Transitions from paediatric to adult health services for people with complex intellectual disabilities: Learning from carers and nurses

Professor Michael Brown, Queen's University Belfast

Professor Zoe Chouliara, Abertay University

Dr Juliet MacArthur, NHS Lothian

Anna Higgins, Edinburgh Napier University

Dr Maria Truesdale, Edinburgh Napier University

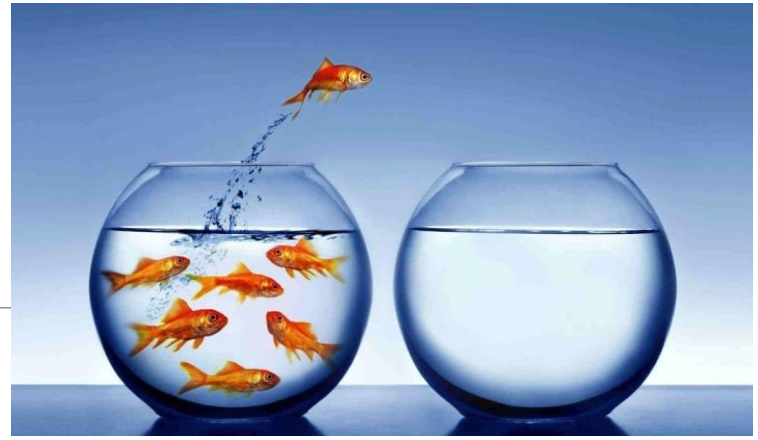
Symposium overview

- The study – background, aims, design and recruitment – Juliet MacArthur
- Paper 1: Setting the international context on transitions: a fragmented landscape for young people with intellectual disabilities and their families – Juliet MacArthur.
- Paper 2: The views and experiences of families of young adults with intellectual disabilities in Scotland – Anna Higgins
- Paper 3: The nursing role in effective transition planning for young adults with intellectual disabilities - Michael Brown
- Paper 4: The development and piloting of an educational resource “Transitions from child to adult health care for young adults with learning disabilities” for nurses – Anna Higgins
- Ways forward and conclusions

Introduction to our study

DR JULIET MACARTHUR

Background



- Changing population of people with ID and complex needs
  - Increased life expectancy
  - Comorbid, complex conditions

