

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

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# Disclaimer and thanks



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Young people, parents; 10 partners, NHS Trusts

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

# Overview

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## 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?



Developmental stage	Transitions
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 <b><u>Paediatric to adult health care</u></b> Health self-management College to Higher education/training/Employment
Emerging adulthood 20-24 years	Independent living Parenthood Health self-management Higher education to employment

# What is meant by 'Transition' and 'Transfer' of young people?

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'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.

# Number of young people in transition



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

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- 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.
2. 2016. American Medical Association. Clinical systems must support **developmentally appropriate care, including** strategies for private and confidential care.
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

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‘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

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## 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

# Operationalising DAH



## 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.

# Transition Research Programme

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## 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

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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

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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

# Research addressing Objective 2

(To identify the features of transitional care that are effective and efficient)



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

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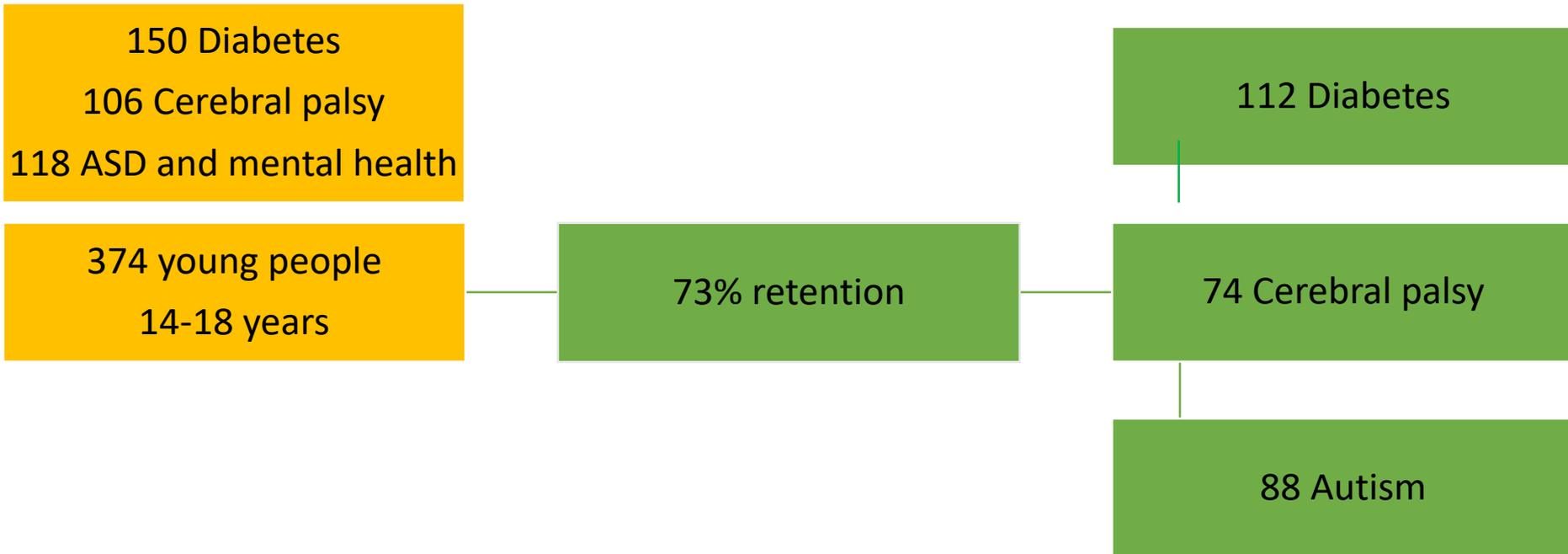


In combination and separately for those with diabetes, cerebral palsy or autism spectrum disorder, access to *proposed beneficial features* determines better *health and social outcomes*

# YP in Longitudinal Study



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



# Proposed beneficial features

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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

# Proposed beneficial features

(continued)



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?

