Improving Health Transitions for Young Adults with Complex Learning Disabilities

Webinar for Healthcare Students and Academics
9th June 2021

The research team & presenters

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Jenny Miller, PAMIS

Fiona Barlow, University of Glasgow

Michelle Wells, family carer

Aims of session

- To raise awareness of the challenges and opportunities to improve the health transition experience for young adults with learning disabilities and their families
- To develop knowledge and understanding of the role of academics and healthcare professionals in facilitating effective health transitions for young adults with learning disabilities

Overview of the Webinar

- Michelle's experience of the health transition of her son
- International context on transitions – systematic review of the literature
- Research study:
  - Views and experiences of families of young adults with intellectual disabilities in Scotland
  - Nursing role in effective transitions for young adults with intellectual disabilities
  - Development and piloting of a transitions learning resource
- What next?

Getting to know you!

Using the chat facility please share with us…

1. Who you are. A student? An academic? Another?
2. What is your interest in joining this Webinar?

Michelle’s story of health transitions

Introduced by Jenny Miller, CEO, PAMIS

Pause for thought ….

In the chat facility, tell us about

- Whether Michelle's story resonated with any of your experiences of health transitions – either personal or professional

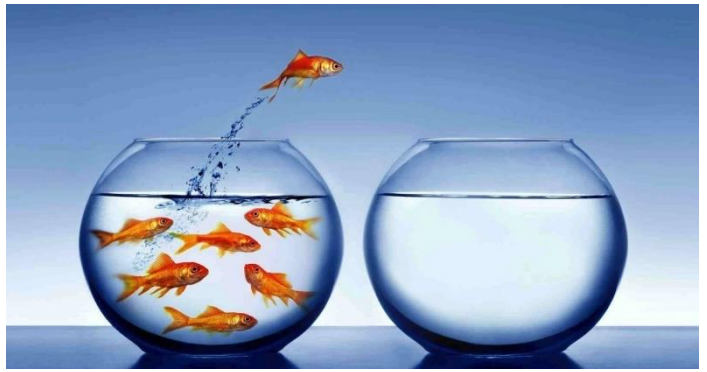
Health Transitions and where it all began

Professor Michael Brown, Queen's University Belfast

Background to the work

Changing population of people with intellectual disabilities and complex needs

- Increased life expectancy
- Comorbid, complex health conditions



- Child healthcare models and services well established and developed with a strong child and family focus with a focus on single condition transition
- People with intellectual disabilities experience multiple transitions, including health transitions
- Limited evidence-base regarding the experiences of young adults with intellectual disabilities and their families at the point of health transition

Definition of transition

"a purposeful, planned process that addresses the medical, psychosocial and educational and vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems."

Department of Health, 2006: 14

Transitions are therefore…

- Purposeful
- Planned
- Personal
- Physical & mental health focused

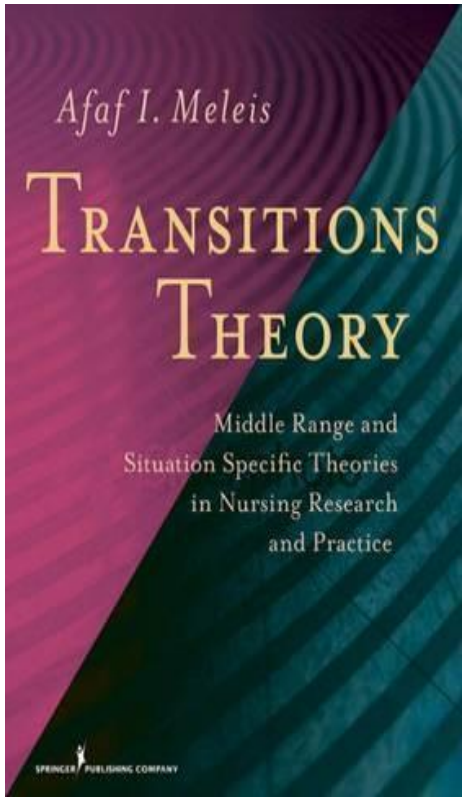
Transitions, including health transitions, is an area of research, education and practice that is attracting increasing attention by nurses and other professionals.

Betz, C. L. (2021). Nursing's influence on the evolution of the field of health care transition and future implications. *Journal of Pediatric Health Care*.