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

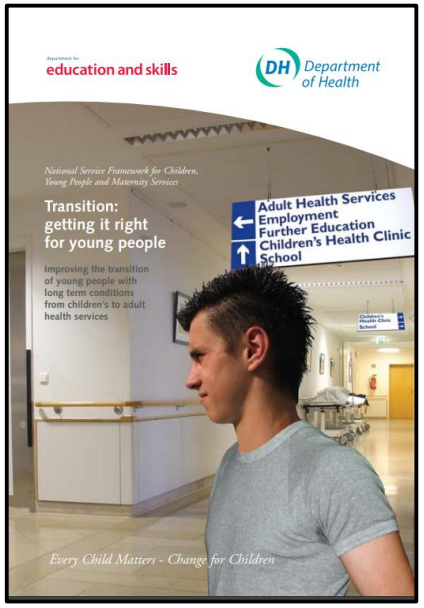
Transition definition

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

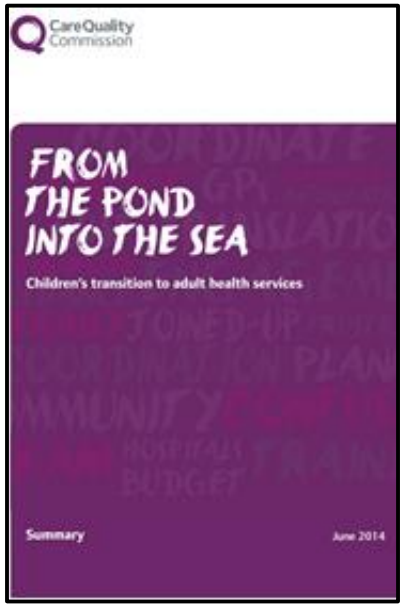
Department of Health, 2006: 14

Transition guidelines

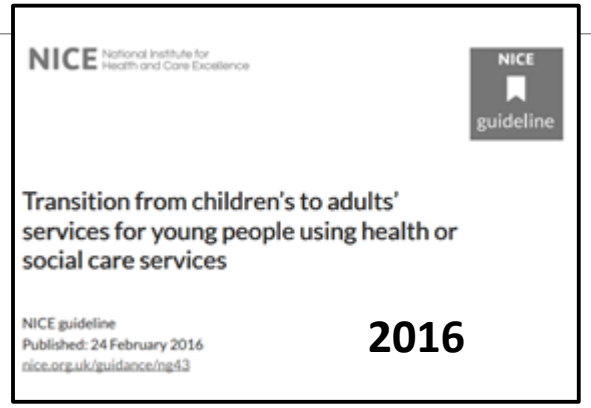
2006



2008

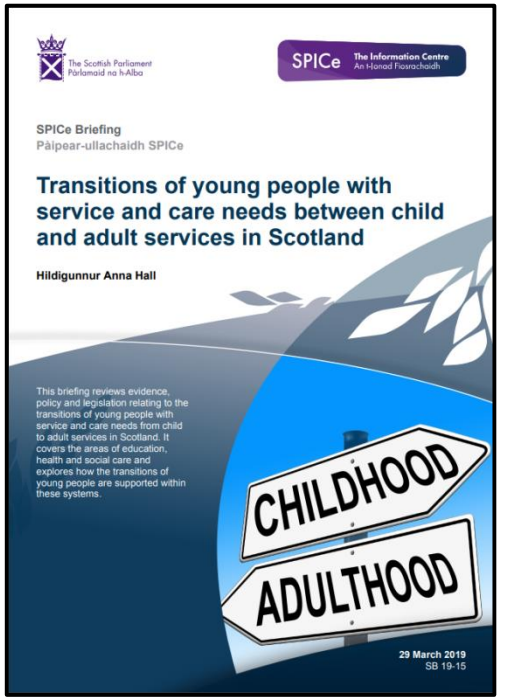


2014



2016

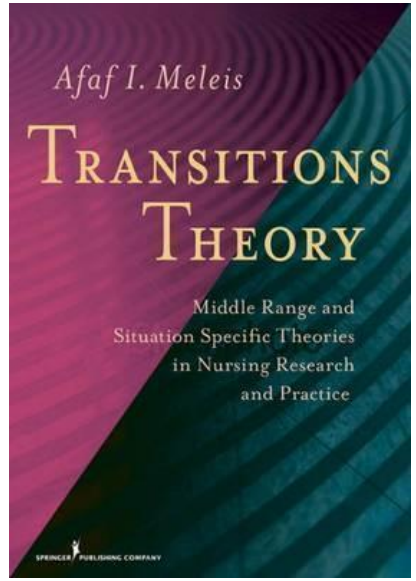
2017



2019

Transitions Theory (Meleis et al., 2000)

- Transitions - complex processes occurring simultaneously in multiple dimensions
- Core properties of transitions from paediatric to adult health services
  - awareness
  - engagement
  - adapting to change and difference
  - time span
  - critical points and events
- Factors that can facilitate or inhibit transition process and health outcomes:
  - personal, community, societal conditions
  - carer's ability to act as an advocate or access to information and support



Study Aims

A three-year, Scotland-wide research study – completion December 2019

PHASE 1

Systematic review international research on transitions & contributions of nurses

PHASE 2

1. Investigate and understand the **experience of transition** from child and adult health services; identify challenges/barriers to the provision of person centred care - **perspectives of nurses, families and carers**

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

PHASE 3

Develop and pilot an **education resource for nurses** - how best to manage transition between child and adult health services for people with learning disabilities and their families and carers

Setting the international context on transitions: a fragmented landscape for young people with intellectual disabilities and their families.