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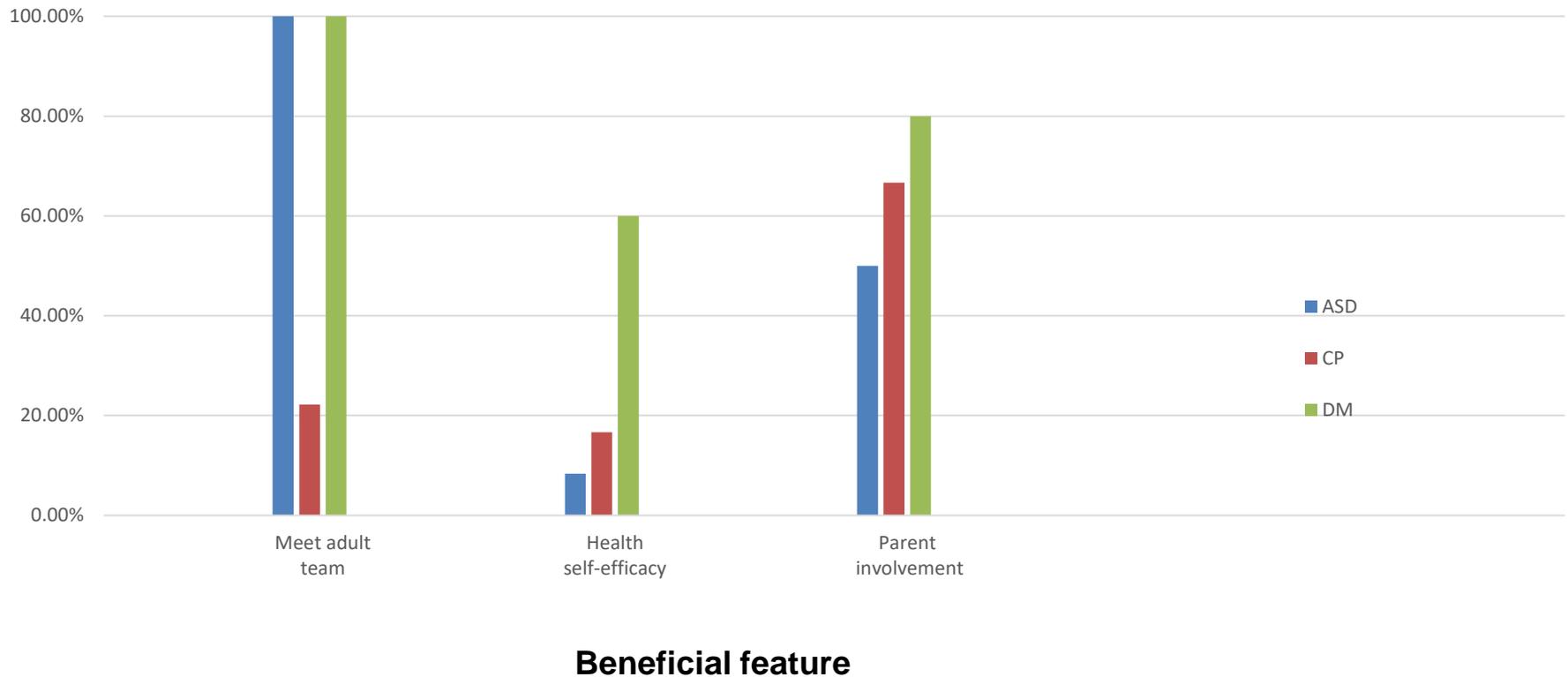


Colver *et al.* *BMC Medicine* (2018) 16:111

## 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



# Which PBFs did not help?



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## 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

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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

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# 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

# Findings about DAH

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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

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- 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

Northumbria  
Healthcare   
NHS Foundation Trust

# Programme implications (See NIHR Report and NIHR Signal)



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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

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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

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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).

# Implications

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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

# Implications



## 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

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## 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.”

