabilities/difficulties or profound learning disability/difficulty, AND involvement and professional education. Not surprisingly they only found one paper that specifically related to education. They concluded that the involvement of people with learning disabilities is happening more in health,

care and research but not much in education. When we conducted our literature search in March 2022, we only found a handful of studies that involved young people with learning disabilities and felt that the work that we have been pioneering as part of our partnership needs to be shared so others can benefit from this practice.

## ADVOCACY PATHWAY

The Advocacy Pathway is a programme of study at UEL offered to year one SW students on the undergraduate social work programme. Typically, we have a cohort of eight to twenty SW student trainees undertaking this programme each year. They will typically come from a wide range of social, economic and cultural backgrounds. The programme lasts five months and is delivered via weekly lectures/reflections, online sessions and a two-hour weekly placement at the school.

## AIMS

The aims of the pathway are twofold: to equip SW students with a new set of skills and to empower learners with the lived experience of PMLD to build relationships and provide opportunities for them to be listened to, respected and included.

Some of the opportunities that the Advocacy Pathway offers to SW students are to:

- advocate on behalf of and with young people with lived experience of PMLD
- communicate with those who are non-verbal, have complex barriers to expressing themselves and may interpret the world through other sensory means
- develop strategies and tools to overcome these barriers, recognising the role technology can play in this process
- develop their digital proficiency skills.

The benefits for the young people with lived experience of PMLD are the following:

- the opportunity to communicate and build relationships with a wide range of people from diverse cultural backgrounds and ages
- working alongside SW students when building their RIX Wikis
- developing better knowledge of self, and self-advocacy skills
- opportunities to practise and develop their leadership skills as part of their own self-advocacy.

Indirectly, the programme also aims to influence and challenge the beliefs, attitudes and assumptions others can have regarding the potential and abilities of those with lived experience of a PMLD. Furthermore, the programme aims to inspire the SW students to recognise and challenge these assumptions and beliefs in others. It seeks to raise aspirations and widen people's belief in the possibilities for people with PMLD being valued members of our community, addressing and valuing the cultural diversity, experiences and backgrounds of everyone and understanding what inclusion means.

## PROCEDURE AND METHODOLOGY

Teaching multimedia advocacy to SW students firstly takes place in a series of lectures and seminars delivered by the authors of this article with the use of previously produced (also by the authors) learning resources. (Those learning resources are available free on Open Learn Works platform <https://www.open.edu/openlearncreate/course/view.php?id=1851> within our course 'Multimedia Advocacy: Making Plans with People with Learning Disabilities' (2016).) Once the underlying principles and theory are understood by the SW students, they are introduced to the young people from CPA with lived experiences of a PMLD.

The SW students are each individually paired with a young person in school

with PMLD. The initial pairing is through sharing something which is meaningful to them in the form of a sensory experience or object. The emphasis is put on developing a rapport and a friendly relationship with the young person, getting to know, and learning to listen to each other. This begins their journey of relationship-building through non-verbal communication and reinforces the importance of SW students engaging with young people in their familiar environment where they can show their strengths and abilities. This process is particularly important as it can take a long time for the relationships to be established. At this stage we also introduce the use of multimedia, assistive technologies, and communication strategies as effective tools for this practice-based learning. The RIX Wiki is a key platform which shows the use of multimedia to enable the SW students to see, reflect upon and value the young person.

Together the young people and SW students collect the resources and build individual sections of their PCP RIX Wiki (see Figure 2). They all start from the school's template which has the following sections: My Story; How best to support me; My Aspirations; Important people to me; My Communication, My Achievements; and Other.

PCP Template- Default- Wiki (rixwiki.org)

RIX Wiki technology enables family and other professionals to contribute to the young person's RIX Wiki. Families often add information about the person in their 'My Story' section, for example. Other people, such as speech and language therapists, could contribute to the 'How I Communicate' section. SW students support the young people during lessons to add information about their achievements at school, what is important to them and examples of communication.

Over the years the authors found that SW students on placements can start feeling overwhelmed and emotional when seeing young people with complex needs, often for the first time in their lives. During the pathway SW students can work through their first emotions, beliefs and expectations and realise that people with the experience of a PMLD have a lot to offer; they have a lot to say but the rest of society should listen and create space for those voices to be heard.