DR JULIET MACARTHUR

Phase 1: Systematic literature review

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

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

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REVIEW

WILEY JAN

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

Michael Brown PhD, MSc, RN, Professor[1] | Juliet Macarthur PhD, MSc, RN, Chief Nurse Research & Development[2] | Anna Higgins MRes, MA, Research Assistant[3] | Zoë Chouliara PhD, MSc, PsyDip, Professor of Mental Health[4]

[1]School of Nursing & Midwifery, Queen's University, Belfast, UK

[2]NHS Lothian, Edinburgh, UK

[3]School of Health & Social Care, Edinburgh Napier University, Edinburgh, UK

[4]Division in Mental Health & Counselling, Abertay University, Dundee, UK

Correspondence
Prof Michael Brown, School of Nursing & Midwifery, Queen's University, Belfast, Northern Ireland.
Email: m.j.brown@qub.ac.uk

Funding information
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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

Method

- 2007-2017
- Inclusion criteria – peer reviewed, English, young adults with intellectual disabilities, transition from child to adult health services
- Exclusion criteria – health transitions other patient groups e.g. diabetes/asthma, patients with learning difficulties
- PRISMA process → n=12 papers
- Critical Appraisal Skills Programme (CASP) Tool:
  - n=8 studies ‘high quality’
  - n=2 studies ‘moderate quality’
  - n=2 studies ‘low quality’

CASP
Critical Appraisal Skills Programme

Location and Design

Location

- United States n=6
- United Kingdom n=3
- France n=1
- Netherlands n=1
- Canada n=1

Design

- Quantitative cross-section n=6
- Longitudinal observation cohort n=1
- Qualitative
  - Interpretative n=1
  - Ethnography n=1
  - Grounded Theory n=2
- Mixed-method n=1

Themes:

1. Becoming an adult
2. Fragmented transition process and care
3. Parents as advocates in emotional turmoil
4. Making transitions happen: **Nursing Contributions**

Theme 1: Becoming an adult

- Balancing autonomy and decision making with parental involvement
- Changing expectations
- Perceptions of unnatural changes
- Progression towards self-management
- Financial disincentive for child health services to facilitate transitioning in some countries

Theme 2: Fragmented Transitions Process

- Poor preparation and planning
- Lack of information about the transitions process
- Lack of a lead agency and coordination
- Unplanned transfer
- Loss of patient information
- Gaps in follow-up following transition
- No holistic overview or coordination of needs within adult health services
- Falling between service gaps
- Incomplete or delayed transition

Theme 3: Parents as advocates in emotional turmoil

- Transitions as an ‘alien’ concept for families
- Parents as advocates - ‘fighting’ for services
- A maze of confusing information
- Parents’ resourcefulness as the driver for transitions
- A sense of loss
- A feeling of rejection
- Fear of the unknown
- Family reluctance to ‘let go’

