

# Transition Research Programme

---



Allan Colver

Professor of Community Child Health

Newcastle University

# Disclaimer and thanks

---



- This conference summarises independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0610-10112). The views expressed are those of the presenters and not necessarily those of the NHS, the NIHR or the Department of Health
- We acknowledge the support of the NIHR Clinical Research Network
- We thank the sponsor, Northumbria Healthcare NHS Foundation Trust
- This presentation is made on behalf of the Transition Collaborative Research Group

# Shakespeare

---



## Romeo and Juliet

Shakespeare looks at teenagers in a spirit of wonder.

Romeo and Juliet meet at a party, are attracted to each other, immediately realise their families are enemies but the same night are talking outside Juliet's bedroom, and within a few days are married secretly. They show the adolescent features of peer reinforcement, close confiding relationships, novelty seeking, impulsivity, not looking far ahead.

# Healthtalk



Video removed

# Outline

---



Adolescence

Transition and Transfer

Aims and objectives of our research

Implications of our research

Conclusion

# Statistics: England 2010/11

---



More young people in the UK aged 10-19 than aged 1-9.

In a typical NHS Trust serving a population of 270,000:

- 3,700 young people aged 10-19 admitted to hospital – an increase of 15% since 1999
- More hospital admissions in those aged 10-19 than aged 1-9
- 24,500 young people aged 10-19 attended outpatients

# Developmentally appropriate healthcare (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.

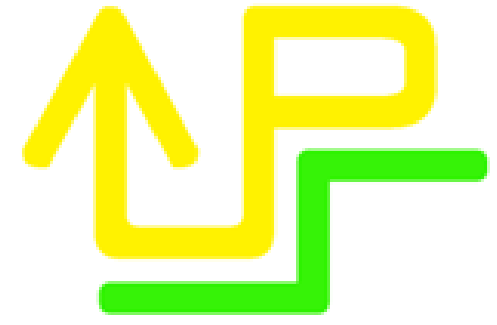
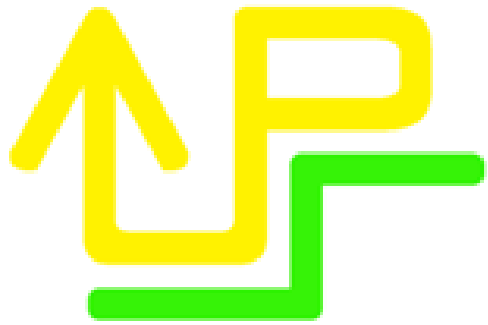
# Islington Group

---



Video removed





# UP Group

---



Video removed

# 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.

# Why Transition is important

---



Many children with long term conditions, who now live into adulthood, might previously have died

# Numbers 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.

# Why Transition is important

---



Many children with long term conditions, who now live into adulthood, might previously have died

Absence of some adult services

Evidence of poor outcomes following transition

Some health conditions have special vulnerabilities at this age

Clinicians in adult health services treat 17-24-year-olds as if they were adults; clinicians in child services treat 12-16-year-olds as if they were children

# Overall purpose of the Research Programme

---



To promote the quality of life and health of young people with long term conditions, by generating evidence to enable NHS Commissioners and Trusts to facilitate successful transition of young people from child to adult health services, thereby improving health and social outcomes

# NIHR Programme Grant on Transition

---



- 5 years, 2012-17
- 12 co-applicants
- 10 partners including Newcastle University, Council for Disabled Children and National Health Service 'Provider Organisations'

<http://research.ncl.ac.uk/transition/>



# The 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

# 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*

# 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

# Implications

---



There are 7 main implications of our research, which I will cover in turn.

The talks that follow mine will summarise methods used and will show how those methods and analyses contributed to the 7 implications I set out.

# Implications

---



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 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).

