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CO-DESIGN AND DELIVERY OF A RELATIONAL LEARNING PROGRAMME FOR NURSING STUDENTS AND YOUNG PEOPLE WITH SEVERE AND COMPLEX LEARNING DISABILITIES

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Abstract

Background: National Health Service (NHS) staff in the UK are required to undergo training about learning disabilities at the appropriate level for their role. However, this requirement does not apply to nurses in training and student nurses report fear and anxiety about caring for people with intellectual learning disabilities (ILDs). Young people with intellectual disabilities report feeling scared of nurses and parents feel staff do not listen to them or involve them in care.

Objectives: (i) For a university and special school for young people with severe and complex ILDs to work in partnership to co-design a programme for nursing students, young people, their teachers, and parents. (ii) To deliver the programme online as part of the university's existing nursing courses.

Design: The partnership between the university and the special school focused on co-design of an interactive programme, parent involvement, safeguarding, and the design of accessible learning resources to support young people with severe and complex ILDs' engagement. The programme was informed by relational inquiry, service user and transformative pedagogies, and parents and teacher's knowledge and views about the young people. Delivery of the programme was designed to fit into existing nursing courses and enable students on

placement and young people at home or in hospital to participate. A rights-based ethnographic evaluation was designed to support participant feedback and programme development.

Setting: The Heritage2Health Virtual Arts and Drama Programme was piloted with nursing students at one UK university and young people with severe and complex ILDs from one special school, their parents and teachers.

Participants: 15 nursing students (BSc Year 2=10, Year 3=3, MSc=2) and 7 young people with severe and complex learning disabilities (age 11-14yrs). Other participants were parents/guardians of young people (7), arts/drama facilitators (2), academic lecturers (2), special needs teachers (2), registered nurse (1).

Methods: An 8-week dynamic programme of arts and drama. Sessions included 30-mins start-up/presencing, 45-mins storytelling/drama with young people and parents, 30-mins reflection/close. Sessions were facilitated by 2 arts and drama specialists. The story of 'Ubuntu the Lion with the Long, Long, Mane' (by TNP) was used to explore difference and ways of being. The evaluation methods were participant observation, semi-structured interviews (2-6 weeks post) and thematic analysis.

Results: Participation in the programme was a challenging, creative, and reflective experience that was transformative for all. Nurses and young people's fears and anxieties

about each other were revealed and addressed by participating in arts and drama activities together. Nursing students learnt how to adopt a relational orientation to young people and their parents and teachers.

Conclusions: A co-designed programme for nursing students and young people with severe and complex ILDs can benefit student knowledge and skills and reduce fears and anxieties between nurses and young people with ILDs. With adequate planning and resources, the programme could be adopted by multidisciplinary partnerships between other universities and special schools.

Key words: nursing education; relational learning; social justice; multidisciplinary; intellectual learning disability; service user involvement

CO-DESIGN AND DELIVERY OF A RELATIONAL LEARNING PROGRAMME FOR NURSING STUDENTS AND YOUNG PEOPLE WITH SEVERE AND COMPLEX LEARNING DISABILITIES

Introduction

In 2022 it became compulsory for all clinical staff working in health and social care in England to receive intellectual learning disabilities (ILD) training at the right level for their role. The requirement has come about because of the growing recognition of the multiple systemic and structural barriers to health care that people with ILDs face. Approximately 1.5 million people in the United Kingdom (UK) have ILD of which 351,000 are children aged 0-17 (Public Health England, 2020). Intellectual learning disability is associated with greater mortality (PHE, 2020), health inequalities (Ploeg, 2011) poorer healthcare outcomes and worse experiences of healthcare (Mencap, 2013). People with ILD are the ‘hidden higher users’ of adult hospital mental health and child services (Kenton, 2019). Nurses in nearly all areas of practice are likely to meet a person with ILD and they are unlikely to be trained in ILD (Northway and Dixon, 2019).

At present the NHS requirement for ILD training does not apply to pre-registration nursing education. In the UK less than 10 percent of students and qualified nurses receive adequate training and education on working with people with ILD (Northway and Dix, 2019) yet student nurses are regularly exposed to stigmatising attitudes of qualified staff towards people with ILD (Pelleboer-gunnink et al., 2017). Nursing students in the UK and elsewhere, have expressed fear and anxieties about caring for people with ILD, including distress at witnessing poor quality care (Northway and Dixon, 2019). Studies of registered nurses have shown NHS staff feel uncertain about caring for children with ILDs (Bekkema et

al., 2014) or how to support families (Brown et al., 2016). A recent study of children's hospitals that do have a Learning Disability Liaison Nurse, found staff valued this provision however they remained unconfident and young people with ILD were not valued or deemed capable at an institutional level (Oulton et al., 2019). Other important and interrelating factors include lack of integration of ILD expertise into all fields of nursing and curricula, severe under investment in the learning disability nursing workforce, and underinvestment in ILD research (Buchan et al., 2019) but the focus here is on nursing education.

Young people with ILDs report feeling scared of nurses (Mansell 2010) and parents feel staff do not listen to them or involve them in care (Mencap, 2013). For many years disabled activists have tried to challenge the stigma, discrimination, and enduring misconceptions about disability in healthcare settings (Paliokosta and Nash, 2019). Authors including Jean Piaget, Lawrence Kohlberg, B.F. Skinner, Carol Gilligan, Elliot Turiel, Judith Smetana have argued that disability should be valued as a source of understanding and justice. Health promotion research in ILD suggests that enhancing quality of life and reducing health disparities requires two things: 'health access' and 'sensitised healthcare providers' (Roll, 2018). Nursing students need to understand the clinical and technical aspects of caregiving and be aware of their duty of care and legal responsibilities, such as their responsibilities under the UK Health & Social Care Act (UK GOV, 2012). However, to be effective practitioners they need to have the knowledge and skills to engage and work with people with ILDs and their families (Buettner-Schmidt and Lobo, 2011).