Theme 4: Making Transitions Happen

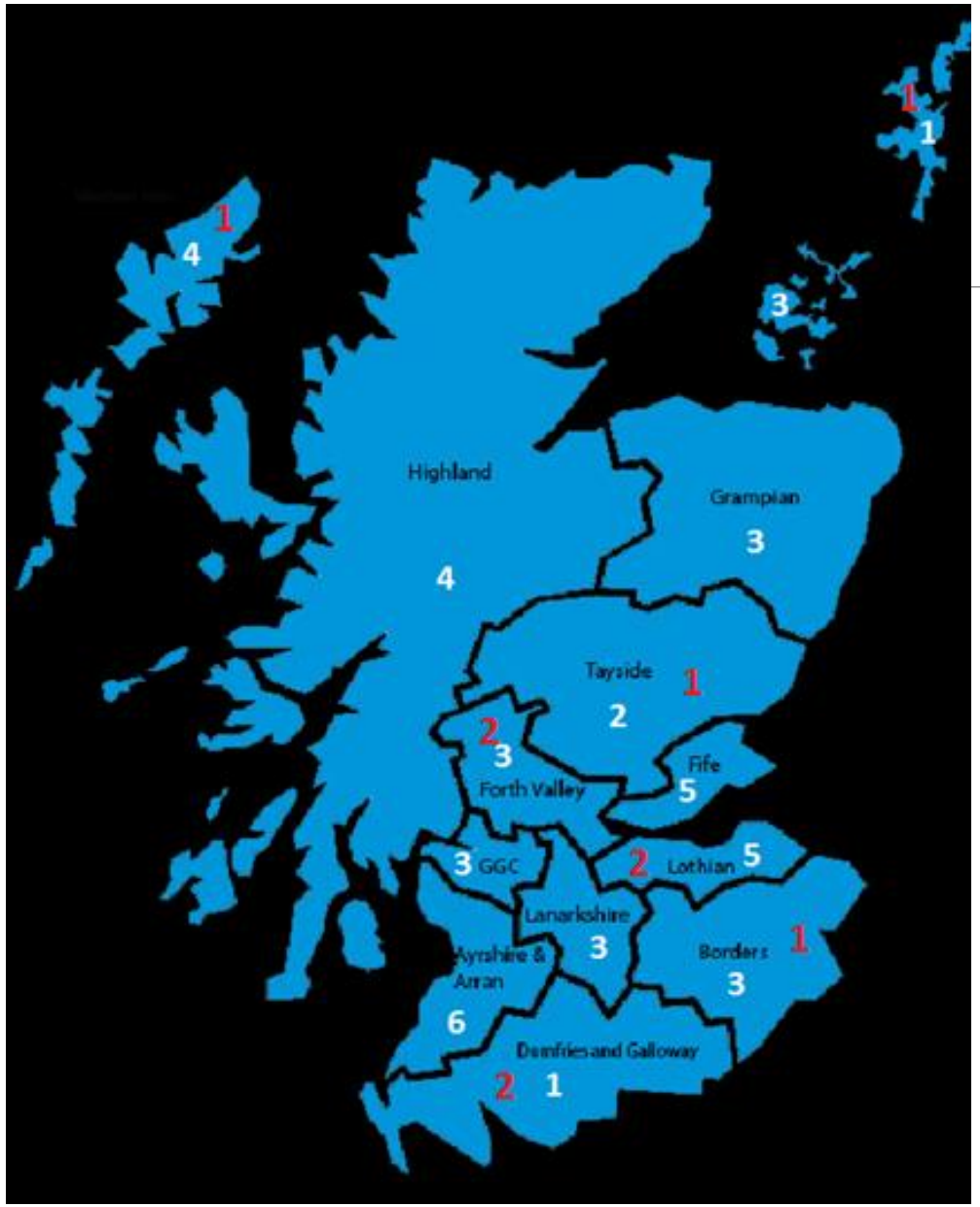
- Early initiation of the transitions process
- Early preparation of the transitions process
- Identifying a lead agency
- Outlining responsibilities
- Parent-provider relationship
- Improved joined-up multiagency working
- Effective information sharing
- Ensuring adequate follow-up and support
- Transitions Coordinator role
- **Nursing contributions**

Systematic review: implications for nursing

- Nurses well-placed to act as care providers, care coordinators and consultants
- Nurses well-placed to address unmet health needs
- Nurses recognised and valued for expert knowledge and adaptability
- Nurses providing support for transition and future care planning
- Nurses well-placed to develop and implement transition programs

Recommendations

- **Policy developments** –strategic-level planning to identify needs now and in the future; Guardianship issues and status of young adults
- **Practice developments** – joined up and collaborative working at an early stage; lead agency and coordinator; joint transitions clinics; transition coordinator role; communicating existing information effectively
- **Education developments** – education for young adults and their families; reflecting transition issues/needs in undergraduate & postgraduate education; legal status of young adults
- **Research developments** – transitions standards and quality indicators; impact & outcome studies; evaluation of roles, impact of education