# Implications

---



6. The following service features were associate 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. (cont'd)

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

# Implications

---



6. The following service features were associate 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

---



## 7. Maximal service uptake:

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

## Value for money

- Appropriate parental involvement
- Promotion of health self-efficacy

# Conclusion

## One-minute elevator conversation

---



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



<http://research.ncl.ac.uk/transition/>

# Evidence for service features

---



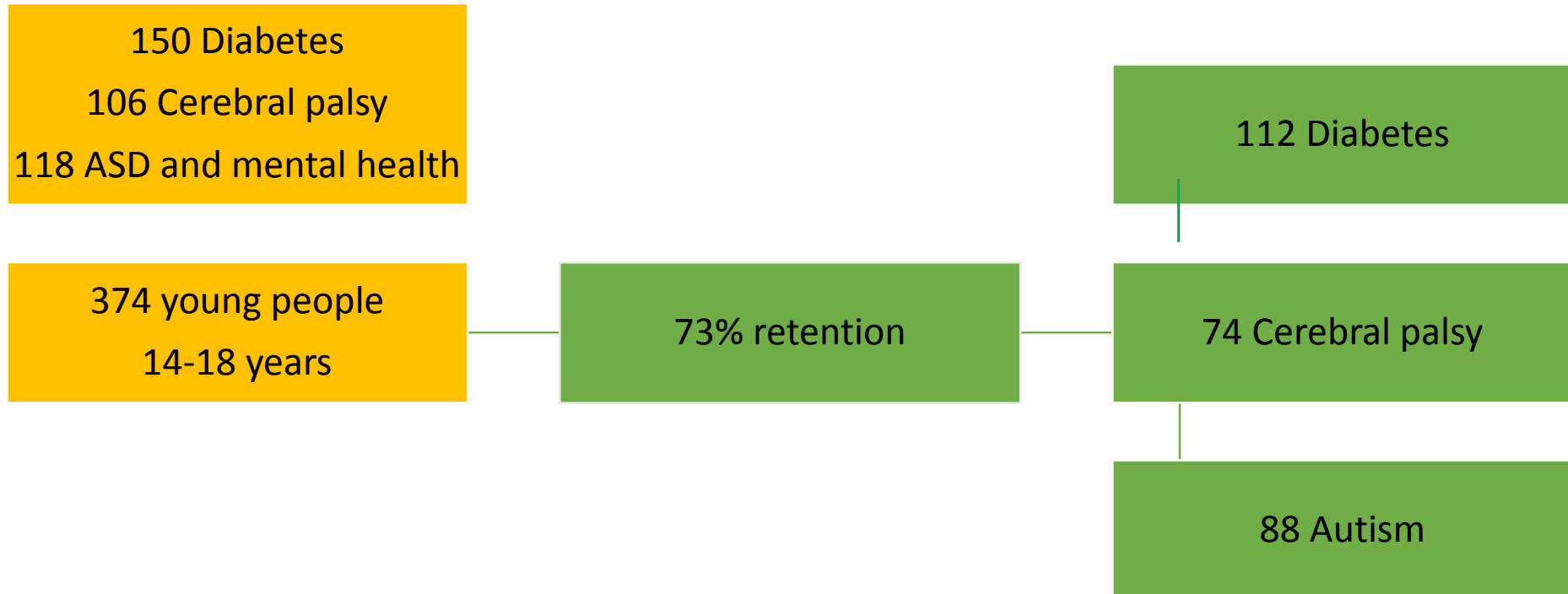
Helen McConachie

Professor of Child Clinical Psychology  
Newcastle University

# Evidence for service features



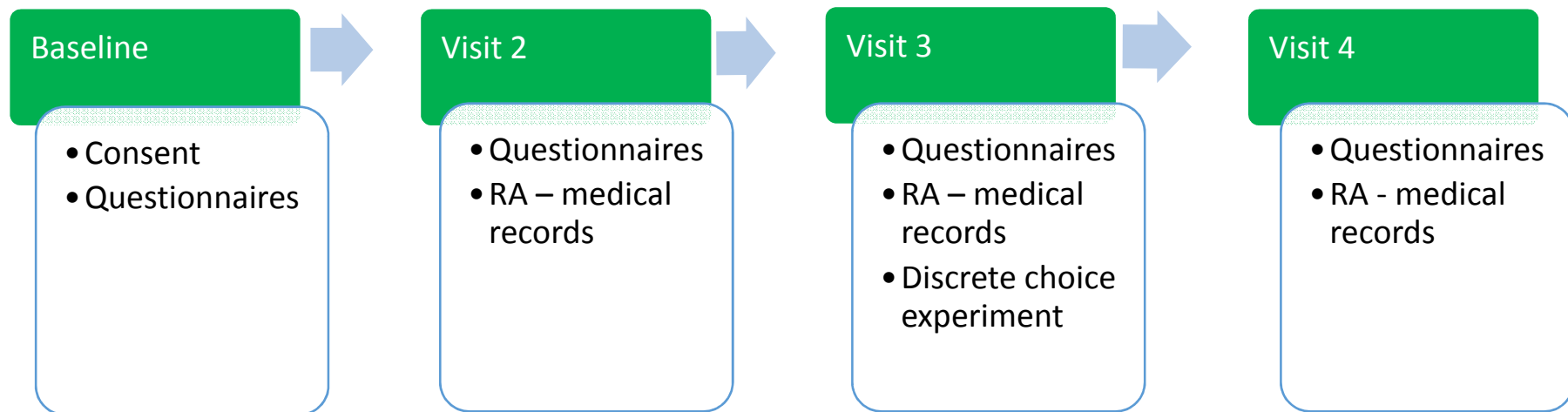
Longitudinal study – three years



# Evidence for service features



Longitudinal study – three years



Embedded qualitative study with 13 young people + family member, health professional



# Evidence for service features

---



## Outcomes measured

### *Generic*

- Satisfaction with services
- Independence in appointments
- Wellbeing
- Participation in life domains
- Social participation

### *Diabetes*

- Satisfactory clinical progression
- Time to first adult appointment

### *Cerebral palsy*

- Unmet needs

### *ASD*

- Anxiety, Depression

# Evidence for service features

---



## Proposed beneficial features

- Age-banded clinic
- Meet adult team before transfer
- Written transition plan
- Holistic life-skills training
- Transition manager for clinical team
- Key worker
- Coordinated team
- Appropriate parent involvement
- Promotion of young person's confidence in managing their health condition (health self-efficacy)

# Evidence for service features



Proposed beneficial features – trajectory over three years

## ***At least once***

- Age-banded clinic
- Meet adult team before transfer
- Written transition plan
- Holistic life-skills training
- Transition manager for clinical team

## ***At least once during two years***

- Key worker
- Coordinated team

## ***At all years***

- Appropriate parent involvement
- Promotion of young person's confidence in managing their health condition (health self-efficacy)

# Evidence for service features

---



Appropriate parent involvement

D: 32%; CP: 38%; ASD: 33%

Promotion of health self-efficacy