# Conclusion

## One-minute elevator conversation

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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

# Young people with ASD and transition



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

# Young peoples' experiences of transition

(n=118 ASD and mental health conditions, no significant intellectual disability)



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))

# Transfer destination, satisfaction with services



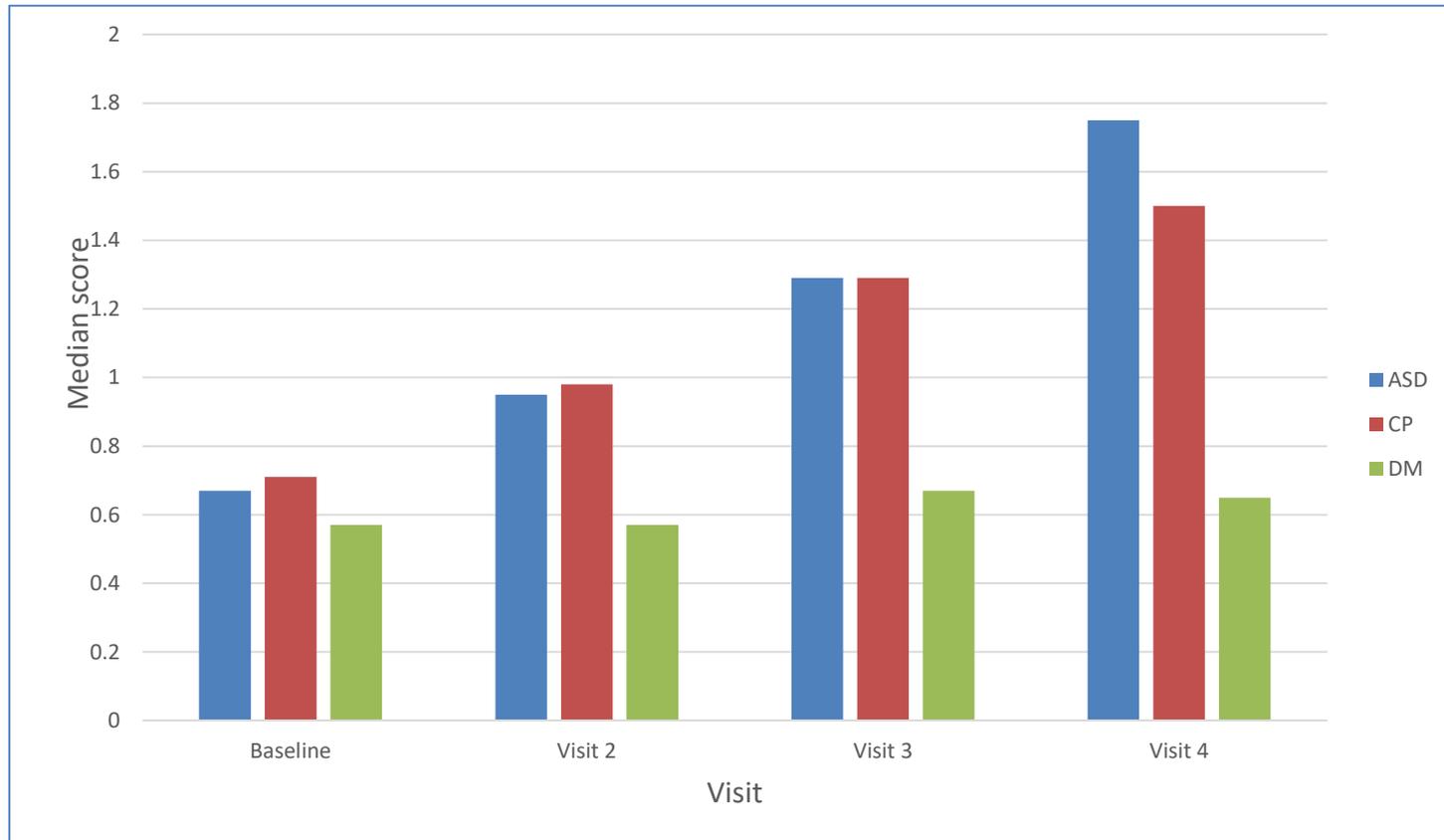
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Healthcare transfer for 65% of young people with ASD was to primary care compared to over 90% of young people with diabetes who transferred to secondary adult healthcare services

