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The transition from child to adult health services for young adults with intellectual disabilities: An evaluation of a pilot of an online learning resource for Registered Nurses

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ABSTRACT

Aim: This study formed the third phase of a national study on the experience of transition from child to adult health services for young adults with intellectual disabilities. The aim of this phase was to evaluate the accessibility and acceptability of an on-line learning resource for Registered Nurses.

Background: The population of young adults with intellectual disabilities and complex needs is increasing. Consequently, more will move from child to adult healthcare, with evidence highlighting that for some their experiences of the transition process is poor. The main study provided contemporary evidence to raise the awareness of Registered Nurses of the needs of young adults with intellectual disabilities and their role in enabling an effective transition from child to adult services.

Methods: The online learning resource was developed and piloted with Registered Nurses involved in the transition from child to adult health services for young adults with intellectual disabilities and complex needs. Data collection involved an online survey and semi-structured interviews.

Results: Twelve Registered Nurses from 2 Scottish NHS Boards completed the questionnaire and 3 participated in a follow-up interview. The findings suggest that the mode of on-line delivery and most of the content of the learning resource were both acceptable and accessible to Registered Nurses across a range of areas of nursing practice. The learning resource was further adapted in response to the participant data.

Conclusion: This on-line learning resources offers the potential for Registered Nurses, and potentially other healthcare professionals to undertake evidence-based, structured further education regarding the effective transitions for young adults with intellectual disabilities and their families.

Tweetable abstract: Registered Nurses have key contributions to enable the transition from child to adult healthcare for young adults with intellectual disabilities.

1. Introduction

Medical advances have led to an increase in the population of young adults with intellectual disabilities, with over 90% of children born with complex health conditions now surviving into adulthood, many with complex neurological disorders (Magai et al., 2020). Therefore, many now require services that extend beyond child health provision, necessitating a “transition” into adult health care. However, international evidence highlights the significant challenges experienced by some young adults with intellectual disabilities, their families and health care

professionals (Brown et al., 2019, 2020a,b; Franklin et al., 2019). Following from this is the need to develop the knowledge of health professionals, including Registered Nurses regarding their role in the transition from child to adult health services for young adults with intellectual disabilities and complex health needs.

This paper presents the findings of the third phase of a national study undertaken in Scotland that investigated the experiences of young adults with intellectual disabilities and their families of the transition from child to adult health services (Brown et al., 2020a,b). This phase involved the development and piloting of an online learning resource

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that was grounded in the findings and recommendations from the research study (Brown et al., 2020a).

In keeping with international terminology, the term intellectual disability has been adopted throughout this paper when referring to learning disability, which is used in the United Kingdom in relation to people with impairments in cognitive and social functioning.

2. Background

Transition is defined as “a purposeful, planned process that addresses the medical, psychosocial and educational and vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.” (Department of Health, 2006: 14).

The primary purpose of transition is to provide uninterrupted, coordinated and developmentally appropriate care before and during the move to adult services (Betz et al., 2021a). Existing best practice recommends a range of actions to make effective health transitions a reality, including early holistic and person-centred planning, effective multidisciplinary coordination, joint working and information sharing between child and adult services, availability of reliable information and appropriate follow-up as key to a successful transition process and outcomes (National Institute for Health and Care Excellence, 2016; White and Cooley, 2018; Schmidt et al., 2020). In Scotland there is an estimated 26,349 people with intellectual disabilities of which some 3000 have a profound impairments and complex health needs, and many will transition from child to adult health services (Scottish Government, 2019). However, identifying the number of young adults who will transition remains a challenge as accurate data is often lacking, thereby relying on best estimates.

