Transition of young people with long term conditions (with a focus on people with ASD)

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Young people, parents;10 partners, NHS Trusts

On behalf of the co-investigator team (Colver, Le Couteur)
Overview

Adolescence
Demography
Brain
Developmentally appropriate healthcare (DAH)

5-year Research Programme on Transition
Aims and methods and overall implications
Young people with autism spectrum disorder
### Transition – but which transition?

<table>
<thead>
<tr>
<th>Developmental stage</th>
<th>Transitions</th>
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| Early Adolescence 10-13      | Pubertal  
Social  
Health self-management  
Primary to secondary school |
| Mid Adolescence 14-16        | Pubertal  
Social  
Health self-management  
School to college          |
| Late Adolescence 17-19       | From parental home  
Pediatric to adult health care  
Health self-management  
College to Higher education/training/Employment |
| Emerging adulthood 20-24     | Independent living  
Parenthood  
Health self-management  
Higher education to employment |
What is meant by ‘Transition’ and ‘Transfer’ of young people?

‘Transition’ is the purposeful, planned process that addresses the medical, psychosocial and educational needs of adolescents and young adults with long term conditions, as they move from child-centred to adult-oriented healthcare systems.

‘Transfer’ is the formal event when the healthcare of a young person moves from services for children to services for adults.
The number of young people in transition to adulthood is increasing

In an NHS Trust serving a population of 270,000, about 100 young people with long term conditions reach age 16 each year. As transition takes place over about seven years, the number in transition at any time in a typical Trust is about 700
The adolescent brain

Whether adolescence is real or a social construction, it is now certain that the brain changes structurally and functionally during adolescence.

The changes continue from ages 11-25

Colver and Longwell, Archives of Disease in Childhood 2013; 98: 902-907
Functions of the pre-frontal cortex

- Executive control of short and long term planning
- Emotional regulation
- Decision making
- Impulse control
- Reflective thought
Understand

My brain is going through a lot at the moment...

It’s a completely different shape to what it was when I was a child, and what it will be when I’m an adult.

Since starting adolescence I’ve lost 15% of my grey matter as synapses I don’t use have been pruned away and the ones I need have been strengthened.

Having my frontal cortex closed for refurbishment makes being rational quite challenging...

Added to that there’s all the freedom I’m just discovering! It’s amazing but comes with pressures – image is a big one. And anxiety about exams!

Having to go into hospital right now would be a nightmare!!
The concept ‘Developmentally Appropriate Healthcare (DAH)’ is now well accepted

1. 2011. Canadian Paediatric Society ; Society of Adolescent Health. The need for proper transitional care is evident as healthcare providers all around the world are taking measures to ensure that developmentally appropriate care is made available for young adults with chronic illness.


3. 2016. NICE. To provide effective support to young people during their transition, practitioners need to understand the concept of developmentally appropriate care and what it means within the context of their role and service. Cited Transition Programme findings

4. 2018. Royal College of Physicians. .....they should therefore receive developmentally appropriate health care.

5. 2018. RCPCH Standards - Standard 6. Service planners ensure there is a designated person within the child health service who is responsible for ensuring that developmentally appropriate transitional care is provided and coordinated by both child and adult services.

6. 2018. NHS 10 year plan. .....that offer person-centred and age appropriate care for mental and physical health needs, rather than an arbitrary transition to adult services based on age not need.
Defining DAH

‘Developmentally Appropriate Healthcare’ recognises the changing biopsychosocial developmental needs of young people, and the need to empower young people by embedding health education and health promotion in consultations.

In operational terms, DAH focuses on the approach of healthcare professionals to and engagement with each young person and their carers, alongside the structure of the organisations in which care takes place (Farre et al., Archives of Disease in Childhood 2016)
Operationalising DAH

**Elements of the Environment:**

- Consulting with the young person alone
- Confidentiality explained
- Flexible access: clinic times
- Information about what to expect: navigation
- Environment: magazines, pictures, staff clothing
Elements of Professional Behaviour:

Be approachable and welcoming. Adolescents like friendliness, with much facial expression.

Graded opportunities for self-management and risk taking

Avoid key decisions at times of excitement or stress

Adolescent health: sexual health, substance misuse etc.