Betz, C. L., Zalon, M. L., Caramanica, L., & Arslanian-Engoren, C. (2021). Nurse competencies for transitions of care: Implications for education and practice. *Nursing Forum,* 56, (2), 358-364.

Transitions Theory

- Meleis et al., 2000 developed *Transitions Theory*
- Transitions Theory highlights the complex processes that occur simultaneously in multiple dimensions
- Core elements of health transitions from child to adult health services
  - Awareness
  - Engagement
  - Adapting to change and difference
  - Time span
  - Critical points and events
- Factors that can facilitate or inhibit the transition process and health outcomes:
  - personal, community, societal conditions
  - families' ability to act as an advocate or access to information and support



About the 3-year transition study

A Scotland-wide research study - completed December 2019

Phase 1

- Systematic review of international evidence on transitions and contributions of nurses

Phase 2

- To investigate and understanding families' and nurses' views and experience of transition of people with complex learning disability between child and adult health services
- To identify best practice strategies in providing person-centred care during health transitions, embedded from the perspectives of stakeholders

Phase 3

- To develop and pilot an education resource for nurses on how best to manage transition between child and adult health services for people with complex learning disabilities

Phase 1: Systematic review of international research evidence

Brown, MacArthur, Higgins & Chouliara (2019) Transitions from child to adult health care for young people with intellectual disabilities: A systematic review. Journal of Advanced Nursing

Aim: To examine the experiences of health transitions for young people with intellectual disabilities and their families and identify the implications for nursing practice.

Received: 21 August 2018 | Revised: 18 December 2018 | Accepted: 8 January 2019
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REVIEW

WILEY JAN

Transitions from child to adult health care for young people with intellectual disabilities: A systematic review

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Abstract

Aims: To examine the experiences of health transitions for young people with intellectual disabilities and their carers and identify the implications for nursing practice.

Design: A systematic review and critical appraisal of qualitative, quantitative, and mixed methods studies.

Data sources: A search of the relevant literature published 2007–2017 was carried out in AMED, ASSIA, CINAHL, MEDLINE, PsycINFO, PubMed, and Science Direct Sociological Abstracts databases.

Review methods: A total of 12 of 637 papers identified in the search met the inclusion criteria for this review. A narrative review of the papers was undertaken by synthesizing the key findings and grouping them into concepts and emergent themes.

Results: Four main themes were identified: (a) becoming an adult; (b) fragmented transition process and care; (c) parents as advocates in emotional turmoil; and (d) making transitions happen.