D: 68%; CP: 24%; ASD: 25%

Meet adult team before transfer

D: 65%; CP: 22%; ASD: 25%

# Evidence for service features

---



Appropriate parent involvement



Satisfaction with services

D: 32%; CP: 38%; ASD: 33%

Promotion of health self-efficacy

D: 68%; CP: 24%; ASD: 25%

Meet adult team before transfer

D: 65%; CP: 22%; ASD: 25%

# Evidence for service features



Appropriate parent involvement

D: 32%; CP: 38%; ASD: 33%



Satisfaction with services

Promotion of health self-efficacy

D: 68%; CP: 24%; ASD: 25%



Satisfaction with services

Meet adult team before transfer

D: 65%; CP: 22%; ASD: 25%



Independence in appointments;  
shorter time to first adult appt. (DM)



Satisfaction with service providers

# Evidence for service features

---



## Conclusions and implications

HOW features are provided is important:  
e.g. the **adult team member** met should be seen  
in the adult clinic.

# Evidence for service features



## Conclusions and implications

HOW features are provided is important: e.g. the **adult team member** met should be seen in the adult clinic.

GP not involved even though 65% of those with ASD do not transfer to an adult mental health service.

	Total N (%)	D N (%)	CP N (%)	ASD N (%)
Remained in child services	49 (18)	19 (17)	10 (14)	20 (23)
Left child services:	225	93	64	68
Adult services	148 (66)	90 (96)	35 (55)	24 (35)
GP	76 (34)	3 (4)	29 (45)	44 (65)



# Evidence for service features



---

## Conclusions and implications

Many features are hardly provided (e.g. **written transition plan** 17% overall)

Our specific recommendations – **appropriate parent involvement, promotion of health self-efficacy, and meeting the adult team before transfer** – require organisation and training.



<http://research.ncl.ac.uk/transition/>

# Transition Research Programme

---



## **Determining young people's preferences and value for money**

Jenni Hislop & Luke Vale  
Health Economics Group  
Newcastle University

# Why do we need to know this?

---



- If we are going to propose changes to the way services are organised then we need to know what those people who are going to use those services want
- The NHS has limited resources so can not do everything it wants to do
- Choices need to be made

# What questions do we address?



- 
- What are young people's views about the care they receive?
  - How important are different features of that care?
  - Could a new way of delivering care represent a good use of NHS services?