Aims

The aim of the programme was to improve nursing student's knowledge and skills to care for people with ILD by supporting nursing students to engage with young people with ILDs. The aim is informed by social justice perspectives of the transformative potential of education on practice and society (Van Schalkwyk et al. 2019) which suggests that nursing education can have a transformative impact on nursing practice and healthcare systems more broadly. From a social justice perspective, teaching and learning about ILD in nursing education could contribute to socially-just professionalism (Matwick and Woodgate, 2016). We perceive this to be a form of professionalism that intentionally seeks to address social injustices associated with the barriers to healthcare and involvement in health care decision making that young people with ILDs face (Oulton et al., 2019; Buettner-Schmidt and Lobo, 2011). From a social justice perspective, we see our students as individual subjects of action and responsibility and enactors of the rights of inclusion and equality (Van Herk et al., 2011) for young people with ILDs.

The objectives were as follows.

- (i) For a university and special school for young people with severe and complex ILDs to work in partnership to co-design a programme for nursing students, young people, their teachers, and parents.
- (ii) To deliver the programme online as part of the university's existing nursing courses.

Design

Young people with severe and complex ILDs, by the very nature of their personal barriers to advocate for themselves, require their families, carers, advocates, friends and involved

professionals to advocate for them (Doukas et al., 2017). Therefore, the approach to the design of the programme was to work in partnership with young people, parents, and teachers. Early conversations about the idea of an interactive arts and drama-based programme were discussed informally (TN) with teachers at the special school (January 2020). The special school aims to be a fun, safe and caring school that promotes the joy of learning, high personal achievement, respect for individual differences, dignity for all and equal opportunities by eliminating discrimination. The special school supported parent involvement in designing the programme through conversations and feedback on the idea. For example, what time of day might work best for young people and parents, preferred names to use, and any special needs to consider. The focus was on seeing and valuing the involvement of young people as individuals with strengths and interests. We did not record or label them by any ILDs diagnosis or clinical condition. The reason that they were invited to participate in the project was because of their membership of the special school and its partnership with the university.

The partnership between the university and the special school focused on co-design of an interactive programme, The Heritage2Health Virtual Arts and Drama Project. The partners discussed and identified strategies for safeguarding of all participants in an online space, including protecting personal information and what to do if anyone showed any signs of distress. The special school teacher advised on the design of accessible learning resources to support young people's engagement. Thus, co-design in this context involved the sharing of ideas, joint decision making, being open about limitations and other challenges (O'Connor et al., 2021), and willingness to try to make the programme work for everyone. Figure 1 illustrates how the elements of the programme design, delivery and evaluation were interrelated.

[INSERT FIGURE 1 NEAR HERE]

Figure 1. Overview of the Heritage2Health Virtual Arts and Drama Project

The partnership was informed by insights from relational inquiry, service user pedagogy and transformative pedagogy, as well as parents and teacher’s knowledge and views about the young people in their care. Relational inquiry is a philosophy designed to underpin nursing curricula and guide nursing care-encounters (Doane, Hartrick-Doane and Varcoe, 2020). It combines perspectives of relational consciousness and pragmatism to encourage student nurses to become conscious of self (inter-personal), others (intrapersonal) and contextual influences (context) in each relational moment. Relational inquiry connects with transformative learning pedagogies (see Freire, Rogers and Scrimshaw reported in Iwasiw and Goldenberg, 2015) which “acknowledge the complexity of the world we live in and questions what we believe we know about it” (Van Schalkwyk et al., 2019).

In terms of the programme’s co-design, relational inquiry meant creating spaces to question how nursing students and young people with ILDs, parents and teachers interact and the possibilities to relate to each other to address fear, anxiety, and uncertainty.

In terms of levels of involvement and influence (Dada et a., 2022) young people with ILDs were listeners to information about the project, and advisors in deciding the approach (via parent communication). They provided their opinions on whether they wanted to join the programme and the format of the drama based online sessions. In delivery of the programme, young people were equal partners in the storytelling and drama. The approach meant changing the traditional pedagogical relation, the diad between student and teacher (Bergum

and Dossetor, 2020) so that all participants were co-travellers and explorers in “working out what we know about what we don’t know”.

The university/special school partnership informed the design of the programme by connecting academic, professional, and community networks to “ask, acquire, appraise, apply, assess and processes information” (Phillips et al., 2016) from different sources and perspectives. This included discussions within the university’s Special Interest Group (SIG) for Inclusion and Social Justice (Paliokosta, 2021), drawing on learning from a previous disability awareness project (Paliokosta and Nash, 2019), and sharing knowledge on safeguarding in special education and healthcare contexts (Rawlings et al., 2014). With the support of their parents and teachers, the young people were given an opportunity to decide, shape the experience, contribute to the learning, and give feedback about their participation and their experience. Nursing student representation in the design of the programme was enabled through StudentHub, a national initiative that creates hubs for service-learning programmes between universities and the community. An Entrepreneurship team supported the programme design by hosting a “hackathon” (a deliberative event focused on perspective sharing to generate solutions to a specific issue) to develop ideas with project partners and student representatives.