However, current evidence highlights that the transition for young adults with intellectual disabilities and complex health needs are poorly managed, with inadequate planning and coordination, poor communication and disjointed multiple “transfers” between different departments and services (Care Quality Commission, 2014; Aldiss et al., 2015; Franklin et al., 2019; Brown et al., 2021). As a result, many families assume advocacy roles for their young adult family member, driving the transition, which for some results in emotional distress and anxiety directly attributed to their experience of the process (Gauthier-Boudreault et al., 2018). Evidence also highlights that an ineffective transition can have further consequences for young people with intellectual disabilities and complex health needs, including poor health outcomes, barriers to accessing health care and failure to promote autonomy and decision-making (Gabriel et al., 2017; Young-Southward et al., 2017). Disruption of the continuity of care can lead to issues regarding the management of existing health conditions and decrease the detection of new ones following the transition to adult healthcare (Young-Southward et al., 2017; Hart et al., 2019). Evidence also points to the increased risk of mental ill-health during the transition process with potentially negative consequences for the individual and their family (Cvejić and Troller, 2018).

In a systematic review by Brown et al. (2019) it was evidenced that despite well-documented opportunities, the contributions made by Registered Nurses before, during and after the transition were often overlooked in this evolving area of nursing practice. The review concluded that developments within policy, nursing practice and nurse education are necessary to enable nurses to contribute effectively and fully throughout the transition process. The review highlighted that as a consequence of their holistic and life-course approach to the provision of nursing care, there are practice and education opportunities for Registered Nurses to play a key role in transition assessment, planning and implementation, health education and clinical skills teaching roles, all currently underdeveloped (Betz et al., 2021b).

The evidence presented in this paper formed part of a Scotland-wide study regarding the transition from child to adult health services for young adults with intellectual disabilities and complex needs from the

perspective of Registered Nurses and families (Brown et al., 2020a,b, 2021). The study involved interviews with 46 Registered Nurses and other healthcare professionals from across the 14 Health Boards in Scotland and with 10 parents of young adults with complex intellectual disabilities who had been through the transition process in the past two years. A Scottish Health Board is a regional authority that reports to the Cabinet Secretary for Health at the Scottish Government. Each of the 14 Health Board has responsibility for the delivery of all health services for their region, including acute, primary care, mental health and learning disability services for children and adults.

The aim of this part of the study was to evaluate the accessibility and acceptability of an on-line learning resource for Registered Nurses regarding the transition from child to adult health services for young adults with intellectual disabilities.

3. Methods

3.1. The development of learning resources

The purpose of the on-line learning resource was to enhance the knowledge and awareness of Registered Nurses regarding the effective transition from child to adult health services for young adults with intellectual disabilities and their role in enabling and facilitating the process. The content was developed by the research team from the findings of the research study (Brown et al., 2021); and by consultation with the Project Advisory Group (PAG) that included family carers and representatives from higher education, health and social care professional and non-government organisations.

The on-line learning resource, entitled “*Transitions from child to adult healthcare for young adults with learning disabilities*”, was divided into four learning four units, which were originally linked to 12 learning outcomes:

Unit 1: The multiple morbidities and health inequalities experienced by people with learning disabilities.

Unit 2: The concept of transition and existing principles of effective transitions from National Institute for Health and Care Excellent clinical guidelines and the evidence derived from the Scottish Transition Forum (National Institute for Health and Care Excellence, 2016; Scottish Transitions Forum, 2016).

Unit 3: The needs of young adults with intellectual disabilities and their families during and after the transition process, focusing on 5 key principles of effective transition which were:

- Early transition preparation
- Collaborative working across services and agencies
- Emergency care planning
- Coordinated handover of care from child to adult health services
- Family carers as equal partners in care

Unit 4: The welfare and legal system changes relevant to transitions.

The contents of Unit 3 were directly linked to the findings and recommendations from the main research study (Brown et al., 2021) and reflected the experiences of parents and examples of best practice from both parents and professionals.

Discussions within the research team and PAG placed emphasis on designing a learning resource that would promote reflection and include application of the learning to the Registered Nurse’s work context and specific role in the care of people with intellectual disabilities. The professional experience of members of the research team who were Registered Nurses was that online learning involved a final assessment using multiple-choice questions generated randomly from a bank of questions, leading to a ‘pass’ rate, often 80%, with a certificate of completion. This assessment approach was not viewed as appropriate to this learning resource, which aimed to enhance knowledge and awareness of effective transitions for young people with complex intellectual disabilities with an emphasis on personal reflection.