# What are young peoples views about the care they receive?



---

Q methodology: Method for studying a person's viewpoints about a particular topic

1. Develop statements - “Q-set”
2. Statements are put onto cards. Each respondent physically “sorts” the cards onto a board
3. Final card positions from all respondents are analysed to group respondents with similar views





# Key findings

---

- There is no one type of service that suits all the young people
- Four distinct viewpoints were identified
  - ‘laid back’,
  - ‘anxious’,
  - ‘autonomy-seeking’
  - ‘socially-oriented’
- All except those with ‘autonomy-seeking’ wanted their parents to remain involved in their care

# How important are different features of health care?



- Based upon other findings we thought about how care might be provided
  - What characteristics might describe a service and how might these characteristics vary?
- Using a survey method called a discrete choice experiment to work out how important these characteristic are
  - In a series of questions, people choose between different ways a service might be organised
  - From the answers to the questions, we work out how a service might be best organised



# Key findings

---



- Changing characteristics of the service makes it more likely a young person will maintain engagement with health services
  - Again, one size does not fit all – ideally the service should be flexible
  - People liked the care they received but
    - Preferences were strongest in those who had not transferred to an adult service
  - Having clinics that welcomed parental involvement was highly valued
  - Also important were:
    - Information being passed on to the right person
    - Staff offering choices and allowing people to make decisions about their care
    - Seeing the the same staff at each clinic but not a key worker
    - Care was holistic (help to prepare for everyday life)
-

# Value for money



- The Pros and Cons of adopting a 'new' practice compared to current practice
- Incorporates all the findings from the study
- Allows judgements about whether care should be changed by highlighting choices and trade-offs

Balance Sheet Template

For new service	Against new service
No evidence of a difference	

## **Favours a new service**

### **Q-Sort & DCE**

A service should be flexible enough to meet the need of individuals

Uptake increased when parent involvement; the same staff are seen; good communication and there is shared decision-making

### **Longitudinal study**

‘Parent involvement’, ‘Promoting health self-efficacy’, ‘Meeting the adult team’ improved outcomes

### **Economic model**

‘Life-skills training’; ‘Having a key worker’, ‘Promoting health self-efficacy’ potentially

## **Favours service not containing the**

### **PBF**

Adopting A PBF will incur costs

Uptake of a service with no proposed beneficial features is high (78%)

A strong preference for current care; no strong preference for a ‘key worker’ or flexibility of appointments

‘Transition manager’, ‘Age-banded clinics’ or ‘Meeting the adult team’ might

# Key implications

---



Adopting a service containing potential beneficial features

- May not save money in the short or longer term
  - It may maximise service engagement and so potentially problems in the longer term
  - A service with 'Appropriate parental involvement', and a 'Protocol for promotion of managing of one's own health' may represent good value for money
  - A service involving a 'Transition manager for clinical team' or 'Age-banded clinic' may represent less value for money
-



<http://research.ncl.ac.uk/transition/>

# What is Developmentally Appropriate Healthcare (DAH)?

---



Tim Rapley

Senior Lecturer in Medical Sociology

Newcastle University

# What is Developmentally Appropriate Healthcare (DAH)?

---



## Stage not age:

A young person's **developmental stage** should be the starting point for appropriate provision of services

# What is Developmentally Appropriate Healthcare (DAH)?

---



## Stage not age:

A young person's **developmental stage** should be the starting point for appropriate provision of services

‘Transitions, probably, um, suggest a **process** where developmentally appropriate healthcare suggests a, **philosophy**’ (Manager)



# What is Developmentally Appropriate Healthcare (DAH)?

---



## DAH in literature (n=62)

Diversity in conceptualisation, terminology and potential age ranges.

Key principle underpinning the practice of adolescent healthcare.