Delivery of the programme (June/July 2020) was designed to fit into existing nursing courses and enable students on placement and young people at home or in hospital to participate. We recognised that pressurised clinical settings are challenging environments to learn about ILD (Mencap, 2013). Furthermore, during the COVID-19 pandemic we were all learning to experiment, adapt and integrate digital communication into our lives, learning and teaching. Members of the team (TNP, EA) had already developed a relationship with a local special needs school through successful in-person drama, film and singing projects. Prior

evaluations had demonstrated that in-person projects led to nurses gaining confidence in their ability to attune to young people with ILD and activate change in clinical settings. Our challenge during COVID-19 was to create a relational programme that could be run virtually and remotely.

Therefore, the partnership between the university and the special school could offer a safe and inclusive way to engage nursing students, young people, parents, and teachers in learning relationships (O'Connor et al., 2021) and opportunities for social justice within nursing education (Konrad and Browning, 2012). We drew on service user pedagogies, which suggest that the inclusion of people with ILD (Rhodes, 2012) can enable the full participation of marginalized people in academic and civic society (Simplican et al., 2015). These pedagogies also suggest that service user involvement can provide students with an engaging approach to student learning (Tobbell et al., 2018) that involves experiential learning (e.g., David Kolb, John Dewey, Kurt Lewin, Jean Piaget, see Kolb et al., 1999) and increased student awareness of agency for change (Iwasiw and Goldenberg, 2015).

Alongside the programme design and delivery, a rights-based ethnographic evaluation (Parker, 2007) was designed to support participant feedback and programme development. The evaluation was rights-based in the sense that it respected the rights of the young person to be involved in issues that affect them (Callus, 2017) whilst also recognising the essential role of parents and teachers as advocates for young people with severe and complex ILDs. We needed to work in ways that supported communication and participation, with teachers and parents as intermediaries to explain to us what the children were expressing and interpret their feelings and responses to participation. The ethnographic approach allowed us to capture feedback from all participants at the time (formative element) and shortly after the

programme had finished in August/September 2020 (summative element). Information about the evaluation methods is provided below.

Setting

The Heritage2Health Virtual Arts and Drama Programme was piloted with degree and master's nursing students at one UK university and young people with severe and complex ILDs from one special school in 2020.

Participants

15 nursing students (BSc Year 2=10, Year 3=3, MSc=2) and 7 young people attending a special school for children with severe and complex ILDs (age 11-14yrs). Other participants were parents/guardians of young people (7), arts/drama facilitators (2), academic lecturers from nursing and education (2), special needs teachers (2), registered nurse (1). The ratio of academic lecturers/facilitators to nursing students was 4:15.

Recruitment of the first nursing student cohort was co-ordinated by a Heritage2Health Student Ambassador and overseen by TNP. Recruitment of the young people with ILDs and their parents was supported by the special school teacher who sent out letters inviting families to take part and explaining the aims and objectives of the project. The special school teacher selected students and families who she believed would enjoy and benefit from participating in the project. There were no control or comparator groups in this pilot study.

Ethical approval was granted by the university (KUREC Ref-1581 2020). All participants gave their informed consent to participate in the programme and rights-based

evaluation, including agreement to use creative group reflection exercises for research purposes (Hydén and Antelius, 2011). No financial incentives or reimbursements were offered or provided to any of the participants. Ethical practice was maintained through establishing trustworthiness of the study findings as credible, transferable and confirmable with participants' original data and participants' views (Moorley and Cathala, 2019). In this context, it involved checking with parents and teachers about whether young people with ILDs were responding positively to their involvement, whether any ethical issues were emerging from their perspective, and whether any modifications or adjustments should be made to the programme or its delivery. Transparency of the process was supported by keeping all participants informed about how the data would be collected and analysed including its management, explained below.

Methods

The programme itself comprised 8 online sessions held weekly at 4.30pm. Each session began with a 30-mins start-up for presencing, acknowledging participation and grounding students, followed by 45-mins of storytelling/drama with young people and parents. Sessions ended with 30-mins for student reflection/close. Storytelling and reflective elements were facilitated by 2 arts/drama specialists and StoryAID (an approach devised by co-author EA that helps participants to find their voice through facilitated storytelling and retelling).

The central feature of sessions was the direct involvement of young people with ILD in storytelling. COVID-19 motivated TNP to write the story of "Ubuntu the Lion with the Long Long Mane". This story aims to enable diverse readers to connect with *ubuntu* philosophy through characterisation, colours, and imagery. Ubuntu philosophy is a collection of values

and practices of Africa or of African origin that offer new directions for nursing pedagogy, curriculum, practice patterns, and policies that emphasise caring constructs (Downing and Hastings-Tolsma, 2016). The young people's special needs teacher created sensory books and Makaton symbols (a form of communication that uses symbols and signs, see <https://makaton.org/>). The purpose of the story books was to support engagement of young people in the sessions and to support recall of parts of the story that had already been told. Storytelling and dramatization of the story by the 2 facilitators encouraged inclusion and interaction between participants. For example, making 'roar' sounds together when the lion in the story roars.

Nursing students were asked to be active participants in the storytelling and they interacted with the young people through sharing in the story and drama activities. To make it clear for young people who the 'nurses' were in the project student nurses and nurse academics agreed to wear uniform. The role and actions of the facilitators was to encourage all participants to feel supported and encouraged to interact with the story and each other over the 8 sessions. Facilitators used ice-breaker activities and invited participants to introduce themselves or express their views, to support engagement and comfort with interacting using the online format. The dramatization was directly related to the Ubuntu story and all participants were invited to dramatic gestures and sounds at various points in the story.

The number of sessions, their frequency, timing, and duration were delivered as scheduled. No significant modifications were made during the course of the programme but learning about the need for more time for student preparation and coaching was fed back into the design of later sessions. Group reflection after each session was identified as an important part of the learning process for nursing students. Nursing students were encouraged to keep a personal reflective journal to encourage critical reflection on assumptions and learning

(Smith, 2010). Personal reflections were respected as such, and we did not ask nursing students to share their journals, or treat them as data in the evaluation.