Three main features were integrated within the learning resource:

1. A fictional case study developed from the collective experiences of the parents who participated in the research study (Brown et al., 2021). The case study involved Sarah, a 15-year-old young adult and included details of her parents and siblings and an overview of her health needs and the range of professionals involved in her care. The case study was designed to enable Registered Nurses to identify care and support needs, services requirements and potential barriers that may be experienced and possible solutions. There were four sequential vignettes from the case study that were integrated into the units to explore the family experience as well as the professional input.
2. 10 reflective questions were embedded within the four units to provide Registered Nurses the opportunity to reflect on their existing knowledge and practice in relation to transitions.
3. Links to external resources that could be followed up to provide more detailed information.

For the purposes of the pilot study the learning content was transferred to an online software, Novi Survey. This was used to provide an accessible resource that could be shared with study participants via an on-line link, rather than invest in the production of a dedicated on-line learning platform, out with the scope of the study funding.

3.2. Design

The pilot study adopted a mixed-methods design, using a questionnaire and semi-structured one-to-one interviews with Registered Nurse participants to identify the acceptability and accessibility following completion of the on-line learning resource.

3.3. Recruitment

During the recruitment phase, Registered Nurse were initially contacted about the study by nurse leaders from NHS Lothian and NHS Ayrshire & Arran. Purposive sampling was used to recruit participants who practiced in the following specialties: community children's nursing, district nursing, child or adult diabetes nursing, child or adult epilepsy and neurology nursing, child or adult gastroenterology and child or adult respiratory nursing. Potential participants were contacted via email, provided with a Participant Information Sheet and a summary of the study. They were screened against the study eligibility criteria, which were, (i) involvement as a Registered Nurse in the care and (ii) support of a young adult with complex intellectual disabilities who had transitioned from child to adult health services in the last two years. During the recruitment phase, Registered Nurse from intellectual disability-specific health services volunteered to participate and were also included, although they were not the specific target audience for the learning resource.

Of the 32 Registered Nurses who initially expressed an interest in participating, 14 did not respond to the invitation and six declined or were not able to complete the qualitative interview due to work demands. Twelve nurses from the two Health Boards participated in the pilot, comprising Registered Nurses from children's services ($n = 5$) and ($n = 7$) Registered Nurses from adult health services. Of the 12, six agreed to participate in a qualitative one-to-one interview; three were interviewed.

Table 1 presents the quantitative demographic profile of the participants who participated in the study, identifying the area of clinical practice, gender, time in role and hours worked.

The self-reported experiences of the Registered Nurses' in the transition process and the provision of care and support to young adults with intellectual disabilities are set out in Table 2.

Table 1
Demographic profile of Registered Nurse participants.

NHS Board	NHS Lothian $n = 9$	NHS Ayrshire and Arran $n = 3$
Area of practice	Children's services $n = 5$	Adult service $n = 7$
Nursing role	Intellectual Disability / Complex Needs $n = 2$ Neurosurgery $n = 2$ Epilepsy $n = 3$	Diabetes $n = 1$ Community Children's Nursing $n = 2$ District Nursing $n = 2$
Gender	Female $n = 10$	Male $n = 2$
Time in current role	1–3 years $n = 6$ 7–8 years $n = 3$	16–21 years $n = 3$
Working hours	Full time $n = 10$	Part-time $n = 2$

Table 2
Registered Nurses experience in transitions and young adults with intellectual disabilities.

