

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

LEARNING FROM FAMILIES AND NURSES



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# EXECUTIVE SUMMARY

## WHAT ARE THE ISSUES?

Due to medical advances, a growing number of children born with increasingly complex health conditions survive into adulthood and require a 'transition' into adult health services. However, evidence suggests that the experience of transition for people with a learning disability and complex health needs (complex learning disabilities) and their families is particularly negative, with many access barriers and a risk of poorer health outcomes. Nurses have previously been suggested as potentially instrumental to improving families' experience of transition but their current involvement in this process is largely unexplored.

## WHAT DID WE DO?

This three-year, Scotland-wide project involved three phases. Phase one focused on a review of international literature on transition. Phase two involved qualitative interviews with 10 parents of young people with complex learning disabilities and 46 nurses and other practitioners from all 14 NHS Boards in Scotland. Their experiences of transition from child to adult health service were used to develop best practice strategies for transition. Phase three involved developing an online educational resource on transition and piloting it with 12 registered nurses from two NHS Boards.

## WHAT WE FOUND OUT

- *Transition from child to adult health services is a challenging time for young people with complex learning disabilities, their families and professionals*
- *There are no well-established processes for transition in the 14 NHS Boards in Scotland*
- *Parents' experiences of transition are captured through five main themes: a deep sense of loss, an overwhelming process, parents making transition happen, a shock to the adult health care system and unbearable pressure*
- *Best practice strategies for transition were captured through five main principles: strategic level transition focus and planning, clear transition processes and pathways, proactive transition preparation, multi-agency transition planning and continuity of care in adult services*
- *Nurses were found to make significant contributions to each stage of the transition process and beyond*
- *An online educational resource on transition was found to be a useful tool to raise awareness of the issues experienced by many young people with complex learning disabilities and their families and help nurses reflect on their role in the transition process*

## WHAT NEEDS TO HAPPEN NOW?

- *The needs of young people with complex learning disabilities and their families and the role of nurses in the transition process need to be reflected at a strategic level through clear policy development and implementation*
- *Transition processes need to be developed through resource and workforce allocation*
- *Adult health services need to adapt in order to meet the needs of the changing population of young people with complex learning disabilities*
- *Raising nurses' awareness of the transition issues through education needs to be prioritised both at an undergraduate and post-registration levels*

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# RECOMMENDATIONS

The evidence from families, nurses and other professionals identified best practice strategies for effective transition through seven main evidence-based recommendations:

## 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 multi-agency transition planning and service coordination.

## RECOMMENDATION 5

A lead health professional needs to be identified and be 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.

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# DEFINITIONS

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

For the purpose of this project, **people with complex learning disabilities** are defined as *having cognitive impairment and multiple co-existing health needs. Their co-existing conditions include physical disabilities, sensory impairments, mental health needs, developmental disorders, challenging behaviour and/or communication difficulties. They require long-term, high levels of support in many aspects of daily living.*

**Person-centred practice** focuses on the needs of the individual rather than the needs of the service by engaging the individual in the process of personalisation, enabling them to express their preferences and needs and responding to those while ensuring the individuals are kept safe from physical, emotional or financial harm.

**Family-centred practice** is defined as an approach to the planning, delivery and evaluation of services that are governed by mutually beneficial partnerships between the individual, their family, carers and practitioners.

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## THE PROJECT COLLABORATORS

Thank you to all Executive Nurse Directors, managers, other professional and carer organisations who supported this project and recruitment of participants.

## THE PARTICIPANTS

Thank you to all the families, nurses and other health professionals who shared their experiences of transition.

## THE PROJECT ADVISORY GROUP

This project was supported by an Advisory Group who provided advice and guidance throughout the project:

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## INTRODUCTION AND CONTEXT

### Changing population of people with learning disabilities

Advances in medicine have dramatically changed the demographic profile of people with learning disabilities, with more than 90% of children born with increasingly complex health conditions surviving into adulthood (Cook, 2013; Cohen et al., 2011; Pai and Schwartz, 2011). As a result, many young people with complex needs require services beyond child health services setting and a 'transition' to adult services, including health care.

Scotland's Census 2011 recorded 26,349 people to have learning disabilities, which represents 0.5% of Scotland's population (Scottish Government, 2019). The prevalence of profound and multiple learning disabilities (PMLD) are estimated at 0.05 per 1000 in the general population and the strategy document *The Keys to Life* (Scottish Government, 2013) estimated that there are approximately 2600 people with PMLD in Scotland. This however, was suggested as an underestimate and therefore a working figure of 3000 was proposed.

In England, the number of people with profound intellectual and multiple disabilities is estimated to be 16,000 and expected to grow by 1.8% each year (Emerson, 2009). Furthermore, the proportion of adults with learning disabilities receiving palliative care is also increasing,

with 0.5% in 2014-2015 and 0.8% in 2017-2018 (Primary Care Domain, NHS Digital, 2019).

For the purpose of this study, the term ‘complex learning disability’ is used to describe this changing population of individuals with a cognitive impairment and multiple co-existing health needs.

## TRANSITION TO ADULT SERVICES

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

The purpose of transition is to provide uninterrupted, coordinated and developmentally appropriate care throughout the process (Kaufman and Pinzon, 2007). However, this can be challenging in practice as many young people with learning disabilities present with complex comorbid conditions, such as epilepsy, diabetes, gastro-intestinal and respiratory problems (Cooper et al., 2015; Truesdale & Brown, 2017). This places them at risk of poor health during the transition process as well as creating additional challenges to accessing health care, which may move from a single point of contact to numerous specialties at different acute hospital locations.

The process of transition from child to adult health services can be particularly complex due to the different ways the two services operate (Table 1). Child services are characterised by a holistic, child and family-centred approach, usually with a single coordinating paediatrician, often from Child Health Services (Department of Health, 2006). While child services are family-focused with parental involvement in the decision-making process, adult services are individual and condition-focused and are reliant on autonomous decision-making (Davies et al., 2011).

## TRANSITION GUIDELINES AND MANAGEMENT

There have been a number of transition guidelines and recommendations published in the UK and internationally (Table 2). All emphasise the importance of key principles, which include:

- *Starting the transition planning process early, usually around the age of 14*
- *Regular multidisciplinary meetings with communication, collaboration and coordination between services and agencies*
- *Holistic and person-centred approach to planning and decision-making, with involvement from the young person and their parents*

**0.5% of the population in Scotland has a learning disability About 0.05 per 1000 or 2600-3000 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.**

### CHILD HEALTH SERVICES

- *Family-centred approach*
- *Parental involvement in decision-making*
- *Care prescribed within a multidisciplinary care team with a coordinating paediatrician*
- *Open access to hospital ward*
- *Regular monitoring of health conditions*
- *Developmentally appropriate input from allied health professionals*

### ADULT HEALTH SERVICES

- *Person-centred approach*
- *Requires autonomous, independent skills*
- *Care prescribed across individual specialties with no coordinating physician*
- *Hospital access through emergency department or primary care*
- *Emphasis on self-management of conditions*
- *Reduced input from allied health professionals*

**Table 1:** Differences between child and adult health services. Based on Brown et al., 2019

- *Access to reliable and consistent information for young people and their parents*
- *Comprehensive support for families and carers*
- *Dedicated transition staff and a single point of contact for the young person and their parents*
- *A continued focus on transitions and supporting the infrastructure*

There are also a small number of resources for the young people, their parents and carers and professionals to help manage the transition process, including:

- **Ready Steady Go** at the Southampton Children's Hospital (2015), UK
- **OnTrac** (Taking Responsibility for Adolescent/Adult Care) developed at Children's and Women's Health Centre of British Columbia (2011), Canada

- **SHARE** (Supports for communication and capability; Healthcare transition and transfer; Activities and engagement; Relationships and wellbeing; Exploring services and supports) developed by Surrey Place (2019), Canada

- **Got Transition** / Center for Health Care Transition Improvement – a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health (2014-2019) in Washington DC, USA

## EXAMPLES OF TRANSITION REPORTS AND GUIDELINES PUBLISHED IN THE UK

- ARC Scotland/Scottish Transitions Forum (2017). *Principles of Good Transitions 3.*
- Care Quality Commission (2014). *From the Pond into the Sea: Children's Transition to Adult Health Services.*
- Department of Health (2006). *Transition: Getting it right for young people.*
- Department of Health (2008). *Improving the transition of young people with long term conditions from children's to adult health services.*
- Department of Health (2008). *Transition: Moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability.*
- HALL (2019). *Transitions of young people with service and care needs between child and adult services in Scotland. SPICe Briefing. The Scottish Parliament.*
- National Institute for Health and Care Excellence (2016). *Transition from children's to adults' services.*

## EXAMPLES OF TRANSITION REPORTS AND GUIDELINES PUBLISHED INTERNATIONALLY

- Canadian Association of Pediatric Health Centres (CAPHC), National Transitions Community of Practice (2016). *A Guideline for Transition from Paediatric to Adult Health Care for Youth with Special Health Care Needs: A National Approach*
- White, P.H., Cooley, W.C., Transitions Clinical Report Authorising Group, American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians (2018). *Supporting the Health Care Transitions from Adolescence to Adulthood in the Medical Home.*

Table 2: Examples of transition reports and guidelines published in the UK and internationally

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Despite the notable focus on the transition process, evidence suggests that internationally, transition receives little attention at a policy level (Hepburn et al, 2015). It continues to be a poorly managed process, with significant negative physical, psychological and emotional impact for both the young person and their family (Cook et al., 2013; Joly, 2015). The UK Care Quality Commission (2014) found that young people with complex needs and their families experience transitions that are poorly planned, confusing and without clearly defined roles and responsibilities, with only 50% of young people involved in this review receiving support from a lead professional.

## THE NURSING ROLE

The concept of transition is well recognised within nursing theory and practice (Schumacher & Meleis, 1994; Meleis et al., 2000; Kralik, Visentin & van Loon, 2006). However, much of the literature continues to be dominated by a medical perspective despite evidence that child and adult nurses can and do play an important and influential role in the transition process and contribute to the development of transition nursing policies and practice standards (Betz, 2013).

Nurses are part of multi-professional teams that involve health, education and social care and it is important to recognise their contributions to enhancing the transition experience and outcomes for young people with complex learning disabilities and their families. However, the current extent of nurses' involvement in the transition process remains largely unknown and this research study sought to address this deficit through the following three phases:

### PHASE 1

- *To conduct a systematic review of the international research evidence of transition, with particular focus on nursing contributions*

### PHASE 2

- *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 and families as the key stakeholders*
- *To develop best practice strategies in providing person-centred care during transition, embedded in the perspectives of stakeholders*

### PHASE 3

- *To develop and pilot an education resource for nurses in practice on how best to support the transition from child to adult health services for people with learning disabilities and their families*



## PHASE 1: REVIEW OF INTERNATIONAL LITERATURE

### Aims & Methods

The aim of this phase of the project was to undertake a review of international literature on transition from child to adult health services, with particular focus on answering the following questions:

*1. What are the transition experiences of young people with learning disabilities and their families?*

*2. What are the transition experiences of professionals involved in meeting the health needs of young people with learning disabilities and their families?*

*3. What are the policy and nursing practice responses required to address individual care and support needs at the point of transition from child health to adult health services?*

Online databases were searched for articles using terms related to transition, learning disability, health care, children services, adult services and nursing. The search identified 637 articles and following initial screening and applying eligibility criteria 12 papers were included in the final narrative review.

A synthesis of key findings from the individual papers was undertaken by grouping them into concepts to allow for contrasts and comparisons to be made between studies. The emergent themes were identified and systematically coded by the research team.

## WHAT DID WE FIND?

Following the review, four main themes with associated sub-themes were identified:

### THEME 1: BECOMING AN ADULT

Progression towards self-management; balancing autonomy and parental involvement; changing expectations; capacity and perception of unnatural changes.

### THEME 2: FRAGMENTED TRANSITION PROCESS AND CARE

Poor preparation and planning; lack of information; lack of lead agency and coordination; unplanned transfer; loss of information; gaps in follow-up; no holistic overview in adult services; falling between the gaps of services; incomplete or delayed transition.

### THEME 3: PARENTS AS ADVOCATES IN EMOTIONAL TURMOIL

Parents as advocates fighting for services; a maze of information; parents' resourcefulness as the driver for transition; a sense of loss and rejection; fear of the unknown; reluctance to 'let go'.

### THEME 4: MAKING TRANSITIONS HAPPEN

Early initiation and preparation for transition; identifying a lead agency; outlining responsibilities; parent-provider relationships; improved joined and multi-agency working; effective information sharing; adequate follow-up; transition coordinator; nursing involvement.

## WHAT THE FINDINGS MEAN

### THEME 1: BECOMING AN ADULT

Supporting young people with learning disabilities to assume some responsibility for decision-making requires extensive planning (Bhaumik et al., 2011; Rehm et al., 2012; Schultz 2013; Okumura et al., 2015). This progression towards self-management can be particularly challenging because of cognitive impairment and the need to balance autonomy and parental involvement (Rehm et al., 2012; Kuchenbuch et al., 2013). This change of expectations not only cause anxiety for the young people and their families, but the transition to

adult-oriented health care might feel unnatural to parents whose children have complex learning disabilities and who will never develop beyond a young child's developmental age (Okumura et al., 2015; Bindels-de Heus et al., 2013).

Becoming an adult can also have financial implications in countries which operate insurance-based health services, such as the United States which have different total annual charges in child and adult services or might have incentives to retain young adults in child services up to mid-20s (Jensen and Davis, 2013; Rehm et al., 2012).

### THEME 2: FRAGMENTED TRANSITION PROCESS AND CARE

A general sense of dissatisfaction with the transition process was found in 11 out of the 12 studies, with families reporting poor transition preparation and lack of reliable information. The poorly coordinated planning process was rarely seen as person-centred, lacked multiagency input or adequate assessments, which often resulted in unmet needs and difficulties with accessing adult services (Camfield et al., 2011; Davies et al., 2011; Bindels-de Heus et al., 2013; Schultz et al., 2013; Woodward et al., 2012; Bhaumik et al., 2011; Barron et al., 2013).

The move to the adult services tended to be a sudden 'transfer' and hand-over rather than a planned 'transition', sometimes sparked by a crisis or 'aging-out' of the child health system (Schultz, 2013; Camfield et al., 2011). This often led to the loss of information, gaps in care, inappropriate management of medical conditions and increased use of emergency care. Incomplete or delayed transition was also common, often related to difficulties with finding equivalent adult physicians willing to care for severely disabled and complex patients (Rehm et al., 2012; Bindel-de Heus et al., 2013, Camfield et al., 2011).

Lack of a paediatrician-like, holistic health coordination role in adult services and separation of care into individual specialties often resulted in general practitioners assuming responsibility for coordinating assessments, treatments and health reviews (Camfield et al., 2011; Bindels-de Heus et al., 2013). Given general practitioners tend to have limited prior involvement in the individual's care and often lacked knowledge of complex learning disabilities, for families this resulted in a feeling of 'falling between the gaps' of services (Bhaumik et al., 2011, Davies et al., 2011).

### THEME 3: PARENTS AS ADVOCATES IN EMOTIONAL TURMOIL

The poor experience of the transition planning process often resulted in parents becoming advocates and guardians and feeling like they had to 'fight' for appropriated adult services and care (Schultz, 2013; Okumura et al., 2015). Parents acted as "information gatherers" while navigating a maze of missing or confusing information and services which lacked transparency regarding available resources (Schultz, 2013; Okumura et al., 2015; Bhaumik et al., 2011). The transition

process appeared to be dependent on parents' resourcefulness and ability to establish new relationships in the adult services (Davies et al., 2011).

The emotional impact of transition was often profound, including fear of the unknown and a deep sense of loss, abandonment or rejection by trusting professionals and services (Bhaumik et al., 2011; Davies et al., 2011; Schultz 2013; Young-Sutherland et al., 2017b; Camfield et al., 2011; Bindels-de Heus et al., 2013). Families were rarely prepared to enter the adult-oriented health system, with some expressing the desire to remain in child services. They expressed feelings of uncertainty about future care, fear of losing specialist support and poorer health outcomes, and this feeling was often reinforced by negative experiences of other families (Camfield et al., 2011; Davies et al., 2011; Woodward et al., 2012; Bindels-de Heus et al., 2013; Jensen & Davis 2013; Kuchenbach et al., 2013).

#### **THEME 4: MAKING TRANSITIONS HAPPEN**

The included studies highlighted transition as a multi-dimensional, multi-agency process with multiple interactions between different sectors of the environment (Bhaumik et al., 2011; Schultz, 2013). There were a number of recommendations for an effective transition, such as early initiation of the process, identifying a lead agency responsible for ensuring all processes and care pathways are adhered to and completing a holistic assessment of needs (including legal requirement such as guardianship) (Davies et al., 2011; Bindels-de Heus et al., 2013; Bhaumik et al., 2011; Camfield et al., 2011; Barron et al., 2012; Woodward et al., 2012).

Other suggestions included a clear definition of responsibilities for professionals, improving access to reliable information and identifying a named health coordinator who could act as an advocate for the family and ensure an effective handover and communication between services and agencies (Davies et al., Bhaumik et al. 2011; Bindels-de Heus et al., 2013; Okumura et al., 2015; Rehm et al., 2012). Improving working relationship between child and adult health services through joint transition clinics was seen as essential for developing standards of care and pathways, promoting information sharing and alleviating families' and clinicians' concerns (Camfield et al., 2011; Bindels-de Heus et al., 2013; Kuchenbuch et al., 2013).

The included studies also highlighted the importance of adequate follow-up and overlap of care, adopting a family and patient-centred approach to transition and adult care and acknowledgement of parental expertise through their involvement in decision-making (Kuchenbuch et al., 2013, Bindels-de Heus et al., 2013, Schultz, 2013). Assistance for parents to navigate and manage available resources could help utilise their networking and advocacy skills and improve their satisfaction with the transition process (Okumura et al., 2015; Bhaumik et al., 2011; Bindels-de Heus et al., 2013).

Due to their holistic, life-course approach, nurses were identified as having the potential to play a central role in

transition planning and implementation as well as development of a transition program (Schultz, 2013; Rehm et al., 2012). They were seen as best suited to address unmet needs for young people with long-term health conditions through their diverse roles of care providers, coordinators and consultants (Rehm et al., 2012; Woodward et al., 2012). Their broad, expert knowledge as well as adaptability to new tools and clinical guidelines was seen as advantageous for helping young people and their families plan for transition and future care (Davies et al., 2011; Rehm et al., 2012).

#### **LITERATURE REVIEW: CONCLUSIONS**

The literature review undertaken as part of this project revealed that current services are often ill-prepared to support the multifaceted needs of people with complex learning disabilities at the point of transition from child to adult health services.

The findings were interpreted within the framework of the Transition Theory (Meleis et al., 2000), which recognised transition as a complex, multidimensional process and highlights transition as being core to nursing practice. The level of awareness and engagement, adapting to change and difference, time span and critical points are among the core properties of health transition and can facilitate or inhibit both the transition process and the health outcomes (Meleis et al., 2000). Other factors include personal, community and societal conditions such as the carer's ability to act as an advocate or access to information. The Transition Theory recognises nurses as able to provide critical input, knowledge and experience to each stage of transition and contribute to facilitating the process.

This review revealed that nurses have the potential to make a significant impact on transition planning and outcomes both in health, social care and school settings (Betz, 2007; Rehm et al., 2012). The opportunities for greater involvement of nurses in transition from child to adult health services are already recognised in existing guidelines, which highlights them as well-placed to act as 'named workers' or transition coordinators, contributing to joint transition clinics and development of transition programmes (NICE, 2016; Royal College of Nursing, 2013).

The findings from the literature review confirmed that the extent of nurses' involvement in transition from child to adult health services remains largely unrecognised and unknown. The study conducted in Phase 2 of the project aims to explore the experiences of families and nurse to identify the nursing roles and develop best practice strategies for transition.