The evaluation methods were participant observation, semi-structured interviews (2-6 weeks post) and thematic analysis. The artist facilitator who had helped to deliver the sessions (BO'D) undertook in-depth semi-structured interviews with students, parents, and a teacher 2 to 6 weeks after the programme. Interviews included questions about concerns, needs, involvement, session timings, improvements, learning, and future planning. Evaluation data were analysed using Lyons and Coyle's (2001) approach to thematic analysis which included familiarisation, coding text, generating themes, reviewing themes, and writing up. To support rigour in the analysis, interview data was read independently (TNP, PP) (member checking) and themes were verified by all team members (Lyons and Coyle, 2001).

Results

Thematic analysis identified issues from the perspective of participants in the Heritage2Health Virtual Arts and Drama Project and reflected the questions asked in the interviews about concerns, needs, involvement, session timings, improvements, learning, and future planning. Findings from all participants, including young people's engagement and responses to the sessions, are presented in the full report (Nash-Patel et al., 2021). Readers can request an e-copy of the report from the corresponding author. The focus of the present article is whether the programme delivers on its aim to improve nursing student's knowledge and skills to care for people with ILD.

Nursing students described a wide range of types of impact they believed the programme had on their knowledge and skills, which was supported by ethnographic observations and

topics discussed in group reflections at the close of sessions. The analysis explored these in terms of the intrapersonal, interpersonal and contextual reflective domain described by Doane, Hartrick-Doane and Varcoe, (2020) and found an additional theme associated with learning about learning environments. We have used these themes to structure this results section, as follows:

- learning about self
- learning about others
- learning about learning environment
- learning about context

An overview of the results relating to impact on nursing student knowledge and skills is provided by table 1 (Table 1).

[INSERT TABLE 1 NEAR TO HERE]

Table 1: Impact on nursing student knowledge and skills

Learning about self

Learning about self (the intrapersonal relational domain described in relational inquiry) included themes and issues about “self-confidence” and “self-awareness”, “personal development or growth”, “self-expression”, “identity formation”, understanding of personal vulnerabilities and weaknesses, openness to trust in others and build understanding by working with parents. Learning about self also included understanding personal communication strengths and how to be oneself in a digital leaning space. A quote from one

nursing student reflects on the position of fear and not knowing, that nursing students felt at the outset of the programme:

“Some of us were a bit rigid, we need to get to know each other more.” (Student nurse 3)

Nursing student participants said that they felt challenged to overcome their self-consciousness about interacting with young people with ILD. This learning about self, and an awareness of personal discomfort, anxiety, or fear associated with engaging with young people with ILDs, is supported by an observation from one of the facilitators:

“You cannot hide who you are in the virtual space. It is unforgiving. If you look worried, it will happen. If you are not confident, it is there. If you do not know what you are doing, it is there, and everybody sees it before you do.” (Drama specialist)

A benefit of learning about self for nursing student learning, was an awareness of personal limitations of knowledge and skills and the importance of interacting with others to work together. This impact on nursing student’s knowledge, was the recognition of the limitations of knowledge, and a clearer understanding of the uncertainties involved in caring for people with ILDs:

“We can then say, we do not have the answers within us, let’s find out together what the answers are.” (Drama specialist)

Learning about others

Nursing students said that they valued the experience of meeting young people with ILDs and their parents and teachers, as illustrated by the following quote from one nursing student who believed that:

“Heritage2Health should be compulsory. It helps you connect with yourself as well as the patient.” (Student nurse 4)

Learning about others (interpersonal relational domain) included understandings about the circumstances and needs of young people with ILDs, the views of parents, teachers, other students, or educators, and ability to empathise and communicate with others and understand complex needs.

As one student explained, they learnt how to calm a young person with ILDs by using mirroring techniques:

“Mirroring, between pupils and me, was the biggest learning curve. I want to find out more and explore different types of communication tools.” (3rd year student nurse)

Nursing students and young people’s fears and anxieties about each other appeared to be overcome by participating in arts and drama activities together. Parent’s also commented that nursing students had appeared to gain confidence and skills to communicate with young people and their parents, as illustrated by one parent’s comment that this:

“[The participating nursing student’s] good communication should be the standard for everyone.” (Parent 3)

Student nurses reported new skills in inclusion and involving young people in decision making, such as choosing who would pretend to be characters in the retelling of the Ubuntu story. In terms of the knowledge and skills to care for young people with ILDs, nursing

student's developing openness and willingness to trust in others, were important potential learning outcomes. The comment below, from a nursing student, demonstrates how trust in others was supported by the special school teacher:

"Their teacher was invaluable. She was great to have as a connection between student nurses and young people and their parents and carers. The pupils associated happiness and friendship with her." (Student nurse 2)

In time, this interpersonal learning could benefit professional practice through nursing student's valuing patient's and carer's knowledge of their own lives, situations, and health.

Learning about learning environments

Learning about learning environment concerned nursing student's developing understanding of the learning opportunities and barriers to learning presented by settings or contexts. For example, student's awareness about busy practice environments or tiredness at the end of long placement shifts having a negative impact on their enthusiasm or ability to participate, and the importance of explaining these environment issues to other participants (an issue discussed in all group reflective sessions).

Reflection on the format of delivery in the online learning environment revealed this enabled some nursing students to receive peer support and non-judgemental learning through creative group reflection, outside of an academic or practice setting. For all students this type of informal feedback was in contrast to more formal approaches to the assessment of learning e.g., individual marks for assignments or exams.