Phase 2: Families and nurses

Methods and Participants

- 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

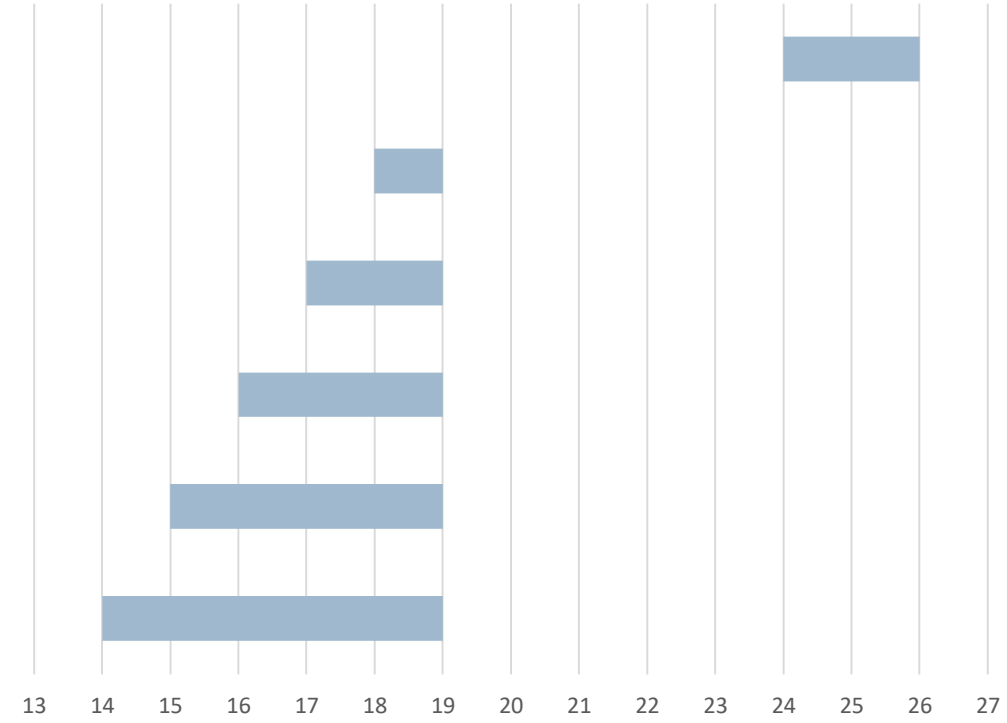
The views and experiences of families of young adults with intellectual disabilities in Scotland

ANNA HIGGINS

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



Families' experiences

Five main themes:

1) A deep sense of loss
2) An overwhelming process
3) Parents making transitions happen
4) A shock to the adult healthcare system
5) 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

A sense of isolation and vulnerability

[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. C07

THEME 2: An overwhelming process

Re-establishing a care team

(…) it's just the sheer fact that you almost have to start again with referrals in many cases, there doesn't seem to be a continuity or a good transition period… C10

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 you're first port of call? C01