**For more information regarding Phase 1, refer to:**

**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.**



## PHASE 2: DEVELOPMENT OF BEST PRACTICE STRATEGIES FOR TRANSITION

### Aims and methods

The aims of the second phase of the project were:

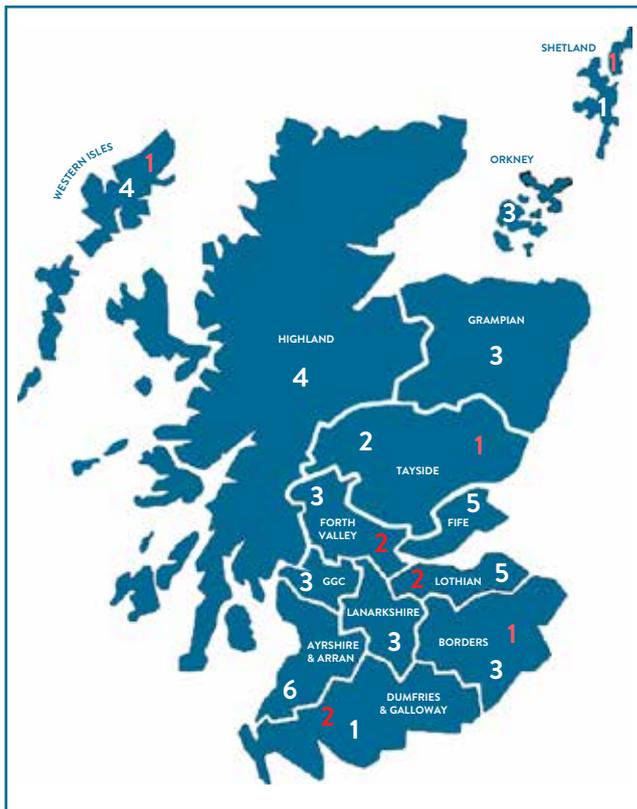
*1. To investigate and understand the experience of transition between child and adult health services, the challenges*

*involved and the barriers to the provision of person-centred care by obtaining the perspectives of nurses and families as key stakeholders*

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

Families' and nurses' experiences were collected using semi-structured interviews designed by the research team. The in-depth interviews, which were either face-to-face or via telephone, lasted between 40 minutes and over one hour and focused on:

- *The experiences of the transition from child to adult health services for young adults with complex learning disabilities*



**Figure 1:** Distribution of participants across all 14 NHS Boards in Scotland, including nurses and other health care professionals (in white) and families (in red)

- Collecting examples of good practice and what works well during the transition process
- Exploring areas for further development and suggested solutions to challenges experienced during the transition process

Participants were recruited from all 14 NHS Boards in Scotland (Figure 1) and included:

- 10 family carers of young people with complex learning disabilities recruited through voluntary organisations.
- 46 registered nurses and other practitioners recruited through local contacts in each NHS Board - 37 nurses, 6 health and social care managers and 3 other health care professionals

All interviews were audio recorded, transcribed by a professional transcription service and anonymised by removing any identifiable information, assigning each participant a code and each young person a pseudonym. Thematic analysis was undertaken by all members of the research team to systematically identify recurring themes (Braun and Clarke, 2006).

## WHAT DID WE FIND? FAMILIES' EXPERIENCES OF TRANSITION

The objectives of this element of the study were to:

1. Explore the experiences of transition from child to adult health care from the perspective of families of people with learning disabilities and complex needs
2. Investigate best practice, including the contributions of registered nurses experienced by families and individuals with learning disabilities and complex needs at the point of transition to adult health care
3. Identify the support needs of young adults with learning disabilities and their families at the point of transition from child to adult health services

The 10 family members recruited for this part of the study included nine mothers and one father who had a child with a complex learning disabilities and were either in the process of or had recently completed the transition process from child to adult health care services. Table 3 gives details of

## DEMOGRAPHIC INFORMATION

### CARERS

#### AGE

- 40 to 49 = 6
- 50 to 59 = 5
- Missing = 3

#### FULL-TIME CARER

- Yes = 8
- No = 2

#### OVERALL EXPERIENCE OF TRANSITION

- Very positive = 1
- Mostly negative = 2
- Mostly positive = 5
- Missing = 5

### PEOPLE WITH LEARNING DISABILITIES

#### GENDER

- Female = 4
- Male = 6

#### AGE

- 16 to 19 = 1
- 20 to 24 = 5
- 25 to 29 = 1
- 30 and above = 1
- Missing = 2

#### DIAGNOSES

- Genetic condition = 2
- Cerebral palsy = 7
- Autism = 4
- Learning disabilities = 4

**Table 3** Demographic information for families and their family members with learning disabilities and complex needs

demographic information for the families and their children with learning disabilities.

The young adults with learning disabilities had a range of diagnoses and comorbid health conditions, including epilepsy, visual impairment or blindness, musculoskeletal conditions, kidney and metabolic issues, gastrointestinal and respiratory problems, speech and language difficulties and mental health issues.

For most, the transition process to adult services commenced after the age of 14 and was completed by the age of 19, although for one individual it took place between the aged of 24-26.

While most of the parents reported their overall experience of transition as 'positive', their interviews painted a story of loss, physical and emotional struggle and inadequate support before, during and after the transition to adult services. Their experiences are captured in five main themes and associated subthemes (Table 4) and described below.

MAIN THEME	SUBTHEMES
A DEEP SENSE OF LOSS	<ul style="list-style-type: none"> <li>● Losing the sense of safety.</li> <li>● Loss of integrated services.</li> <li>● A sense of isolation and vulnerability.</li> </ul>
AN OVERWHELMING PROCESS	<ul style="list-style-type: none"> <li>● Re-establishing a care team.</li> <li>● Lack of coordinated planning.</li> <li>● Confusion and the state of unknown.</li> </ul>
PARENTS MAKING TRANSITIONS HAPPEN	<ul style="list-style-type: none"> <li>● Parents as transition coordinators.</li> <li>● The battle of transition.</li> </ul>
A SHOCK TO THE ADULT HEALTHCARE SYSTEM	<ul style="list-style-type: none"> <li>● Unprepared adult services.</li> <li>● The paradox of adult hospitals.</li> <li>● Lack of continuity of care.</li> </ul>
THE UNBEARABLE PRESSURE	<ul style="list-style-type: none"> <li>● Parents taking responsibility for health monitoring.</li> <li>● Alone in a new environment.</li> <li>● Impact on parents' health.</li> </ul>

Table 4: Themes and subthemes relating to parents' experiences of the transition process

## THEME 1: A DEEP SENSE OF LOSS

### LOSING THE SENSE OF SAFETY

Parents expressed feelings of deep trust towards their child health team, which provided them with a strong sense of safety. The introduction of the concept of transition to adult services was often sudden and unexpected and parents commonly viewed transition as a loss of the entire professional support network and relationships that had been built over many years:

*"all of a sudden it's like somebody taking a rug and just pulling it out".*

(Parent 05)

### LOSS OF INTEGRATED SERVICES

Parents described feelings of fear and anxiety about losing access to what they viewed as vital health services and clinical expertise, often provided by single clinicians and specialist nurses. Their concerns about the ability of adult services to meet their child's complex needs were driven by the move to a range of specialists and had often been reinforced by negative stories from other parents, who had already gone through transition:

*"I've heard these horror stories of parents being told, "you're off paediatrics now, you're back to the GP"; and of course the GP in our case doesn't know our son. All of a sudden, you've been a parent of a little lad, and this is a boy that had people at a major UK children's hospital, and you've had that level of expertise. Now you have a different person for the bones, you have a different person for the spine, you have a different person for the gastric, you have a different person for neurology, you have all these people".*

(Parent 05)

### A SENSE OF ISOLATION AND VULNERABILITY

This stressful time had a negative impact on parents who expressed feelings of isolation and being overwhelmed while continuing to meet their child's highly complex care needs. There was a sense that transition to adult services also meant a loss of emotional support from professionals who had known their family for many years:

*"Children's Community Nurse would drop off the supplies, but she would say, "how's it going?" or whatever, so I'd see her approximately once a month, and she was always at the end of the phone. If I hadn't seen her every six months approximately, she would come and have a cup of tea and just chat how things are. If you were admitted to hospital, she would know about it and she'd pop in to see you".*

(Parent 07)

## THEME 2: AN OVERWHELMING PROCESS

### RE-ESTABLISHING A CARE TEAM

These parents described the process of establishing a new care team in the adult services as complex and confusing, with multiple meetings and what they felt was a 'minefield' of information:

*"obviously, you have to move on at some point. So, then that involved more people, more information given, more meetings, things like that".*

(Parent 01)

Parents reported a lack of continuity of information sharing between professionals and felt drained by having to continually repeat the same information to different health care teams:

*"it's just the sheer fact that you almost have to start again with referrals in many cases, there doesn't seem to be any continuity or a good transition period".*

(Parent 10)

One parent, however, did experience effective continuity through having a named transition nurse and found them to be an invaluable source of information and support to navigate the transition process:

*"I don't think it would have been half as easy without the transition nurse, you would just have these appointments arriving, telling you to turn up at the health centre for your first vent team. You wouldn't know who...quite what it was for or who it was. The transitions nurse was a really good resource".*

(Parent 07)

### LACK OF COORDINATED PLANNING

Parents described a lack of coordination, which created uncertainty about who would take over responsibility of care or actions to take in a crisis situation. This in turn increased their child's vulnerability:

*"there was to be one meeting where the Adult Hospital nursing staff were to come up to the Children's Hospital to meet Hannah, that they called off that morning, that never happened. So, we were discharged from Children's Hospital having not met anyone from the Adult Hospital, and all this time Hannah's legs were getting worse and worse and Hannah was getting worse and worse".*

(Parent 09)

There was often a sense of there being a lack of responsibility for multiagency coordination, resulting in a transition being largely service-driven rather than person-centred. This gave parents little confidence in the quality of this process:

*"we used the tool book in person-centred planning that I had provided because I had been away on a course and everybody*

*filled things out, but nobody wanted to take responsibility for it and nobody wanted to collate it. So that process has not been followed through, so I don't think for Richard his transition has been person-centred at all".* (Parent 04)

However, some carers gave examples of excellent coordination and multi-agency planning between health and social care, who worked together to ensure a well-managed transition process:

*"there was a lot of multi-agency planning in the run up to Mark's transition, which as I said was both health and social care. I think that is a really key thing to have and if you can have the same people and people who know them well and that plans are put in place as best they can".* (Parent 02)

### CONFUSION AND THE STATE OF UNKNOWN

This feeling of confusion and uncertainty about future care seemed to be further reinforced by the lack of access to reliable and consistent information:

*"I know what's happening with regards to therapy, but I don't know what's happening exactly and the paediatrician when I spoke to her she thought it was the paediatric orthopaedic surgeon that would see Richard and she did write to him. It's only since then that we've discovered that that's not the pathway, so she didn't know".*

(Parent 04)

Parents expressed feelings of confusion about accessing services and expert advice, and were often excluded from communication between professionals or not provided with clear points of contact in adult services:

*"you're not quite sure which route you're supposed to be going. You know, who to contact? Who's your first port of call?"*

(Parent 01)

## THEME 3: PARENTS MAKING TRANSITION HAPPEN

### PARENTS AS TRANSITION COORDINATORS

The poor coordination and management of the transition process led to many parents having to take responsibility for ensuring there were no gaps in their child's care. Parents were found to take the initiative from initiating the transition process and handover between professionals to organising training for staff, daytime activities and referrals to adult services:

*"it's taken me sort of saying 'I'm really worried about this; for them to say we'll refer to the spasticity service who will refer to a neurologist locally. Things like that should happen without me having to ask for it; you know, she's got an ongoing condition, it's never going to get any better".*

(Parent 10)

Taking a proactive approach and becoming the driving force behind transition planning demanded focus and perseverance, however it was often the only way to ensure successful outcomes. Although the majority of the participants appeared to have the skills and ability to act as strong advocates for their children, as one carer pointed out some people with complex learning disabilities can be disadvantaged if their parents are not in this position:

*“not everybody has the skills, and that’s not a criticism. Not everybody has the time, people are working full time. We were semi-retired when we came up here, so this could be our life’s work. Other people, they’ve got other children, we’ve only got Duncan. It’s easier to make that our entire focus”.*

(Parent 05)

One parent highlighted how having support from a dedicated professional, in this case a transition nurse made a significant difference to the experience. Some of the areas of support that this mother appreciated most included identifying suitable day care provisions, making specialist care and training arrangements, preparing letters and reports to support funding decisions, liaising with consultants, helping identify appropriate adult health care services, advocating for the family, providing emotional support and guiding the family through the transition process:

*“she met with us, she was involved in the transition from school to adult services to adult day services, I suppose, really, from a social work point of view, but she was also involved in the sort of health aspect, and she was like your sort of champion”.*

(Parent 07)

## THE BATTLE OF TRANSITION

Despite taking responsibility for coordinating many aspects of the transition process, parents reported an overwhelming feeling of having to ‘fight’ or ‘battle’ for services that their children were not only entitled to but were often essential to their health and wellbeing. This included accessing appropriate treatments, care service provisions, funding or timing of leaving education:

*“so, once we had quashed this age 16 leaving school, no sooner had we done that than we were battling leaving at age 18. So, we then found ourselves in a battle on when would his transition begin. Although a council funding issue, the date obviously impacts on NHS as well. Paediatrics need to know”.*

(Parent 05)

Parents described many struggles to access services and appropriate care, needing to act as strong advocates for their child’s rights. This demanded stamina for what they often perceive as a continuous fight:

*“I’ve just come to the conclusion everything is a struggle. Everything is arguing the toss, sort of on bended knee, “could we do this?... could we do that?... it would be really helpful...” and I think it is sad, it’s quite sad that it’s not a standard”.*

(Parent 07)

## THEME 4: A SHOCK TO THE ADULT HEALTH CARE SYSTEM

### UNPREPARED ADULT SERVICES

Parents’ first experiences of acute hospitals for adults were rarely described as positive and the participants gave the impression of the young adults with complex learning disabilities causing a ‘shock’ to the adult health care system. Parents viewed services as being unprepared for their level of complex needs and lacking essential adaptations, including appropriate hoists, changing facilities, suitable beds or monitoring equipment. This placed additional pressure on parents, who sometimes had to source the essential equipment themselves.

Adult hospitals tended to lack facilities for parents to stay overnight, even though most parents were not prepared to leave their child alone. They reported instances where adult health care professionals lacked training or knowledge of the specific medical equipment or technologies that had been commonplace in the child health settings:

*“the PEG tube came out three times while he was in the hospital and this is a PEG that had never come out before ever in like the ten years he’d had a PEG in. We were a bit concerned they weren’t maybe...and they admitted themselves they’d never seen a PEG like that before”.*

(Parent 02)

*“quite often when I’m with Andrew I feel I’m ground breaking sometimes, thinking, what, have you never come across somebody with an established trachie?”(Parent 07)*

Such experiences reinforced parent’s perceptions that many adult health care professionals lacked essential knowledge of learning disabilities, nor the skills and experience to recognise and appropriately respond to the complex needs of the population. Furthermore, they felt that the staffing resource to provide adequate care was often not there. This increased parents’ anxiety and further diminished their confidence in the quality of care their children received:

*“my 20-year-old doesn’t speak, can’t move, can’t press buttons, can’t get anybody’s attention, she could be just left there if nobody’s seeing to her. She’s not able to say that she needs changing or she’s hungry or thirsty or that, you know, and that really worries me, and that’s down to lack of numbers to be honest, lack of staff. (Parent 10)*

### THE PARADOX OF ADULT HOSPITALS

The interviews revealed that standard hospital procedures were not always adapted to take account of legal guardianship. Parents often felt dismissed and not listened to, such as during hospital admissions, where they were asked to wait in another room while their adult child was interviewed and their condition assessed:

*“it did feel like that was unnecessary. We could have helped them. They didn’t know anything about Mark. They didn’t know anything about physically what he would be like or his communication other than what we filled in which would be quite basic when we first went into A&E”.* (Parent 02)

Although some health care staff were described as open and receptive to parent’s suggestions, others were perceived as very resistant to accepting their guidance:

*“it was a long process to get a person who could actually listen and take on board what I was saying... to go through the notes to find out what happened on the previous occasion”.* (Parent 01)

Excluding parents and carers from the process of assessment, decision-making and care did on some occasions lead to serious and potentially life-threatening situations:

*“the day before he was due to leave, we realised they actually hadn’t been giving him the right medication. We then realised he hadn’t been getting the right amount of bolus feeds because again nobody had really asked us and in fairness, I hadn’t really thought about it. It was partly our fault as well”.* (Parent 02)

At the other end of the spectrum, parents could sometimes be made to feel fully responsible for medical decisions, which diminished their confidence in the adult team being able to provide appropriate care. As a consequence, some even turned to their well-known child health team for support:

*“they didn’t hoist Hannah out of her wheelchair. They didn’t feel her (tone). They asked me what did I want to do? And I kind of looked at them to say, well, yes, I am the best person who knows Hannah, but that was always a decision made by a clinician at the Children’s Hospital. So, in the end we didn’t really do anything. Came home, and in desperation I picked up the phone to our old neurologist, who was absolutely fantastic. He said, bring her in”.* (Parent 09)

Some parents gave examples of excellent practice in the adult hospitals, with nurses and other professionals readily adapting standard procedures and working with them to ensure that their children’s stay was as smooth and comfortable as possible:

*“they even said we can get a bed down from the children’s ward so you can stay over, but actually they managed to reassure me that... I was sufficiently close to the hospital, a ten-minute drive, and they were going to take good care of him, that I felt that I could leave him”.* (Parent 07)

## LACK OF CONTINUITY OF CARE

The experiences of families highlighted the lack of continuity of care between children and adult health and social care services, with limited availability and access for young adults with learning disabilities. In some cases, this threatened the continued therapeutic care and monitoring of conditions:

*“Richard was also seen by the vision service because he has an eye condition and a processing condition and again their priority is 0 to 19. So, he’s not going to get that same level of input just because he’s become an adult”.* (Parent 04)

The sudden drop in services, which to families were guided by arbitrary age criteria rather than clinical need, made parents feel abandoned and concerned their child’s health was no longer a priority anymore, despite their ongoing high levels of needs. Parents described falling ‘between the gaps’ of services due to poor coordination and rigid criteria resulting in them being left without support for extended periods of time:

*“she ended up in hospital for three months, she came home having a central chest line in, having antibiotics that I was doing. And the children’s community nurse, that time I could have done with some support, but I never saw her again... She stopped seeing her at 16, but the adult nurses don’t pick them up till they’re 18”.* (Parent 10)

There was an overwhelming sense that young adults with complex learning disabilities do not readily ‘fit’ into the adult health and social care systems including day centres, respite and complex care facilities, and that parents encounter multiple barriers when trying to access services and resources:

*“everything that I do for Andrew... I feel it’s ground breaking. They make decisions for Andrew and Andrew alone, because that’s what they told me when they did his day centre. They said, ‘this is for Andrew and Andrew alone’, presumably to sort of cover themselves to say, well, if somebody else comes along and says, how come Andrew’s going there? they say, well, that was a unique one-off decision.* (Parent 07)

However, there were also examples of good continuity of care, with nurses helping parents establish points of contact in specialist adult health services. This seemed to give confidence that they would be able to access help when required:

*”very much the specialist nurse, who is a lovely, lovely person. She has linked to the spasticity management consultant, and obviously a lot of Hannah’s issues are tone based, or can be tone based, and she can always be contacted on our behalf. We don’t see her every time, but she can also be contacted. So, we now have the two prongs, so to speak, through the specialist nursing staff that hopefully would access us up, yeah”.* (Parent 09)

## THEME 5: THE UNBEARABLE PRESSURE

### PARENTS TAKING RESPONSIBILITY FOR HEALTH MONITORING

Diminished adult services that were more difficult to access, coupled with a lack of regular input from the adult health

team led to parents having to take more responsibility for monitoring their child's general health and complex conditions. Even with successful transitions to specialist services, the young person was sometimes immediately discharged from the adult service with nobody charged with monitoring their condition:

*“we did get referred to the adult service well in time, we saw the adult doctor once, had us back another time and then discharged us. And that I find hard, I mean, she's got ongoing problems, she's on a really high dose of one drug to keep her gut working, and yet nobody's now looking after it but me, so you're left high and dry”.* (Parent 10)

However, there were also examples of excellent practice, with one parent highlighting how good communication and agreeing a clear plan can help manage parents' anxiety about monitoring the young adult's health conditions and minimise waiting time:

*“we sometimes just need that instant access to the doctor to say, look, this is happening, do you think we should increase this drug?, because we know there's parameters within certain meds. The doctor will say, right, I would like you to do this, and I'm going to send you an appointment for three week's' time, and then we'll review how it's going. Rather than you go for the meeting and then you've got to make a change, and then you still don't know if it's going to work. So, all of the doctors agreed that I can contact them”.* (Parent 05)

There were also excellent examples of General Practitioners taking a leading role in ensuring continuity of care, both in terms of managing general health as well as acute care:

*This GP said to me, I would like to be Hannah's named GP. And now we just see him all the time and it's just...the difference is huge.* (Parent 09)

## ALONE IN A NEW ENVIRONMENT

Following the transition to adult health services, the pressure experienced by parents seemed to increase significantly. The first admission to a general hospital was often not only stressful, it was also an isolating experience, with little support available to help parents navigate this unfamiliar environment:

*“there was no help, no advice. I have never felt so isolated in my entire life. We did meet some very nice people along our way. But at the point where we were at the lowest we could possibly be was when we were going from the Children's Hospital to the General Hospital with nothing in place to back us or help us in the adult hospital situation”.* (Parent 09)

This feeling seemed to be reinforced by the loss of the practical support offered by child health nurses, leaving parents responsible for most aspects of everyday personal care while their child was in hospital. Even when a level of support was available in the form of Learning Disabilities

Liaison Nurses, poor referral practices led to parents being 'missed' and unable to take a break from caring responsibilities.