Students said that because of the way the sessions were facilitated, they learnt active listening and interaction skills, while inspiring them to take a more active lead on group reflection at the end of sessions. Having watched how the drama specialist (EA) and artist (BO'D) interacted with young people and their parents, the nursing students felt more comfortable to reach out to young people, using playfulness or humour for example. As one nursing student described it:

“It is sort of a weird way to do emotional work but using drama and acting has been a playful way to engage and break down the seriousness of the subject matter...Singing, drama, drawing, shows we are all human.” (2nd year student nurse)

The facilitator controlled who appeared on screen so young people and parents were not overwhelmed by faces. Some nursing student participants felt devalued by being left off screen.

“It made me think does it matter if I don't fully commit to the session, if I can't be seen anyway? I was sad they didn't see me.” (2nd year student nurse)

Similarly, nursing students said they understood why the facilitators decided to control everyone's microphones (to enable everyone to participate in turns and not speak over each other) but some students felt this limited their interactions with the young people. Some students said taking information in from so many screens at once felt overwhelming and fewer participants online might have worked better. These issues created a feeling amongst the students that the group was slow to gel, however a more equal group dynamic was achieved as facilitators adapted to be more inclusive, ensuring retention of all students.

“Everyone was committed and because we had the same goal, the sessions felt energetic and positive. It was not about obligation, but about wanting to make it work.” (3rd year student nurse)

Nursing students felt that running the sessions online promoted a new way of learning based around the inclusion of young people with ILD and their parents (corresponding with a service user pedagogy):

“We can interact with people who are not able to do the event days through this kind of online work. In this way, it is limitless.” (3rd year student nurse)

However, students said that a counter to opening themselves up would be to have more time for closure or re-grounding:

“You open yourself up and then it all stops” (2nd year student nurse).

Group reflection exercises were important for nursing student group bonding, development of nursing student’s confidence and consolidation of learning (e.g., reinforcing learning with perspectives from relational inquiry), and checking that the materials and the educational strategies were being delivered as originally planned. Through the group reflection exercises it became evident that few nursing students practiced self-directed reflective journaling between sessions, perceiving this to be a ‘task’ rather than a supportive tool. This is something that might need to be supported with additional time and guided instruction to work well for students. Three students who did practice reflective journaling reported that this technique helped them to “emotionally process” their experiences while on the programme and on practice placements.

Learning about context

Nursing student's learning about context (relational context) was evident in their comments about how social, political, cultural, economic, and academic contexts impact on their care for young people with ILD and on healthcare more generally. Some students explained how they had learnt skills to enact professional standards e.g., awareness of the Nursing Midwifery Council Code or knowledge of the rights disabled people. These understandings of ILD in context helped nursing students to transfer their learning to practice (e.g., being able to draw on relational inquiry to inform their practice).

After participating in the programme nursing students reported feeling more aware of their position in a context of caregiving (e.g., "who I am as a nurse") their agency (e.g., "what I can do in my job") and their choices about how to relate to patients in clinical settings (e.g., "who am I being"). This issue is illustrated by a student who explained how she put her knowledge and skills of how to relate to a person with ILDs into practice. She reports:

"It was incredibly powerful, the patient responded really well, and his family told me how fantastic it was that he had gotten so much out of the experience. I felt very empowered afterwards to actually use what we had developed in the sessions." (2nd year student nurse)

For the academic lecturers, student's accounts of how they have used their learning in practice demonstrate the impact of the programme on the wider context of nursing care. For example, one nurse academic observed that:

"When students go into practice placements, they bring that relational lens with them, and they appreciate they have a choice about who they are being and how to be with people." (Nurse academic)

In relation to the academic context, nursing students became more aware of limitations of academic curricula. This was because the relational learning space enabled students to take more responsibility for their own learning and developing sense of professionalism:

“It takes academics and students working together to facilitate personal growth. It is important to be that support, handing over the reins, so that they become kinder more inclusive people and not fearful and judgemental practitioners. If they are anxious in practice and ‘put up the barriers’, they will not be the best they can be.” (Nurse academic)

Discussion

The results of the thematic analysis suggest that nursing student participants in the Heritage2Health Virtual Arts and Drama Project gained a range of knowledge and skills to care for young people with ILDs. This pilot project did not aim to formally assess or measure nursing student’s knowledge and skills, so as not to make assumptions about the types of impact that nursing students might experience. It did not aim to capture base-line nursing student data about disability awareness or attitudes towards people with ILDs. However, the evaluation is an important step towards identifying indicators and measures of knowledge and skills development in the future, and to refine the aims of the programme. However, the observed and self-reported impact on nursing student’s knowledge and skills seems to be significant in terms of student’s carrying a relational orientation into their professionalism, practice settings and clinical encounters with people with ILDs (Northway and Dix, 2019). This evaluation did not aim to capture longer term impact on patient care quality or patient

outcomes. Finding evidence of clinical significance would require further research with participating students and corresponding patient data.

The evaluation provides insights into how a relational learning experience that was coproduced in partnership with young people with severe and complex ILDs, teachers, and parents (Dada et al., 2022), had an impact on nursing student's knowledge and skills. The way the programme influenced nursing students was by building student's awareness and confidence (Konrad and Browning, 2012) to adopt a relational orientation (Doane, Hartrick-Doane and Varcoe, 2020). This included coaching in relational inquiry and nursing student reflection on self, others, environments, and contexts. The relational approach is intrinsic in ILD specialist education and social care, and this programme and its findings demonstrate how it applies to nurse education and could improve nursing care.