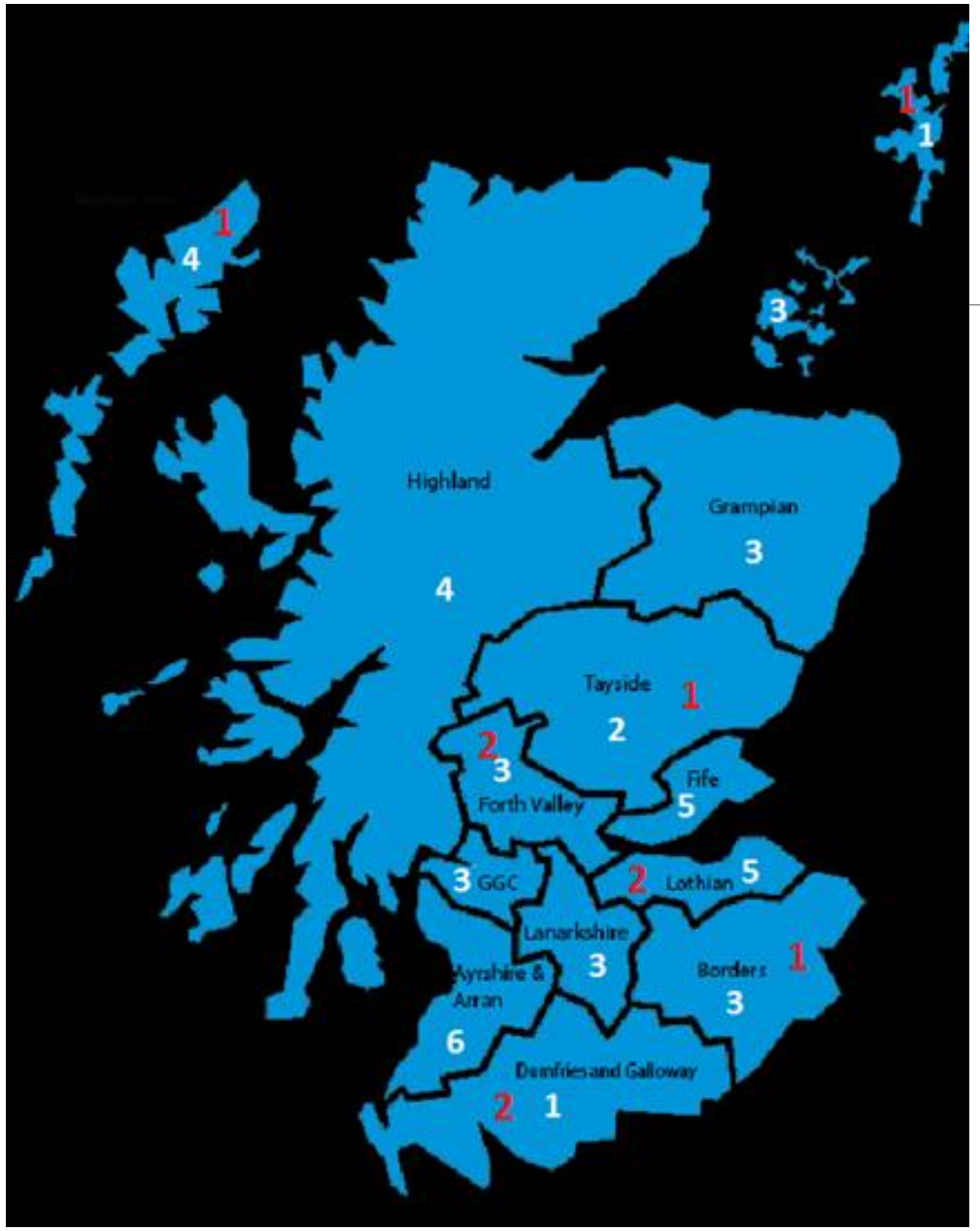
Conclusion: The range of issues that have an impact on the transition from child to

Themes from the research evidence

- Theme 1: Becoming an adult
- Theme 2: Fragmented transition process and care
- Theme 3: Parents as advocates in emotional turmoil
- Theme 4: Making transitions happen: The nursing contributions

Health transitions and families

Dr Juliet MacArthur, NHS Lothian



Phase 2: Families and Nurses

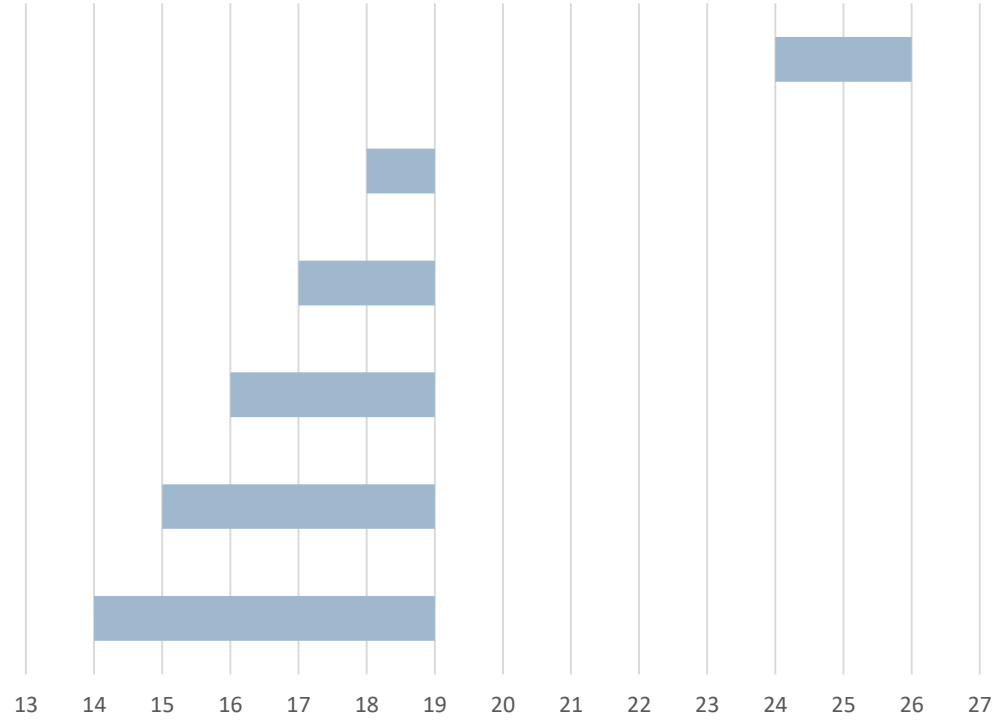
Methods and Participants: data collection 2017 - 2019