One parent who received support from a Learning Disability Liaison Nurse while her daughter was admitted to hospital, saw this role as invaluable and felt that the nurse was able to advocate for the family and help adult staff adapt their procedures:

*“I was able to explain the situation to her, and obviously she had a better understanding than the actual doctors had, so she could go and speak to the doctors, and then obviously, things kind of relaxed a bit and they were a bit more helpful. Which shouldn't have been the case, you know”.* (Parent 01)

One mother described the gap in support she experienced after being discharged from the children's community nursing service, which left her feeling isolated:

*“there's no equivalent to children's community nurse in the adults, and they're a great source of reassurance and talking to...especially through things that are just everyday things, stupid things like bowel habits. But it does affect him if he doesn't go to the toilet, but also if you were concerned about him health-wise, his breathing or whatever, you could speak to anybody in the CCN office”.* (Parent 07)

## IMPACT ON PARENTS' HEALTH

The increasing pressure placed on parents as a result of transition and the reduction of services such as respite, complex care and hospice support was seen to impact on their own mental and physical health. Losing valuable support to respond to the workload of the hugely challenging task of caring for a person with complex learning disabilities had a significant effect on parent's quality of life, ability to continue working and could put a strain on their marriages and relationships.

*“I get 42 nights respite a year which is a hell of a drop down. My children's hospice is gone, so I don't get my three weeks there, and complex care, rather than having three or four visits a week or somebody helping out in the evenings for a few hours from half five to half nine. I'm lucky, I count myself lucky if I get one shift a week, and that just means that Andrew goes in the bath once a week, because I don't always have time to bath him”.* (Parent 07)

Furthermore, the pressure of providing continuous care and support to their child in the hospital setting, along with a deep sense of isolation, could sometimes lead to a rapid decline of parents' mental health and affect their ability to look after their child:

*“they're very, very, very nice people down in the wards, but there was not enough of them to be able to say to me, go away for an hour, do something. So, I was with her constantly the whole time, physically drained and mentally on the verge of... I really was toiling hugely”.* (Parent 09)

Given that the needs of the individual with complex learning disabilities remain the same or can sometimes increase, the demands placed on the aging parents was felt to be unrealistic and detrimental to their health:

*“I get sore backs, I’m exhausted because there’s no support. The other thing, this year especially, I’m never ill, never ill, don’t even get colds in the winter, but this year I have been ill and I’m sure it’s because physically I’m so tired. I could barely get off the settee, but I still had to shower two severely disabled young adults”.* (Parent 10)

## **FAMILIES’ EXPERIENCES OF TRANSITION: CONCLUSIONS**

The interviews with parents of young adults with complex learning disabilities across Scotland revealed that transition to adult health services continues to be hugely challenging, as parents described “a deep sense of loss”, “an overwhelming process”, “parents making transitions happen”, “a shock to the adult health care system” and “unbearable pressure”.

The results mirror previous studies on transition for young adults with learning disabilities, which highlighted the sense of loss of trusting relationships with child nurses and other professionals, uncertainty and anxiety about future care and a bewildering and uncoordinated process with limited access to reliable information (Bindels-de Heus et al., 2013; Leonard et al., 2016; Young-Southward et al., 2017a; Schultz, 2013; Okumura et al., 2015; Bhaumik et al., 2011).

The transfer to adult health services could be rapid, with little or inadequate preparation, which can increase the parent’s feeling of vulnerability. Arrangements related to legal changes, such as guardianship, are also often overlooked and could delay parents’ full involvement in their child’s health care (Davies et al., 2011; Betz et al., 2015).

Many parents felt they had to assume responsibility for the transition process to ensure their children’s needs continued to be met and this mirrors findings from the literature review in the first phase of this study, which identified a theme of “parents as advocates in emotional turmoil”. While families expressed wanting to be at the heart of the transition process, they did not want to assume full responsibility for every aspect of it, feel like they have to ‘fight’ for appropriate services or solely rely on own resourcefulness (Crowley et al., 2011; Davies et al., 2011).

Parents in this study also highlighted the detrimental impact of transition on their physical and mental health and quality of life and by causing significant stress and additional pressure as a result of decreased services following transition.

However, families also identified the positive impact of nurses on their experience of transition, including transition planning, communication, information sharing, ensuring continuity and offering emotional and practical support.

Child nurses develop a wealth of knowledge of the young person and their family and can ensure a person-centred planning and handover through collaboration with adult services (Betz, 2013). Some families in this study also benefitted from the involvement of a dedicated transition nurse, who was able to help them navigate the transition process, access appropriate adult services, advocated for the family and provided emotional support.

In line with existing studies, parents considered adult health services as ill-prepared for the complex needs of people with learning disabilities, including knowledge of specialist health equipment and awareness and availability of necessary adaptations. They worried about access to adult services and highlighted the importance of their continued involvement in their child’s care. A number of parents recognised the role of Learning Disability Liaison Nurses in hospital settings to be able to act as a point of contact and ensure necessary adaptations are in place.

The interviews with parents of young adults with complex learning disabilities confirmed previous findings about multiple challenges experienced during transition to adult services and beyond. However, they also highlighted the opportunities for increased nursing involvement to help families navigate the transition process and minimise their anxiety. Families are not passive recipients of care and the reciprocal nature of the relationship among the health care professionals, the young adult with complex learning disabilities and their family needs to be acknowledged and their needs addressed. This could not only help facilitate a more effective transition process but also ensure families’ health and wellbeing are not negatively affected.

## **PHASE 2: WHAT DID WE FIND? BEST PRACTICE STRATEGIES FOR TRANSITION**

- *The objectives of this element of the project were to:*
- *Identify the contribution of nurses to the transition process from child to adult health services for people with complex learning disabilities*
- *Identify best practice strategies for transition from child to adult health services*

All potential participants were screened against the eligibility criteria, which were: having direct experience of facilitating transition or providing direct nursing care and support at the point of transition from child to adult health services for people with learning disabilities and their families, and the ability to provide examples of good practice and possible solutions to challenges experienced during the transition process.

In some NHS Boards other health care professionals or health and social care managers were identified as more involved in the transition process in their area than nurses and were invited to take part.

In total, 46 registered nurses and other practitioners from all 14 NHS Boards across Scotland took part in a one-off qualitative interview, including: child health nurses (n=21), adult health nurses (n=16), health and social care managers (n=6) and other healthcare professionals (n=3) (Tables 5 and 6).

Table 7 presents demographic profile of the nurses and other practitioners and Figure 2 identifies participants' self-reported roles in the transition process.

NHS BOARD	Number of registered nurses and other practitioners
• NHS Ayrshire and Arran	n = 6
• NHS Borders	n = 3
• NHS Dumfries and Galloway	n = 1
• NHS Fife	n = 5
• NHS Forth Valley	n = 3
• NHS Grampian	n = 3
• NHS Greater Glasgow and Clyde	n = 3
• NHS Highland	n = 4
• NHS Lanarkshire	n = 3
• NHS Lothian	n = 5
• NHS Orkney	n = 3
• NHS Shetland	n = 1
• NHS Tayside	n = 2
• NHS Western Isles	n = 4
<b>TOTAL</b>	<b>n = 46</b>

Table 5: Participant distribution across NHS Boards in Scotland.

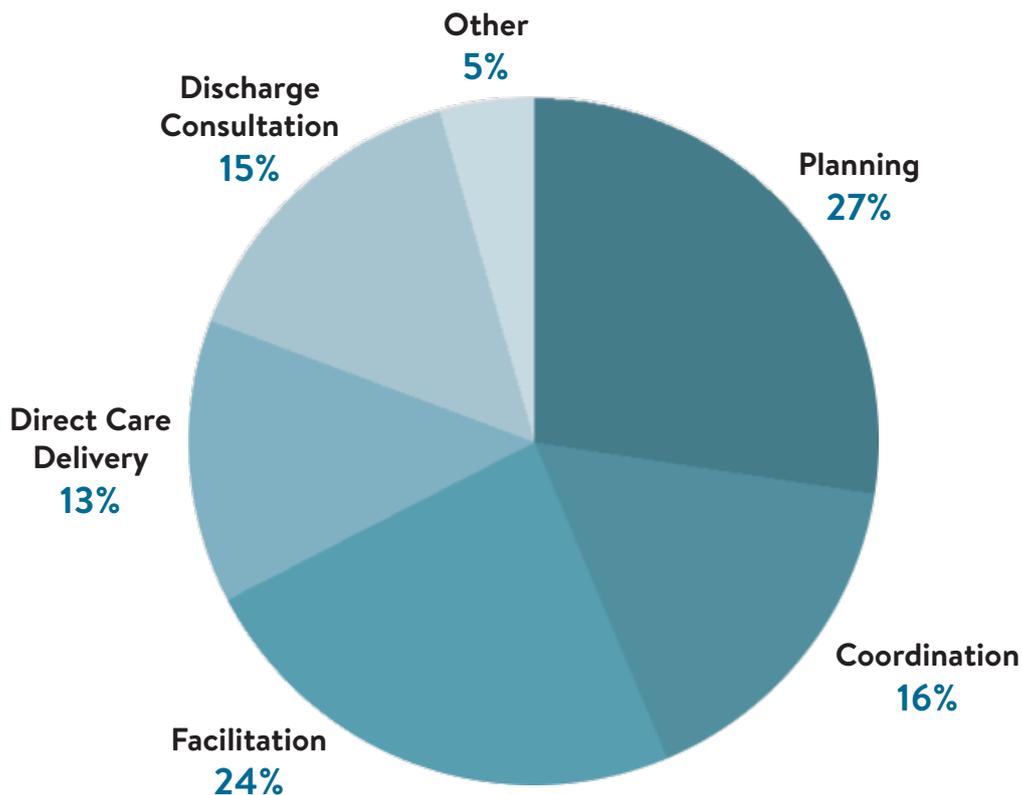
AREA OF PRACTICE	Role Setting
CHILD HEALTH NURSES n=21	<ul style="list-style-type: none"> <li>• Community services n=10</li> <li>• Specialist services (including epilepsy/neurology, gastroenterology, respiratory, complex care/respite) n=8</li> <li>• LD service n=1</li> <li>• LD liaison service n=1</li> <li>• Coordination/transition role n=1</li> </ul>
ADULT HEALTH NURSES n=16	<ul style="list-style-type: none"> <li>• LD liaison service n=7</li> <li>• LD service n=5</li> <li>• Transition role n=3</li> <li>• Specialist service (epilepsy) n=1</li> </ul>
HEALTH & SOCIAL CARE MANAGERS n=6	
OTHER HEALTH CARE PROFESSIONALS n=3	<ul style="list-style-type: none"> <li>• Physiotherapist n=1</li> <li>• Occupational therapist n=1</li> <li>• Clinical psychologist n=1</li> </ul>
<b>TOTAL</b>	<b>n = 46</b>

Table 6: Nurses and other health care professionals. Participant distribution across nursing groups and services.

DEMOGRAPHIC INFORMATION	
GENDER	<ul style="list-style-type: none"> <li>• Female: n = 41</li> <li>• Male: n = 5</li> </ul>
AGE	<ul style="list-style-type: none"> <li>• 20 to 29: n = 1</li> <li>• 30 to 39: n = 5</li> <li>• 40 to 49: n = 14</li> <li>• 50 to 59: n = 23</li> <li>• 60 to 69: n = 2</li> </ul>
WORKING HOURS	<ul style="list-style-type: none"> <li>• Full-time: n = 39</li> <li>• Part-time: n = 6</li> </ul>
AREA & POPULATION SERVED	<ul style="list-style-type: none"> <li>• Mainly urban: n=15</li> <li>• Urban and rural: n=15</li> <li>• Rural with some towns: n=9</li> <li>• Mainly rural: n=7</li> </ul>

Table 7: Demographic information of nurses and other healthcare professionals

**AREA OF TRANSITION INVOLVEMENT**  
**N=45; MISSING DATA N=1**



Based on the interviews with nurses, other practitioners and parents, five main themes and related subthemes were identified. They represented principles underpinning improved transition care and associated elements of transition management (Figure 3) and are described in detail, focussing on areas for further development, intended outcomes, the role of nurses and examples of good practice.

PRINCIPLES UNDERPINNING IMPROVED TRANSITION CARE	Elements of Transition Management
<ol style="list-style-type: none"> <li>1. STRATEGIC LEVEL FOCUS</li> <li>2. CLEAR TRANSITION PROCESSES &amp; PATHWAYS</li> <li>3. PROACTIVE TRANSITION PREPARATION</li> <li>4. MULTI-AGENCY TRANSITION PLANNING</li> <li>5. CONTINUITY OF CARE IN ADULT SERVICES</li> </ol>	<ul style="list-style-type: none"> <li>• Strategic level commitment</li> <li>• Population projection and service planning</li> <li>• Transition education and training</li> <li>• Transition pathway development</li> <li>• Cross-health board transition practices</li> <li>• Early preparation</li> <li>• Timely initiation of the transition planning process</li> <li>• Collaborative working across services and agencies</li> <li>• Lead coordinator</li> <li>• Assessment and care planning</li> <li>• Emergency care planning</li> <li>• Coordinated handover of care</li> <li>• Holistic overview in adult health services</li> <li>• Access to services and quality care</li> <li>• Family carers as equal partners in care</li> </ul>

Figure 3: Five main themes and related subthemes representing principles underpinning best practice strategies for improved transition care and associated elements of transition management.

## PRINCIPLE 1: STRATEGIC LEVEL TRANSITION FOCUS AND PLANNING

### 1.1 STRATEGIC LEVEL COMMITMENT

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"><li>1. Inconsistent transition focus across NHS Boards in Scotland</li><li>2. Transition is not considered a priority at the strategic level</li><li>3. Dissemination and implementation of existing national guidelines is inconsistent and not prioritised</li><li>4. Lack of clearly defined roles and responsibilities related to transition</li></ol>	<ol style="list-style-type: none"><li>1. Transition to adult services is recognised as an important aspect of care and considered in all strategic planning</li><li>2. Each NHS Board in Scotland has a dedicated 'transition champion' at a strategic level</li><li>3. A national standard of transition for people with learning disabilities is incorporated into services at the strategic level through clear policy</li><li>4. Clear joint health and social care policies are developed</li><li>5. *Families feel confident that transition to adult services is a priority at the strategic level</li></ol> <p><small>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</small></p>

Any attempts to improve the transition process from child to adult health services will remain challenging or unsustainable unless it is consistently recognised as an important aspect of care across all NHS Boards in Scotland.

*“there’s never any talk about learning disabilities, how we can help young people, how we can help young adults. Because if that’s the situation, why do they put so much effort into getting my son to walk, why was so much effort put in, in the early years, you know”.* (Parent 08)

*“I think sometimes the word “transition” means everybody thinks that somebody else is doing it but they’re not actually taking responsibility for it”.*  
(N32, adult health nurse: learning disabilities liaison)

A strategic-level ‘transition champion’ in each NHS Board is required to 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 to each locality.

*“we need people further up in the organisation to be committed to addressing the transition”.*  
(N03, adult health nurse: transition role)

*“if it was based in policy, and there were protocols to follow or policy, and guidelines are fine, protocols are fine, but if it’s in policy and then people have to do it, no matter what’s in their job description”.*  
(N18, adult health nurse: learning disabilities liaison)

Ensuring that the unique needs of people with complex learning disabilities and their families are considered in all strategic level planning including service developments and planning, the roles and responsibilities of professionals and training should be a priority.

### STRATEGIC LEVEL COMMITMENT: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

Nurses are advocates for the needs of people with learning disabilities and their involvement was notable in any initiatives undertaken at a NHS Board level.

In some NHS Boards, there was evidence of managers acknowledging the need to improve transition and showing commitment to developing existing processes through arranging regular steering group meetings, consultation with other services, agencies and families and carers or appointing transition workers to review current processes:

*“having a national standard, or some kind of standard. Roles and responsibilities for both the paediatric end and the receiving end”.* (N09, child health nurse: community service)

*“the joint manager of the learning disability service, when he came to work at the team he had a couple of agendas and one of them was the transitions. So he’s started up a steering group that meets every six weeks and we look at what needs to be done. It was out of that steering group that the need for the transitions development worker came about”.*  
(N30, health and social care service: transition role)

## 1.2 POPULATION PROJECTION AND SERVICE PLANNING

### AREAS OF FURTHER DEVELOPMENT

1. *Lack of strategic planning to respond to the needs of the rapidly changing population of people with complex learning disabilities*
2. *Limited population modelling and projections prevent appropriate service planning and development*
3. *Inadequate resources and staff capacity limit involvement in transition planning and delivery*

### INTENDED OUTCOMES

1. *Population identification and projections are consistently carried out at the strategic level*
2. *Population projections are used for child and adult services planning*
3. *\*Resources are available to ensure availability of adequate services and sufficient staffing levels to meet the growing service requirements of people with complex learning disabilities*

**\*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS**

Reliable population modelling and projections are crucial for ensuring adequate resources, services and workforce are in place to meet the growing service requirements of people with complex learning disabilities at the point of transitions and beyond. However, we found little evidence of long-term strategic level focus or planning for individuals who are likely to require ongoing specialist input in adult health services. This not only creates systemic barriers for young adults with complex learning disabilities and their families but was also perceived to undermine transition awareness raising and positive work undertaken in that area.