Consider possibility of associated mental health problems

Health is just one of many upheavals for a young person: education, sexuality, separation from parents, friendships, etc.
Overall purpose

To promote the quality of life and health of young people with long term conditions, by generating evidence to enable purchasers and providers of health services to facilitate successful transition of young people from child to adult health services, thereby improving health and social outcomes
The Research Programme had three objectives

1. Work with young people with long term conditions to determine what successful transition means to them and what is important in their transitional care

2. Identify the features of transitional care that are effective and efficient

3. Determine how transitional care should be organised, provided and commissioned
Research addressing Objective 1

Establish a Programme Young Person Working Group - UP

Evaluation of a “health passport” in a study co-led by UP

A Q sort study to explore what young people mean by ‘successful transition’
Examples of work

Input to most programme Work Packages
Responded to findings of Work Packages: e.g. Training DVDs
Dissemination activities throughout the Programme. Blogs for website.
Interview panels and the External Advisory Board.
Training materials in partnership with the RCPCH, MindEd & AYPH.
Worked with Council for Disabled Children to disseminate to other young people’s groups & develop workshop resources.
Delivered their own programme work packages: i.e. Improving HCP DAH skills; Workshop resources; Health Passports
Q-sort: Young people’s attitudes

40 young people with wide range of long term conditions

Four broad approaches were identified:

• Laid-back
• Anxious
• Wanting to be in control
• Socially-oriented (welcoming support from and frequent discussions with family, friends and healthcare professionals)

‘Personality types’. Emphasises the need to individualise transition planning for each young person including consideration of their communication needs and skills
Three-year longitudinal study.

Young people visited on four occasions, a year apart.

First visit before transfer to adult care

374 young people from 10 secondary care UK health service providers.

Young people had one of three conditions:
- Diabetes, as exemplar of chronic illness
- Cerebral palsy, as exemplar of complex physical problem
- Autism with associated mental health problem, as exemplar of neurodevelopmental problem

Questionnaires administered to capture outcomes and exposure to ‘proposed beneficial features’ in previous year.
Hypothesis for longitudinal study

In combination and separately for those with diabetes, cerebral palsy or autism spectrum disorder, access to proposed beneficial features determines better health and social outcomes.
YP in Longitudinal Study

Longitudinal study – three years (82% transferred, median age 19 years)

- 150 Diabetes
- 106 Cerebral palsy
- 118 ASD and mental health

374 young people 14-18 years

73% retention

112 Diabetes
74 Cerebral palsy
88 Autism
Proposed beneficial features

PBFs are features of transition services that have been recommended as good practice and for which there is preliminary evidence of benefit

1. Meet adult team before transfer
2. Age-banded clinic
3. Appropriate parent involvement
4. Written transition plan
5. Promotion of young person’s confidence in managing their health condition (health self-efficacy)

6. Key worker - advocate for the individual

7. Coordinated team

8. Holistic life-skills training

9. Transition manager for clinical team
The PBFs that services report they provide

Recommended features of good transition services are poorly provided in the UK

Fewer than half of services stated that they provided an age-banded clinic, written transition plan, coordinator at managerial level, a protocol for promotion of health self-efficacy, or holistic life-skills training
Outcomes

• Participation: Rotterdam Transition Profile Social Participation Scale
• Wellbeing: Warwick-Edinburgh Wellbeing Scale
• Young person/carer experience of services: Mind the Gap Scale
• Condition specific outcomes:
  – Diabetes: HbA1c, eye screening, keto-acidosis, out-patient attendance
  – Cerebral palsy: Unmet needs relating to pain, spasticity management, epilepsy and other health needs
  – Autism: Hospital Anxiety and Depression Scale (HADS)
Which PBFs helped?


Service features associated with better outcomes:

• Meeting the adult team before transfer

• Promotion of young person’s confidence in managing their health condition (health self-efficacy)

• Appropriate parent involvement
Percentage of "yes" responses for the three ‘beneficial features’ by services for each condition

Meet adult team
Health self-efficacy
Parent involvement

ASD
CP
DM

Beneficial feature
Which PBFs did not help?

