



Embracing authenticity and challenging norms: Including people with an intellectual disability as lecturers in third level intellectual disability nursing programmes

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ABSTRACT

Underrepresentation of voices from people with intellectual disability in nurse education: In the Republic of Ireland and the United Kingdom, university level programmes for intellectual disability nurses have traditionally incorporated the perspectives of people with intellectual disabilities but have been delivered by non-disabled educators. Perspectives are interpreted through the lens of the non-disabled person, with the voices of people with intellectual disabilities rarely heard.

An alternative approach: including people with intellectual disability as educators: In this article, an alternative approach is proposed that addresses this problem by including individuals with intellectual disabilities as educators within university programmes. Such inclusion will benefit students, academics, and ultimately the individuals who will receive health and social care from these nurses.

Many countries have seen legislative and policy changes promoting inclusion for people with an intellectual disability. These are welcomed, but if they are to have a meaningful impact, societal attitudes and perceptions towards people with intellectual disabilities must be challenged.

Drawing upon the concepts of social reconstruction and the ideologies of Paulo Freire and John Dewey, we argue that education can catalyze societal transformation. By including individuals with intellectual disabilities as educators in undergraduate programmes, such as nursing, traditional hierarchies of educators can be challenged, and students can learn from experts with lived experiences. This approach fosters critical thinking, reflection, and the development of authentic and informed healthcare professionals. The experiences of a co-author with a lived experience of intellectual disability as an educator, highlights the positive impact of such inclusion on students' perspectives, understanding, and empathy.

Specialist nursing in intellectual disabilities has been a distinct discipline of the nursing profession in Ireland and the United Kingdom, for many decades, leading to registration as intellectual disability or learning disability nurses (McCarron et al., 2018). In other countries similar roles are undertaken by general nurses and, in some places by social educators, for example, *vernepleier* in Norway (Måløy et al., 2023). Designers of preparatory programmes for specialist intellectual disability nurses have increasingly sought to include the perspectives of people with an intellectual disability, however, often these perspectives are included as part of a wider non-inclusive programme (Feely et al., 2022) and are relayed by non-disabled academics and not by the individuals themselves. Sometimes, people with intellectual disabilities

are invited to present lectures or engage in discussion, but this is typically in the context of a visiting role, rather than the person being an integral member of the teaching team (Mevold et al., 2023). Including people with an intellectual disability in such programmes in a more integrated manner – for example, as educators – would, it is proposed, benefit students, the discipline, the educator with lived experience and ultimately those that the nurses will go on to serve.

People with an intellectual disability have experienced discrimination, stigmatisation, and oppression throughout history. The negative effects of such stigmatisation have had a detrimental effect on the lives of many people with intellectual disability, well beyond any impairment in intellectual and adaptive functioning (Hotez et al., 2023). In Ireland,

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for example, there have been legislative changes such as the Education Act (1998) and the Equal Status Act, (2000-2011), which have ensured that children with an intellectual disability receive education and that discrimination is prohibited. The [United Nations Convention on the Rights of People with Disabilities \(UNCRPD\) \(2006\)](#) which has been ratified by over 190 countries aims to promote full equal human rights and fundamental freedoms, as well as the promotion of dignity and respect. These positive legislative changes work to ensure people with an intellectual disability are able to participate fully and meaningfully in society. However, for legislation to have full and meaningful effect, attitudes and perceptions of people with an intellectual disability in wider society still need to be challenged. This vision of a more equal society aligns with the ideology of social reconstruction, whereby education provides the means to transform society, grounded in the concept of social justice ([Schiro, 2012](#)). Including a person/people with an intellectual disability as educators in an undergraduate intellectual disability nursing programme challenges the normative view and traditional hierarchies of educators and allows student nurses to learn from experts by experience, thus also shaping how they may practice as registered nurses.