*“transition at the moment is about ‘what’s’...what resources are available and what funds are available. That...that’s the two key things here. It’s not... at the moment, I don’t think either the Council or the NHS have the luxury of being able to say, this is person-centred”.*  
(N22, child health: school nurse)

*“you just feel as if you’re a little person in a big scheme of things and sometimes I think is it worthwhile what I’m doing? Am I listened to? Is it helpful? Sometimes I feel it is kind of dismissed or that’s not really that important”.*  
(N35, adult health nurse: transition role)

It is vital that resources are available for development, redesigning or increasing capacity of specialist services and roles. This includes increasing sustainability of services such as physiotherapy, occupational therapy and speech and language therapy into adulthood, expanding remit of care provided by district nursing as well as additional specialists in adult health services with expertise in complex needs:

*“if we could have a consultant post that has an interest in multiple specialities, you know, comorbidities, rather than just being a specialist in GI, or diabetes, or cystic fibrosis or...you know. So, we know they exist but they’re just very few of them”.*  
(N27, child health nurse: liaison role)

### POPULATION PROJECTION AND SERVICE PLANNING: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

There are opportunities for nursing contributions to identify population projection and service planning and workforce developments. One example is through supporting early identification of children in out-of-area placements and assessing their needs to enable strategic-level planning to develop local services able to meet them:

*“the child that’s there [out of area] now, may well be the last one, because the Council are certainly saying, we can meet the needs of the children locally, now. You know, they’ve done a lot of, you know, up skilling of staff, and of facilities, locally, so that these children don’t have to go out of the area”.*  
(N01, child health nurse: specialist service)

With strategic and managerial planning and support, it was identified that nurses play a significant role in ensuring services consider and respond to the needs of people with complex learning disabilities at the point of transition and beyond. This could be achieved through the development of new roles such as ‘transition facilitator’ and appointment of learning disabilities nurses with a specific role in transition:

*“the all age learning disability service locally, we haven’t had a learning disabilities nurse and they have just been appointed, and also a learning disability occupational therapist, and they’re all age disabilities. So I think that is actually a really positive step, that there will be people, and I think these people are hopefully going to take quite a good role of actually doing that transition”.* (N26, other health care professional)

## 1.3 TRANSITION EDUCATION AND TRAINING

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"><li>1. Transition is not incorporated into any formal training</li><li>2. Gaps in knowledge with regards to transition challenges experienced by people with learning disabilities</li></ol>	<ol style="list-style-type: none"><li>1. *Awareness of the needs of people with learning disabilities and their families and carers during the transition process and beyond is raised through education and training</li><li>2. Information and resources on transition are centralised and made easily available to nurses and other practitioners</li><li>3. *Child and adult health counterparts are able to learn about each other's roles, for instance through shared learning days</li><li>4. *Nurses and other practitioners in adult services are upskilled to provide care to the increasingly complex population of people with learning disabilities</li></ol> <p><b>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</b></p>

There is limited attention to transition in existing education and training, with nurses and other practitioners tending to rely on professional experience. Many nurses felt that knowledge on transition and challenges experienced by people with learning disabilities was limited in both child and adult services, for example with regards to legal requirements for care delivery to adults with learning disabilities:

*"I had to take over a pad to the children's ward with an adult with incapacity certificate, because they hadn't considered that if you're treating somebody that's over 16 it's an adult with incapacity certificate that's needed".*

(N17, adult health nurse: learning disabilities service)

Nurses and families agreed that building the knowledge base about transition is paramount and should include raising awareness of the needs of people with learning disabilities and their families; legal considerations such as Adults with Incapacity (Scotland) Act 2000 and Legal Guardianship as well as differences between child and adult health services.

Transition training should be incorporated into the pre-registration nursing curriculum, made easily available as part of continuous professional development and facilitated through shared learning between child and adult health services. Areas of learning should focus on general care delivery to people with complex learning disabilities as well as specialist treatments which are becoming increasingly common in the adult population of people with learning disabilities:

*"I think probably training maybe for people within adult services or understanding...so that they can understand what the transition is like for people".* (Parent 02)

*"according to our paediatric colleagues, more young people coming through on this specific treatment. So as an adult service, we need to get ourselves better placed to be supporting this as well. That will involve upskilling staff, being aware of what the treatment is and what it involves. And being prepared to support care providers with it as well".*

[N03, adult health nurse: transition role]

### TRANSITION EDUCATION AND TRAINING: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

We found some evidence of transition-related training, including Welfare Guardianship and consent to treatment.

*"we've had, from the CEN Network, we've had training around guardianship and transition. And we've had some in-house multidisciplinary training around the audits that were done on the transition clinics".*

(N07, child health nurse: community service)

There was an example of sharing training materials between child and adult support-at-home services, and the exchange of knowledge was further facilitated by overlap of care until the adult services fully take over.

There was also an example of carers participating in lectures for student nurses and presenting their perspective on health care and their child's needs, which was thought to have been very well received by the students.

*"I've had a student who has heard one of my parents and they said that was the best lecture of the week. Actually hearing the reality and the difficulties these parents face".*

(N12, child health nurse: specialist service)

## PRINCIPLE 2: CLEAR TRANSITION PROCESSES AND PATHWAYS

### 2.1 TRANSITION PATHWAY DEVELOPMENT

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"><li>1. <i>Inconsistent focus on transition development work across Scotland</i></li><li>2. <i>Reliance on unwritten processes or outdated guidance not suitable for people with learning disabilities</i></li><li>3. <i>Lack of resources and capacity to develop pathways</i></li><li>4. <i>Lack of obvious referral routes from coordinating paediatrician creates a barrier for development of consistent pathways</i></li><li>5. <i>Disjointed processes with little integration between services and agencies</i></li></ol>	<ol style="list-style-type: none"><li>1. <i>Transition development work is enabled through resources and time allocation</i></li><li>2. <i>*Clearly defined written transition pathways and guidelines exist nationally and locally and are followed consistently in a reflective way</i></li><li>3. <i>Integrated health and social care transition pathways are developed and utilised where appropriate</i></li><li>4. <i>*Transition pathways are designed to empower families to navigate the adult healthcare system</i></li><li>5. <i>*Feedback on the transition process is obtained from families and used to improve the transition pathway</i></li></ol> <p><b>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</b></p>

The degree of transition development varied considerably across Scotland and there currently do not seem to be any well-established pathways in any of the 14 NHS Boards. Nurses and other professionals continue to rely on unwritten processes and experience as a basis for transition planning and implementation, leading to inconsistencies or sudden transfers to adult services with no meaningful preparation and planning.

Described as “hit and miss”, with inconsistent quality and lack of clear guidance, there seems to be a lot of confusion about the definition of responsibilities and overall management of the process..

*“some will transition at 18, some will transition at 20, some will transition before that. So when do you start the transition process? Do you start the transition process at 14 or do you start it at 24?”*  
(N32, adult health nurse: learning disability liaison)

Where transition guidelines exist, they are often perceived as outdated, unclear, unrealistic or not fit for purpose. Both nurses and families advocated for clearly defined transition pathways, which would empower carers to navigate the transition process and provide clear person-centred and family-centred guidance to professionals, such as a clear transition timeline.

*“I think there needs to be guidelines across the whole of Scotland, the same guidelines everybody follows, a bit of a kind of checklist pathway to follow like a standard template, and then you could adapt it for your locality.”*  
(N06, adult health nurse: learning disability service)

Nurses and families highlighted the development of a transition pathway needs to be reflective, involve consultation with families and be enabled through allocation of time and resources. This could be achieved through the appointment of a dedicated worker or a team of workers leading on pathway development within the capacity of their existing roles.

Nurses also highlighted the opportunities for creating joint pathways between education, social care and healthcare, as a result of recent policy changes and Health and Social Care Integration, leading to a seamless process:

*“it’s a prime time in that landscape to really influence how we take this forward and improve upon it in the health component of that. We need to have strong advocates and people that are compassionate and passionate to really address for the families and young people that transition, we could do better”.*  
(N05, child health nurse: coordination/transition role)

Nurses felt that lack of an equivalent role to a coordinating child health doctor in adult health services creates a barrier for designing and implementing a clear health transition pathway as there is no obvious referral route, like in the case of young adults with single conditions such as cystic fibrosis “or diabetes:

*“they have very defined pathways to go through because at the adult side they have a doctor who deals with diabetes and there’s a nursing team in the adult side who look after people with diabetes”.*  
(N19, child health nurse: community service)

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## TRANSITION PATHWAY DEVELOPMENT: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

This study found some nurses playing a leading role in developing, piloting, implementing and evaluating transition pathways for people with learning disability. This was particularly evident for nurses in specific transition-related roles (n=4):

*“for several years, we’ve been trying to pilot a pathway for young people with learning disabilities during the transition. That is to encourage more health professionals to be involved in transition planning, that it’s not all just down to one person”.*  
(N03, adult health nurse: transition role)

However, other nurses also took the initiative to collaborate, problem-solve and implement positive changes within their existing role:

*“we had a phone call from the acute liaison learning disability nurse, who wanted to know what happened when children with really complex needs transition, as far as their medical information goes. What we’re going to do is look at a pathway and set up a working group to look at that, to make transition smoother”.* (N36, child health nurse: specialist service)

There was an example in one NHS Board, with development work on practice and service models for a transition team, the creation of a new transition role and a new framework in adult services, equivalent to GIRFEC, called GIRFEA, ‘Getting It Right For Every Adult’ for people with learning disabilities.

## 2.2 CROSS-NHS BOARD TRANSITION PRACTICES

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"> <li>1. Attending joint transition meetings is challenging for professionals due to distance</li> <li>2. Cross-NHS Board transitions rely on unwritten processes, which also vary depending upon the Council and NHS Board area</li> <li>3. Different criteria or care management in the two NHS Boards</li> </ol>	<ol style="list-style-type: none"> <li>1. Written processes for transition between different NHS Boards exist</li> <li>2. Children who are due to transition back to their local NHS Board are identified early through efficient population monitoring</li> <li>3. Joint transition planning is undertaken through the development of robust networks between professionals in different NHS Boards</li> <li>4. The number of young people whose health is managed out with their local area is minimised through strategic planning, service development and education</li> </ol>

Due to the absence of clear processes and pathways, transitions between NHS Boards, where a young adult is due to return from an out-of-area child placement or whose health condition required tertiary care management can be particularly challenging. This group of children tend to have highly complex health needs, are rarely linked to their local services and there might be significant differences in terms of criteria or care management between the NHS Boards and local authorities:

*“they’re not accessing community nursing, they’re not accessing physiotherapy, locally. So when it comes to transition for them, it is really challenging, to be able to then start linking them up with services, that they’re not linked to already”.* (N01, child health nurse: specialist service)

Nurses agreed that there is a need for clear processes for transitioning young people whose health is managed out with their local NHS Board or local authority area. They advocated for more clarity on different service and local authority-specific systems to enable better transition management.

Robust networks and good communication between nurses and other healthcare professionals in different health boards were identified as paramount for enabling effective joint working. Furthermore, children who are due to return to their local NHS Board need to be monitored and identified early to enable transition planning:

*“when the child goes to school out with their home area, that we need to be sure that it is happening. And I’m now thinking about other children. So yeah, we need to be sure that it is happening, that they are getting booked into our transition clinics, so we at least trigger our part of it”.* (N07, child health nurse: community service)

### CROSS-NHS BOARD TRANSITION PRACTICES: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

Where cross-health board transitions worked well, nurses liaised with practitioners in the host NHS Board area, shared detailed background information regarding the person with learning disabilities, prepared the young person and their family and ensured legal arrangements such as Welfare Guardianship were in place. A carer highlighted a central role of a community children’s nurse in this process:

*“Mark was a wee bit more complicated because he straddled two health boards. Although consultants and paediatricians weren’t part of that [school transition] review, the community nurse was and links with GPs, et cetera, and with hospital were made via the health people that were involved with him at that point”.* (Parent 02)

A manager of community children’s nurses in one health board also highlighted the development of early identification and transition planning processes for young people whose health is managed out with the local health board:

*“we still have a post-16 group where we’re looking at transitions, but we now are identifying a plus-14 group, so we were identifying youngsters with a lot of complex needs that are either out of area in this health board right now and will be coming back in to this health board. We’re also planning where they’re going to stay in their local community. So that...these meetings have just started or are being developed”.* (N21, child health nurse: community service)

## PRINCIPLE 3: PROACTIVE TRANSITION PREPARATION

### 3.1 EARLY PREPARATION FOR THE UPCOMING TRANSITION

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"><li>1. No preparation or early planning for the upcoming transition increases families' anxiety</li><li>2. Families lack information on the transition and what it involves</li><li>3. Lack of clear pathways creates a barrier for professionals informing families on the transition process and future care</li><li>4. Some families struggle with the changing legal requirements for providing care to their maturing child</li></ol>	<ol style="list-style-type: none"><li>1. *All health professionals take responsibility for routinely discussing transition to adult services with the young person and their family from the age of 14</li><li>2. *Family carers understand the concept of transition before it is initiated and receive reliable information about what it involves</li><li>3. *If required, professionals signpost families to services that can provide support with Welfare Guardianship and other legal requirements</li><li>4. *Young person is informed about and prepared for the approaching transition</li><li>5. *It is recognised that transition is a difficult time for the family who may experience a sense of loss</li><li>6. *Child and adult health services communicate about young people approaching transition</li></ol> <p><b>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</b></p>

The initiation of the transition process can be a sudden, unexpected event that the families do not understand or feel prepared for. It is the responsibility of all professionals to prepare the young person and their family for transition by discussing it as part of a normal process from the age of 14 and providing families with reliable information on future care in adult health services as well as their changing legal status:

*“if we can have that conversation with families earlier on in the process and we can plan and prepare and give people time to understand some of the changes that are likely to be happening. I think that puts them in better place for actually coping when the time comes”.*

(N03, adult health nurse: transition role)

It is paramount that all professionals recognise transition as a major life change, often associated with feelings of fear, uncertainty 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)

Some families also struggle emotionally and practically with the changing legal situation of their maturing child and the need to obtain Welfare Guardianship:

*“applying for guardianship and going through that process is traumatic, it's difficult, it's very frustrating for some parents”*  
(N26, other health care professional)

It is crucial that child and adult health professionals communicate about the needs of young people who are due to transition and prepare for that:

*“if you are supporting any young person, you should be starting to think about their adult transfer and their adult support”.*  
(N05, child health nurse: coordination and transition role)

### EARLY PREPARATION FOR THE UPCOMING TRANSITION: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

Nurses were found to be significantly involved in early preparation by familiarising the young person with learning disabilities and their family with the concept of transition and encouraging parents to consider and plan for future care and services after the young person leaves school:

*“we very much speak about transition as a normal process, that's a part of growing up. So, we very much introduce the concept of transition at a young age, so it's not going to be quite the surprise it is”.*

(N12, child health nurse: specialist service)

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This included preparation for the changing legal status when the young person became 16 years of age by explaining the legislation and signposting the family to further information and support:

*“I always bring up guardianship as well at this point, because some of them just don't know about it. They are really quite shocked that they need to go through the court and get a piece of paper that says they're now able to make decisions for them”.*

(N35, adult health nurse: transition role)

In one NHS Board, a 'teenage clinic' for children between 13-15 years old helps familiarise the young person and their family with the adult health care system:

*“this is for the children's complex needs and with learning disabilities, because we try to get them involved with the same as all the other patients. It prepares them for going into the adult services, whereas their parents won't always be with them, so we do that as well”.*

(N13, child health nurse: specialist service)

### 3.2 TIMELY INITIATION OF THE TRANSITION PLANNING PROCESS

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"> <li>1. Late identification of young people due to transition or late initiation of the transition process does not allow for sufficient planning</li> <li>2. Over-reliance on education to initiate the transition process can lead to late health referrals</li> <li>3. Where pathways exist, health professionals are resistant to taking responsibility for initiating the transition process</li> <li>4. Gaps in services and limited staff capacity act as barriers to undertaking proactive transition planning work</li> <li>5. No clear starting point and ad hoc transition processes, with timing often dependent on individual working practices</li> </ol>	<ol style="list-style-type: none"> <li>1. Children approaching transition are identified early through multiple identification routes</li> <li>2. Proactive procedures are in place for timely initiation of the health transition planning process</li> <li>3. *It is recognised that the transition planning process needs to be initiated earlier - around the age of 14 - for young people with complex learning disabilities who will require an ongoing input from multiple specialist services</li> <li>4. Health professionals accept responsibility for the initiation of the transition planning process</li> </ol> <p>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</p>

In many areas there were no proactive processes in place which would allow for early initiation of the transition planning process. Transition to adult services can be dependent on individual consultants, who often lack capacity for coordinated planning or apply the more traditional model of transition that does not allow for early planning:

*“the acute consultants, who may be condition-specific, have a more, I would say, the traditional model of transition. Okay, and as they approach 17 or 18 they start to think and then the start to think, who should I contact?”*

(N05, child health nurse: coordination/transition role)

There is over-reliance on school authorities for initiating transition, which is often education and social work-focussed, and can lead to the health element being overlooked or referrals made too late, not allowing for meaningful preparation. Some adult services were also perceived as difficult to engage with, to enable proactive planning, usually due to strict application of age criteria and capacity.

It is important that reliable identification processes are in place to allow early initiation of the transition planning process, which involves all aspect of transition, including health.

*“I think they actually need to say, okay, you’ve moved into first year of secondary school, let’s look ahead, let’s see what your end of school date is. Although that’s scary. Let’s keep everyone posted, and you know, let’s have a, you know, a yearly transition check-up”.* (Parent 08)

Nurses highlighted that even with transition pathways in place, a professional is required to take responsibility for initiating the process, avoiding unnecessary delays:

*“there is actually now a transition pathway in this health board but, again, it’s you still need the person to initiate it”.*  
(N02, child health nurse: community service)

#### TIMELY INITIATION OF THE TRANSITION PROCESS: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

Nurses were able to identify young people who would be due to transition through multiple identification routes, including clinical practice, joint working with education and social work colleagues or participation in meetings.

*“we would either, through our own health identification process, they can be identified through the additional support needs schools, where we have joint working, through their own transitional planning processes, from an education component and also they can be identified through social work services”.*

(N05, child health nurse: coordination/transition role)

This study revealed several examples of effective processes where nurses were involved in and which minimised the risk of young people being ‘missed’ and allowed for sufficiently early initiation of the transition planning process:

*“so, at the start of each calendar year, we get a list of all the children turning 14, and ensure that they’re in clinics, so they are going to get seen over the next 12 months”.*

(N07, child health nurse: community service)

*“there are multiagency groups set up to identify when young people are two years away from leaving school. And there’s a charter... there’s a transitions charter within this health board”.*

(N21, child health nurse: community service)

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Some nurses also initiated the transitions process by making appropriate referrals, liaising with families and other services and agencies, or prompting other healthcare professionals to begin planning:

*“I go along to clinic appointment in the last year of school and just support the family member or whoever is there and ask, you know, what is the plan for transition? It usually does prompt the consultants to think about it, because they don't always, some of them are thinking about it, but not all of them, and some like to keep them as well”.*

(N35, adult health nurse: transition role)

## PRINCIPLE 4: MULTI-AGENCY TRANSITION PLANNING

### 4.1 COLLABORATIVE WORKING ACROSS SERVICES AND AGENCIES

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"><li>1. Poor collaboration between agencies and services with disjointed transition processes and different age criteria</li><li>2. Families feel confused due to unreliable or conflicting information on the transition process and future care</li><li>3. Poor networks between child and adult health services, with limited knowledge of equivalent services and their referral pathways makes collaboration and early planning difficult</li><li>4. Education and social-work focussed transition processes, with health often not involved in the multi-disciplinary transition meetings</li><li>5. Parents are sometimes excluded from communication between services</li></ol>	<ol style="list-style-type: none"><li>1. *Planned multidisciplinary meetings with active involvement from education, social work and health representatives take place on a regular basis</li><li>2. *Parents are involved in multidisciplinary planning meetings with professionals working as a coordinated team</li><li>3. Health transition is recognised and fully integrated as a central element of the wider transition process by all agencies</li><li>4. Robust relationships between services and agencies are developed, with a better understanding of individual roles and services</li></ol> <p>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</p>

Health services continue to be overlooked in the wider transition process, which is often education and social work-led. Health professionals are often not invited to school reviews or lack capacity to attend, which results in a disjointed transition process. Nurses and families agreed that the transition should be planned through multidisciplinary meetings with active involvement from education, social work, health and families.

*“With the integration of health and social care it should be a joined-up approach. If there’s a multidisciplinary meeting and Angela has maybe various health problems if there’s a health professional at that meeting it helps the whole process”.*  
(Parent 03)

We also found evidence of some networking and collaboration between child and adult health services, with nurses and other health professionals having limited knowledge of equivalent services, their remit and roles and referral pathways.

