# TRANSITION FROM CHILD TO ADULT HEALTH SERVICES FOR PEOPLE WITH COMPLEX LEARNING DISABILITIES

LEARNING FROM FAMILIES AND NURSES **BRIEF REPORT**

RESEARCH TEAM

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FUNDED BY THE BURDETT TRUST FOR NURSING

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# BACKGROUND

**Due to medical advances**, a growing number of children born with increasingly complex health conditions are surviving into adulthood and will require a 'transition' into adult health services:

> *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 healthcare systems.*[1]

A number of key policy reports have addressed issues about transition for people with additional needs in the UK in the last few years, including the Doran review[2] with relevant recommendations accepted by the Scottish Government in 2012[3], the NICE guidelines[4] and the Principles of Good Transitions 3[5]. All highlight the importance of early person-centred transition planning, multidisciplinary collaboration and coordination, access to information, support for families and carers, dedicated transition staff, a single point of contact and continued focus on transition and supporting the infrastructure.

## TRANSITION EXPERIENCES OF PEOPLE WITH LEARNING DISABILITIES

Despite recommendations, evidence suggests that the experience of transition continues to be negative for people with learning disabilities and complex health needs - complex learning disability - and their families, putting them at risk of poorer health outcomes. A review of international evidence revealed that parents are often forced to drive the fragmented and poorly managed transition process. Many describe 'fighting' for appropriate care, which caused them a high level of anxiety and emotional turmoil and depended on their own resourcefulness.[6] Nurses have been suggested as potentially instrumental to enhancing the transition experience and outcomes for people with complex learning disability and their families. However, their current contributions to the multi-professional teams that involve health, education and social care has largely been unexplored.

[1] Department of Health (2006, p14) Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services. London: Department of Health

[2] Scottish Government (2012) The Right Help at the right time in the right place: Strategic Review of Learning Provision for Children and Young People with Complex Additional Support Needs. Retrieved from: *https://www.gov.scot/publications/ right-help-right-time-right-place-scotlands-ten-year-strategy-learning-provision-children-young-people-complex-additional-support-needs/*

[3] Scottish Government (2012) Meeting the needs of Scotland's children and young people with complex additional support needs: The Scottish Government's response to the Doran Review. Retrieved from: *https://www.gov.scot/publications/meeting-needs-scotlands-children-young-people-complex-additional-support-needs/*

[4] National Institute for Health and Care Excellence (2016) Transition from children's to adults' services. Retrieved from: *https://www.nice.org.uk/guidance/qs140*

[5] ARC Scotland/Scottish Transitions Forum (2017) Principles of Good Transitions 3. Retrieved from: *https://scottishtransitions.org.uk/summary-download/*

[6] Brown, M., MacArthur, J., Higgins, A., & Chouliara, Z. (2019) Transitions from child to adult health care for young people with intellectual disabilities: A systematic review. Journal of Advanced Nursing, 75(11), 2418-2434.

# STUDY AIMS AND METHODS

**1.** 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 and families as the key stakeholders

**2.** Develop best practice strategies in providing person-centred care during transition, embedded in the perspectives of stakeholders

**3.** 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.

**0.5% of the population in Scotland has a learning disability. About 0.05 per 1,000 or 2,600-3000 people in Scotland have a profound and multiple learning disability.**

**In England, this number is about 16,000 and expected to grow by 1.8% each year.**

**The number of people with learning disability receiving palliative care has grown from 0.5% in 2014-2015 to 0.8% in 2017-2018.**