# What is Developmentally Appropriate Healthcare (DAH)?

---



## DAH in literature (n=62)

Diversity in conceptualization, terminology and potential age ranges

Key principle underpinning the practice of adolescent healthcare

## **DAH in practice** (n=3: District General, Pediatric Tertiary, Adult Tertiary)

Observations: 1,600 hours, health professionals (n=103) and managers (n=72)

Interviews: 65 with health professionals (n=41) and managers (n=24)

# DAH – Diverse Values and Commitment



---

## Below the radar

‘It's small enough [numbers] that if you don't, if you don't buy into it, there's plenty to be getting on with the other 90%’ (Manager)

## Lack of Senior Leadership

‘there isn't a designated clinical lead for adolescents or a designated board member who's flying the flag high up for adolescents? I don't know’ (Manager)

## Questions of Sustainability

‘about consistency of approach, not a person’ (Health professional)

# DAH – Informal cultures of good practice

---



‘lots of great pockets of work’ (Health professional)

## **Acknowledgement of young people as a distinct group**

‘We need to recognise they’re not mini adults and neither they’re not big kids, they are their own group with their own needs’

# DAH – Informal cultures of good practice



---

## Understanding biopsychosocial development and holistic care

‘Integrate biological, psychological, social and vocational aspects of development, looking beyond the physical aspects’ (Health professional)

## Adjustment of care as the young person develops

‘It never stops changing. That’s the challenge ... you see one person one time, and three months later ... some other developmental issue has taken primacy’ (Manager)

# DAH – Informal cultures of good practice



---

**Empowerment of the young person by embedding health education  
and health promotion in consultations**

‘It feels a bit like a gentle educational role ... to sort of try and highlight  
those areas that do need exploring’ (Health professional)

**Working across teams and organisations**

‘I think, as I say, it is important from a trust-wide perspective that  
people are thinking in a joined up manner’ (Health professional)

# DAH – Informal cultures of good practice

---



## Uneven distribution

People, teams, spaces offer such holistic care - 'We were getting so much inquiries regarding adolescents from the other wards, even just for the basics' (Health professional)

## Networks of trust

'Um, so we've got a good group of people across the Trust that we can actually send these youngsters to who've got more awareness of the issues that they could have' (Health professional)

# DAH – (In)formal cultures of training

---



## Informal

‘it's just really by hearsay and talking to people and networking throughout [this organisation] over many years’ (Health professional)

## Trust-wide

‘to increase awareness across the [organisation] so as to make sure it wasn't just the, the chronic illness patients that were being looked at ... but it was the patients coming through A&E, coming through X-ray’ (Health professional)



# DAH – How to facilitate?

---



**Conflicting views** on the value and worth of DAH.

To move beyond pockets of good practice you need buy-in and **formal support** from senior managers in both **child and adult** services.

You need to provide a **trust-wide strategy** and training on **organisational, team, clinic and consultation** level factors.

# DAH – How to facilitate?

---



## Making healthcare work for young people

---

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

You need to provide a **trust-wide strategy** and training on **organisational, team, clinic and consultation** level factors.



<http://research.ncl.ac.uk/transition/>

# Lessons learnt and Implications for commissioners

---



Dr Gregory Maniatopoulos

Institute of Health & Society

Newcastle University, UK

# Aims of study

---



- To identify the structures, processes and relationships between commissioning entities in the NHS and other agencies
- To identify the facilitators of and barriers to commissioning transition services
- To identify how transition services could be better commissioned
- Four stages

# Stage 1: Literature review

---



- No published papers were identified
- Of 66 publications whose full-text was reviewed, 17 were potentially informative for the wider work of the Transition Programme, in particular recommendations for providers
- The grey literature did not identify anything more of significance

# Stage 2: Qualitative interviews

---



- 2 regions (North East, West Yorkshire); 29 face-to-face semi-structured interviews
- Purposively selected according to their role/involvement in commissioning for transition
  - CCG
  - Health and Wellbeing boards
  - Secondary care clinicians/managers
  - Local Authorities
  - Third sector

# Overall themes around commissioning for transition

---



Policy and  
legislation

Organisational  
structures

Professional  
roles and  
relationships

Commissioning  
process and  
practice



# Key factors that might facilitate commissioning for transition

---



- Joint commissioning (within health and between agencies)
- Trustwide Transition Coordinator
- Financial incentives (Commissioning for Quality and Innovation – CQUIN-)
- Commissioners and Providers effectively working together