*“there’s still that massive divide between paediatrics and adult and there’s that Grand Canyon of a gap between them linking in and knowing”.*  
(N04, child health nurse: specialist service)

This can create confusion and anxiety among families, who often receive incorrect or conflicting information and may be excluded from communication between services. It is crucial that both child and adult health services are engaged in establishing professional networks and information

sharing within their own specialties and beyond to ensure patients receive high quality care:

*“what has happened in the past is that I’ve went out full of motivation and met with a family and we’ve created a plan and then the next thing I see that they’ve been back to paediatrics twice and the paediatrics have maybe altered their medicines or things”.*  
(N20, adult health nurse: learning disability specialist service)

Limited capacity means that it can be difficult to coordinate meetings with all of the relevant professionals present, which is challenging for the more remote NHS Boards such as the Scottish islands:

*“you might find that your adult counterpart has got a clinic in one of the islands the day you have your transition clinic and your gastric counterpart is in another health board or whatever”.*  
(N13, child health nurse: specialist service)

### COLLABORATIVE WORKING ACROSS SERVICES AND AGENCIES: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

The findings highlighted the central role of nurses in collaborative working by attending multiagency meetings and liaising with other professionals. While the hospital

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consultant is often seen as responsible for transition planning, one epilepsy nurse highlighted how nurses often take the lead on the practical aspects of the process due to their close relationship with families, links to community services and more time to liaise with other professionals:

*“the one question that we asked is, well, yeah, he’s into an adult facility. What happens if he takes ill while he’s still under paediatric care? If an ambulance goes to that care home do they take him to adults, would they go to [adult hospital], or would he come to paediatrics? And of course, everybody goes, oh, never thought of that”.*

(N13, child health nurse: specialist service)

Nurses often acted as health representatives at school transition meetings and ensured the health needs of the young person were included in the planning process. They initiated collaborative working between services and agencies; for example, one children’s nurse initiated multidisciplinary meetings for one young person with 11 professionals involved in his care:

*“when I got that information that there’s all these people plus the parents saying how anxious they were, it was me that recommended the care co-ordination plan meeting in the first instance, just because of the numbers of people that were involved”.*

(N02, child health nurse: community service)

The data identified collaborations and networking across Scotland between child health and adult nurses, strengthening the links between two often separate professionals and highlighting the needs of young people who are preparing for transition. This was often facilitated by nurses in transition-specific roles, who could act as a single point of contact for transition-related questions.

*“the number of professionals in child health don’t know who to refer on to. They were unsure of what the learning disability service can do or offer. The pathway is one way to try and resolve that, for our child health colleagues to feel that there’s a service that they can refer to”.*

(N03, adult health nurse: transition role)

## 4.2 LEAD COORDINATOR

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"><li>1. <i>Disjointed transition process with no coordinator</i></li><li>2. <i>Finding a health professional willing to act as a lead transition coordinator for people with complex needs is challenging</i></li><li>3. <i>Capacity to take on a coordination role and attending school transition meetings</i></li><li>4. <i>Having a dedicated transition nurse can lead to other professionals becoming deskilled</i></li><li>5. <i>Coordination of the transition process is often assigned to consultants, who lack capacity and professional networks for coordinated planning</i></li><li>6. <i>Parents often feel responsible for ensuring the transition process is coordinated</i></li></ol>	<ol style="list-style-type: none"><li>1. <i>*Transition to adult services is coordinated by a named health care professional</i></li><li>2. <i>Nurses and other health care professionals recognise their role in the transition process and have capacity for meaningful involvement where appropriate</i></li><li>3. <i>*A lead coordinator provides a level of support to the family of the young person with learning disabilities</i></li></ol> <p><b>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</b></p>

There was a perception that health care professionals are resistant to acting as lead transition coordinators for people with complex learning disabilities, either because they lack capacity or do not see it as their role.

*“sometimes as soon as you mention complex needs it’s, oh, that’s nothing to do with me. You often get it, they stand back and say, oh, well, no, that’s not my responsibility. That should be so and so”.*

(N13, child health nurse: specialist service)

Nurses highlighted that the disjointed transition process led some parents to taking responsibility for ensuring it is coordinated and of good quality:

*“She actually gave up her work for the year before to concentrate on her daughter’s transition, so that she got it right”.*

(N35, adult health nurse: transition role)

Both nurses and families agreed on the positive impact of a named coordinator on the quality and experience of the transition process for families, the young person and professionals.

*“I think that would make that definitely better if there was somebody there to take the lead on how the... it would just be that they coordinate that. They would make the referrals where appropriate or contact whoever would be making the referrals”.*

(Parent 02)

However, nurses and families had different views on who should undertake this coordinating role. While some argued for a specific transition nurse role, others highlighted the importance of upskilling nurses and other professionals to coordinate transitions within the remit of their existing roles.

A transition nurse argued that her role could be dedicated to more complex transition cases, while the more straightforward transitions could be coordinated and facilitated by other nurses:

*“we need other people to be helping out with some of the more straightforward cases and then that would then free up my time to maybe deal with some of the more complex cases that maybe need to happen over a longer period of time. But we need other health professionals from children...from adult services to make it work”.*

(N03, adult health nurse: transition role)

*“we need more people that could be good at transitions”.*

(N21, child health nurse: community service)

### LEAD COORDINATOR: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

In some circumstances, nurses assumed a coordinator role and four NHS Boards had nurses in transition-specific roles to coordinate the process between services and agencies and act as a conduit for health-specific and other relevant information for the family and other professionals:

*“my role is really as the coordinator to coordinate between school, social services and consultants and the families to pull it all together to make sure that the families have as smooth a transition as possible to adult services from paediatrics and be the kind of focal point. Mainly for the family to come to me and say, what’s happening with social work? I’ve not heard anything”.*

(N35, adult health nurse: transition role)

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One of the transition-specific nurses was based in an integrated health and social work team and in one NHS Board, the adult learning disability team had a designated nurse who acted as a “lead person” for transition.

However, the data also revealed examples of specialist and other nurses taking ownership of coordinating aspects of the transition process:

*“the main driver [of transition] was the specialist ophthalmology nurse. She highlighted him. She knew about him. She phoned up. She made the referral. She’s like, this is what we do, how can we make this better? She co-ordinated the meeting with mum and invited the GP along”.*

(N32, adult health nurse: ID liaison)

## 4.3 ASSESSMENT & CARE PLANNING

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"> <li>1. Over reliance on school to coordinate the transition can lead to lack of health-specific assessments of needs</li> <li>2. Inappropriate assessment tools used for people with complex learning disabilities</li> <li>3. Learning disability and other diagnostic assessment not completed in a timely manner</li> <li>4. Lack of funding and appropriate post-school resources for young adults with complex learning disabilities</li> </ol>	<ol style="list-style-type: none"> <li>1. An appropriate holistic assessment of needs is undertaken at the point of transition, and used for care planning in adult services</li> <li>2. *The impact of the wider determinants of health are considered and mitigated</li> <li>3. *Regular multidisciplinary meetings focus on creating a written transition plan, including a detailed health plan, and identifying key professionals, with their roles and actions clearly documented</li> <li>4. All diagnostic assessments, for example to identify a learning disability are completed during the transition process to avoid delays in access to appropriate adult services</li> <li>5. Service development is undertaken to ensure the growing needs of people with learning disabilities are met in a person-centred way</li> <li>6. *Family carers are involved in the care planning process and reliably informed about viable options</li> </ol> <p><b>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</b></p>

Families and nurses felt that overreliance on schools for coordinating the transition process could lead to health needs being overlooked in the assessment process, including learning disability assessments. Furthermore, one carer highlighted existing health assessment as inappropriate for people with complex learning disability:

*“we filled out this horrendous document called the ‘21st century health check’. It was a complete waste of time, completely inappropriate. It was 98 pages long, things like, do you get breathless walking about outside, how many pints of alcohol do you drink a week, this sort of nonsense”.*  
(Parent 05)

Nurses and families agreed that a clear, detailed holistic assessment of needs, including health needs is crucial for future planning. The focus of regular multidisciplinary transition meetings to develop a written plan, including a detailed health care plan, and identifying key professionals accountable for taking actions forward. The impact of the wider determinants of health, such as lack of meaningful day activities, also needs to be recognised and mitigated.

*“I would want to see a health action plan as being part of a transition process, that’s the plan...and that would be, you know, subsumed within a bigger individual care planning”.*  
(N33, health and social care manager)

*“there needs to be, you know, up to date care plans put in place, and if they’re not up to date care plans, then people need to be accountable, you know, for it”.*  
(Parent 08)

There was an overwhelming perception that current care planning is more service-led than person-centred, with adult health services and many day centre and respite provisions not able to support or respond to the unique needs of young people with complex:

*“even though we’re supposed to be family centred not all services can work like that.... this girl that we know is... going to go to three hospitals for her adult life whereas.... up until this year she’s only been coming to the Children’s Hospital, to one place”.*  
(N27, child health nurse: liaison role)

Furthermore, families were seen as having to ‘fight’ or ‘push’ for services that they felt would best meet their child’s needs or higher number of support hours:

*“they had to really push for it and dig their heels in to get that. Then other families just say, right, we’ll just, we’ll go with that because they get fed up”.*  
(N35, adult health nurse: transition role)

It is crucial to acknowledge that existing adult services lack the capacity to meet the growing needs of the population of people with complex learning disabilities, and further development is essential to enable person-centred care. In the meantime, both families and nurses identified the need for transparency regarding available services and funding.

*I don’t like these secret meetings that go on, you know. I want to know what is being spoken about. I get that people have got budgets, I get that. But I want to actually go to that meeting... I just think, more openness. More openness, less secrecy.*  
(Parent 08)

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## ASSESSMENT AND CARE PLANNING: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

The findings highlighted the contributions of nurses in care planning, completing holistic needs assessments, including joint assessments with social work during the transition planning process. There were examples of nurses collaborating to collect up-to-date information required by the receiving services:

*“I’m going out with a joint visit, with a learning disability nurse to introduce them to the family and to do a combined healthcare assessment. It’s their template... I’m almost definite that the GP gets a copy of that”.*

(N05, child health nurse: coordination and transition role)

This included ensuring that the learning disability service’s assessment was in place before a young person with complex learning disabilities leaves school:

*“it means then that when it comes to planning, we know in advance that they meet the criteria for the Adult Learning Disability Service. It reduces waiting time to get other assessments from other disciplines so if the diagnosis can be confirmed in child services, then that would be fantastic”.*

(N03, adult health nurse: transition role)

It emerged that nurses and other health care professionals working in the Scottish Islands, with small populations in remote locations, were in a strong position to support person-centred care planning process with other members of the multi-disciplinary team:

*We’re a small team of the professionals that work here, and it’s very seldom that we have cases that are the same, so basically each one has to be person-centred and family-centred.*

(N26, other health care professional)

## 4.4 EMERGENCY CARE PLANNING

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"><li>1. No planning for emergency admissions to adult hospitals</li><li>2. Where available, inefficient processes referring to the Learning Disability Liaison Nurse in general hospitals</li><li>3. Young adults admitted to adult wards at a vulnerable time, without any support or history available to nurses and other health professionals</li></ol>	<ol style="list-style-type: none"><li>1. An emergency support plan is developed, appropriately recorded and disseminated during the transition process</li><li>2. Communication passport - or a similar document - is completed during the transition process</li><li>3. *Where available, people with complex learning disabilities and their families are introduced to a Learning Disability Liaison Nurse during the transition process</li></ol> <p>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</p>

Once in adult health services, young adult with complex learning disability lose their fast track and “open access” to the hospital wards and instead access emergency care through out-of-hours and Emergency Departments, where health professionals may lack knowledge of the individual and their health needs:

*“the parents often have to tell the same thing over and over again, the person has to wait and, before the age of 18, they would have been straight in and be seen and that can be quite difficult”.*

(N39, adult health nurse: learning disability service)

Currently, emergency admission plans are rarely developed. The young adult’s first encounter with an adult hospital may be when very unwell, putting them and their family in a vulnerable position. In some instances, families were of the view that the adult team lacked crucial information on their child’s complex needs and turned to their former child health services for advice and support:

*“the mum felt that she wasn’t listened to by the medical staff and mum had to persuade...it took a lot of persuasion for one of the paediatric doctors to come up to the ward to explain the child’s situation”.*

(N36, child health nurse: specialist service)

Developing an emergency support plan and summary documents should be one of the main priorities during the transition planning process to ensure that adult emergency services have access to information required for essential care delivery. Furthermore, families expressed the importance of having the opportunity to prepare the young person for any future admissions:

*“it should have been started earlier and in a slower way for someone of Hannah’s level of needs, who takes longer to get to know different people, who takes longer to know that we’re not going to be going to the Children’s Hospital. And even for us to*

*have visited once or twice when there was nothing wrong with her just to have gone in to have said to her, this is the hospital, if you are poorly we may have to come here, and this is one of the people that you may meet”.*

(Parent 09)

Where available, nurses and families also called for improved referral processes to Learning Disability Liaison Nurses to ensure families are not missed and left without support:

*“ideally what I would like is some sort of a meeting, three monthly, whatever, to give me a list of people that are coming through so that I can start to flag up their names to relevant people. So whether it be other specialist nurses or have a chat with the people, so that I can put alerts on the system even to say that they have a learning disability or that they need particular things”.*

(N17, adult health nurse: learning disability service)

### EMERGENCY CARE PLANNING: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

By collaborating, organising acute care planning meetings and sharing information through summary documents such as health passports and emergency care plans, nurses helped prepare general hospital professionals by ensuring that standard procedures and processes were adapted to meet the needs of young adults with complex learning disability:

*“we had one young person who had a respiratory problem and immune problem, and he went in regularly for medication to increase his immune system and also antibiotics to reduce the risk of infection but, out-with that, there would be an emergency call and an emergency support plan. That was one of the meetings that I did have with the acute staff, was to look at what we could put in that emergency support plan to try and reduce him having to go to accident and emergency”.*

(N39, adult health nurse: Learning Disabilities service)

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Nurses reported that having an emergency care plan or summary document and being introduced to a professional in the general hospital, such as a Learning Disability Liaison Nurse, reduced patient anxiety regarding transition and improved the quality of future emergency care:

*“the learning disability liaison nurses they have got a document called ‘My Important Health Information’. I would go out to the parents when they were getting discharged from the Children’s Hospital and get them to fill in this document with them. Type it up, send it to them. It’s then their responsibility to have that and I send that to learning disability liaison nurses at the hospital and I let the family member know who the nurse is for that hospital and say, this is who to contact if you’re having difficulties or need help”.*

(N35, adult health nurse: transition role)

In one NHS Board a nurse and her manager developed a hospital ‘admission pack’ for people with learning disability, which was completed as part of the transition process. It included a hospital passport and background health information, aimed at improving the admission experience in adult services:

*“we also have a personal belongings checklist which consists of things like hearing aids, spectacles, PEG feeds, built-up cutlery or any other adapted personal things that they require that they bring into hospital. Also, on that form we have a checklist to make sure the hospital passport is being utilised and we also check the legal frameworks are in place. We make sure there is a tick box for AWI<sup>1</sup> in place and one for a DNACPR<sup>2</sup>, if that’s in place”.*

(N38, adult health nurse: learning disability liaison)

<sup>1</sup>AWI – Adults with Incapacity Act (Scotland) 2000 is a legal framework for safeguarding the welfare and managing the finances of adults (people aged 16 or over) who lack capacity due to mental illness, intellectual disability, dementia or a related condition, or an inability to communicate.

<sup>2</sup>DNACPR - Do Not Attempt Cardio-pulmonary Resuscitation – The purpose of a DNACPR decision is to provide immediate guidance to those present (mostly healthcare professionals) on the best action to take (or not take) should the person suffer cardiac arrest or die suddenly.

## PRINCIPLE 5: CONTINUITY OF CARE IN ADULT SERVICES

### 5.1 COORDINATED HANDOVER OF CARE

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<ol style="list-style-type: none"><li>1. Lack of clear transition or referral pathway for people with complex needs</li><li>2. Challenges with finding equivalent adult services for certain aspects of care managements</li><li>3. Delayed or incomplete discharge from children's services</li><li>4. Poor communication and the transfer of information between services</li><li>5. Limited capacity and poor networks make organising joint transition clinics challenging</li><li>6. Families might lack trust or confidence in adult services to provide appropriate care</li><li>7. Lack of flexibility and coordinated planning can lead to young people being transitioned at the most vulnerable time</li></ol>	<ol style="list-style-type: none"><li>1. Processes are in place for efficient, comprehensive information sharing and handover between services, for example transition clinics and handover meetings</li><li>2. *Good quality, comprehensive written historical information is shared with adult services</li><li>3. *The transition plan is implemented and knowledgeable professionals facilitate building of trusting relationships with the adult healthcare professionals, including primary care</li><li>4. *Parents are copied into communications between services and regularly updated about the transition progress</li><li>5. *Families receive a contact list for key health professionals in adult services</li><li>6. *Young people are appropriately followed-up until the transition process is complete and adult healthcare is in place</li><li>7. *Transition decisions are made in a flexible, person-centred way, on a case-by-case basis with recognition of individual complex care needs</li></ol> <p><b>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</b></p>

Lack of transition pathways and clear referral routes and poor networks between child and adult health services were highlighted as important challenges to achieving a coordinated health transition:

*“we don't know who to pick up the phone to, you know. We don't have like a directory”.*  
(N27, child health nurse: liaison role)

Nurses and families agreed that a gradual handover of care from child to adult health services, where both services are actively engaged in joint transition meetings are crucial for people with complex learning disabilities. These could take form of regular transition clinics or ad-hoc meetings for specialties where regular clinics are not feasible:

*“doing a wee bit of joint work initially rather than just handing a person over in one appointment or one session. A few shared, joint appointments. Some kids are probably handed over quite quickly, some of them take a wee bit longer just depending on how complex they are”.*  
(N41, child health nurse: learning disability service)

Having an opportunity to meet and build trusting relationships with key professionals during the transition process, including the General Practitioner is important to

families and helps them develop confidence in the adult health system.

*“there's a certain point at which you reach where you don't want to see doctors all the time, and you know them sufficiently well. As long as you know.. it's nice to develop a relationship with them and get to meet them and for them to meet Andrew and to get to know what he's like. So you reach a point where I feel confident that one, I know who to contact if there's a problem”.* (Parent 07)

A particular challenge is young people who are not receiving active treatment for some of their health conditions and therefore do not meet the existing criteria for specialist input in adult services. They might not be transitioned to adult consultants and only become known to adult services in an emergency:

*“the other difficulty sometimes is when they have complex health needs but they're not actually receiving active treatment and the young person will be transitioned back to the GP which means that we sometimes don't know anything about them. So we'll find out when they arrive at our A&E department and usually in those cases there is very little health transition being done for that young person”.*  
(N32, adult health nurse: learning disability liaison)

There was a perception that some paediatricians ‘hold onto’ and delay the transition for young people with complex learning disabilities. In some cases, this is caused by professionals not being able to find an equivalent service to manage certain aspects of care. For instance, a community children’s nurse highlighted that district nurses are often not able to support the families with management of tracheostomies or feeding tubes.

*“we think we’ve transitioned somebody into the black hole so to speak because we haven’t actually really transitioned them to a person that’s equivalent... there’s not someone like fulfilling the role that we do, filling the gap so to speak”.*  
(N25, child health nurse: community service)

These are important challenges, which must be addressed in order to ensure young adults with complex learning disability continue receiving appropriate, high quality care and families have trust in the adult health service and do not continue relying on children’s services for advice.

*“in adults they use different medications than we do, so they’ve been in touch to ask, you know, what do you think, do you think this is appropriate. You’re like, well I can’t actually answer that, sorry”.* (N40, child health nurse: specialist service)

Families and nurses also emphasised the importance of excellent communication and information sharing between child and adult services as well as keeping families informed by coping them into relevant communications in order to avoid unnecessary confusion:

*“all of a sudden mum gets a letter in saying that she has to attend the adult hospital and there’s no information as to why she’s to attend or what he’s going there for so she just never kept the appointment”.*  
(N32, adult health nurse: learning disability liaison)

Furthermore, it should be communicated clearly to parents what their role in health management is after the transition:

*“say the paediatrician had just stopped seeing Angela when she was 18 and that was it. By now I’d be thinking, gosh, no-one’s checking her health. What...do I need to do something? But no-one told me. Maybe if the paediatrician said... or health professionals are saying, right, now it’s... you need to lead this”.*  
(Parent 03)

Transition should be a person-centred, flexible process where care planning decisions are made in view of the person with learning disabilities’ needs, such as current health status or most appropriate treatment plan and young people followed-up until all adult services are in place.