Inconsistent associations:

- Having a key worker

We found no evidence for:

- Having a transition plan
- Having access to holistic life-skills training
- Attending an age-banded clinic
- Having a transition manager for the clinical team
- Coordinated team
Maximal service uptake and values for money

Evidence for maximal service uptake:

- Appropriate parental involvement
- Good communication with young people
- Encourage young people to make decisions about healthcare

Evidence for value for money

- Appropriate parental involvement
- Promotion of health self-efficacy
Conclusions and implications

Many features are infrequently provided

Mismatch between what service say it provides and what young people experience

Our specific recommendations: appropriate parent involvement, promotion of health self-efficacy, and meeting the adult team before transfer

Require organisation and training but are not costly to implement
Research addressing Objective 3
(To determine how transitional care should be organised, provided and commissioned)

1. Process evaluation of introduction of “Developmentally Appropriate Healthcare”

2. Study of commissioning:
   - Literature review
   - 35 interviews with commissioners
   - Four in depth site visits investigating barriers to and facilitators of commissioning for transitional healthcare
   - Testing of our proposed commissioning recommendations in a series of meetings with commissioners
Barriers and solutions to DAH provision

- **Ethnographic study** examining the implementation and embedding of DAH organisation-wide; took place in **Three hospitals** providing paediatric tertiary, adult tertiary and general secondary care in England

- **192 participants**, including health professionals (n=121) and managers (n=71). **65 formal qualitative interviews** and **approx. 1600 hours of non-participant observations** in clinics, wards and meetings
Organisational barriers to introducing DAH:

i) no single group in an NHS Trust was responsible for young people

ii) perceived small numbers of young people attending hospital

iii) the mind-set and skill-set of many staff

iv) good practices led by enthusiasts in one paediatric medical specialty rarely generalised to other paediatric specialties or adult services
Solutions to DAH provision

i) buy-in and formal support at Chief Executive and Board Level; and with senior managers in both child and adult services

ii) Ensure that DAH planning engages adult and child services from the outset

iii) A Trust-wide strategy including training for DAH

Rapley et al, BMJ Open 2019
DAH Toolkit cards

Making healthcare work for young people

A toolkit to support delivery of “Developmentally Appropriate Healthcare” in the NHS

See: [www.northumbria.nhs.uk/dahtoolkit](http://www.northumbria.nhs.uk/dahtoolkit) for free access to the toolkit to use in your organisation

Please share this card and the website with others
Programme implications
(See NIHR Report and NIHR Signal)

1. Commission for transition in adult services as well as child services.
   Where appropriate, commission for transfer to primary care.

2. A framework to provide ‘Developmentally Appropriate Healthcare’ across all NHS Provider Organisations should be commissioned with the stipulation that this is owned at Chief Executive and Board level. We have developed a toolkit to support implementation.
Implications

3. NHS Providers should adopt an organisation-wide approach to implementation of better transitional care. Needs a Transition Steering Committee and Coordinator.

4. Child health clinicians should plan transition procedures jointly with adult clinicians and general practice.
Implications

5. Young people adopted one of four broad interaction styles when approaching transition:

- ‘laid-back’
- ‘anxious’
- ‘seeking autonomy’ (being in control)
- ‘socially-oriented’ (welcoming support from and frequent discussions with family, friends and healthcare professionals).
6. The following service features were associated with better outcomes:

- Meeting the adult team before transfer
- Promotion of young person’s confidence in managing their health condition (health self-efficacy)
- Appropriate parent involvement
6. (continued)

We found no evidence for:

- Having a key worker
- Having a transition plan
- Having access to holistic life-skills training
- Attending an age-banded clinic
- Having a transition manager for the clinical team
- Coordinated team
Implications

7. Maximal service uptake:
   - Appropriate parental involvement
   - Good communication with young people
   - Encourage young people to make their own decisions about healthcare
Impact: NHS (E) 10-year plan

Page 46 “The NHS plays a crucial role in improving the health of children and young people: from pregnancy, …………….; to help in navigating the demanding **transition** to adulthood.”

Page 51 “A new approach to young adult mental health services for people aged 18-25 will support the **transition** to adulthood.”

Page 52 “Keyworker support will also be extended……………………………including to young people in **transition** to adult services.”

Page 55 “Failure to achieve a safe **transition** can lead to disengagement, failure to take responsibility for their condition and ultimately poorer health outcomes. By 2028 we aim to move towards service models for young people that offer person-centred and age-appropriate care for mental and physical health needs, rather than an arbitrary transition to adult services based on age not need.”