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



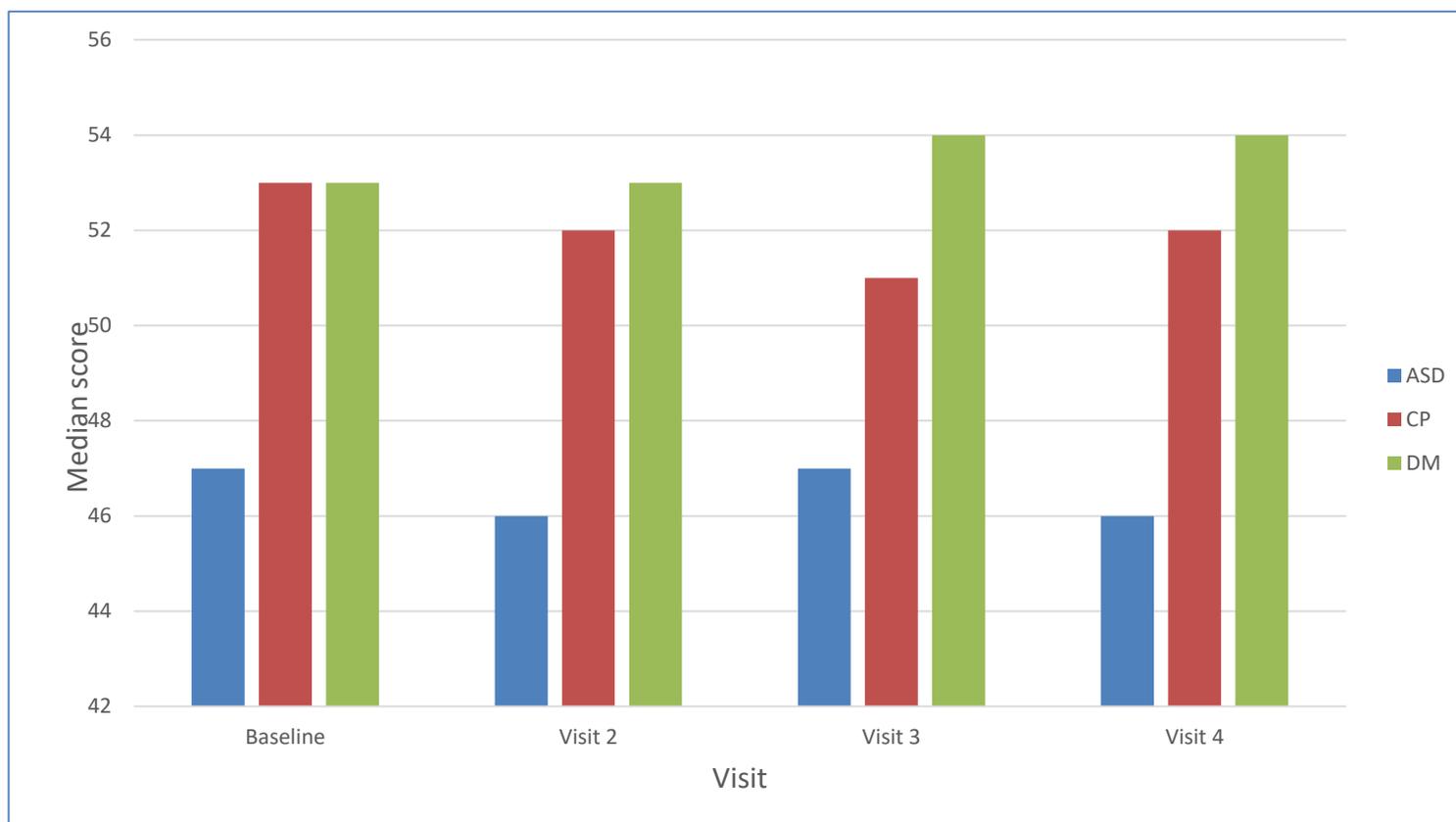
# Health and wellbeing in young people with ASD

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Wellbeing scores lowest for young people with ASD

# Warwick-Edinburgh Wellbeing Scale



# Health and wellbeing in young people with ASD

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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?



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**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?



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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)

Final Report: [www.ncbi.nlm.nih.gov/pubmed/31116547](http://www.ncbi.nlm.nih.gov/pubmed/31116547)

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