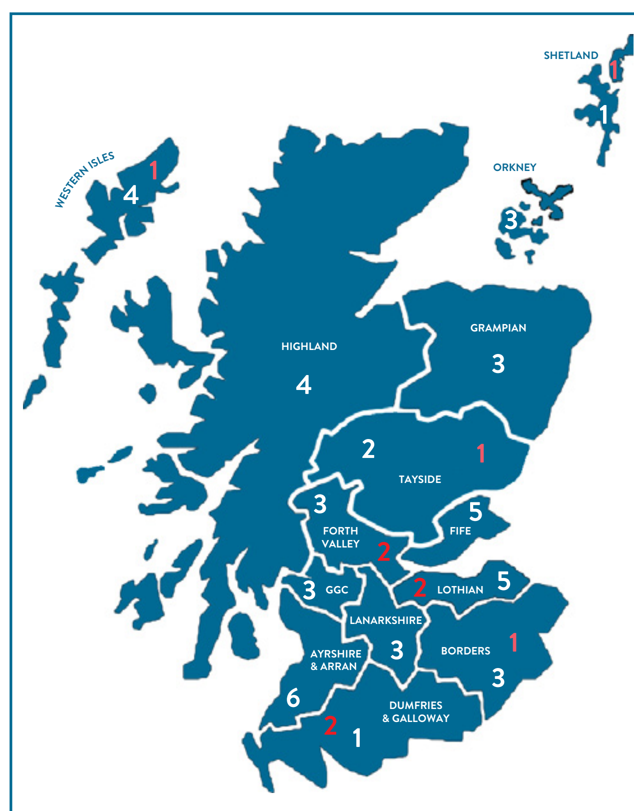
# PARTICIPATING NHS BOARD AREAS

**Participants** (n=56) were recruited from all 14 NHS Boards in Scotland (Figure 1):

- *10 family carers of young people with complex learning disabilities recruited through voluntary organisations, nine mothers and one father.*

- *46 registered nurses and other practitioners recruited through NHS Boards, 37 nurses, 6 health and social care managers and 3 other healthcare professionals.*

The nurse participants included child health (n=21) and adult health nurses (n=16) from across community, specialist, learning disability, learning disability liaison and transition services. Families' and nurses' experiences were collected using one-to-one interviews focussing on their experiences of transition and examples of good practice.




**Map to the right shows:**
Participant distribution across all 14 NHS Boards in Scotland, including nurses and other healthcare professionals (white) and families (red).

# FAMILIES' EXPERIENCES OF TRANSITION FROM CHILD TO ADULT HEALTH SERVICES

**The interviews** with families revealed a story of loss, physical and emotional struggle and inadequate support during and after transition to adult services through five main themes and associated subthemes:

- *A deep sense of loss: losing the sense of safety; loss of integrated 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 transition 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; impact on parents' health*

Parents were commonly anxious about their child losing access to vital services and expertise and receiving inadequate care from multiple specialist across disjointed adult services following transition. The process of establishing an adult care team was seen as overwhelming and confusing, with poor multidisciplinary coordination and a 'minefield' of unreliable information. Lack of clear points of contact was reported as increasing the young person's vulnerability, particularly in emergency situations. Transition was described as service-driven rather than person-centred but where available, a dedicated professional such as a transition nurse was seen as an invaluable source of support to navigate the process.

Many parents felt driven to take responsibility for the transition process but often felt that they had to 'fight' or 'battle' for essential services. The young adults were seen as causing a 'shock' to the adult healthcare system, which seemed ill-prepared for their level of complex needs.

They described a lack of basic adaptations and knowledge of equipment and technologies which are commonplace in paediatric settings. Standard hospital procedures were not always adapted to take account of legal guardianship and parents felt either dismissed or made fully responsible for making medical decisions. Lack of continuity of care often threatened continued therapeutic input and young adults with complex learning disabilities experienced multiple barriers when trying to access services and resources. Nurses helping parents establish points of contact in adult services was seen as a good strategy to increase their confidence in being able to access care when required.

As a result of decreased support and services following transition, parents were often left responsible for monitoring their child's health as well as providing most aspects of personal care while at home and during hospital admissions. With little opportunities to take a break, these unrealistic pressures were reported to have an impact on their physical and mental health, ability to continue working professionally and put a strain on their relationships.