Number of times involved in transition planning or facilitation in the last 2 years	Estimated number of patients with intellectual disabilities on case load every year	Number of caseload patients with intellectual disabilities who transitioned in the last 2 years
Under 5 times $n = 4$	1–10 $n = 5$	Under 5 $n = 8$
5–10 times $n = 4$	20–30 $n = 4$	5–10 $n = 2$
11–20 times $n = 1$	Over 80 $n = 3$	11–20 $n = 1$
21–30 $n = 3$		Over 20 $n = 1$

3.4. Data collection methods

The learning resource and study questionnaire were delivered on-line, using Novi Survey. An evaluation questionnaire with 7 open and 7 Likert-Scale questions was developed for the purpose of the study by the research team to identify the following aspects of the online learning resource:

1. The acceptability and accessibility of the online learning resource in terms of length, duration to complete, the relevance of the case study and the visual presentation
2. General satisfaction and learning outcomes: the achievement of the learning outcomes, the level of the learning resource content in relation to the participant's existing knowledge, areas where new knowledge and understanding was developed or enhanced and the units that were most helpful and those requiring further development
3. Application to clinical practice: the relevance to everyday nursing practice and the usefulness of the reflective questions

The evaluation questionnaire was included and completed immediately following completion of the learning resources by the participants. Registered Nurse participants who agreed were contacted to undertake a telephone interview and invited to expand on their on-line evaluation. All data was transcribed verbatim and anonymised. Data were collected between June and August 2019.

3.5. Ethical considerations

Ethical approval was granted by the University Research Ethics and Governance Committee (XXXX removed for blind peer review) with all ethics governance procedures followed throughout. The Participant Information Sheet described the nature and purpose of the pilot study and highlighted that participation as voluntary with all responses anonymous and completed a consent form.

3.6. Data analysis

All questionnaire data were exported into Microsoft Excel for

analysis. Responses from the quantitative questions were analysed using descriptive statistics and the open-ended questions were coded by the research assistant and analysed using thematic content analysis (Anderson, 2007) to provide a descriptive expression of the participants' feedback. Data obtained from the qualitative telephone interviews in response to the evaluation questions provided additional detail used to inform the refinement and further development of the learning resource.

4. Results

4.1. Overall perception

In terms of the overall acceptability and accessibility of the learning resource, many of the participants were of the view that it was engaging and easy to navigate (n = 8) and the case study (n = 11) and external links (n = 8) were helpful. The only exception being the length of the learning resource, where half of participants considered it too long and repetitive in places (n = 6). Other areas requiring further development included visual presentation, improved division of individual learning units and additional graphics and diagrams and ensuring the external links were not "heavy duty" and links to further examples of good transition practice.

4.2. Satisfaction and learning outcomes

Regarding the overall satisfaction with the learning outcomes seven of the 12 participants were of the view that they were "about right" in relation to their existing knowledge, with outcomes achievable. For those that were unsure, they suggested that the learning outcomes be developed further to ensure clarity of intention.

The participant data evidenced the units that were most helpful in developing their knowledge of transition:

- Unit 4 "Welfare and legal system changes relevant to transition" (n = 5),
- Unit 2 "What is transition and why does it matter?" (n = 2),
- Unit 3 "Needs of the young person with a learning disability and their family at the point of transition - the nursing perspective" (n = 2)
- All units were equally helpful (n = 1)

When asked to identify three areas where their knowledge of health transition from child to adult services for people with intellectual disabilities had been developed and enhanced, eight participants (n = 8) highlighted the changing legal context of health transition. Other areas of learning included the importance of a formalised transition pathways, the distinct needs of the young adults and their families, the roles of Registered Nurses in transition, the need for emergency care planning and the making of reasonable adjustments throughout the process.

4.3. Application to clinical practice

Six participants (n = 6) reported that the resource was relevant and applicable to their everyday nursing practice, finding the reflective questions helpful. Six participants (n = 6) also suggested that there was a need to review the reflective elements of the learning resource to ensure that they related more closely to the case study and were targeted around the specific learning outcomes of each unit.