Paulo Freire viewed the role of higher education as promoting political and moral practice and considered pedagogy to be the 'Practice of Freedom' ([Freire and Mellado, 1970](#)). John Dewey promoted a democratic means of education, which promotes the growth of the individual. Both [Dewey \(1916\)](#) and [Freire and Mellado \(1970\)](#) emphasize the need for human interaction and experience to accomplish change, action, and growth and reject the idea of the educator as the authoritarian figure, rather promoting a dialogue between educator and learner. The idea of education as a dialogic process, promoting critical thinking to become informed citizens and authentic thinkers, was central to both writers.

Education is a means by which society can be reconstructed, through challenging deep social structures that underlie many problems, including racism, war, sexism, poverty, and discrimination ([Schiro, 2012](#)). A core function of higher education is to create new kinds of knowledge based on student's experiences, with the aim of questioning their view of the world ([Southworth, 2022](#)). Through providing students the opportunity to learn from people with an intellectual disability, they will be challenged to question preconceived ideas and encouraged to create new kinds of awareness and knowledge of the lived experience of a person with an intellectual disability that could not be gained from an educator who has not experienced intellectual disability.

In 'Pedagogy of the Oppressed', [Freire and Mellado \(1970\)](#) introduces problem-posing education, which he contextualises around the 'teacher-student' dyad. He challenges the notion that the teacher deposits information to the student, suggesting that education is more concerned with a dialogue between the two, teacher-learner, learner-teacher, where both teacher and learner are partners in the dialogue. [Freire and Mellado \(1970\)](#) posits that the teacher cannot think for the student, but rather promotes authentic thinking from the student's perspectives, which happens through communication but not when the traditional teacher is isolated in an 'ivory tower'. It is concerned with reality of experiences ([Freire and Mellado, 1970](#)). Learning directly from the experiences of people with an intellectual disability, would promote authentic thinking and the opportunity for nursing students to reflect on themselves and their role as professional nurses in a way that could be readily applied to their practice.

1. "Nothing about us without us"

In recent years, Ireland has been a leader in inclusive higher education with a certificate programme in a leading Irish university opening up tertiary education to people with an intellectual disability (Certificate in Arts, Science and Inclusive Applied Practice, [Trinity Centre for People with Intellectual Disabilities, 2023](#)). While this is a positive and necessary step, the next step of including people with intellectual disability as members of academic staff speaks directly to the popular

slogan from the 90s 'Nothing About Us Without US'. This slogan was embraced by the disability rights movement ([Charlton, 1998](#)) and refers to the principle that people with disability should be included in any conversation, topic or discourse that relates to them or that may affect them. This movement came about following decades of oppression and exclusion. Historically, people with disabilities, and in particular people with intellectual disabilities, were viewed solely from a deficits-based approach, influenced by the medical model. Focusing only on deficits rather than strengths meant that people were considered helpless and dependent on others, with limited opportunities to contribute to society. This oppression and stigmatisation of people with an intellectual disability led to further disablement beyond any physical or cognitive deficit. A clear message from this movement was that 'professionals' and 'experts' were *speaking for*, rather than *speaking with* people with disabilities, and that the opinions of people with disabilities, were not as valid as those of professionals ([Charlton, 1998](#)). More recently, with the ratification of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) in Ireland, this has once again been challenged. Within the Preamble of the United Nations Convention on the Rights of People with Disabilities it is stated that:

"...persons with disabilities should have the opportunity to be actively involved in decision making process about policies and programmes, including those directly concerning them"

(UNCRPD Preamble).