# BEST PRACTICE STRATEGIES FOR TRANSITION

**Based on the interviews** with families, nurses and other practitioners, five main principles underpinning improved transition care and associated elements of transition management were identified (Figure 2).

### PRINCIPLE 1
### STRATEGIC LEVEL TRANSITION FOCUS AND PLANNING

Transition needs to be recognised as an important aspect of care at the strategic level across all NHS Health Boards in Scotland. A strategic-level 'transition champion' in each NHS board could ensure that national standards of transition are followed at all levels of care delivery, and relevant policies - including joint health and social care policies - are developed and implemented at each locality. The rapidly growing service requirements of people with complex learning disabilities need to be addressed through reliable population modelling and ensuring adequate resources, services and staffing levels are in place.

Development of a 'Complex Learning Disabilities Advanced Nurse Practitioner' role could be a viable response to the increasing needs of this population.

Building the knowledge base around transition and needs of people with complex learning disabilities and their family is paramount, and training should be incorporated into pre-registration nursing curricula and be made easily available as part of continuous professional development for child and adult health care professionals.

### PRINCIPLE 2
### CLEAR TRANSITION PROCESSES AND PATHWAYS

None of the 14 NHS Boards in Scotland appears to have a well-established transition pathway, which would provide clear guidance to professionals and empower carers to navigate this process.

Opportunities exist for creating joint health and social work pathways as well as clear processes for young people whose health is managed outwith their local health board or local authority area.

### PRINCIPLE 3
### PROACTIVE TRANSITION PREPARATION

It is the responsibility of all professionals to prepare the young person and their family for transition to adult health services. It should be discussed from around the age of 14 and families should be provided with reliable information on future care and their changing legal status. It is paramount that all professionals recognise transition as a major life change, often associated with feelings of fear and anxiety:

*"I have to say it's always stuck with me that one of my mums said to me - her child died when he was 18 - she said if I can see anything positive in it, I didn't have to go through the transition process with him. And I thought, oh, my God, that's so powerful. That's how worried that lady was about transition for her child. I don't think any of us can understand how difficult it is".*
(N19, child health nurse: community service)

Reliable identification processes need to be in place to allow early initiation of the transition planning process, which involves all aspect of care, including health.

### PRINCIPLE 4
### MULTI-AGENCY TRANSITION PLANNING

Health needs to be recognised as a crucial aspect of the wider transition process and health professionals need to be involved in the multiagency meetings which currently tend to be education and social work-focussed. A named transition coordinator can improve the quality of the process for families, the young person and professionals. These could be nurses in transition-specific roles or nurses or other professionals upskilled to facilitate transitions within the remit of their exiting roles.

Transition planning should involve a detailed holistic assessment of needs, creating a written plan, assigning responsibilities to key professionals and recognising and mitigating the impact of the wider determinants of health, such as lack of meaningful day activities. Another priority should be preparing the young adult for potential emergency care by developing emergency support plan and summaries of needs and introducing the family to learning disability liaison nurses where available.

PRINCIPLE 5
## CONTINUITY OF CARE IN ADULT SERVICES

A gradual handover of care should involve active engagement from child and adult health services as well as an opportunity for the person with learning disability and their family to meet and build trusting relationships with key professionals. Transition should be a person-centred, flexible process where care-planning decisions are made in view of the person with learning disabilities' needs and individuals should be followed-up until all adult services are in place.

Relevant education and training for adult healthcare professionals, including General Practitioners, is crucial to ensure people with complex learning disabilities continue receiving a high standard of care across the lifespan. Adult health services need to be open to adapting standard procedures and taking a family-centred approach when working with people with complex learning disabilities. Their parents and families have to be recognised as equal partners in care, who provide expertise on their children's complex needs as well as vital, unpaid support to the adult health service.