## **COORDINATED HANDOVER OF CARE: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE**

Many nurses were involved in transition clinics, including nurse-led clinics, and chaired ad-hoc transition meetings that involved professionals and parents. They provided the

opportunity for effective transfer of health information and an opportunity to ask questions and were viewed as helpful for reducing parents’ anxiety regarding the transition and future care:

*“for somebody quite complex with a lot of health issues then, yeah, we would do the transition clinic and that would give us a clear action plan for what all our roles are. So, it is a good way of getting people round the table and it kind of takes away from, I suppose, the more social aspect of some of the school transition meetings where health isn’t really discussed”.*  
(N39, adult health nurse: learning disability service)

Nurses helped ensure continuity of personal care needs for some young people with learning disabilities by acting as coordinators between child health and adult services. This was viewed as important as not all young people with learning disability required immediate access to general hospital services. Some nurses established contact and built relationships with adult health services to promote family confidence regarding future care arrangements:

*“we refer to the endoscopy nurse specialists, who meet with every young person at transition, not because they’re going to take over changing the buttons - gastrostomy tubes - but because then they have a point of contact, should there be an issue. And they don’t just do a phone contact, they actually meet the young persons, young adults at that point”.*  
(N07, child health nurse: community service)

Where available, families appreciated the input of transition nurses who were able to support families through the first appointments in adult health services:

*“I don’t think it would have been half as easy without the transition nurse, you would just have these appointments arriving, telling you to turn up at the health centre for your first vent team. You wouldn’t know who...quite what it was for or who it was. The transitions nurse was a really good resource”.*  
(Parent 07)

The data analysis identified examples of positive communication, with nurses sharing essential information about the young person and their family or even making arrangements for replication of care delivery. Nurses also played a central role in introducing good practice within services by developing standard handover summary templates. There were examples of nurses proactively providing transition follow-up to enable flexible, person-centred care thereby minimising the possibility of gaps in care. This could take form of continued appointments until an appointment in adult services was offered or arranging overlap of care:

*“we had a wee three-month overlap where paediatrics still remained involved but adult services were in charge of his care”.*  
(N32, adult health nurse: learning disability liaison)

## 5.2 ACCESS TO SERVICES AND QUALITY CARE

### AREAS OF FURTHER DEVELOPMENT

1. People with complex learning disabilities 'don't fit' the existing adult health care system
2. Young adults and their families experience a sudden drop in services despite the needs remaining the same
3. Families do not have a direct access to specialist advice, and the referral process is often time-consuming and causes delays
4. Nursing and other hospital staff do not have the knowledge or training of specific treatments or medical devices
5. Hospital staff lack capacity for high-level personal care
6. Learning Disability Liaison Nurses are not always alerted to hospital admissions of people with learning disabilities

Nurses and families agreed that the adult health services remain largely unprepared to meet the changing needs and service requirements of people with complex learning disabilities. It is crucial that services are adapted to ensure a high standard of person-centred care is consistently maintained:

*“the system fitting people rather than people fitting the system”.*

(N32, adult health nurse: learning disability liaison)

People with complex learning disabilities can experience multiple access barriers in adult services, including lack of local services and having to use tertiary care, strict referral criteria affecting eligibility for support and delaying access, and losing open access to hospital wards. As soon as they reach adulthood, they experience a sudden decrease in services such as physiotherapy, occupational therapy, specialist services as well as respite and day care opportunities despite their needs remaining the same. Some services, including nursing posts, are not replicated in adult services, further limiting the young adult's healthcare support network and access to preventative care.

*“we've got a community children's nursing team and an advanced nurse practitioner. If a child becomes unwell at home on their caseload, then they'll go out and visit. They will try to support. They'll try to prevent a hospital admission. I'm not quite sure whether that's replicated in adult services”.*

(N21, child health nurse: community service)

In some cases, young adults have no access to appropriate or preferred accommodation options, such as own tenancy

### INTENDED OUTCOMES

1. \*Individuals with complex learning disabilities are able to access quality services and care that meet their individual needs
2. \*General hospitals have knowledge of and are able to meet the needs of people with complex learning disabilities through necessary adaptations – both for planned and unplanned admissions
3. Communication resource packs and easy read information are available
4. \*Where available, individuals with complex learning disabilities are automatically referred to Learning Disability Liaison Nurses when admitted to hospital
5. \*Parents are able to access services for their children and are confident that they are going to receive the best quality care

**\*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS**

or even unable to return home from the hospital due to barriers related to funding and staff training:

*“she's taken quite poorly recently and landed in hospital and it's...looked like she won't come out of hospital. And there's no facilities going to be put in place to get her home, which is really, really sad 'cause this mum is desperate to get her home. Because she's ventilated now, it's...they don't think there is adequate money to train somebody, get somebody to take her”.*

(N23, health and social care manager)

Insufficient training and lack of facilities can reduce the availability and quality of care young adult with complex learning disability receive in adult services, including premature hospital discharge without aftercare:

*“once he was extubated straight home, because the ward just couldn't cope with him because he would be out of the bed. So, he gets discharged from ITU. No aftercare really in the hospital, like what he got at the Children's Hospital”.*

(N35, adult health nurse: transition role)

Nurses and families also highlighted that in some cases adult health professionals are unfamiliar with technologies and health equipment that young adults with complex learning disability rely upon, such as established tracheostomies or PEG equipment.

*“one mum, for instance, she had been in with her son and he was PEG fed and she was going to go home for a rest, and the nurse...she said the nurse said to me, but who is going to do his feed? The mum said, you. Oh, but I don't know how to do that, you will need to stay and do that”.*

(N35, adult health nurse: transition role)

Training to raise awareness of the Learning Disability Liaison Nursing Service, where available is paramount for ensuring the needs of people with complex learning disabilities are considered and reasonable adjustments in place where required.

*“I just want Stuart to be safe, that’s all. I just want them to be able to show me, and show Stuart, that they can have an understanding. And they’re happy to wait, and listen, and get to know him”.*

(Parent 08)

Development of new services should also be considered, such as an adult equivalent to ‘Children with Exceptional Healthcare Needs’ (CEN) and palliative services for young adults with complex needs to respond to the needs of this growing population.

*“so for the children that I’m talking about, palliative care, they need to transition to people who are very knowledgeable about symptom management and taking a family towards end of life care and planning for things like that”.*

(N19, child health nurse: community service)

## **ACCESS TO SERVICES AND QUALITY CARE: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE**

Nurses were found to make significant contributions to improving access to adult health services, such as general hospital care. Learning Disability Liaison Nurses, who are in post in most NHS Boards across Scotland, played important roles in coordinating planned and unplanned hospital admissions by undertaking assessments of needs, arranging adaptations and reasonable adjustments during admission and by providing emotional and practical support to the young adult with learning disabilities, their family and colleagues in general hospitals.

*“I do a little admission plan form. Again, it’s looking at all those complex needs. They perhaps have a PEG, nutritional needs, different things like that. I take all my information and I meet either with the nurse in charge of the ward or the nurse practitioner for that ward and I’ll say to them, this lady or gentleman’s coming in, these are the highlighted issues. This is what needs to be in place for this person and that’s the communication that I’ve had”.*

(N24, adult health nurse: learning disability liaison)

A day surgery unit manager evidenced how services can evolve and adapt to providing high quality, person-centred care by reflecting on the specific needs of people with learning disability and adapting existing processes that eventually became ‘common practice’:

*“we have dedicated theatre lists for patients with learning difficulties. We have a specialised form that we ask certain questions of patients with a learning difficulty so that we can ascertain what we can put in place to make it as easy as we can for them. We also would make arrangements, if it would help*

*them, to have a look round the department before they came. I think it’s common practice with us here now, so anyone that comes here to work, they just watch and learn”.*

(N37, health and social care manager)

Families also gave examples of excellent support provided by nurses, such as acting as points of contact for easy access to specialist services or arranging reasonable adjustments during hospital admissions. Nurses were also found to advocate for the young adult with complex learning disabilities and their families to ensure they receive person-centred care:

*“the paediatrician in the paediatric ward who was actually saying that he should be in the orthopaedic ward and the consultant was saying he should be in the paediatric ward. Anyway in amongst all this I just went to the ward and said, I think you’re forgetting one thing, we’ve got a person here. We’ve got a young man here. Where do you think he would feel comfortable?”*

(N24, adult health nurse: learning disability liaison)

In some areas, nurses led on the development of new roles aimed at responding to the growing complexity of care needs of some young adults with learning disability:

*“this adult learning disability epilepsy service didn’t exist and he - epilepsy nurse - saw the need for it, the niche for it, and built it from there and I joined him because the caseload was too big basically. There were too many people with increasingly complicated epilepsy and increasingly complicated needs that overlapped into their epilepsy management”.*

(N20, adult health nurse: learning disability specialist service)

## 5.3 HOLISTIC OVERVIEW IN ADULT SERVICES

AREAS OF FURTHER DEVELOPMENT	INTENDED OUTCOMES
<p>1. A different approach in adult services means that care is disjointed among multiple specialists rather than coordinated by one paediatrician</p> <p>2. There are no clear mechanisms for holistic health reviews or monitoring of existing, well-controlled health conditions</p> <p>3. General practitioners are not confident in coordinating care to people with complex learning disabilities</p>	<p>1. *A lead consultant and health coordinator is identified in adult health services to coordinate care for the individual with complex learning disabilities</p> <p>2. *Families have a named nurse or other health professional in adult services to contact for support and advice</p> <p>3. *People with learning disabilities are invited to regular, holistic health reviews and mechanisms are in place for routine monitoring of health conditions</p> <p>4. *People with learning disabilities and their families have a good relationship with their primary care services</p> <p>5. *General practitioners are confident in providing care to patients with complex learning disabilities</p> <p><b>*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS</b></p>

A transition challenge for people with complex learning disability is that as they enter adult health care system, they lose the coordinating paediatrician and can receive disjointed care from multiple specialists:

*“if a parent comes in to an X clinic, that “ologist”, will see that X part of the child. They then have to go to Y clinic, and they’ll see that leg, and the next clinic will see that heart, and the next clinic will see that other bit, and they don’t marry together so well, because their numbers are just huge”.*

(N12, child health nurse: specialist service)

With some NHS consultants lacking capacity to take on a coordinating role, it is often assumed that the general practitioners take on the responsibility of the overall lead role. However, nurses highlighted that some general practitioners may not be familiar with and confident in assuming that role for people with complex learning disability. Nurses and families identified the need to provide further education and training for GPs to provide care to people with complex learning disabilities and developing relationships with families while still in child health services:

*“I think if we encouraged families more, from the very beginning, to be going to their GP with routine coughs and colds, sore throats, spots, you know, skin lesions, concerns of any kind, then I think the GPs would become more confident at seeing them”.*

(N01, child health nurse: specialist service)

Both nurses and families felt that given the multiple complexities experienced by people with learning disabilities, there could be opportunities for having a coordinating physician or Advanced Nurse Practitioner role in the adult health services who would be able to approach their needs more holistically. From the families’ perspective, having a point of contact in adult health services, such as a named consultant or a named nurse, would make a difference to their experience:

*“if we’d had a named consultant, or a named physiotherapist, or a named nurse, something like that, who could have got to know Hannah very slightly, not in any great detail, it takes a long time to get to know Hannah in a great detail, but one person who was aware of Hannah coming into the adult world then that would have been a start”.*

(Parent 09)

Mechanisms should also be put in place to ensure that people with learning disabilities continue to receive regular, holistic health checks and their existing, well-managed conditions are monitored:

*“there may be things, even as a parent, that you don’t see because you’re spending time with someone every single day and it can be early intervention... even if it was once a year, there’s a regular health check by a professional who maybe knows them”.*

(Parent 03)

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## HOLISTIC OVERVIEW IN ADULT SERVICES: THE ROLE OF NURSES AND EXAMPLES BEST PRACTICE

The findings highlighted that nurses were in a position to counteract the sense of disjointed care in adult services following discharge from a paediatrician in child health services, thereby building and strengthening relationships with primary care:

*“within each of the GP practices in this area, they have an enhanced service for people with learning disabilities and my role is to update the enhanced service register. So, anybody that is coming of age, so people that are 16 and above they would be put onto the register and that would then invite them along for a tri-annual health check”.*

(N08, adult health nurse: learning disability liaison)

Learning disability-trained nurses, such as learning disability epilepsy and Learning Disability Liaison Nurse was highlighted as adopting a holistic approach to an individual's complex needs by supporting communication and information sharing between child health, primary care and general hospitals:

*“I’ll maybe ask the consultant to contact the paediatrician that was involved with that person to gather more information or contact the GP as well. Sometimes they need to speak to each other because they very much concentrate on, this person’s come in with chest sepsis, that’s what we look at, that’s what we’ll do. They don’t look at the person. They don’t look at their needs outwith their actual condition of being actually admitted with”.*

(N24, adult health nurse: learning disability liaison)

In one NHS Board, a newly appointed Learning Disability Nurse was also responsible for ensuring that people with learning disability receive regular annual health checks:

*“a key part of that is developing individualised health action plans as a consequence of that process. So, these are plans that are ongoing, individualised but also make reference to best practice with regard to specific areas of the need in relation to learning disabilities”.*

(N33, health and social care manager)

## 5.4 FAMILIES AS EQUAL PARTNERS IN CARE

### AREAS OF FURTHER DEVELOPMENT

1. Families either feel dismissed when trying to provide important information on their child's care needs or services over-rely on their knowledge
2. Families are expected to provide unrealistic level of day-to-day care when the person with learning disability is admitted to hospital

Nurses and carers highlighted that parents can often feel excluded and dismissed, particularly in emergency situations when trying to communicate key information about their child's needs or best course of treatment based on the previous experience:

*“mum was clearly telling the medical staff what was going on and how to resolve it and was clearly not being listened to. In her own words is what she did in the end, was ‘lost the plot’. She had to scream and shout and stamp her feet and demand that somebody go and get someone from paediatrics which is what they did do. Then they came in and they basically gave the same information that mum had been providing but wasn't being taken on board”.*

(N42, adult health nurse: learning disability liaison)

It is of paramount importance that adult health care professionals recognise the families' expertise in their children's needs. Parents of young adults with complex care conditions must be actively involved throughout the care episode and their knowledge of effective course of treatment needs to be considered alongside clinical pathways.

*“it's getting medical staff to follow that guideline that mum knows and not just looking at the clinical signs”.*

(N42, adult health nurse: learning disability liaison)

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. Parents and families of people with complex learning disabilities have to be recognised as equal partners in care, who provide vital, unpaid support to the adult health service. By taking responsibility for most of the day-to-day caregiving while their child is in hospital, parents provide care which is usually undertaken by nurses in child health services. This change following transition to adult services cannot be underestimated, with families routinely expected to provide a significant amount of care:

*“parents are expected to do absolutely everything. And they could be on their absolute knees because they've had days and days of a child being unwell before they'd admitted and then they go in to the hospital and they still have to crack on and do things, you know”.* (N22, child health nurse: respite)

### INTENDED OUTCOMES

1. \*A family-centred approach is adopted and carers are recognised as equal partners in adult health care
2. \*The wellbeing of family carers is considered and a level of support is available when the person with learning disability is admitted to hospital

\*PERSON AND FAMILY-CENTRED OUTCOMES HIGHLIGHTED BY CARERS

Without appropriate support, these aging parents might become unable to care for their child:

*“they need to be family centred because if the parents for example aren't being heard, aren't being supported, then they're less... they may be less able to care for the person”.* (Parent 03)

### FAMILIES AS EQUAL PARTNERS IN CARE: THE ROLE OF NURSES AND EXAMPLES OF BEST PRACTICE

Nurses were often at the forefront of leading family-centred practice, ensuring families continued to be involved throughout the transition process and beyond:

*“oh, family is massive. The first thing that I started doing when I took this post up was to meet families prior to individuals coming in for procedures. It's just that bit more personal, bit more reassuring. You're meeting them in their own home so everything is a bit more relaxed, questions are more likely to come to mind quickly rather than sitting in a strange pressurised environment so I promote family involvement at all stages”.*

(N38, adult health nurse: learning disability liaison)

*“everything we do is agreed with the parents. The care plan's agreed with the parents. The package of care is agreed with the parents. We've got various different agreements and they're the experts in their child. They know”.*

(N31, health and social care manager)

A Day Surgery Unit Manager emphasised the importance of involving parents in care and treating them as a resource to inform the provision of the best care and ensuring they do not cause avoidable distress and anxiety for the young people with learning disability:

*“with the patients with learning difficulties or the vulnerable patient, we make sure that the family stays here and feels supported by us and feels near to their relative”.*

(N37, health and social care manager)

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One carer highlighted excellent care provided by nurses during her child's first admission to adult hospital, who also ensured that the mother was able to return home for a rest:

*"I was sufficiently close to the hospital, a ten-minute drive, and they were going to take good care of him, that I felt that I could leave him".*

(Parent 07)

Carers also gave examples of instances where their expert knowledge of their child was recognised either in hospital settings or everyday health management:

*"we sometimes just need that instant access to the doctor to say, look, this is happening, do you think we should increase this drug, because we know there's parameters within certain meds. The doctor will say, right, I would like you to do this, and I'm going to send you an appointment for three weeks' time, and then we'll review how it's going, rather than you go for the meeting and then you've got to make a change, and then you still don't know if it's going to work. So all of the doctors agreed that I can contact them. I've had to use that last year. So that was all very positive".*

(Parent 05)

## IMPROVING THE TRANSITION EXPERIENCE: WHAT NEEDS TO HAPPEN

The transition needs of young people with complex learning disabilities are not currently widely reflected in policy. The strategic level focus on transition is inconsistent across NHS Boards in Scotland and nurses were found to show a lot of initiative to improve the transition experiences and outcomes for young people with complex learning disabilities and their families. Development of clear transition policies which define responsibilities with recognition of the complex, multidimensional nature of transition and reflect existing guidelines and recommendations should be a priority (NICE, 2016; ARC, 2017). These should include joint transition policies focusing on collaboration between health, social work and education.

Such focus on transition should also be incorporated into nurse education both at pre-registration level and as part of a continuous professional development to enable better understanding of the challenges and responses and the contributions required from nurses.

Nurses and families provided a multitude of recommendations for improving the transition process itself, including examples of how nurses are already making an impact through good practice.

It is crucial that effective transition processes and pathways are developed, which also take account of transition between NHS Board areas. Early, proactive transition preparation with active involvement from the young person and their family is likely to reduce the feelings of anxiety and uncertainty. Nurses have a significant role to play in capacity building for the young person and their family by providing information about future services and care, supporting decision-making and developing skills to navigate the adult health care system (Joly, 2015).

The findings from this study also revealed nurses' central role in initiating the transition planning process and collaborative working with other services and agencies. In some health board areas, nurses in specific transition-related roles such as Transition Nurses or Facilitators acted as transition coordinators. By taking a leading role in facilitating the handover of care to adult services, they ensured that appropriate processes are followed and the needs of the young person and their family are considered. Betz and Redcay (2005) argued for the benefits of a 'transition services coordinator' as an advanced practice role for nurses, who could provide leadership, promote change, educate and acts as clinical experts and consultants.

By adopting a person-and-family-centred approach, such roles are suggested to bridge the gap between child and adult health services (Davies et al., 2011). A recent review of evidence by the Scottish Parliament (Hall, 2019) recommended dedicated transition roles to improve the transition process and the current study confirms their

potential value. Where available, both nurses and families in this study perceived them as instrumental to developing and implementing transition pathways, supporting collaborative working and communication between services and agencies. However, strong support at an organisational level as well as dedicated funding are necessary to ensure its long-term effectiveness and sustainability.