This makes a clear argument for people with intellectual disability to have roles in programmes that prepare health care and other professionals to support people with such a disability, particularly as academic staff. This will support the person with an intellectual disability to take on a socially valued role, but will also enhance, the education and training that students receive, as shown in previous research in this area ([Horgan et al., 2018](#); [Scanlan et al., 2022](#); [Winn and Lindqvist, 2019](#)), where the need for a more strategic approach is emphasised ([Happell et al., 2022](#)). Including people with an intellectual disability as members of the academic team in the undergraduate curriculum would add a new perspective for the students, not possible for an academic educator without intellectual disability. While many have experience working with people with an intellectual disability, the power dynamic of this relationship is one where the nurse is providing care to the person with an intellectual disability, and the person with intellectual disability is the receiver of care and support from the nurse. Including a person with intellectual disability as a member of the academic team should allow this power dynamic to be reversed and could provide an additional perspective on teaching content to other educators on the team. Where the person with intellectual disability would be responsible for marking a component of the course, this may further force a shift in the power dynamic. Such a shift has been reported widely, where people with disabilities have taken on such roles ([Anderson, 2006](#); [Pritchard, 2010](#); [Mueller, 2021](#)).

How classes are organised may differ from traditional lectures, to support the educator with intellectual disability and to promote open communication to generate authentic thinking. Inverting the classroom, by taking events that usually happen outside the classroom, into the classroom, and vice versa, can increase student performance through interactive activities and thought-provoking discussion by providing more opportunities for student-teacher interaction ([Lage et al., 2000](#)). Including people with an intellectual disability in the teaching curriculum in this way, will allow for a more inclusive teaching and learning practice and will enable students to confront values, thoughts, and any preconceptions they may have had. This can also lead to reflective practice, stimulated by the reflective teaching style inherent in the lived experience of a person with intellectual disability where students challenge preconceived ideas about people with an intellectual disability themselves. Such reflection has been found to enhance engagement and meaning for students and to encourage critical thinking ([Harford and MacRuairc, 2008](#)).

Recommendations from 'Shaping the Future of Intellectual Disability Nursing in Ireland' (McCarron et al., 2018) include a strong emphasis on person-centredness and advocacy, which can only occur where the person supported is put in the centre of all decisions. This necessitates a genuine reflection and understanding of the lived experience of the person with an intellectual disability which could be facilitated by a member of the academic team who has such a disability.

2. Inclusive teaching approach

The idea of including people with lived experience in education is not a novel one and has been adopted in the fields of social care and non-medical mental health training, but less so in other health disciplines (Spencer et al., 2011). In an evaluation of case studies that included people who use services as educators, a common response from students was that preconceptions were challenged, with some students reporting that this inclusion made them re-evaluate their idea of living with the disease, an idea that translates easily to the area of intellectual disability (Spencer et al., 2011). These findings are supportive of the problem-posing education espoused by Freire and Mellado (1970), the promotion of authentic thinking encouraged by reflective practice, and supports the Deweyian belief that those affected by institutional systems should be involved in producing and managing them (Dewey, 1916).

While examples of people with disabilities being involved in education have been noted (Anderson, 2006; Pritchard, 2010; Mueller, 2021), the inclusion of people with an intellectual disability has been less frequently documented. However, there are some examples. The importance of this involvement is highlighted by a recent example where people with an intellectual disability collaborated with academics at a leading Irish university to design, teach and mark a module in the school of social work (Feely et al., 2022). The results of the endeavour were overwhelmingly positive, with reports of greater understanding and greater empathy. Students reported an initial unease about the ability of educators with an intellectual disability to deliver course content, a reticence to ask questions that might offend, and a fear that their grades would be affected if marked by someone with an intellectual disability. These beliefs were challenged by the co-educators with an intellectual disability and open conversation was encouraged around these preconceptions, in which students were encouraged to be reflexive and investigate problematic beliefs (Feely et al., 2022). This is akin to the 'practice of freedom' discussed by Freire and Mellado (1970) wherein it is proposed that education must promote the constant development of critical thinking and debate. Through this type of education, societal beliefs about disability can be challenged, beginning with those who will be working with and supporting people with disabilities – connecting student, institution, and society.