THEME 3: Parents making transitions happen

Parents as 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

Unprepared adult services

(…) 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? C07

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

Parents taking responsibility for health monitoring

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 C10

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

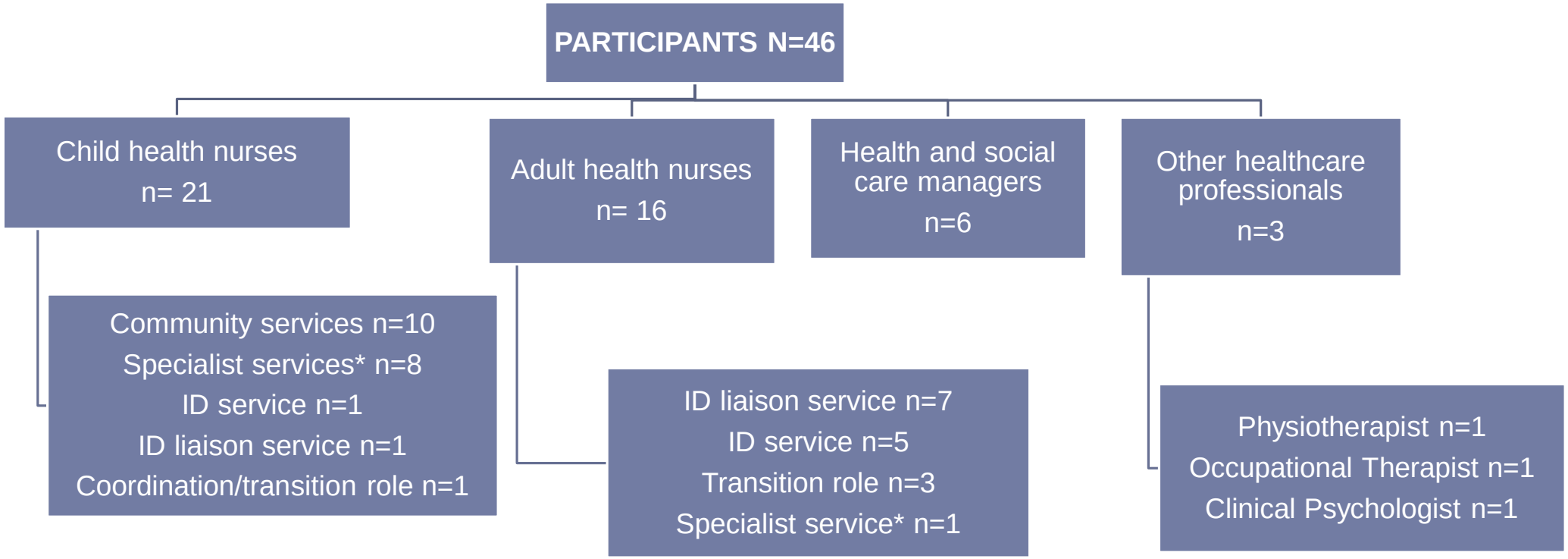
The unbearable pressure and its impact on health

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

The nursing role in effective transition planning for young adults with intellectual disabilities