The findings from this study also revealed that nurses are already making significant contributions to assessment of needs and care planning, which are crucial not only for effective transition but also family satisfaction (Davies et al., 2011; Bindels-de Heus et al., 2013; Bhaumik et al., 2011; Woodward et al., 2012; Kuchenbuch et al., 2013). However, nurses' impact extends beyond the transition process, where they were found to play a significant role in improving access to adult health services and ensure holistic overview of the individual with learning disabilities and their families' needs. For instance, Learning Disability Liaison Nurses were found to coordinate care and ensure reasonable adjustments are in place in general hospitals, which mirror previous research on their role (MacArthur et al., 2015; Brown et al., 2016). There is also an opportunity to developed Advanced Nurse Practitioner roles, with the knowledge and skills in health assessment, diagnostics and prescribing.

Nurses can act as advocates for the young adult with complex learning disabilities and their families and ensure that parents are at the centre of care and decision-making in the adult health system.

**For further information on Phase 2, refer to:**

**Brown, M., Higgins, A., & MacArthur, J. (2020).  
Transition from child to adult health services:  
A qualitative study of the views and experiences  
of families of young adults with intellectual  
disabilities. *Journal of Clinical Nursing*,  
29(1-2), 195-207.**

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## PHASE 3: DEVELOPMENT AND PILOTING OF AN EDUCATIONAL RESOURCE



# Aims & Methods

The findings from the first two phases of this study identified implications for nurses' education, both at the undergraduate level and as part of continued professional development. It has highlighted the need to raise awareness of the unique, complex needs of people with learning disabilities as well as the importance of a well-managed transition to adult services to avoid negative outcomes for both the person with the learning disability and their families.

Phase 3 of this project attempted to address this need, with the following aim:

- *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*

## DEVELOPMENT OF THE EDUCATIONAL RESOURCE

The development of the content of the resource was guided by the findings from Phases 1 and 2 of the study, from which key areas deemed most relevant to nurses were identified.

The aim of the resource was to enhance the knowledge and awareness of effective transition from paediatric to adult health services for young adults with learning disabilities and the contributions required from nurses to enable and facilitate that process. The resource, entitled 'Transitions from child to adult healthcare for young adults with learning disabilities', was divided into four units of learning, which formed the learning objectives:

**Unit 1** looked at multiple morbidities and health inequalities experienced by people with learning disabilities.

**Unit 2** introduced the concept of transition and existing principles of effective transitions from NICE guidelines and the Scottish Transition Forum.

**Unit 3** focused on the needs of young people with learning disabilities and their families during the transition process and beyond. We focussed on five main principles of effective transition, looking at why they are important and examples of good practice for each. These 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** looked at the welfare and legal system changes relevant to transition.

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



#### CASE STUDY

Sarah is a 15-year-old who lives at home with her parents and two younger brothers. She has a rare genetic condition that has resulted in a range of complex health issues and has severe learning disability. Sarah is visually impaired, has epilepsy and a chronic kidney disease. She has an established tracheostomy and a gastrostomy tube which is used for administering all her nutrition and over 20 doses of daily medication.

The monitoring of Sarah's conditions is coordinated by her paediatrician but she is also under the care of many specialist paediatric services including: a neurologist and an epilepsy nurse specialist, a gastroenterologist, a respiratory nurse specialist, a nephrologist, a physiotherapist and a speech and language therapist. Sarah also has a community children's nurse who coordinates her medical supplies and provides ongoing assessment and support in her home.

Sarah uses an adapted wheelchair and needs to be moved with a hoist. Sarah is a sociable, content young girl who is non-verbal but is able to communicate in her own way.

1. What is your role in supporting transition from paediatric to adult health services for a person with learning disabilities and complex needs like Sarah?

### UNIT 4: Welfare and legal system changes relevant to transition

Legal changes relating to consent and decision-making are an important aspect of transition to adulthood. These changes have particular implications for people with learning disabilities, who might not be able to make independent decisions and could require a welfare guardian.

#### WELFARE GUARDIANSHIP

Under Scottish law, young people can make independent decisions from the age of 16 and do not require parental consent. The Adults with Incapacity (Scotland) Act 2000 legislation provides a legal framework to safeguard the welfare and manage the finances of adults, aged 16 and over, who lack capacity due to mental illness, learning disability or due to an inability to communicate.

If an adult is unable to make decisions or safeguard their own welfare, specific legal powers can be sought, termed a "welfare guardian". Welfare guardians, who are usually a parent, family member or social worker, is legally allowed to make decisions about the individual, in areas such as, financial decisions and health care. If such powers are not held, only the young adult can, in law, make decisions about their welfare, including healthcare.

For more information about Adults with Incapacity (Scotland) Act 2000 and welfare guardians, please visit:

<https://www.legislation.gov.uk/asp/2000/4/contents>

<https://www.mwscot.org.uk/the-law/adults-with-incapacity-act/welfare-guardianship/>

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### UNIT 3: Principle 1: Early transition preparation

**Why is it important?** The transition into adulthood can be a highly emotional experience for young adults with learning disabilities, their families and those involved in their care and support. It is therefore important to introduce the concept at an early stage to allow the young adult, their family and carers to familiarise themselves with the future changes that can evoke a sense of loss, vulnerability, abandonment by trusted professionals, as well as fear of the unknown. In the words of one parent involved in the Scotland-wide research, transition to adult health services can feel like "taking a rug and just putting it out".

#### Good practice

- Preparation for transition starts around the age of 14 years, with introduction of the concept to families and carers and the young person and providing information about the future services and care.
- Transition is recognised as a highly emotional experience.
- Families are able to ask questions about the transition process and what is involved and receive support to access information about adult health services.

1. What can you do in your nursing role to enable young adults with learning disabilities and their families minimise their feelings of loss, vulnerability, abandonment and fear of the unknown?

0 / 2000

Figure 4: Sample pages of the online educational resource

Through extensive discussions among the research team members, it was decided to incorporate three main features into the design of the resource:

1. *Reflective questions in each unit to give nurses an opportunity to reflect on their existing practice in relation to transition*
2. *A case study to help nurses consider the needs, services requirements and challenges experience by people with complex learning disabilities and their families*
3. *Links to external resources that could be followed up on for more information*

The survey was designed using an online software Novi Survey supported by Edinburgh Napier University, which enables development and management of online surveys. Figure 4 shows sample pages from the online educational resource.

## EVALUATION METHODS AND PARTICIPANTS

The aim of this pilot was to test the feasibility and acceptability of the online educational resource developed by the research team. The evaluation, included at the end of the learning units sought feedback on three main areas:

1. *The overall perception of the resource: length, the case study, visual presentation*
2. *General satisfaction and learning outcomes: were they achieved? Was the information at the right level in relation to nurses' existing knowledge? The areas, where they developed new knowledge or their knowledge was enhanced, units that were most helpful and which require further development*
3. *Application to clinical practice: was the content relevant to everyday practice, perception of the reflective questions*

Participants were also given an opportunity to provide further feedback in a short telephone interview.

Local contacts were used to recruit 12 nurses who in the last two years were involved in care of a patient with a complex learning disability who transitioned from child to adult health services. In total, 12 nurses from two NHS Boards in Scotland took part in the evaluation of the educational resource (Table 8).

## DEMOGRAPHIC PROFILE

NHS BOARD	<ul style="list-style-type: none"> <li>● NHS Lothian n=9</li> <li>● NHS Ayrshire &amp; Arran n=3</li> </ul>
AREA OF PRACTICE	<ul style="list-style-type: none"> <li>● Children Services n=5</li> <li>● Adult services n=7</li> </ul>
NURSING ROLE	<ul style="list-style-type: none"> <li>● Learning Disability - complex needs n=2</li> <li>● Neurosurgery n=2</li> <li>● Epilepsy n=3</li> <li>● Diabetes n=1</li> <li>● Community Children's Nursing n=2</li> <li>● District Nursing n=2</li> </ul>
GENDER	<ul style="list-style-type: none"> <li>● Female n=10</li> <li>● Male n=2</li> </ul>
TIME IN CURRENT ROLE	<ul style="list-style-type: none"> <li>● 1-3 years n=6</li> <li>● 7-8 years n=3</li> <li>● 16-21 years n=3</li> </ul>
WORKING HOURS	<ul style="list-style-type: none"> <li>● Full time n=10</li> <li>● Part-time n=2</li> </ul>

**Table 8:** Demographic profile of Phase 3 nurse participants

Nurses had a varied experience of planning and facilitating transition from child to adult health services (Table 9) – from under 5 times to over 30 times in the last two years. They mostly reported fewer than 5 patients with learning disabilities who transitioned in the previous 2 years.

NUMBER OF TIMES INVOLVED IN TRANSITION PLANNING OR FACILITATION IN THE LAST 2 YEARS	ESTIMATED NUMBER OF PATIENTS WITH LEARNING DISABILITIES ON CASE LOAD EVERY YEAR	NUMBER OF CASELOAD PATIENTS WITH LD WHO TRANSITIONED IN THE LAST 2 YEARS
<ul style="list-style-type: none"> <li>• Under 5 times: n=4</li> <li>• 5-10 times: n=4</li> <li>• 11-20 times: n=1</li> <li>• 21-30 times: n=3</li> </ul>	<ul style="list-style-type: none"> <li>• 1-10 times: n=5</li> <li>• 20-30 times n=4</li> <li>• Over 80 times n=3</li> </ul>	<ul style="list-style-type: none"> <li>• Under 5 times n=8</li> <li>• 5-10 times n=2</li> <li>• 11-20 times n=1</li> <li>• Over 20: times: n=1</li> </ul>

Table 9: Nurse participants' experience of transition planning and facilitation

## WHAT DID WE FIND? PILOTING OF THE EDUCATION RESOURCE

### OVERALL PERCEPTION

In terms of the overall perception of the resource, the majority of the nurses provided positive feedback, where they felt it was engaging and easy to use and felt the use of a case study and external links were helpful. The exception was the perception of the length of the resource, where half of the participants felt it was too long and repetitive. Other feedback for further improvement concerned visual presentation, with better division of individual sections and including more pictures and diagrams as well as ensuring that the external links are not too 'heavy duty' and including links to other examples of good transition practice.

	POSITIVE FEEDBACK	REQUIRES IMPROVEMENT
RESOURCE LENGTH	<ul style="list-style-type: none"> <li>• About right: n=6</li> </ul>	<ul style="list-style-type: none"> <li>• Too long: n=6</li> </ul>
THE USE OF A CASE STUDY	<ul style="list-style-type: none"> <li>• Helpful: n=11</li> </ul>	<ul style="list-style-type: none"> <li>• Not helpful: n=1</li> </ul>
VISUAL PRESENTATION	<ul style="list-style-type: none"> <li>• Engaging and easy to use: n=8</li> </ul>	<ul style="list-style-type: none"> <li>• Improvements needed: n=4</li> </ul>
EXTERNAL LINKS	<ul style="list-style-type: none"> <li>• helpful / quite helpful and likely to follow up on them n=8</li> </ul>	<ul style="list-style-type: none"> <li>• Unsure: n=4</li> </ul>

Table 10: Nurse participants' overall perception of the educational resource

## SATISFACTION AND LEARNING OUTCOMES

In terms of satisfaction and learning outcomes, the opinion was divided but 7 out of 12 nurses felt the level of the resource was 'about right' in relation to their existing knowledge and they mostly achieved the learning outcomes. For those that were unsure, they felt that the learning outcomes were not explained clearly enough.

	POSITIVE FEEDBACK	REQUIRES IMPROVEMENT
RESOURCE LEVEL IN RELATION TO EXISTING KNOWLEDGE	<ul style="list-style-type: none"> <li>About right: n=7</li> </ul>	<ul style="list-style-type: none"> <li>Too basic: n=5</li> </ul>
LEARNING OUTCOMES	<ul style="list-style-type: none"> <li>Fully / mostly achieved: n= 7</li> </ul>	<ul style="list-style-type: none"> <li>Unsure if achieved: n=5</li> </ul>

**Table 11:** Nurse participants' satisfaction with the learning resource and learning outcomes

According to nurses, the units that were most helpful to develop their knowledge of transitions included:

**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)

**Unit 4: Welfare and legal system changes relevant to transition** (n=5)

One nurse felt that all units were equally helpful (n=1) and answers from three nurses were missing. One nurse reported two units as most helpful so the total number of answers equals 13.

When asked to list three areas where their knowledge of transition to adult services for people with learning disability was developed or enhanced, eight nurses quoted the legal aspects of transition. This suggests a significant gap in nurses' existing knowledge and a clear training need. Other areas of learning included the importance of a formalised pathway, the needs of the young adults and their families, the role of nurses in transition, emergency care planning and reasonable adjustments and other (Table 12).

### AREAS OF NEW LEARNING AND ENHANCED AWARENESS:

1. Legal aspects of transition: n=8
2. The importance of a formalised transition pathway: n=3
3. The role of the family: n=3
4. The role of nurses and other professionals in transition: n=2
5. The needs of young adults with learning disabilities: n=2
6. Emergency care planning: n=2
7. Reasonable adjustments: n=1
8. The meaning / definition of transition: n=1
9. Health passports: n=1
10. Stresses associated with transition: n=1

**Table 12:** Areas of new learning and enhanced awareness identified by the nurse participants as a result of completing the learning resource

## APPLICATION TO CLINICAL PRACTICE

Six nurses were of the view that the resource was relevant and applicable to their everyday nursing practice, they found the reflective questions helpful. However, six participants were unsure about the applicability of the resource to their role and felt the reflective questions were repetitive, too generic and not based on the case study.

*'it gets you to reflect on what you're doing, why and can you do it better'* (P11)

	POSITIVE FEEDBACK	REQUIRES IMPROVEMENT
CONTENT RELEVANT AND APPLICABLE TO NURSING PRACTICE	<ul style="list-style-type: none"> <li>• Yes: n=6</li> </ul>	<ul style="list-style-type: none"> <li>• Somewhat: n=4</li> <li>• Unsure: n=2</li> </ul>
REFLECTIVE QUESTIONS	<ul style="list-style-type: none"> <li>• Helpful / very helpful: n=8</li> </ul>	<ul style="list-style-type: none"> <li>• Not helpful / unsure: n=4</li> </ul>

**Table 13:** Nurse feedback on the educational resource's application to clinical practice

## QUALITATIVE INTERVIEWS

Of the 12 nurses, initially six agreed to participate in a telephone interview with three nurses responding to a follow-up invitation and were subsequently interviewed.

The nurses liked that the resource provided a good overview of the main issues related to transition and that it was suitable for nurses at different levels – either as part of new learning or as a refresher. They felt it raised their awareness of the needs of people with complex learning disabilities and their families.

Nurses also offered some suggestions for how to improve the resource, and that included: improving the reflective questions so they do not feel repetitive and providing clearer instructions on how to use them. They also suggested making the learning outcomes clearer and more explicitly dividing the teaching / learning sections from the reflective sections.

### Positive Feedback:

1. *A good overview of main issues*
2. *Suitable for nurses at different levels*
3. *Raised awareness of the needs of people with complex needs and their parents*

### Requires Development:

1. *Reflective questions repetitive and lack of clarity on how to use them*
2. *Expectations and learning outcomes not explained clearly enough*
3. *No clear division between teaching and reflective questions*

## ADAPTATIONS TO THE LEARNING RESOURCE

The feedback from the piloting of the resource suggested that it is helpful relevant to their practice, facilitating reflection on their role in the transition process.

Apart from positive feedback on the educational resource, nurse participants also provided suggestions for improving the resource. This included better division of teaching and learning and reflective questions, ensuring units and questions are not repetitive, better explanation of how the resource should be used and the learning outcomes. The learning resource was comprehensively revised to reflect these suggestions and recommendations and the new version is included in this report (Appendix 1). The main changes related to the reflective questions, which were condensed and focused more closely on the case study.

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## UTILISING THE LEARNING RESOURCE TO IMPROVE PRACTICE

This study is the first to focus on the nursing contributions to facilitating and supporting the transition from child to adult health services for young people with learning disabilities and their families. With the increase in the number of young people with learning disabilities, many more will transition from child to adult health services in the future. The transitions process can be complex and challenging for young people with learning disabilities, with a need for access to additional support, information, assessment of care needs and care planning. There is therefore a need to ensure that nurses and other professionals have the knowledge and skills necessary to contribute to effective transitions.

The development and piloting of the learning resource is a promising addition to the information already available regarding the transition from child to adult health services. It provides nurses and other professionals with access to a structured, evidence-based resource that develops their knowledge and understanding of the key issues that need to be considered and responded to, thereby seeking to improve the transitions experience for young people with learning disabilities and their families. There is scope to integrate the resource within all nursing and midwifery programmes and pre-registration programmes for other professionals such as doctors, social workers and therapists. The transitions learning resource can also be used within continuing professional development programmes for practitioners across a range of education, health and social care services.

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# FINAL CONCLUSION & RECOMMENDATIONS

This Scotland-wide study is the first to explore the extent of the contributions made by nurses to transition from child to adult health services for people with complex learning disabilities and their families. From the evidence, it is clear that there is a need for significant improvements across education, health and social care services. This is necessary to ensure that young people with learning disabilities are prepared for and supported throughout all aspects of the transition process.

The evidence from families, nurses and other professionals identified a wide range of best practice strategies, for effective transition which have led to seven evidence-based recommendations:

## RECOMMENDATION 1

Strategic level planning and leadership is required in all NHS Boards to ensure there are 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.

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# PROJECT DISSEMINATION

The findings from the project have been shared and disseminated at a range of local and international events and conferences including:

**February 2019** - Learning Disability MCN 'Transition Planning for School Leavers' event, NHS Fife

**April 2019** - Transition Steering Group meeting, NHS Borders

**May 2019** - *Transition for Palliative care workshop*, NHS Lothian

**May 2019** - Mental Health & Learning Disability Professional Forum, NHS Lothian

**June 2019** - Scottish Transition Forum Member Event and newsletter, Transition Forum

**August 2019** - The World Congress of the International Association for the Scientific Study of Intellectual Disabilities (IASSID), Glasgow

**September 2019** - Royal College of Nursing (RCN) International Nursing Research Conference, Sheffield

**February 2020** - Children with exceptional healthcare needs national Managed Clinical Network annual conference, Glasgow

**February 2020** - Scottish Executive Nurse Directors Group, Glasgow

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# APPENDIX 1: THE LEARNING RESOURCE

Welcome to the module 'Transitions from child to adult healthcare for young people with learning disabilities'. The module should take about 40 minutes to complete.

## AIMS

The aim of this module is to enhance knowledge and awareness of effective transition for young people with complex learning disabilities from child to adult health services and the contributions required from nurses to enable and facilitate the process.

## LEARNING OUTCOMES

By the end of this module, you will be able to:

1. *Describe the changes in demographic profile of people with learning disabilities and its impact on services*
2. *Explain the term 'complex learning disability'*
3. *Identify your practice role in relation to the transition from child to adult health services*
4. *Detail your understanding of health transitions and the challenges that may be experienced by young people with complex learning disabilities and their families*
5. *Describe the core principles underpinning an effective health transition for young people with complex learning disabilities and their families*
6. *Identify the differences in care delivery approaches between child and adult health services*
7. *Identify your practice role in applying the principles of well-managed health transition in your everyday practice*
8. *Identify needs of young people with complex learning disabilities and their families at the point of health transition and beyond*
9. *Identify your contributions in relation to your practice role to facilitate an effective health transition for young people with complex learning disabilities and their families*
10. *Develop your understanding of the legal changes and obligations related to transition, including Welfare Guardianship and reasonable adjustments*

11. *Detail the challenges experienced by families of young people with complex learning disability related to legal status changes and identify your supporting practice role*

12. *Identify your practice role in making and communicating reasonable adjustments as part of the transition process from child to adult health services*

This learning resource comprises four units:

**Unit 1: Young people with learning disabilities and their multiple morbidities and health inequalities**

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

**Unit 3: Needs of young people with complex learning disabilities and their family at the point of transition**

**Unit 4: Welfare and legal system changes relevant to transition**

This learning resource is built around a case study, based upon the real experiences of ten families of people with complex learning disabilities who participated in the transitions study.