4.4. Qualitative interviews

Of the 12 Registered Nurses who completed the questionnaire, six consented to participate in a telephone interview, with three completing. The three participants were of the view that the learning resource provided a good overview of the main issues related to transition for young adults with intellectual disabilities and their families and that it was suitable for a range of nurses with different previous

experiences and levels of knowledge. It was suggested that the resource could be offered at induction and as part of a continuing professional development refresher programme. The participants stated that completing the resource increased their awareness of the transition issues and needs of young adults with intellectual disabilities and their families. The resource presented a good overview of the main concerns to be addressed and was deemed appropriate and relevant for a range of Registered Nurses in different roles by increasing their knowledge and understanding of the needs of this often-vulnerable population and their families. Regarding how the learning resource could be developed for the future, participants suggested, improving the reflective questions to avoid possible repetition and clearer instructions on how to use them. There was a request to clarify the learning outcomes and more explicitly separating the learning from the reflective sections was also highlighted.

4.5. Further development of the learning resource

Having reviewed the findings from the survey and interviews, the research team revised the learning resource. The revisions included a reduction in the learning outcomes from 12 to seven, which became:

1. Describe the multiple morbidities and health inequalities experienced by young adults with learning disabilities and complex health needs
2. Explain what is meant by transition
3. Identify factors around effective transition for the young adults with learning disabilities and the roles of the families and professionals
4. Identify the needs of young adults with learning disability and their family at the point of transition and beyond
5. Explain legal issues and welfare system changes in the context of transition
6. Identify the role of nurses in the process of transition
7. Reflect on the nursing role in facilitating effective transitions for adults with learning disabilities and their family

The 10 reflective questions were revised and adapted to become reflective points and were made more distinct within the learning resource, set out in [Box 1 and 2](#).

5. Discussion

As young people reach adulthood, often around the age of 16, they transition into the adult world (Hagell et al., 2018). For many this occurs naturally as they move into employment, further education and start to assume the legal, social and personal responsibilities of becoming an adult (Lechner et al., 2017). Long-term health conditions are usually met within adult services (Pape and Ernst, 2022). However, there is growing evidence that for some young people with lifelong health conditions, the transition from child to adult healthcare can be challenging and problematic with issues that need to be addressed (Betz et al., 2015; Lemke et al., 2018). Consequently, there is growing attention on the contributions required from Registered Nurses throughout the health transition process (Betz, 2021). There are therefore practice development gaps that need to be addressed to ensure that young adults with intellectual disabilities experience a smooth and effective health transition, facilitated by knowledgeable professionals (Brown et al., 2019).

The population of young adults with intellectual disabilities and complex needs is increasing, with more living into adulthood (Dolan et al., 2019). Consequently, there is and will be growing demand for access to healthcare and other services such as education, housing, and social care supports (Jacobs et al., 2018; Constantino et al., 2020). Many of these young adults present with a range of 'complex needs' with multiple long-term health conditions necessitating access to adult health services (van Timmeren et al., 2017). There has however been a limited focus and attention on the specific needs and experiences of these young adults and their families and the contributions required from Registered

Box 1

Provided examples of the reflective questions included in the initial learning resource.

Have you ever been involved in the care of someone like Sarah? What do you see as her main health priorities as she moves through her adolescence?

How can you contribute in your nursing role to effective collaboration across services and agencies throughout the transition process and help parents and carers feel less overwhelmed and responsible for driving the transition process?

Box 2

Examples of Reflections Points included in the final resource.

What do you need to do in your practice role to include families and paid carers more effectively in the planning and delivery of healthcare during and after the transition to adult health services?

Based on your experience of working with young people with complex learning disabilities like Sarah, what elements of care need to be considered as part of the emergency care planning to reduce the risk of harm in an emergency situation and parent's anxiety about adult emergency care?

Nurses and other health professionals to ensure an effective transition (Lestishock et al., 2018; Brown et al., 2019). Despite these needs, health professionals, including Registered Nurses, do not appear to receive structured, targeted education regarding health transitions as part of their initial preparation or continuing professional development (Betz et al., 2021b). This is an important gap the study starts to address to ensure the health transition of these young adults are effectively identified and addressed (Campbell et al., 2016).