The partnership between the university and special school was important for the success of the programme's design and delivery, but it may not be the main reason for the impact on nursing student knowledge and skills. In relation to transferability of the programme, we should not assume that another approach might not work better or be delivered in different ways e.g., by other types of partnerships, networks, or collaborations. After all, this programme was devised as an online solution during the pandemic. Face-to-face learning environments might suit other participants or have a greater impact on benefit for participants. From a social justice perspective there may be other approaches that inspire or enable nursing students to address social injustices and the barriers to healthcare and involvement in health care decision making that young people with ILDs face (Oulton et al., 2019; Buettner-Schmidt and Lobo, 2011).

We have captured and reported on the impact of the programme on nursing student knowledge and skills. It is more challenging to answer the question of whether the programme has delivered on its second intention, for young people with ILD and their parents to feel that nurses listen to them. We can say that the programme enabled connection and built relationships between all participants during a time of great fear and trauma in health services and society. Participants shared in a relational experience and found belonging and hope as part of a group of people that came together to learn about each other. After the lifting of COVID-19 shielding restrictions, the nursing students were keen to arrange a whole group picnic event with the young people, parents, and teachers, to connect in person with each other.

Conclusion

The co-design, delivery and evaluation of the Heritage2Health Virtual Arts and Drama Project, created opportunities for nursing students and young people with severe and complex ILDs to interact and learn about themselves and each other. Participants in the programme learnt about the learning environments, and wider contexts that affect their lives and work. Not only did the programme benefit student knowledge and skills, but it also reduced fears and anxieties between nurses and young people with ILDs. With adequate planning and resources, the programme could be adopted by multidisciplinary partnerships between other universities and special schools and learning could be translated into other educational settings and fields of practice.

References

- Bekkema N, de Veer AJ, Albers G, Hertogh CM, Onwuteaka-Philipsen BD, Francke AL. (2014) Training needs of nurses and social workers in the end-of-life care for people with intellectual disabilities: a national survey. *Nurse Educ Today*. 34(4):494-500. doi: 10.1016/j.nedt.2013.07.018. Epub 2013 Jul 25. PMID: 23972684.
- Bergum, V. and Dossetor, J. (2020) *Relational Ethics. The full meaning of respect*. Bergum and Dossetor. ISBN-13:979-8668209811
- Brown M, Hoyle L, Karatzias T. The experiences of family carers in the delivery of invasive clinical interventions for young people with complex intellectual disabilities: policy disconnect or policy opportunity? *J Clin Nurs*. 2016 Feb;25(3-4):534-42. doi: 10.1111/jocn.13090. PMID: 26818378.
- Buettner-Schmidt, K. and Lobo, M. (2011) Social justice: a concept analysis. *Journal of Advanced Nursing* 68(4), 948–958.
- Buchan, J., Charlesworth, A., Gershlick, B. and Seccombe, I., (2019) A critical moment: NHS nurse staffing trends, retention and attrition. The Health Foundation. https://www.health.org.uk/sites/default/files/upload/publications/2019/A%20Critical%20Moment_1.pdf
- Callus, A. (2017) *Developing Inclusive Research Methods: Collaborating With People With Intellectual Disability as Co-Researchers*. SAGE Research Methods Cases Part 2. DOI: <https://dx.doi.org/10.4135/9781473989184>
- Dada, S, May, A, Bastable, K, et al. (2022) The involvement matrix as a framework for involving youth with severe communication disabilities in developing health education materials. *Health Expect*. 25: 1004- 1015. [doi:10.1111/hex.13445](https://doi.org/10.1111/hex.13445)

Doane, J., Hartrick-Doane, G., and Varcoe, C. (2020) How to Nurse: Relational Inquiry in Action. 2nd edition.

Downing C. and Hastings-Tolsma M. (2016) An integrative review of Albertina Sisulu and ubuntu: Relevance to caring and nursing. Special Edition. Health SA Gesondheid, 21: 214-227.

Hall E. (2010) Spaces of social inclusion and belonging for people with intellectual disabilities. J Intellect Disabil Res. 54 Suppl 1:48-57.

Iwasiw, C., and Goldenberg, D. (2015) Part I: Introduction to Curriculum Development in Nursing Education; The Evidence-Informed, Context-Relevant, Unified Curriculum. In: Curriculum Development in Nurse Education. (Third edition) ISBN-13: 978-1-284-02626-9.

Kolb, D., Boyatzis, R., and Mainemelis, C. (1999) Experiential Learning Theory: Previous Research and New Directions. Case Western Reserve University. OH.
<https://learningfromexperience.com/downloads/research-library/experiential-learning-theory.pdf>

Konrad, S. C. and Browning, D., M. Relational learning and interprofessional practice: Transforming Health Education for the 21st Century. 1 Jan. 2012: 247 – 251.

Lyons, E., and Coyle, A. (2001) Analysing Qualitative Data in Psychology. Third Edition. Sage Publishing.

Matwick AL, Woodgate RL. (2017) Social Justice: A Concept Analysis. Public Health Nurs. 34(2):176-184. doi: 10.1111/phn.12288. Epub 2016 Aug 23. PMID: 27549919.

Mencap (2013) Death by Indifference: Equal Healthcare for All. Mencap.

<https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf>

Moorley C, Cathala X. (2019) How to appraise qualitative research. *Evid Based Nurs*. 2019 Jan;22(1):10-13. doi: 10.1136/ebnurs-2018-103044. Epub 2018 Dec 1. PMID: 30504448.

Nash-Patel, T., Paliokosta, P., Dundas, J., Anderson, E., O'Donaghue, B., Rajah, R., Morrow, E., Scrivener, H., Dean, S., Pierre, S. (2021) Relational Learning to Overcome Fear and Uncertainty: A report of the Heritage2Health Virtual Arts and Drama Project for student nurses, young people with intellectual disabilities, their parents and teachers. Full Report. Kingston University & St Georges University London.