The purpose of this resource is to help you identify areas where you can enhance your contributions, recognising that roles differ significantly depending on the area of practice. There is therefore there are no 'right' answers. Throughout the resource you will be asked to reflect on your role in supporting and facilitating health transitions as part of your everyday practice.

## UNIT 1: YOUNG PEOPLE WITH COMPLEX LEARNING DISABILITIES AND THEIR MULTIPLE MORBIDITIES AND HEALTH INEQUALITIES

By the end of Unit 1 you will be able to:

- *Describe the changes in demographic profile of people with learning disabilities and its impact on services*
- *Describe the term 'complex learning disability'*

## CASE STUDY

Sarah is 15 years old and lives at home with her parents and two younger brothers. She is a sociable, content young girl who is non-verbal and is able to communicate in her own way. She has a rare genetic condition that has resulted in a range of complex health issues and she has severe learning disability. Sarah is visually impaired, has epilepsy and a chronic kidney disease. She has an established tracheostomy and a gastrostomy tube which is used for administering all her nutrition and over 20 doses of daily medication. Sarah uses an adapted wheelchair and requires to be moved with a hoist.

The review and monitoring of Sarah's health conditions is coordinated by her paediatrician. She is also under the care of many specialist child health services including, a neurologist and an epilepsy nurse specialist, a gastroenterologist, a respiratory nurse specialist, a nephrologist, a physiotherapist and a speech and language therapist. Sarah also has involvement from a community children's nurse who coordinates her medical supplies and provides ongoing assessment and support at home.

As a result of advances in healthcare, the demographic profile of people with learning disabilities is changing, with over 90% of children born with multiple and increasingly complex health conditions surviving into adulthood.

For the purpose of this resource, these young people are referred to as having 'complex learning disabilities', characterised by a significant cognitive impairment and multiple physical and mental health needs, alongside coexisting difficulties such as sensory impairments, mental health needs, developmental disorders, challenging behaviour and communication difficulties. Life-long, high levels of support is required in aspects of daily living, including healthcare.

This growing number of young people with complex learning disabilities requires services extending beyond child health provision, which can bring many challenges for education, health and social care professionals and services. Evidence suggests that people with learning disabilities do not receive equal access to services compared to the general population, which can affect their health, life expectancy and quality of life (Mencap, 2007, 2012; Michael, 2008; Scottish Government, 2013; Truesdale & Brown, 2017).

## UNIT 2: WHAT IS TRANSITION AND WHY DOES IT MATTER?

By the end of Unit 2 you will be able to:

- *Detail what is meant by transitions and why it can be challenging for people with complex learning disabilities*
- *Describe the core principles underpinning an effective health transition for young people with complex learning disabilities*
- *Describe the differing approaches in service and care delivery between child and adult health services*
- *Reflect on your own role in applying the principles of an effective health transition in your practice role*

In contrast to a 'transfer' from child to adult health services, transition is a multi-dimensional concept, which 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 healthcare systems." (Department of Health, 2006: 14).

The purpose of transition is to provide uninterrupted, coordinated and developmentally appropriate care throughout the process (Kaufman and Pinzon, 2007).

### PRINCIPLES OF AN EFFECTIVE TRANSITION

Elements and principles underpinning well-managed transition to adulthood for people with complex needs are highlighted in a number of guidelines and reports, including NICE guidelines (2016) 'Transition from children's to adults' services for young people using health or social care services' and 'Principles of Good Transitions 3' by the Scottish Transition Forum (2017). Some of the principles include:

- *Starting the transition planning process early, around the age of 14*
- *Regular multidisciplinary meetings with collaboration and coordination between services and agencies*
- *Holistic and person-centred approach to planning and decision-making, with involvement from the young person and their parents*
- *Access to reliable and consistent information for young people and their parents*
- *Comprehensive support for families and carers*
- *Dedicated transition staff and a single point of contact available for the young person and their parents*
- *A continued focus on transitions and supporting infrastructure*

Evidence suggests that due to their cognitive impairment and medical comorbidities, young people with complex learning disabilities and their families can be disadvantaged at the point of transition to adult health services and beyond. They may experience poorer health outcomes, which can be partly associated with the different ways in which the child and adult health services are delivered:

CHILD HEALTH SERVICES	ADULT HEALTH SERVICES
<ul style="list-style-type: none"> <li>● <i>Family-centred approach</i></li> <li>● <i>Parental involvement in decision-making</i></li> <li>● <i>Care prescribed within a multi-disciplinary care team with a coordinating paediatrician</i></li> <li>● <i>Open access to hospital ward</i></li> <li>● <i>Regular monitoring of health conditions</i></li> <li>● <i>Developmentally-appropriate input from allied health professionals</i></li> </ul>	<ul style="list-style-type: none"> <li>● <i>Person-centred approach</i></li> <li>● <i>Requires autonomous, independent skills</i></li> <li>● <i>Care prescribed across individual specialties with no coordinating physician</i></li> <li>● <i>Hospital access through emergency department or primary care</i></li> <li>● <i>Emphasis on self-management of conditions</i></li> <li>● <i>Changes in involvement from allied health professionals</i></li> </ul>

**Table 1:** Differences between child health and adult health services. Based on Scotland-wide project on transition from child to adult health services for people with complex learning disabilities (Brown et al., 2019).

## CASE STUDY

Sarah and her parents have an excellent relationship with the child health services, who have been involved in her care and support since she was a baby. Sarah's parents feel safe in the children's services and know they can contact the paediatrician or specialist nurses if they have any concerns. They think that the professionals in child health services have a good understanding of Sarah's multiple health complexities, with well-established and trusted relationships.

Sarah will soon be 16 and the head teacher at her special school is organising a 'transition meeting' to start planning for Sarah moving to adult services when she leaves at 19. Sarah's parents are very anxious about it as the 'transition' hasn't been discussed with them before and they don't know what to expect. They have heard negative stories from other parents, and this makes them not want to think about it and they would like Sarah to stay in child health services. They are worried they will be left with no support and that existing trusted services will be changed and removed.

## REFLECTION POINT

**Choose three principles underpinning well-managed transition and briefly explain how you could apply them in your nursing practice to help ensure Sarah and her family have a more positive transition experience.**

## UNIT 3: NEEDS OF YOUNG PEOPLE WITH COMPLEX LEARNING DISABILITIES AND THEIR FAMILY AT THE POINT OF TRANSITION

By the end of Unit 3 you will be able to:

- *Identify key needs of young people with complex learning disabilities and their families at the point of transition and beyond*
- *Reflect on your contributions in your practice role to help minimise the challenges experienced by young people with complex learning disabilities and their families at the point of transition from child to adult health services and beyond*

Nurses are recognised as being potentially instrumental for enabling and facilitating an effective transition process from child to adult health services for young people with learning disabilities. This is partly due to their holistic, life-course perspective that includes family and the wider psychosocial needs of the individual. Nurses are recognised for their expert knowledge and ability to easily adopt new tools, assessments and clinical guidelines. They are therefore seen as well placed to develop and implement transition programs and provide support and information throughout the transition process. In this Scotland-wide research study, families, nurses and other professionals identified many ways in which nurses enabled and facilitated the transition process. Five key principles will be examined in more detail with specific focus on the nursing contribution.

Principles for effective health transition for young people with complex learning disabilities:

1. *Early transition preparation*
2. *Collaborative working across services and agencies*
3. *Emergency care planning*
4. *Coordinated handover of care from child to adult health services*
5. *Families as equal partners in care*

### PRINCIPLE 1: EARLY TRANSITION PREPARATION

#### Why is it important?

Effective transition into adulthood is important as it can be a highly emotional experience for young people with learning disabilities, their families and those involved in their care and support. It is therefore important to introduce the concept at an early stage to allow the young person and their family to familiarise themselves with the future changes and the implications. Transition can evoke a sense of loss, vulnerability and abandonment by trusted professionals, as well as fear of the unknown as they move into adult health care. In the words of one parent involved in the research study, it can feel like ‘taking a rug and just pulling it out’.

### GOOD PRACTICE

- *For young people with complex learning disabilities, preparation for transition starts around the age of 14. The concept of transition is introduced to the young person and their family and they are given reliable information regarding the local transition process*
- *Families are able to ask questions about what is involved in the transition process and receive support to access information about adult health services*
- *Transition is acknowledged as a highly emotional experience*

### PRINCIPLE 2: COLLABORATIVE WORKING ACROSS SERVICES AND AGENCIES

#### Why is it important?

Health professionals, including nurses, need to play an active role in the wider transition process and collaborate with education and social care colleagues to ensure that there is adequate time for assessment of needs, care planning and information sharing. It is crucial that young people with learning disabilities and their families receive accurate and timely information about the transition process and future care. Adopting a partnership approach with the young person and their family can help prevent being overwhelmed and taking on responsibility for facilitating the transition process. It will also reduce the feeling of having to “fight” for services and quality care, an important finding from the transition research study.

### GOOD PRACTICE

- *Due to a number of professionals involved in care of young people with complex learning disabilities, the transition planning process is to be initiated around the age of 14 to allow adequate time for collaborative, multidisciplinary planning and transition of care to adult health services*
- *Multidisciplinary transition planning meetings with active involvement from health, education and social work representatives take place on a regular basis. They focus on working with the young person and their family to develop a shared transition plan*
- *Transition is coordinated by a lead agency and professional that includes a clear focus on health needs*
- *A holistic health assessment and care plan is the starting point for a person and family-centred transition plan*
- *Parents or main carers are a vital source of information about the health history and needs of the young person with complex learning disability. They remain actively involved throughout the transition process and can provide information regarding future healthcare provision and support needs*

## CASE STUDY

Sarah is prone to respiratory infections and having open access to the paediatric ward where she is known well, gives her parents confidence in the quality of care she receives. Sarah feels comfortable in the children's ward and the nurses know her well and understand her needs. The nurses know that loud noises can, for example, trigger spasms in Sarah and therefore try to provide a side-room in a quieter area of the ward. Due to Sarah's frequent admissions to the paediatric ward throughout her childhood, her parents are anxious about future adult hospital admissions. Sarah's older friend was recently admitted to an adult hospital and his parents felt isolated, excluded and not listened to.

## REFLECTION POINT

**What is your current involvement in the wider, multidisciplinary and multi-agency transition process for people with complex learning disabilities? If not currently involved, how can you increase your collaboration with other services and agencies during the transition process?**

## PRINCIPLE 3: EMERGENCY CARE PLANNING

### Why is it important?

Poor planning for emergency care during the transition process can result in young people with complex learning disabilities and their family experiencing their first admission to an adult care setting at their most vulnerable time. Adult hospital professionals may have limited experience of providing care for people with complex learning disabilities and differing policies, procedures and practices between child and adult health services may result in families being excluded from the assessment and decision-making process. Furthermore, the receiving care setting might have limited background history regarding the specific needs of the young person and be unfamiliar with the medical treatments or equipment commonly used in child health services. These factors can potentially place young people with complex learning disabilities in care situations that do not meet their individual needs, with potentially significant consequences.

## GOOD PRACTICE

- *A written emergency care plan, which reflects the needs of the young person with complex learning disabilities and their family, is developed as part of the wider transition planning process*
- *Health passports or other health needs summaries are in place and easily accessible to professionals in adult health service*
- *The needs of the young person with complex learning disabilities and their family are considered and addressed through 'reasonable adjustments'*\*

- *Examples include adaptations related to day-to-day care or the admission process, such as direct admission to wards that by-passes the Emergency Department*
- *Emergency care decisions, including DNACPR decisions regarding resuscitation, are discussed in advance with the young person and their family and their wishes taken into account and documented*
- *Young people with complex learning disabilities and their families are introduced to the Learning Disability Liaison Nurse as part of the transitions planning process*
- *Families and paid carers are fully involved throughout the admission process, thereby drawing on their knowledge, skills and expertise of the needs of the young person with complex learning disabilities*

\*Under the Equality Act 2010, 'reasonable adjustments' are adaptations to the way buildings, policies and services are organised to take into consideration needs of people with disabilities. For more information, please visit <https://rcni.com/hosted-content/rcn/first-steps/reasonable-adjustments>

## REFLECTION POINT

**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?**

## PRINCIPLE 4: COORDINATED HANDOVER OF CARE FROM CHILD TO ADULT HEALTH SERVICES

### Why is it important?

The world of adult healthcare can be frightening and confusing for young people with complex learning disabilities and their family and may not be fully responsive to their distinct needs. Their feelings and experiences may be further complicated by an unplanned transition, where essential information between child and adult healthcare professionals is not shared and communicated, thereby leading to gaps in service provision. Some young people with complex learning disabilities remain in child health services long into adulthood and such delayed transition can lead to care being managed simultaneously across both child and adult health services, creating further confusion and challenges with care coordination and effective service provision. Different practices in adult health services meant that some services may not offer continued, on-going and regular review and monitoring of long-term conditions and other aspects of care. This can place additional pressure upon parents and affect their confidence in adult health services and the ability to provide appropriate care and support.

## GOOD PRACTICE

- *The multi-disciplinary transition plan is gradually implemented by knowledgeable professionals, who facilitate building of trusting relationships with adult health services, including primary and acute care*
- *A flexible, person and family-centred approach to transition is adopted taking into account the health status of the young person with complex learning disabilities and any recent or planned changes to treatment plan*
- *Processes are in place that enable effective information sharing between the child and adult health services, the young person with learning disabilities and their family. This should include transition clinics and care handover meetings*
- *Continuity of care is maintained and people with complex learning disabilities are able to access necessary adult health services and their long-term conditions and general health are appropriately and regularly monitored*
- *Young people with complex learning disabilities and their families are included in communications between child and adult health services and receive a contact list of key professionals in adult services*
- *People with complex learning disabilities and their family are supported and followed-up throughout the transition process until all aspects of adult healthcare are in place*

## REFLECTION POINT

**What processes are in place in your area of nursing to ensure a comprehensive handover of care from child to adult health service? How do you think the handover of care could be improved? For example, transition clinics, transition meetings between child and adult health services, improved transfer of essential health information.**

## PRINCIPLE 5: FAMILY CARERS AS EQUAL PARTNERS IN CARE

### CASE STUDY

Sarah's mum works part-time and her dad works full-time. Sarah will be in full-time education until she is 19. She has a complex care team delivering support four evenings a week and accesses respite regularly. Sarah's mum is concerned about changes in support when Sarah moves to adult day care, as well as the possible reduction in respite and complex care provision. She is particularly concerned about the impact it will have on Sarah's mental and physical health. She feels she may have to give up her job to provide more of Sarah's care and day activities.

## Why is it important?

As the young person with complex learning disabilities moves from education and child to adult health and social care services, they may experience changes in availability of services such as respite, day activities, support-at-home as well as support with every day and personal care during hospital admissions. This may place unrealistic expectations on the aging parents, leaving them without support for extended periods of time and responsible for many aspects of care. This can impact on their physical and mental health, personal relationships, financial circumstances, employment and their ability to look after their adult child with complex learning disabilities. Some young people with complex learning disabilities cannot communicate their needs and rely on their family's detailed knowledge and understanding of every aspect of their lives. However, the emphasis on autonomy and independent decision-making in adult health services means that standard procedures might not be adapted to take into account Legal Guardianship. These issues are explored in more detail in Unit 4. Parent's attempts to provide vital information might be dismissed, placing the young person with complex learning disabilities at a significant risk of receiving care not responsive of reflective of their unique needs.

## GOOD PRACTICE

- *The potential impact of the change of services as a result of transition to adult health and social care services is understood by all practitioners*
- *Adult health services take a person and family-centred approach to care delivery for young people with complex learning disabilities*
- *Families and carers are recognised as experts in the needs of their young person with complex learning disabilities and involved in care delivery and decision-making*
- *The expertise of families and paid carers regarding care delivery, reasonable adjustments and service adaptations and changes in health status are acknowledged and responded to professionals in primary and acute care*
- *Families and paid carers are supported in the acute hospital environment to minimise the expectation that they provide care for the young adult with complex learning disabilities throughout their admission.*

## REFLECTION POINT

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

## UNIT 4: WELFARE AND LEGAL SYSTEM CHANGES RELEVANT TO TRANSITION

By the end of Unit 4 you will be able to:

- *Detail the legal changes related to transition, including Welfare Guardianship*
- *Describe the challenges experienced by parents of young people with complex learning disabilities related to legal status changes and reflect on your role in providing support*
- *Detail the legal basis for making reasonable adjustments for young people with complex learning disabilities*
- *Reflect on your practice role in making and communicating reasonable adjustments as part of the transition process*

Legal changes relating to consent and decision-making are an important aspect of transition to adulthood. These changes have particular implications for young people

with complex learning disabilities who might not be able to make independent decisions. Families, often parents, may therefore require to apply to become the Welfare Guardian for their family member with complex learning disabilities.

### WELFARE GUARDIANSHIP

Under Scots law, young people can make independent decisions from the age of 16 and do not require parental consent. The Adults with Incapacity (Scotland) Act 2000 legislation provides a legal framework to safeguard the welfare and manage the finances of adults, aged 16 and over, who lack capacity due to mental illness, learning disability or due to an inability to communicate.

If an adult is unable to make decisions or safeguard their own welfare, specific legal powers can be sought, termed a 'welfare guardian'. Welfare Guardians, who are usually a parent, family member or social worker, are legally allowed to make decisions about the individual in areas such as, financial decisions and health care. If such powers are not held, only the young adult can, in law, make decisions about their welfare, including healthcare.

#### Why is it important?

Many young people with complex learning disabilities will have a significant degree of cognitive impairment and lack capacity for independent decision-making. Some parents incorrectly assume that they do not need to apply for Welfare Guardianship to continue making decisions for their adult child. This can lead to parents having no legal basis to make health care decisions for their child once they are 16 years of age and older.

### GOOD PRACTICE

The requirement to apply for Welfare Guardianship is discussed with parents as part of the preparation for transition around the age of 14 and parents are signposted to services that can provide support with legal requirements

### REFLECTION POINT

**Who can support parents with Welfare Guardianship or other legal requirements as a result of transition in your organisation or local authority?**

### THE EQUALITY ACT 2010

The Equality Act 2010 and Public-Sector Equality Duty is UK-wide legislation that protect the rights and equality of opportunity, including people with disabilities. It places a duty on public bodies and authorities, including health services, to act to eliminate unlawful discrimination and make 'reasonable adjustments' for people with disability. Reasonable adjustments are changes to the services and environment to enable people with disabilities to access the care and support they need safely.

#### Why is it important?

Evidence suggests that people with complex learning disabilities can experience a reduction in support and experience barriers to accessing healthcare in adult services, impacting on the quality healthcare as a result of transition. The transitions study that informed the development of this learning resource identified that some young people with complex learning disabilities present a "shock" to the adult healthcare system, as they are unprepared for their level of complex needs.

### GOOD PRACTICE

- *The needs of young people with complex learning disabilities are considered and reasonable adjustments made where necessary. Examples include special arrangements for appointments or ensuring hospital rooms have adequate equipment and adaptations*
- *Reasonable adjustments are clearly communicated to adult health services at the point of transition. Child and adult services should work together to ensure arrangements such as special arrangements for health appointments are replicated in adult health services*

### REFLECTION POINT

**Nurses working with children. What examples of reasonable adjustments you have made that need to be communicated to adult services at the point of transition can you identify?**

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## REFLECTION POINT

**Nurses working with adults. Please give examples of reasonable adjustments that you anticipate may be necessary for young adult with complex learning disabilities following their transition to adult services can you identify?**

## FURTHER INFORMATION

For examples of transition programmes for young people with long-term conditions and special health care needs, please visit:

- *Ready Steady Go (Southampton Children's Hospital, UK)*
- *OnTrac (Children's and Women's Health Centre of British Columbia, Canada)*
- *SHARE (Surrey Place, Canada)*

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