- Qualitative design
  - semi-structured interviews
  - face-to-face and telephone
- Participants
  - 10 carers from 7 NHS health boards
  - 46 nurses and other healthcare professionals from all 14 NHS health boards in Scotland
- Thematic analysis of data set

Family Carers: Sample (n=10)

DEMOGRAPHIC INFORMATION		
CARERS		
Relationship to the person with LD	Mother = 9	Father = 1
Age	40-49 = 2	50-59 = 5
	Missing = 3	
Full time carer?	Yes = 8	No = 2
Overall experience of transition	Very positive = 1	Mostly positive = 5
	Mostly negative = 1	Missing = 3
PEOPLE WITH LD		
Gender	Female = 4	Male = 6
Age	20-24 = 5	25-29 = 1
	>30 = 1	Missing = 3
Diagnosis	Genetic condition = 2	Severe autism = 3
	Cerebral palsy = 6	Learning disability = 3

Transition timing



The Experiences of Families

Five themes:

i) A deep sense of loss

ii) An overwhelming process

iii) Parents making transitions happen

iv) A shock to the adult healthcare system

v) The unbearable pressure

Theme 1: A deep sense of loss

Losing the sense of safety

You feel you're going into a very vulnerable situation, to let go of a doctor that you deeply respect, like, there's real affection for each other and mutual respect for each other, and all of a sudden it's like somebody taking a rug and just pulling it out. C05

Loss of services

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. (…) this is a boy that had people at a major UK Children's Hospital and you've had that level of expertise, 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. C05

Theme 2: An overwhelming process

Lack of coordinated planning

We saw her [the visiting paediatrician] about three weeks ago and she told us it would be her last appointment and that Richard (…) would be seen by somebody in adult services but I'm not sure who. She didn't know who so I'm assuming…well, she's not done any handover but there will be notes somewhere. C04

Confusion and the state of unknown

…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? C01

Theme 3: Parents making transitions happen

Parents as the transition coordinators

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. C10

The battle of transition

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, but that's always been the case, it's always been the case, and I think it is sad, it's quite sad that it's not a standard. C07

Theme 4: A shock to the adult health care system

The paradox of adult hospitals

they have very little understanding of somebody as complex as Mark (…). we were put in the waiting room while they were in getting him changed and stuff like that instead of we should have been part of that. We should have been in there. We should have been saying, right, this is how he lies. This is what he does. C02

Lack of continuity of care

My feeling with transfer to adult services is that suddenly – and I'm not the only person who said this– people seem to think their condition gets better and they don't need the services they're getting as children, and in actual fact they probably need them more because things deteriorate and stuff like that. C10

Theme 5: The unbearable pressure

Alone in new 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. C09

The unbearable pressure and its impact on health

The isolation has increased greatly, the physical workload has increased greatly, the mental thing of thinking (…) what's going to happen to these two girls of mine when I'm not here to look after them is phenomenal. (…) being a carer can take, you know, it makes you not as resilient as you would be. C10

Pause for thought ….