There is a need to ensure that the participation and valuing of people with an intellectual disability is actively promoted, and that any involvement as educators in third level education is not tokenistic. Rather, the educator with an intellectual disability should be supported throughout the process to engage meaningfully with the students. The flipped classroom approach (Lage et al., 2000) provides a more inclusive pedagogy to enable a member of the academic team with lived experience to ensure the most impactful and thought-provoking delivery. The goal would be to engage the students to reflect meaningfully, critically, and creatively about their role in the lives of people with an intellectual disability, beyond the instrumentalized knowledge and rigid training, to be strong advocates for people with an intellectual disability and support them in a manner in which they would like to be supported. The educator must also be included as a member of the teaching team and broader school structure. This demands that accommodations be explored and that issues related to accessibility (for example, social, informational, physical) must be addressed so the person can experience inclusion on an equal basis to other members of staff. For true integration into the teaching team, institutional barriers and processes need to be examined to truly embed this within the institution, and to include an

educator with lived experience as a member of the academic team. These institutional barriers present perhaps the biggest challenge to integration of an educator with lived experience, including the appropriate title used for this role and appropriate remuneration.

3. Perspective from lived experience

I am one of the co-authors of this paper with lived experience of intellectual disability and teach on a module for students undertaking an intellectual disability nursing degree in Ireland. I was paid per hour at the standard guest lecturer rate for the institution. This section gives details of this from my perspective. In my experience, the feedback at the end of the module was always extremely positive, with students emphasising how valuable it was to have a lecturer with lived experience, as it gave them great insight into living with a disability.

Unfortunately, I was not met with the same enthusiasm at the beginning of the module. I felt a strong sense of cautiousness and judgement among the students, as if they were afraid to say the wrong thing. This resulted in some awkward silences. As time went on, the students began to feel more comfortable, and a sense of camaraderie began to build among lecturer and students. I attributed this to the students taking a walk in my shoes by listening to my story and the challenges I face daily. I felt the students were more willing to speak their minds as they began to get used to the experience of having a lecturer with an intellectual disability.

Similarly, I felt less confident in the beginning when instructing the class to stay quiet and adhere to the rules. This was not attributed to an imbalance of power, but more to a lack of confidence due to the initial reluctance among the students. However, as time went on this dynamic shifted and I felt more confident controlling the class. I felt validated, valued, and loved the experience of lecturing.

I felt that having a lecturer with a lived experience enabled students to truly view the world from my perspective, providing them with more knowledge and insight into what it is like to have a disability; whether that's seen, unseen, inherited or acquired. However, I did find that the students were initially uncomfortable speaking to someone with an intellectual disability and I believe that employing a lecturer with a lived experience would be a great way to educate students and address this. This is extremely important for those who intend to work with or support individuals with a disability. With respect to healthcare, in particular, I have found that professionals often do not know how to relate to me and sometimes patronise or completely overlook me.

Additional supports are required to ensure accessibility when employing lecturers with a lived experience. I believe it is important to make sure that the content of the lectures is understandable by all. This was achieved in the module I had previously lectured on by using Easy Read material to present text (Foundation for People with Learning Disabilities, 2023) and the development of accessible marking schemes for assessments. A buddy system among the academic staff could also be useful to help educators settle in.

4. Conclusion

Social constructionists view education as the means by which inequality and injustice in society can be addressed and where the goal of education is to promote critical and authentic thinking in students. Intellectual disability student nurses receive education in all aspects of nursing care, and on the theory of person centred care and how it may impact the lives of people with an intellectual disability. Through involving people with an intellectual disability in the education of nurses, preconceptions and beliefs previously held can be challenged, and give those on the receiving end of care the chance to shape the education of those providing care. Inclusion of people with lived experience as educators has become more accepted in educational settings, however, to date people with an intellectual disability are largely excluded from this. Creative and meaningful solutions should be sought

to address this and to ensure an education for nurses that encourages empathetic thinking.

CRedit authorship contribution statement

Eimear McGlinchey: Writing – review & editing, Writing – original draft, Conceptualization. **Stephanie Corrigan:** Writing – review & editing. **Fintan Sheerin:** Writing – review & editing, Conceptualization. **Mei Lin Yap:** Writing – original draft, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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