Northway, R., and Dix, A. (2019) Improving equality of healthcare for people with learning disabilities. *Nursing Times*, 115: 4, 27-31.

O'Connor, S., Zhang, M., Kovach Trout, K., Snibsoer, A.K. (2021) Co-production in nursing and midwifery education: A systematic review of the literature, *Nurse Education Today*, 102, 2021, 104900, ISSN 0260-6917, <https://doi.org/10.1016/j.nedt.2021.104900>.

Oulton, K, Wray, J, Hassiotis, A, Kenten, C, Russell, Jessica, Tuffrey-Wijne, I., Whiting, M. and Gibson, F. (2019) Learning disability nurse provision in children's hospitals : hospital staff perceptions of whether it makes a difference. *BMC Pediatrics*, 19(192), ISSN (online) 1471-2431

Paliokosta, P. and Nash, T. (2019) Fighting for our rights: perceived gains from transforming the curriculum through a narrative of activism. *International Journal for Cross-Disciplinary Subjects in Education*, 10(2), pp. 4041-4047. ISSN (online) 2042-6364.

Paliokosta, P. (2021) Developing a community of practice through the special interest group (SIG) on inclusion and social justice. Kingston University Report, unpublished.

<https://eprints.kingston.ac.uk/id/eprint/47936/>

Parker M. (2007) Ethnography/ethics. *Soc Sci Med*. Dec;65(11):2248-59. doi:

10.1016/j.socscimed.2007.08.003. Epub 2007 Sep 14. PMID: 17854966.

Pelleboer-Gunnink HA, Van Oorsouw WMWJ, Van Weeghel J, Embregts PJCM.

Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review. *J Intellect Disabil Res*. 2017 May;61(5):411-434. doi:

10.1111/jir.12353. Epub 2017 Feb 15. PMID: 28198094.

Phillips, A.C., Lewis, L.K., McEvoy, M.P. et al. Development and validation of the guideline for reporting evidence-based practice educational interventions and teaching (GREET).

BMC Med Educ 16, 237 (2016). <https://doi.org/10.1186/s12909-016-0759-1>

Ploeg Booth KV. (2011) Health disparities and intellectual disabilities: lessons from individuals with Down syndrome. *Dev Disabil Res Rev*. 17(1):32-5. doi:

10.1002/ddrr.136. PMID: 22447753.

Public Health England (2020) Deaths of people identified as having learning disabilities with COVID-19 in England in the Spring of 2020, Report.

Rawlings, A., Paliokosta, P., Maisey, D., Johnson, J., Capstick, J. and Jones, R. (2014) A Study to Investigate the Barriers to Learning from Serious Case Reviews. Kingston University Institute for Child Centred Interprofessional Practice. Department for Education, UK.

Rhodes, C. (2012) User involvement in health and social care education: A concept analysis. *Nurse Education Today*, 32(2), 185-189.

Richard-Eaglin, A. (2021) The significance of cultural intelligence in nurse leadership, *Nurse Leader*, 19(1): 90-94. ISSN 1541-4612, <https://doi.org/10.1016/j.mnl.2020.07.009>.

Rolfe, G. (2014) Rethinking reflective education: What would Dewey have done?', *Nurse Education Today*, 34 (8) 1179-1183.

Roll, A. (2018) Health promotion for people with intellectual disabilities – A concept analysis. *Scand J Caring Sci*; 32; 422– 429.

Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in developmental disabilities*, 38, 18-29.

Smith, E. (2011) Teaching critical reflection, *Teaching in Higher Education*, 16: 2, 211-223
DOI: 10.1080/13562517.2010.515022
URL:<http://dx.doi.org/10.1080/13562517.2010.515022>

Tobbell, J., Boduszek, D., Kola-Palmer, S., Vaughan, J., & Hargreaves, J. (2018). Evaluating service user pedagogy in UK higher education: Validating the Huddersfield Service User Pedagogy Scale. *Nurse Education Today*, 63, 81-86.
<https://doi.org/10.1016/j.nedt.2018.01.014>

UK GOV (2012) Health & Social Care Act, UK Legislation.
<https://www.legislation.gov.uk/ukpga/2012/7/contents>

Van Herk KA, Smith D, Andrew C. Examining our privileges and oppressions: incorporating an intersectionality paradigm into nursing. *Nurs Inq.* 2011 Mar;18(1):29-39. doi:

Van Schalkwyk SC, Hafler J, Brewer TF, Maley MA, Margolis C, McNamee L, Meyer I, Peluso MJ, Schmutz AM, Spak JM, Davies D; Bellagio Global Health Education Initiative. Transformative learning as pedagogy for the health professions: a scoping review. *Med Educ.* 2019 Jun;53(6):547-558. doi: 10.1111/medu.13804. Epub 2019 Feb 14. PMID: 30761602. 10.1111/j.1440-1800.2011.00539.x. PMID: 21281393.