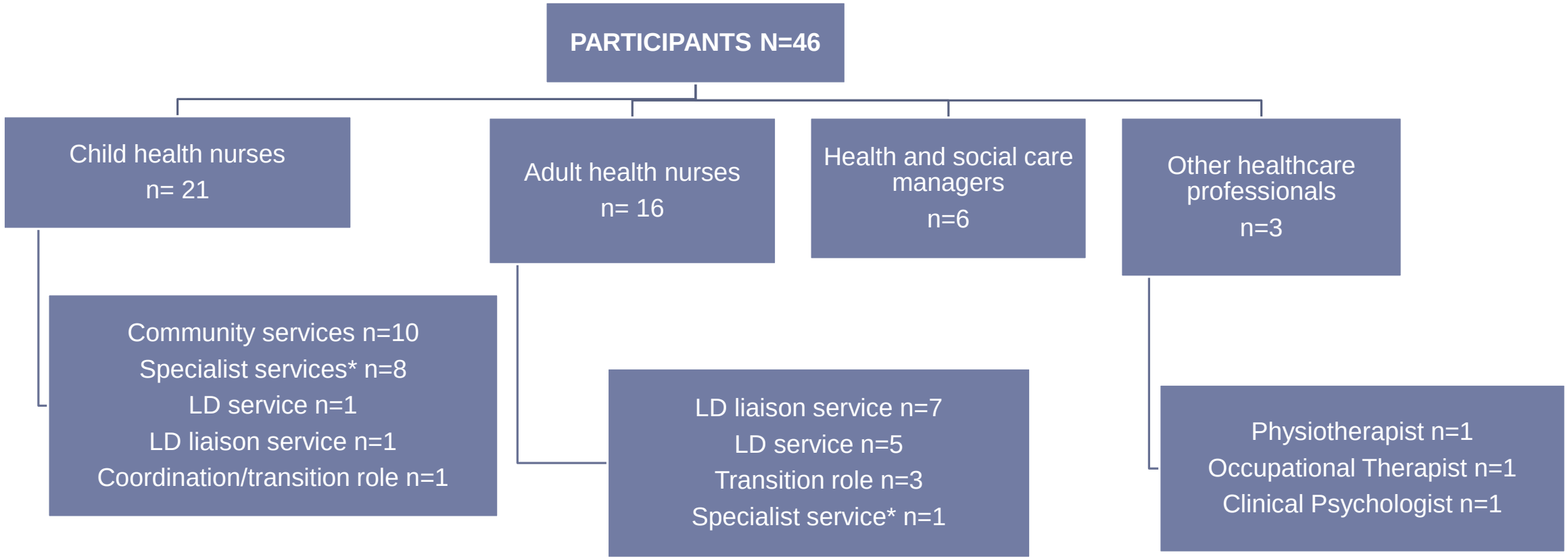
In the chat facility, tell us about

- Whether you think these experiences could be happening in health services where you work?
- Any examples that you have come across where family carers had a positive experience of health transition

Health Transitions, Nurses & other Professionals

Professor Michael Brown, Queen’s University Belfast

Phase 2: Nurse Participants



*specialist services included: epilepsy/neurology, gastroenterology, respiratory, complex care/respite

Themes: Nurses and other professionals

PRINCIPLES UNDERPINNING IMPROVED TRANSITION CARE	• **ELEMENTS OF TRANSITION MANAGEMENT**
1. Strategic level focus	• Strategic level commitment • Population projection and service planning • Transition education and training
2. Clear transition processes and pathways	• Transition pathway development • Cross-NHS Board transition practices
3. Proactive transition preparation	• Early preparation • Timely initiation of the transition planning process
4. Multiagency transition planning	• Collaborative working across services and agencies • Lead coordinator • Assessment and care planning • Emergency care planning
5. Continuity of care in adult services	• Coordinated handover of care • Holistic overview in adult health services • Access to services and quality care • Family carers as equal partners in care

68 measureable outcome statements – will be available as standalone publication shortly

Theme 1: Strategic level focus

- Integration of 'transitions' within Government and Health and Social Care Policy
- Strategic leadership required to ensure that transitions are prioritised and integrated within health and social care
- Strategic-level commitment to enable population identification
- Strategic-service planning and resources allocation required to meet increasing needs
- Strategic-approach required to support the integration of health transitions within continuing professional developments programmes for nurses and other professionals

Good practice examples

- Population needs assessments and planning
- Transition-related training
- Family involvement in nurse education

Theme 2: Clear Transition Processes and Pathways

- Significant contributions made by nurses across all aspects of the transitions process and the implementation of transitions care pathways
- Nurses play an important role by developing, piloting, implementing and evaluating transition pathways
- Nurses involved in collaborating, problem-solving and implementing positive changes within their existing roles by incorporate a transitions focus