Page 119 “The NHS, together with partners at national and local level, will commit to improve outcomes for our most vulnerable children ……………., by improving access to targeted support for these children, especially during **transition** to adult services.”
Unique design
Commissioning: Adult and child services
Developmentally Appropriate Healthcare

Three features:
• Appropriate parent involvement
• Promotion of young person’s confidence in managing their health condition
• Meet adult team before transfer

Conclusion
One-minute elevator conversation
Most people are discharged to GPs; we know that most people who transfer to AMHS have an ‘enduring MHC’ transfer to adult services.

TRACK studies show limited access for YP with neurodevelopmental disorders, including ASD.

Numerous reasons for this include:

- YP refusal / resolution of MHC
- Assumptions wouldn’t meet criteria, or professionals didn’t have expertise

Young people with ASD may not access secondary mental health services and/or relevant support at a time of increased uncertainty and risk.
Thematic analysis identified seven categories

• Concerns about ASD/ developmental and adolescent issues
• Engagement
• Family involvement
• Access to support services
• Educational and post-schooling opportunities
• Impact of mental health
• Crisis including self-harm

(Merrick et al. and Le Couteur, BMJ Open (to be published 2020))
Healthcare transfer for 65% of young people with ASD was to primary care compared to over 90% of young people with diabetes who transferred to secondary adult healthcare services.

Diagnosis of ADHD and taking medication were the best predictors of transfer to AMHS.

Across health conditions, parents more dissatisfied with services than young people.
Mind the Gap: Young person report
Health and wellbeing in young people with ASD

Wellbeing scores lowest for young people with ASD
Warwick-Edinburgh Wellbeing Scale

![Bar chart showing median scores for different visits and conditions]

- Baseline
- Visit 2
- Visit 3
- Visit 4

Legend:
- ASD
- CP
- DM
Health and wellbeing in young people with ASD

Hospital Anxiety and Depression Scale (HADS) - a 14 item self-report questionnaire designed to measure mental health symptoms in the week prior to the research visit (reliable and valid in young adults)

At each visit over the 3-years nearly 60% of young people had abnormal or borderline abnormal HADS anxiety scores
Associations with better HADS outcome

Compared with those who had poorer outcomes on HADS trajectories over time, young people in the ‘doing well’ group had:

- Successful engagement by the young person (and their family) with services (school counsellors, social services and mental health services)
- Experienced relative stability in educational provision and family life

Evidence that these young people were gaining skills in:

Social participation, learning to manage their mental health concerns, developing an awareness of the impact of their ASD and learning to negotiate, with support, some of the developmentally appropriate aspects of transition (elements of health self-efficacy)
Associations with poorer outcome

For some, discharge to primary care was not successful with crisis team involvement and time-limited support from AMHS before being discharged again.

A common concern from families and young people was their perceived lack of support and ‘unmet need’ – much more common in the poorer outcome groups.

The importance of positive parent support was clear, with parents taking on roles co-ordinating support and in some cases providing employment opportunities.

The poorer outcome groups were characterised by poor attendance and compliance with treatment, more significant impact of their ASD on progress, negative experiences with services leading to longer term disengagement, and young people not able to access services offered.

People at University more likely to struggle – adjustments to academic and social environments.
How can we better support young people with ASD through transition?

Main transition programme findings are directly applicable – advocate for evidence based organisational change to support Transition

Context of service organisation outside everyday control, so what can we do day by day?

Personal characteristics key (social, cognitive ability)

Appreciate skill differences as well as deficits

Understand what a ‘good outcome’ means for each young person and whether traditional outcomes of transition are developmentally appropriate

Early preparation and planning with young people and their families to maximise opportunities for successful engagement with the young person, and work at an appropriate pace
How can we better support young people with ASD through transition?

Using a regular self-report check (e.g. HADS) may help young people, their families and the professionals supporting them identify the young person’s trajectory, and the impact of individual and family life experience.

This may promote discussion about ways to manage mental health needs that interfere with personal goals and achievements.

HADS might help identify those individuals especially at risk of negative outcomes and crisis presentations.

Identify their own transition goals for participation and future social relationships before they disengage with services and/or are discharged from CAMHS.
Website:  http://research.ncl.ac.uk/transition
(from which our 14 published papers can be downloaded open access as pdfs)


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