Figure 1. Overview of the Heritage2Health Virtual Arts and Drama Project

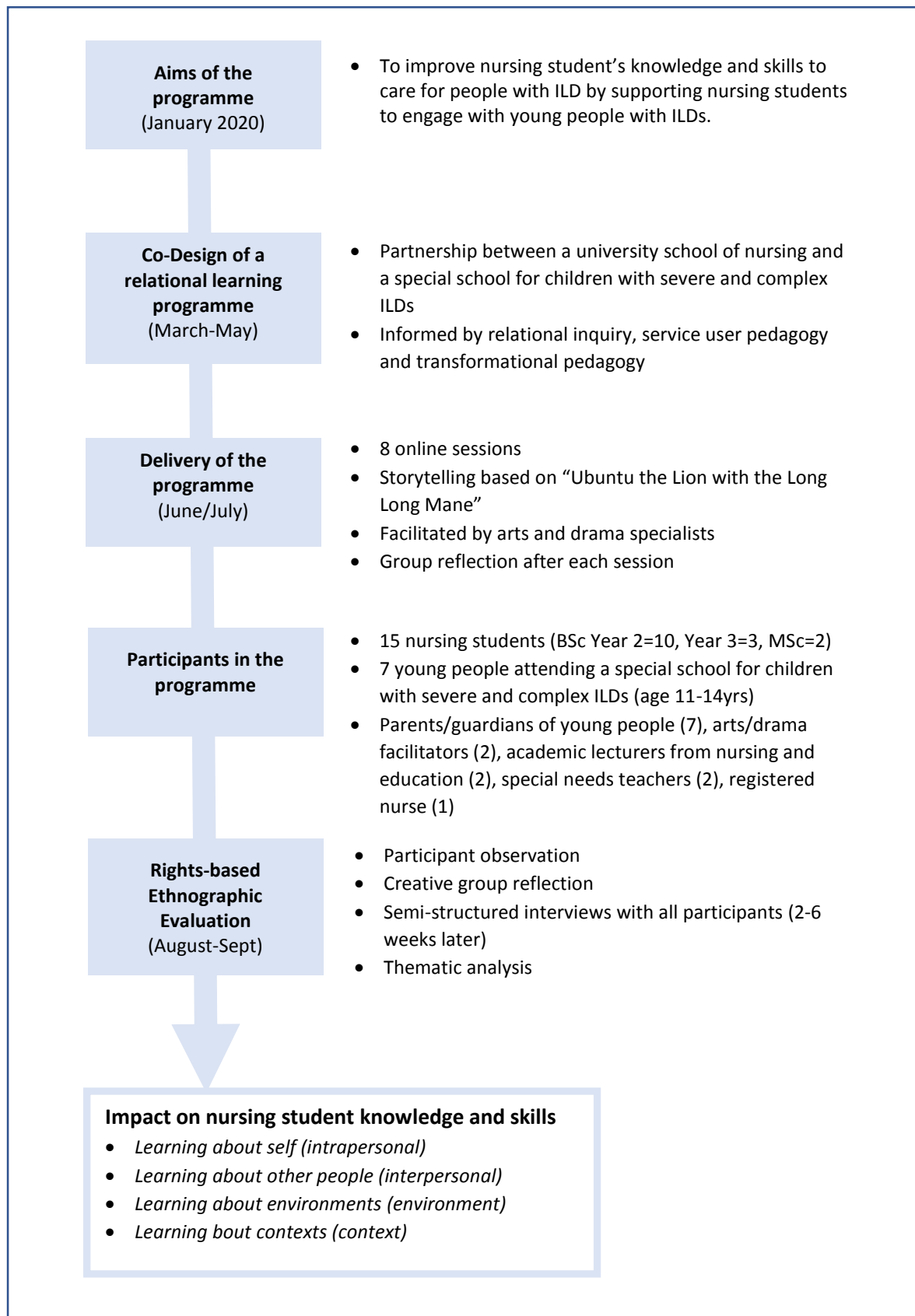


Table 1: Indicative impact on nursing student's knowledge and skills

<i>Relational domains</i>	<i>Nursing student self-reported learning</i>	<i>Supporting ethnographic observations during the programme</i>
<p>Learning about self (intrapersonal) personal awareness, growth, expression of self, identity formation, vulnerabilities, and uncertainties</p>	<ul style="list-style-type: none"> • Skills and confidence to engage with young people with ILD, parents and teachers • Self-awareness and ability for openness and to trust in others • Communication skills • Digital technology skills 	<ul style="list-style-type: none"> • Participant nursing students initiating conversations, asking questions, displays of playfulness and openness to engage with other participants • Overcoming anxiety and fear about talking to parents or young people with disability, openness to participate in drama activities • Learning and using Makaton symbols, using non-verbal communication, explaining, listening skills • Online interaction and relationship building in a digital space
<p>Learning about others (interpersonal) understandings of young people with ILDs, parents, teachers, other students, or educators</p>	<ul style="list-style-type: none"> • Ability to empathise with others and understand complex needs • Knowledge of inclusion and involvement techniques • Skills in shared decision making • Skills in reflection <i>in</i> action and <i>on</i> action 	<ul style="list-style-type: none"> • Students engaging with young people while in hospital or home settings • Taking turns in storytelling or drama, thinking about how to involve other participants in activities • Deciding what to do next in the drama activities, helping to decide how to run the sessions • Critical reflection on professional identities and choices about professionalism
<p>Learning about environment (learning environment) settings, mode of delivery, learning styles and preferences</p>	<ul style="list-style-type: none"> • Knowledge of ethics and safeguarding • Ability to provide and receive peer support and non-judgemental learning • Active listening and interaction • Facilitation skills/group management • Course leadership and management skills 	<ul style="list-style-type: none"> • Understanding and preserving confidentiality within the group • Creative group reflection and peer-to-peer feedback skills • Participation in the drama based on the storytelling • Students leading end reflection sessions • Students involved in co-production of the programme and influencing session design
<p>Learning about context (relational context) social, political, economic context</p>	<ul style="list-style-type: none"> • Skills to enact professional standards • Knowledge of the rights of people with disabilities and social justice • Ability to transfer relational learning experience to practice or organisational/work contexts/employability 	<ul style="list-style-type: none"> • Student awareness of professional standards and codes of conduct • Students explaining their understanding of human rights, equality law and the meaning of reasonable adjustments • Students reporting using a relational orientation in practice contexts

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