# Stage 3: Case studies

---



- Case study 1: Financial incentive - Commissioning for Quality and Innovation (CQUIN) – North West
- Case study 2: Commissioners and Providers effectively working together (Strategic Clinical Network) – South West
- Case study 3: Joint commissioning (within health and between agencies) (Partnership 3 CCGs and 1 LA) – West Midlands

# Lessons learnt: Benefits

---



- Raised the profile of transition
- Standardised a pathway for transition
- Maximised the sharing of local, regional and national learning and good practice
- Developed a Transition Steering Committee, with a Trustwide Transition Coordinator
- Shared vision about service improvement
- Commissioners and user engagement

# Lessons learnt: Barriers

---



- Lack of engagement of adult services
- Some young people transfer to other Trusts
- Difficulty of introducing CQUIN due to limited time, and limitations of numerical targets
- Difficulty engaging carers and patients in planning services
- Reluctance to adopt new service configuration
- Lack of information-sharing procedures

# Stage 4: Additional interviews with adult commissioners

---



- Face-to-face interviews (n=5)
  - 2 CCGs in North East England (n=3)
  - 1 CCG in South East England
  - Regional specialised commissioner for NHS England in the Midlands

# Testing our implications with commissioners

---



- Academic expert: evidence based commissioning
- Child health commissioner (also GP): CCG NE England
- Chief Executives: 2 CCG consortia in NE and SE England
- Clinical Leadership Committee for specialist services: NHS England
- Commissioner of specialist services for mental health: North England
- Commissioner of specialist services for long term conditions in adults: Midlands

# Implications for commissioners



- Ensure that transition is commissioned for both adults' as well as children's services
- Commission for a framework to provide **'Developmentally Appropriate Healthcare'** across healthcare services and stipulate that this is owned at Chief Executive and Board level
- Where an adult service to which transfer young people with a long term condition is not commissioned, commissioners should set out explicitly that the transfer arrangements will usually be to primary care
- Commission healthcare organisations to establish a Transition Steering Committee with a Trustwide Transition Coordinator