There have been significant developments in access to continuing professional development delivery for Registered Nurses, with a growing focus on self-directed and on-line learning (Chakkaravarthy et al., 2018). A recent literature review identified that nurses were satisfied with the use of self-directed on-line learning, highlighting the improvement and development in their knowledge, and understanding of the relevance to their practice (Rouleau et al., 2019). The findings from the current study supports this, suggesting that the self-directed, on-line delivery approach and the content of learning resource is acceptable and accessible across different areas of nursing practice (Miambo et al., 2021). The case study and the reflective elements were viewed as most relevant to practice. Some of the participants, notably those with an intellectual disability-specific role, and some district nurses and a community children's nurse suggested case study developments to present further complexities and practice realities, to respond to complex assessment, care planning and support needs (Campbell et al., 2019).

The findings suggest that the learning resource could be specifically targeted at Registered Nurses with less routine contact with adults with intellectual disabilities, thereby developing their knowledge and confidence (Trollor et al., 2018). The learning resource could also be used within pre-registration nursing and midwifery programmes to raise their awareness of their health transition role (Shaffer et al., 2018). A further important finding relates to the legal context regarding capacity and consent to treatment as many parents continue to provide care for their adult child following transition into new health services (Franklin et al., 2019). Parents require to proactively apply to become legal guardians when the young person becomes 16 and older to enable decision-making on their behalf (Lindahl et al., 2019). Therefore the "legal aspects of transition" is as an area of new learning and one that required further development to increase awareness.

6. Limitations and strengths

As far as the authors can identify this is the first study undertaken to develop and pilot an on-line learning resource for Registered Nurses regarding the transition into adult health services for young adults with complex intellectual disabilities. The current study therefore opens a new area of research enquiry of international relevance that has attracted limited attention. There are strengths to the current study, including the range of nursing disciplines from diverse practice backgrounds with 12 Registered Nurses participating. A key limitation of the study was the sample size, which reflected challenges in recruitment, particularly adult general hospital nurses. Within the timescale of the wider research study and funding period, this evaluation was limited to focussing on the accessibility and acceptability of the learning resource, and therefore did not extend to measure the change to nurses' knowledge and clinical practice. This is an area that needs to be addressed in future research. The resource was designed using an online survey platform and further work is required to identify the range of digital platforms used across health services to enable delivery.

7. Future research

The acceptability and impact of the learning resource needs to be researched involving Registered Nurses from a wider range of practice settings. The testing of the resource should be extended to include other professionals with a practice focus on the needs of young adults including general practitioners, hospital doctors, social workers, schoolteachers and allied health professionals. There is also an opportunity to undertake multicentred studies involving different geographical locations and countries. Longitudinal studies are also indicated to identify and measure the impact of undertaking the learning resource on the outcomes and satisfaction achieved for young adults with complex intellectual disabilities and their families.

8. Conclusion

With the increasing population of young people with intellectual disabilities and complex needs transitioning into adult health services, there is a need to ensure that Registered Nurses and other healthcare

professionals have the necessary knowledge to contribute effectively. The findings from the current study suggests that access to an evidence-based, structured on-line learning resource provides Registered Nurses with additional knowledge and information regarding the specific issues that need to be addressed to help ensure a safe, effective and person-centred transition.

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Ethics

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CRedit authorship contribution statement

All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the manuscript. Conception and design of study: MB AH, JMCA, MT. Acquisition of data: AH, JMCA. Analysis and/or interpretation of data: MB, AH, JMCA, MT. Drafting the manuscript: AH, MB, JMCA, MT. Revising the manuscript critically for important intellectual content: MB, JMCA. Approval of the version of the manuscript to be published: Michael Brown, Juliet MacArthur, Anna Higgins, Maria Truesdale.

Declaration of conflicting interests

No conflict of interest are declared.

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