

## **Transition from paediatric to adult health services for people with learning disabilities: development of an educational resource for nurses in practice**

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### **Progress summary: June 2019**

#### **Background and aims**

Due to advances in medicine, the population of people with learning disabilities (LD) is changing rapidly, with young people with increasingly complex needs surviving into adulthood (Cook, 2013; Cohen et al., 2011). As a result, a growing number of young people with LD require services extending beyond paediatric provisions and a "transition" to adult healthcare. Transition is defined as "a purposeful, planned process that addresses the medical, psychosocial and educational/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).

Despite existing guidelines and recommendations for effective transition management, a systematic literature review undertaken as part of this project revealed that people with LD continue to experience fragmented transition processes and care, which forces parents to become advocates and having to fight for services in a maze of confusing information. The negative emotional impact of transition on family carers is also well-documented (Brown et al., 2019).

Although nurses have long been recognised as potentially instrumental for addressing some of the barriers related to transition (Betz, 2007; 2013) and despite their involvement in the multidisciplinary team of health, social work and education professionals, their role in the transition process is not well documented. The aims of this Scotland-wide project are as follows:

1. To investigate and understand the experience of transition between child and adult health services, the challenges involved and the barriers to the provision of person centred care by obtaining the perspectives of nurses, families and carers as the key stakeholders (Phase 1)
2. To develop best practice strategies in providing person centred care during transitions, embedded in the perspectives of stakeholders (Phase 1)
3. To develop and pilot an education resource for nurses in practice on how best to manage transition between child and adult health services for people with learning disabilities and their families and carers (Phase 2)

#### **Phase 1 (completed)**

Qualitative, semi-structured interviews were used to explore health transition experiences from the perspective of nurses and carers of people with LD and complex health needs. In total, 10 carers of young adults with complex LD from 7 NHS health boards and 46 nurses and other healthcare professionals from all 14 health boards in Scotland participated in this project. The sample of nurses included: paediatric service nurses (n=20), Learning Disability service nurses (n=17), health and social care managers (n=6) and other healthcare professionals (n=3).

## Carer Perspectives

Although the interviews focused on positive experiences of transitions and identifying good examples of nursing practice and strategies that work for managing effective transitions, the thematic analysis of data also revealed the challenges that family carers continue to experience at the point of transition. These are captured in the five main themes below:

Main theme	Subtheme
A deep sense of loss	Losing the sense of safety
	Loss of services
	A sense of isolation and vulnerability
An overwhelming process	Re-establishing a care team
	Lack of coordinated planning
	Confusion and the state of unknown
Parents making transitions happen	Parents as transition coordinators
	The battle of transition
A shock to the adult healthcare system	Unprepared adult services
	The paradox of adult hospitals
	Lack of continuity of care
The unbearable pressure	Parents taking responsibility for health monitoring
	Alone in a new environment
	Unbearable pressure and its impact on health

In summary, the carer interviews revealed transition as a very emotional time, during which carers experience a sense of loss, isolation and broken relationships. Having to establish new relationships with multiple professionals with little support and coordination leaves parents feeling overwhelmed and confused. As a result, they often assume responsibility for coordinating the transition process while feeling like they have to “fight” for services they see as necessary for the wellbeing of their child. Parents often perceive adult services as unprepared and unable to meet the unique needs of people with LD and despite legal guardianship, they feel their voice is often not heard. The struggle to access required services can leave parents having to take responsibility for their child’s health monitoring and the physical, psychological and financial pressure can impact on their own health.

## Effective Transition Planning

These results demonstrate that family carers of people with LD and complex needs in Scotland face many challenges at the point of transition from paediatric to adult health services and beyond. However, the carer and nurse interviews also revealed many examples of excellent practice and best practice strategies to providing person- and family-centred care, as captured in the themes below:

MAIN THEME	SUBTHEME
Strategic level focus	Strategic level commitment
	Population projection and service planning
	Transition education and training
Clear transition processes and pathways	Transition pathway development
	Cross-health board transition practices
Proactive transition preparation	Early preparation
	Timely initiation of the transition planning process
Multiagency transition planning	Collaborative working across services and

	agencies
	Lead coordinator
	Assessment and care planning
	Emergency care planning
Continuity of care in adult services	Coordinated handover of care
	Holistic overview in adult services
	Access to services and quality care
	Family carers as equal partners in care

### **Nursing Role**

Although transition from paediatric to adult health services is rarely an official part of nurses' role, the results revealed that nurses across Scotland have significant involvement in all aspects of transition development, planning, facilitation and care. Despite varied strategic level focus on transition across the Scottish NHS health boards, nurses were found to show a lot of initiative and commitment to support people with LD and their carers at the point of transition and beyond. They were found to be involved in development and implementation of transition pathways and processes as well as encouraging parents to start planning for future care and the changing legal status. Nurses were found to play a central role in the multiagency transition planning, supporting and in some instances driving the collaboration between services and agencies, undertaking holistic assessments and person-centred adult care planning. Carers expressed great appreciation for support and coordination provided by nurses in transition-specific roles as well as opportunities to establish relationships with adult healthcare professionals. Ensuring continued holistic overview and access to quality care in adult services was identified as particularly important for the population of people with LD. Both nurses and carers also highlighted the importance of treating parents as experts in the needs of their child and equal partners in care.

### **PHASE 2 (ongoing)**

Based on the findings from Phase 1, the second phased of this project focuses on developing an educational resource aimed at nurses across a range of services in paediatric and adult health care. The resource is intended to enable nurses to consider and identify their contributions to promoting effective transition for young adults with LD and assist them in delivering person-centred and family-centred care and support.

The learning resource contains four units:

Unit 1: Young adults with learning disabilities: multiple morbidities and health inequalities

Unit 2: What is transition and why does it matter?

Unit 3: Needs of the young person with a learning disability and their family at the point of transition - the nursing perspective

Unit 4: Welfare and legal system changes relevant to transition

The resource will be piloted in two NHS health boards (NHS Lothian and NHS Borders) and the participants will include 20 child and adult health nurses from the following specialties: district nursing, community children's nursing, diabetes, epilepsy/neurology, gastroenterology and respiratory nursing.

Participants will be asked to evaluate the resource using an online questionnaire and some participants will be invited to provide further feedback in a telephone interview.

This project is funded by the Burdett Trust for Nursing and is due to be finalised by December 2019. It is led by Queen's University Belfast and involves researchers from Edinburgh Napier University, Abertay University and NHS Lothian.