PROFESSOR MICHAEL BROWN

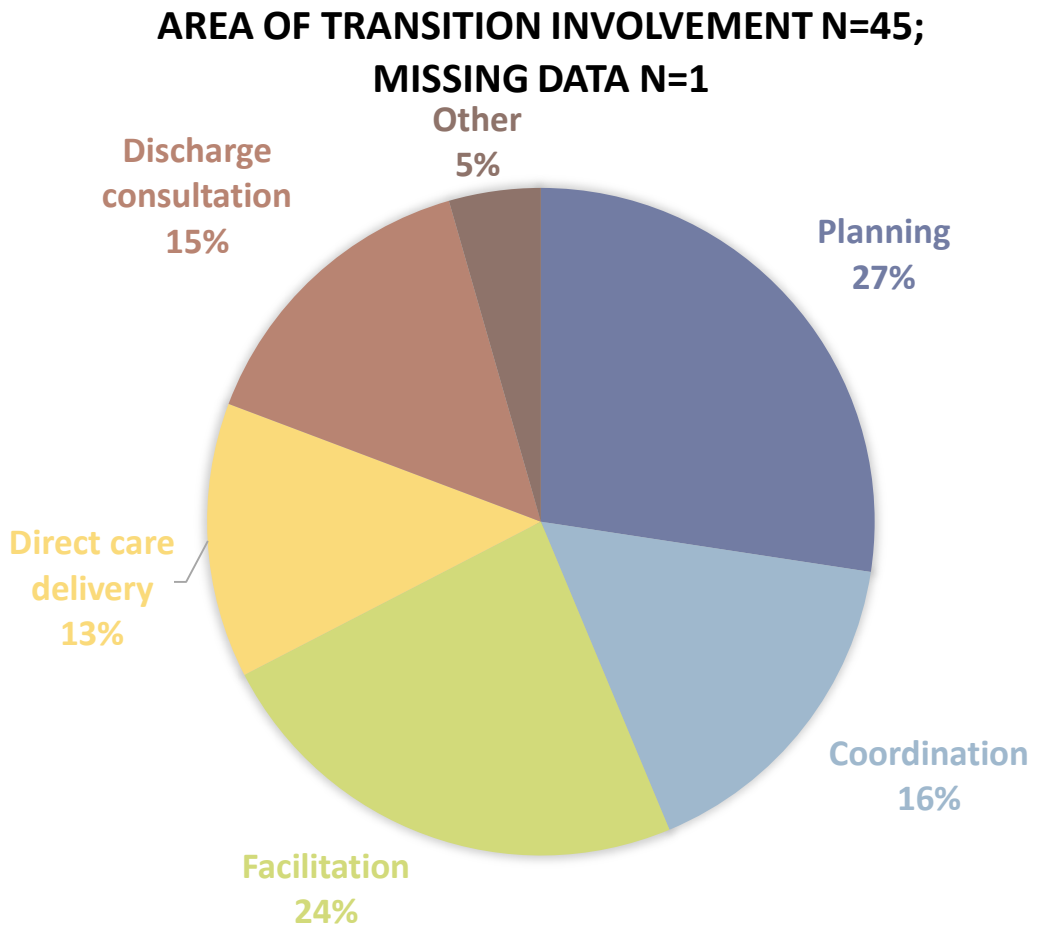
Nurse participants (n=46)



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

Demographic information: nurses

NURSES: DEMOGRAPHIC INFORMATION	
Gender	Female = 41 Male = 5
Age	20-29 = 1 30-39 = 5 40-49 = 14 50-59 = 23 60-69 = 2
Working hours	Full-time = 39 Part-time = 6



Results: nurses and carers

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

Each subtheme analysed and coded:

- areas for further development
- intended outcomes
- good practice examples identified

Theme 1: Strategic level focus

- Integration of 'transitions' within Government & Health and Social Care Policy
- Strategic leadership required to ensure 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 concept of 'transition' and what the process involves to young adult and their family
- Early initiation of transitions process required to ensure the young adult and their family are at centre of 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 changing legal status

Theme 4: Multiagency transition planning

- Communication, information sharing and care coordination required to facilitate smooth transitions across services and agencies involved in providing services and support
- Lead coordinator required to ensure information is collated, shared and acted upon
- Multiagency assessment of needs, including health assessments, required to inform the development of care plans
- Nurses have 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 needs of young adult with intellectual disabilities to ensure a smooth transition
- Nurses have a key role in ensuring handover of care from child to adult health services is smooth and effective
- Possible role of nurses in primary care and intellectual disability services in ensuring is overview and coordination of 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 intellectual 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

The development and piloting of an educational resource “Transitions from child to adult health care for young adults with learning disabilities” for nurses.

ANNA HIGGINS

Phase 3: Educational resource - identifying aims

“Transitions from child to adult health care for young adults with learning disabilities”

Resource aims: 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 the process.

Educational resource: content development

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

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

UNIT 3: Needs of the young adult with LD 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

Educational resource: design

Design features:

- Reflective questions
- Case study
- Links to external resources
- Online NOVI Survey

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?**

0 / 2000

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 pulling 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

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.mwcscot.org.uk/the-law/adults-with-incapacity-act/welfare-guardianship/

Resource pilot and evaluation

AIMS

- Feasibility and acceptability

METHODS

- Questionnaire
  - Overall perception
  - General satisfaction and learning outcomes
  - Application to clinical practice
- Optional: short follow-up telephone interview

Educational resource evaluation: recruitment and sample (n=11)