Good practice examples

- Transition steering group developed as a result of managerial commitment to improving transition
- Strategic-level transitions consultation undertaken with care agencies and families

Theme 3: Proactive Transition Preparation

- Schools well placed to introduce the concept of 'transition' and what the process involves to the young adult and their family
- Early initiation of the transitions process required to ensure the young adult and their family are at the centre of the process
- Important role for School Nurses and Child Health Nurses with extensive knowledge of the needs of the young adult and their family
- Early preparation of the young adult and their family, with early planning required to ensure there is an effective, person-centred transition
- Cross-health services information sharing and communication between professionals involved in the care and support of young adults at their family during the transitions process

Good practice examples

- New roles, for example, Transition Coordinator
- “Teenage clinics” and transition appointments
- Preparation for the changing legal status

Theme 4: Multiagency Transition Planning

- Communication, information sharing and care coordination required to facilitate a smooth transitions across services and agencies involved in providing services and support
- Lead coordinator required to ensure that information is collated, shared and acted upon
- Multiagency assessment of needs, including health assessments, are required to inform the development of care plans
- Nurses have an important contribution to make by providing health assessments that form part of the wider assessment of needs and future planning of adult services
- Emergency care plans required to ensure that care plans take account of the often-changing health of young adults with intellectual disabilities and complex health needs

Good practice examples

- Completion of a holistic health assessment as part of the transition planning process
- Preparing adult acute services through planning meetings, support plans & “Admission packs”
- Referral to a Learning Disability Liaison Nurse as part of the transition process

Theme 5: Continuity of Care in Adult Health Services

- The central role of families in sharing knowledge, skills and expertise of the needs of the young adult with learning disabilities to ensure a smooth transition
- Nurses have a key role in ensuring the handover of care from child to adult health services is smooth and effective
- Possible role of nurses in primary care and learning disability services in ensuring there is an overview and coordination of the transition of care from child to adult health services
- Nurses have a significant contribution to make in facilitating and coordinating access to adult health services, including acute and primary care and specialist adult learning disability services

Good practice examples

- Strengthening relationships with primary care and GPs
- Specialist Learning Disability Nursing roles to facilitate and coordinate the transitions process
- Transition planning meeting and clinics

Pause for thought ….

In the chat facility, tell us about

- Any examples of effective transition process and pathways
- If you give us examples please can you tell us where you work so, if we need to, we can make contact with you
- We are planning to share our findings with policy makers in the 4 UK countries and will share examples

Health Transitions and a new learning resource

Dr Juliet MacArthur, NHS Lothian

Phase 3: Educational resource - Content

Case Study embedded – Sarah (age 15) living with parents and two siblings

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

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

UNIT 3: Needs of the young adult with intellectual disabilities and their family at the point of transition - the nursing perspective

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

UNIT 4: Welfare and legal system changes relevant to transition

We want your feedback

- Evaluation form being posted in the chat – please complete before you leave

What needs to happen?

Jenny Miller

A reality check

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)

What needs to happen…

1: Strategic level planning and leadership in all NHS Boards

2: Education, health and social care services need to develop and implement **clear transition processes** and pathways

3 : Young people with learning disabilities and their families need to be **central to and fully involved** in proactive transition preparation

4: Education and health and social care services need to **collaborate at an early stage** to ensure there is effective **multiagency transition planning** and service coordination.

5: A **lead health professional** needs to be identified and responsible for coordination before, during and after the health elements of the transition process.

6: The **role of nurses** in supporting and facilitating the transitions needs to be further developed.

7: Registered nurses, undergraduate students and other healthcare professionals need to undertake **further education** regarding effective transitions

And now…Improving Health Transitions

“Change will not come if we wait for some other person or some other time. We are the ones we’ve been waiting for. We are the change that we seek.”

President Barack Obama

Your own commitment….

In the chat facility, tell us about

- What commitment will you make to improve the experience of health transitions for young people with complex learning disabilities?

Summary points from the chat

Maria Truesdale

Some Questions …

Please put any final questions for the discussion in the chat

And finally…

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To access the Transitions Reports

https://www.qub.ac.uk/schools/SchoolofNursingandMidwifery/News/HealthTransitionsStudy.html

Learning resource is in the final report and is available as Word document from the research team

Publications

Brown, M., MacArthur, J., Higgins, A., Chouliera, 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

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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