SW students will also often ask for the disability or medical information on the young people before or at the beginning of the placement. We deliberately avoid giving any initial medical description, allowing the SW students to pair on shared interests and personalities and develop the relationship and rapport with the individuals without preconception. This gives them the opportunity to reflect

and challenge their own thoughts and feelings and to focus on the individual's strengths and abilities.

'Labelling theory suggests that humans manage the world around them through categorization and by applying labels to themselves and to individuals or groups around them" (Becker, 1963; Link & Phelan, 1999). We feel this is important to acknowledge, as labelling has been criticised for instigating and supporting stigma; activists with intellectual disabilities have campaigned against this, using the slogan 'Label jars, not people' (Mencap, 2021).

After each visit, SW students must record their personal reflections and at the end of the module produce a reflective paper on lessons learned. Additionally, on completion, we celebrate the Advocacy Pathway and SW students work with the young people on presenting their learning together. This helps to capture the genuine change in SW students' beliefs regarding young people with PMLD. For the young people it is an acknowledgement and recognition of their contribution to the learning and development of others while celebrating their positive attributes and achievements.

## FINDINGS

If we are going to affect the outcomes for those with the most complex needs and create greater inclusion, then we believe this model of partnership and practice-based teaching is a positive step to creating change.

This agrees with conclusions from Duffy *et al.* (2021) which argued that adopting a 'hybrid model in social work education, recognising the differing knowledge from simulation, and lived experience, can make an important combined contribution to the competence development of SW students to enable them to enter field practice with confidence' (p. 637).

The most significant outcome for our pathway has been the role young people with lived experience can play in changing

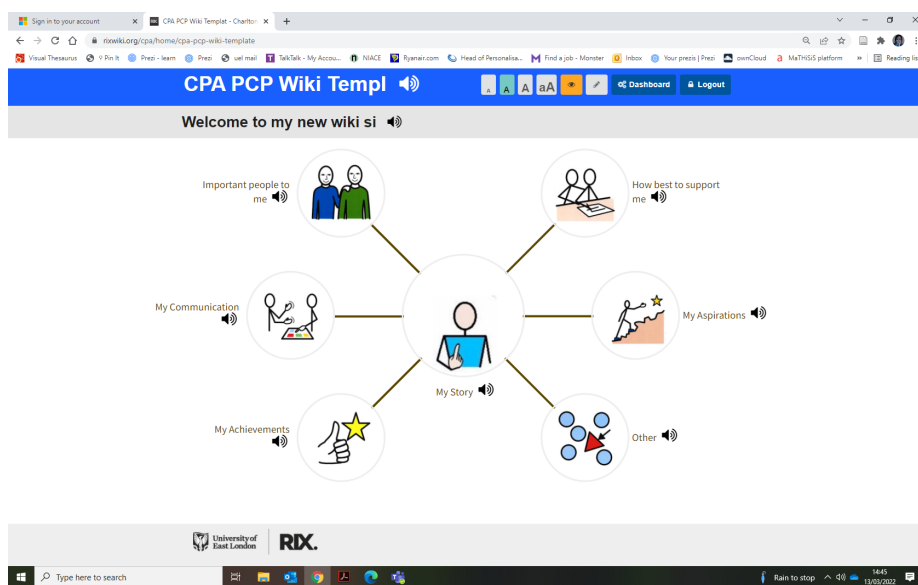


Figure 2. PCP RIX Wiki Template made using Widgit © Symbols.



the beliefs, attitudes and core values of others.

'The significance of interpersonal relationships also reinforces the idea that person-centredness is more than the "doing" of practices but is much more about a way of "being" as a practitioner' (McCance *et al.*, 2021). Individual attitudes are not easy to address in social work education (Ward *et al.*, 2016). The change is possible when people address their own attitudes and assumptions, as we have seen over the years running this programme.