This study found nurses across Scotland to be actively involved in each element of the transition care, demonstrating multiple examples of excellent practice.

| PRINCIPLES UNDERPINING IMPROVED TRANSITION CARE | ELEMENTS OF TRANSITION MANAGEMENT |
|---|---|
| **1. STRATEGIC LEVEL FOCUS AND PLANNING** | • *Strategic level commitment*<br>• *Population projection and service planning*<br>• *Transition education and training* |
| **2. CLEAR TRANSITION PROCESSES AND PATHWAYS** | • *Transition pathway development*<br>• *Cross-health board transition practices* |
| **3. PROACTIVE TRANSITION PREPARATION** | • *Early preparation*<br>• *Timely initiation of the transition* |
| **4. MULTI-AGENCY TRANSITION PLANNING** | • *Collaborative working across services and agencies*<br>• *Lead coordinator*<br>• *Assessment and care planning*<br>• *Emergency care planning* |
| **5. CONTINUETY OF CARE IN ADULT SERVICES** | • *Coordinated handover of care*<br>• *Holistic overview in adult health services*<br>• *Access to services and quality care*<br>• *Family carers as equal partners in care* |

**Above:** Five main principles underpinning improved transition care and associated elements of transition management

# DEVELOPMENT OF AN EDUCATIONAL RESOURCE ON TRANSITION FOR NURSES

**The final stage of this project** involved development and piloting of an educational resource for nurses in practice entitled **'Transitions from child to adult healthcare for young adults with learning disabilities'**. The resource aimed to enhance the knowledge and awareness of effective transition from child to adult health services for young adults with learning disabilities and the contributions required from nurses to enable and facilitate that process through four units of learning:

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

**2.** What is transition and why does it matter?

**3.** The needs of the young person with a learning disability and their family at the point of transition - the nursing perspective:

- *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*
- *Welfare and legal system changes relevant to transition*

The resource was piloted with 12 nurses from across different areas of nursing practice in child and adult health in two NHS Boards. The evaluation questionnaire and follow-up interviews focused on testing its feasibility and acceptability based on the overall perception, general satisfaction, learning outcomes and application to clinical practice.

Overall, nurses provided positive feedback on the resource and highlighted a number of areas where they felt their knowledge was developed including welfare and legal system changes, the importance of a formalised pathway, the needs of the young adults with learning disabilities and their families, the role of nurses in transition, emergency care planning other.

Nurses' recommendations for improvements were used to revise the resource to make its format clearer and more user-friendly.

# CONCLUSION & RECOMMENDATIONS

**The families' and nurses' accounts** demonstrate that current health care models are not fit for the 21st century and the increasingly complex needs of some groups of patients, such as individuals with complex learning disabilities. Nurses are well-placed to improve the experience and outcomes of transition for this population. Based on the findings from this study, the following recommendations are made:

## RECOMMENDATION 1

Strategic level planning and leadership is required in all NHS Boards to ensure there is effective transitions planning, service and workforce developments.

## RECOMMENDATION 2

Education, health and social care services need to develop and implement clear transition processes and pathways that take account of and respond to the needs of young people with complex learning disabilities and their families.

## RECOMMENDATION 3

Young people with learning disabilities and their families need to be central to and fully involved in proactive transition preparation to ensure the process is effective and meets their needs.

## RECOMMENDATION 4

Education and health and social care services need to collaborate at an early stage in the transition from child to adult health services to ensure there is effective multiagency transition planning and service coordination.

## RECOMMENDATION 5

A lead health professional needs to be identified and responsible for coordination before, during and after the health elements of the transition process from child to adult services.

## RECOMMENDATION 6

The role of nurses in supporting and facilitating the transitions from child to adult health services for young adults with learning disabilities and their families needs to be further developed.

## RECOMMENDATION 7

Registered nurses, undergraduate students and other healthcare professionals need to undertake further education regarding effective transitions for young people with learning disabilities and their families.

Created by: www.eh6design.co.uk

ISBN: 9781913643010