Demographic information		
NHS Health Board	NHS Lothian n=8	NHS Ayrshire and Arran n=3
Area of practice	Children's services n=4	Adult service n=7
Nursing role	Intellectual Disability / Complex Needs n=2 Neurosurgery n=2 Epilepsy n=3	Diabetes n=1 Community Children's Nursing n=1 District Nursing n=2

Number of times involved in transition planning in the last 2 years	Number of caseload patients with LD who transitioned in the last 2 years	Estimated number of patients with LD on case load every year
Under 5 times n=3	Under 5 n=7	1-10 n=5
5-10 times n=4	5-10 n=2	20-30 n=3
11-20 times n=1	11-20 n=1	Over 80 n=3
21-30 n=3	Over 20 n= 1	

Results: overall perception

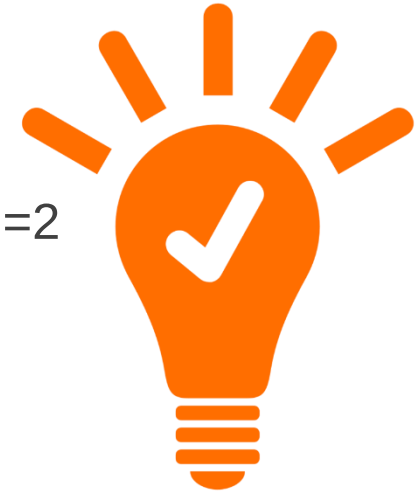
	Positive feedback	Requires improvement
Resource length	“about right” n=6	“too long” n=5
The use of a case study	“helpful” n=10	“not helpful” n=1
Visual presentation	Engaging and easy to use n=7	Improvements needed n=4
External links	Helpful / quite helpful and likely to follow up on them n=7	“unsure” n=4

Results: satisfaction and learning outcomes

	Positive feedback	Requires improvement
Resource level in relation to existing knowledge	“about right” n=7	“too basic” n=4
Learning outcomes	“mostly achieved” n= 6	“unsure” if achieved n=5

Areas of new learning and enhanced awareness:

- legal aspects of transition n=7
- the importance of a formalised transition pathway n=3
- the role of the family n=3
- the role of nurses and other professionals in transition n=2
- the needs of young adults with LD n=2
- emergency care planning n=1
- reasonable adjustments n=1
- the meaning of transition n=1
- health passports n=1
- stresses associated with transition n=1



Results: application to clinical practice

	Positive feedback	Requires improvement
Content relevant and applicable to nursing practice	Yes n=5	Somewhat n=4 Unsure n=2
reflective questions	helpful (n=7)	Not helpful / unsure n=4

“it gets you to reflect on what you’re doing, why and can you do it better” P11

Qualitative interviews: results (n=3)

Positive feedback:

- a good overview of main issues
- suitable for nurses at different levels
- raised awareness of the needs of people with complex needs and their parents / carers

Requires improvement:

- reflective questions repetitive and lack of clarity on how to use them
- expectations and learning outcomes not explained clearly enough
- no clear division between teaching and reflective questions

Next steps

- Revising the education resource based on phase 3 findings
- Potential for future resource development and implementation?
- Further research – Child and Adolescent Mental Health?
- Available to all registered nurses and other professionals?
- Integrated within undergraduate nurse education?

Conclusions

- Number of young adults with intellectual disabilities & complex needs is increasing
- International evidence indicates health transitions can be highly challenging for parents and may impact on health outcomes of the young person
- Period of change – developmental, legal, organisational, geographical
- Scottish study demonstrates strong parallels with systematic review
- Need for strategic responsibility in planning and resources
- Examples of good practice characterised by lead professional, early engagement, transition processes and effective communication
- Nurses have key role to play – LD nurses, school nurses, specialist nurses, practice nurses – all nurses

Contacts

m.j.brown@qub.ac.uk

a.higgins@napier.ac.uk

juliet.macarthur@nhslothian.scot.nhs.uk