*'When I first started I was quite shocked I was a bit like, oh my goodness have I chosen the right pathway, I felt quite overwhelmed because when I first saw the multiple disability needs they had, I felt a bit helpless, what am I going to do, how am I supposed to communicate if they are non-verbal, how will I understand, how can I create a Wiki for them that is theirs when they are not able to tell me what they want. Over the weeks I really did learn they are telling me so much, that even without verbally communicating... It has been humbling actually; I would say it is a wonderful experience for everyone to have.'* (SW student feedback, 2019)

*'This placement is an eye opener, it allowed me to feel a range of emotions and really opened my eyes and mind to just how much people in general go through. Personally, I felt both emotional and humbled. This experience has given me a great insight of "expecting the unexpected" going forward with my social work career and I feel the experience has taught me not to prejudge or bring my own agenda or assumptions into personal-centred work.'* (SW student, 2021)

*'I was invited into a world I have never been a part of before. I saw how non-verbal young people communicate and were understood... [B]y using a range of specialised tools and appliances*

*young people are given a voice!'* (SW student feedback, 2022)

The immersion of the SW students into the world of the young people meant the young people then became the teachers, inviting the SW students to be part of a completely unique way of engagement and pace of conversation. These non-verbal conversations and interactions were key to instigating changes in SW students' beliefs and, most importantly, raising the aspirations they held for the individuals. The SW students were able to realise that to communicate effectively they needed to slow down, adjust their pace, listen and be guided by the young person. Although the Advocacy Pathway was delivered with a mix of theory, practice and reflection, we believe it was the relationships which had the most important impact. The shift in the SW beliefs cannot be taught in a lecture theatre. It is the lived experience of the SW students being exposed to such interactions that makes the change, allowing them to acknowledge and reflect on their own feelings, attitudes and responses.

*'I feel like it should be compulsory, it is so important to learn these skills, do not be scared off by the level of needs that these students have because their abilities will surprise you, they can do so much. It is so important that we as social workers are there to support them and to teach other people the importance of advocating for these people and the importance of knowing the right skills to communicate with them.'* (SW student feedback, 2019)

*'It makes you discover who you are, it helps you grow as a person and learn about people's individualism, that people regardless of whatever challenges they might be facing, they have dreams, they have aspirations, they know who they are and what they want out of life, and I think it is just an enriching pathway where you learn to grow.'* (SW student feedback, 2019)

Advocacy Pathway also enables SW students to develop a range of other

important skills, abilities and strategies to draw on in their future roles. Because the placement was within an educational environment, they were exposed to a range of teaching tools, strategies and communication systems. The classroom staff became role models, and an awareness of multidisciplinary working and involvement of families was emphasised. The use of multimedia was highlighted as an effective tool in teaching a reflective pace and a way of working with individuals to celebrate achievements and to advocate with them. By building the PCP RIX Wiki together, SW students were exposed to and understood the value of PCP in showing the young person's aspirations and strengths, and how best to support potential. The exposure to alternative communication was critical in understanding and observing behaviour as an essential way of interacting with those who have complex needs and are non-verbal.

*'Through active listening, and observation I have learnt to realise all behaviour is also communication.'* (SW student feedback, 2022)

*'It has been an extremely rich experience and made me aware of the different ways to communicate, how important it is to build a relationship with the young people, in order to effectively communicate with them.'* (SW student feedback, 2022)

*'I've learnt that children with complex needs are very much capable to communicate quite effectively if the right support is provided to them.'* (SW student feedback, 2022)

## CONCLUSIONS AND RECOMMENDATIONS

Over the years of this pathway, the outcomes have been inspiring for all those involved, strengthening the belief that this way of delivering this module, through partnership between individuals, is creating a long-term change with lasting benefits not only for these SW students but the future young people and their families.

The SW students learnt best from this practice-based opportunity and directly from those with their own life experience. We believe that far greater consideration should be given to the role that people with PMLD can play in the learning process of future professionals. We would encourage more partnerships between universities and schools to pursue this training model, which could benefit a far wider range of professional trainees from different disciplines. Embedding this practice-based teaching right from the beginning of professional training is far more impactful for a short commitment of time on placement.

This area of research is extremely limited; as stated at the beginning of this article, we only found one other academic paper that involved a PMLD individual in social work education.

However, there is convincing evidence that this practice does change attitudes while providing positive inclusive opportunities for those involved.

We would like to conclude by thanking the many young people involved in our programme over the years, some of whom have the most complex barriers to communication and learning, and to recognise their unique ability to teach

and affect SW students' way of being as practitioners.

*'Patience is key, it has been humbling experience for me, and it has helped me become more connected with my inner self.'* (SW student feedback, 2022)

*'I have developed a positive attitude and open-mindedness as important qualities while engaging with people with complex needs, as no day is the same.'* (SW student feedback, 2022). ■

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