<http://research.ncl.ac.uk/transition/>



# What are the implications of the research findings for adult services?

---



Dr Helena Gleeson

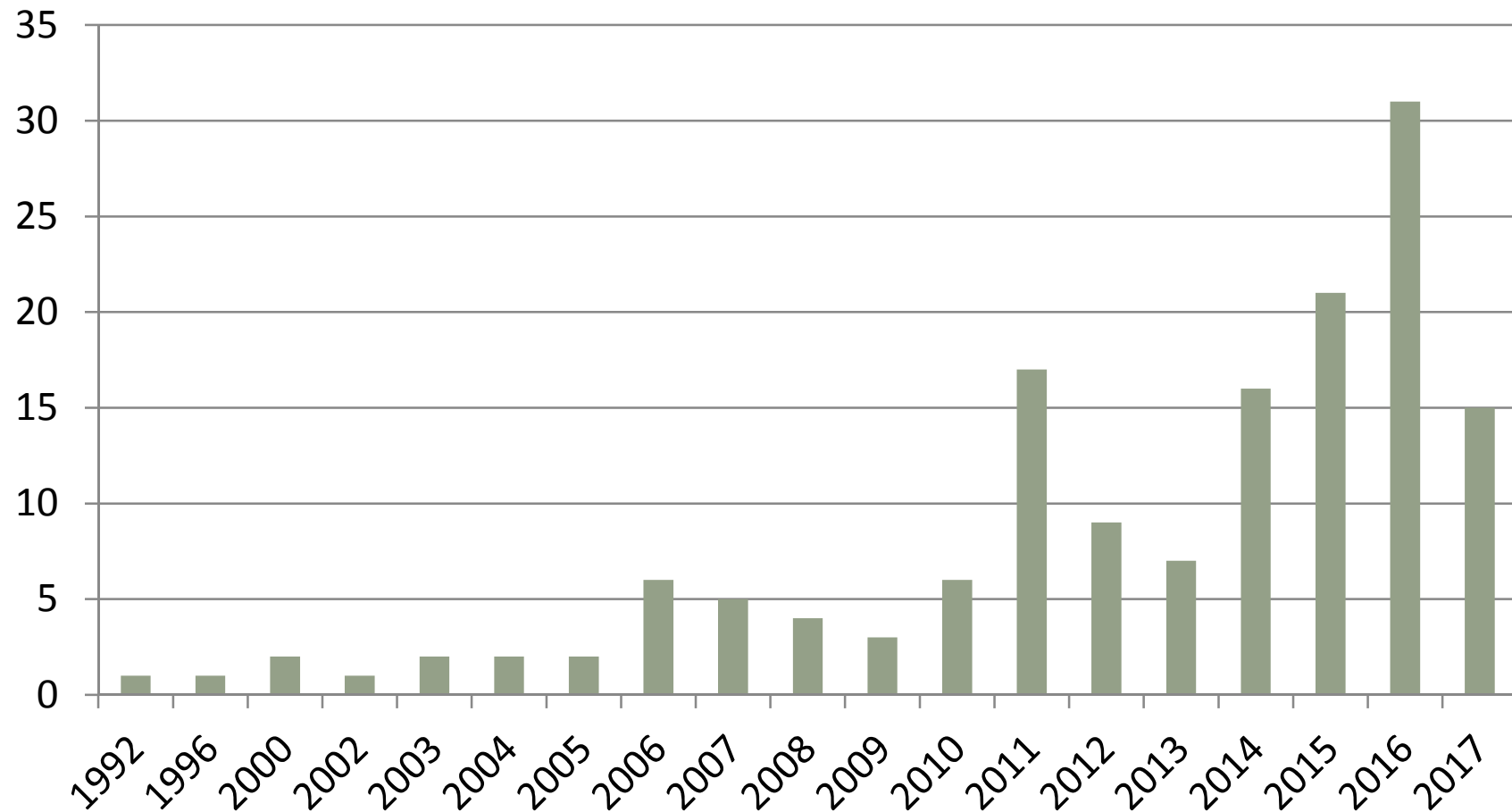
Consultant Endocrinologist

Queen Elizabeth Hospital, Birmingham

&

Chair of the Young Adult & Adolescent Steering  
Group, Royal College of Physicians

# Systematic Reviews & Meta-analyses published on Pubmed on “Transition”



# Adding to the evidence base

---



Recent Cochrane Review (2016)

Only 4 Randomised Controlled Trials

238 participants

Campbell F et al. Transition of care for adolescents from paediatric services to adult health services. Cochrane Database of Systematic Reviews 2016, Issue 4. Art. No.: CD009794

# 374 young people - 274 retained in the study – 149 in adult services



Recruited	Retained	Adult Services
150 with diabetes	112	90 (3)
106 with cerebral palsy	74	35 (29)
118 with ASD	88	24 (44)

UK  
Data

# What are the implications of the research findings for adult services?

---



## 1. Adding to the evidence base

# Bringing meaning to DAH



empowerment of the young person by embedding health education and health promotion

interdisciplinary and interorganisational work.



biopsychosocial development and holistic care

adjustment of care as the young person develops

acknowledgement of young people as a distinct group

# Bringing meaning to DAH



## Why do they need Age Appropriate Healthcare?

---

### Clinical challenge

- Complex and atypical presentations
- Multiple pathology
- Polypharmacy
- Cognitive impairment
- Decreased organ reserve
- Importance of family or community support
- Biopsychosocial impact of illness and trauma
- Opportunity for comprehensive assessment including health promotion



# Bringing meaning to DAH



## Why do they need DAH?

### Clinical challenge

- Complex and atypical presentations
- ~~Multiple pathology~~
- ~~Polypharmacy~~
- ~~Cognitive impairment~~ Learning disabilities & mental health
- ~~Decreased organ reserve~~
- Importance of family or community or peer support
- Biopsychosocial impact of illness and trauma
- Opportunity for comprehensive assessment including health promotion





# What are the implications of the research findings for adult services?

---



1. Adds to the evidence base
2. **Adult services should be the master of DAH and we are now closer to knowing what it looks like BUT we need buy in from senior managers**

# Timely : 2006 to date



# NICE guidance

---



[1.1 Overarching principles](#)

[1.2 Transition planning](#)

[1.3 Support before transfer](#)

[1.4 Support after transfer](#)

[1.5 Supporting infrastructure](#)

56 recommendations  
5 quality standards

# Opportunity to focus

---



Meet adult  
team before  
transfer

Transition  
manager

Coordinated  
team

Age banded  
clinic

Holistic life  
skills

Appropriate  
parent  
involvement

Key worker

Promotion of  
self efficacy

Written  
transition plan

# Opportunity to focus

---



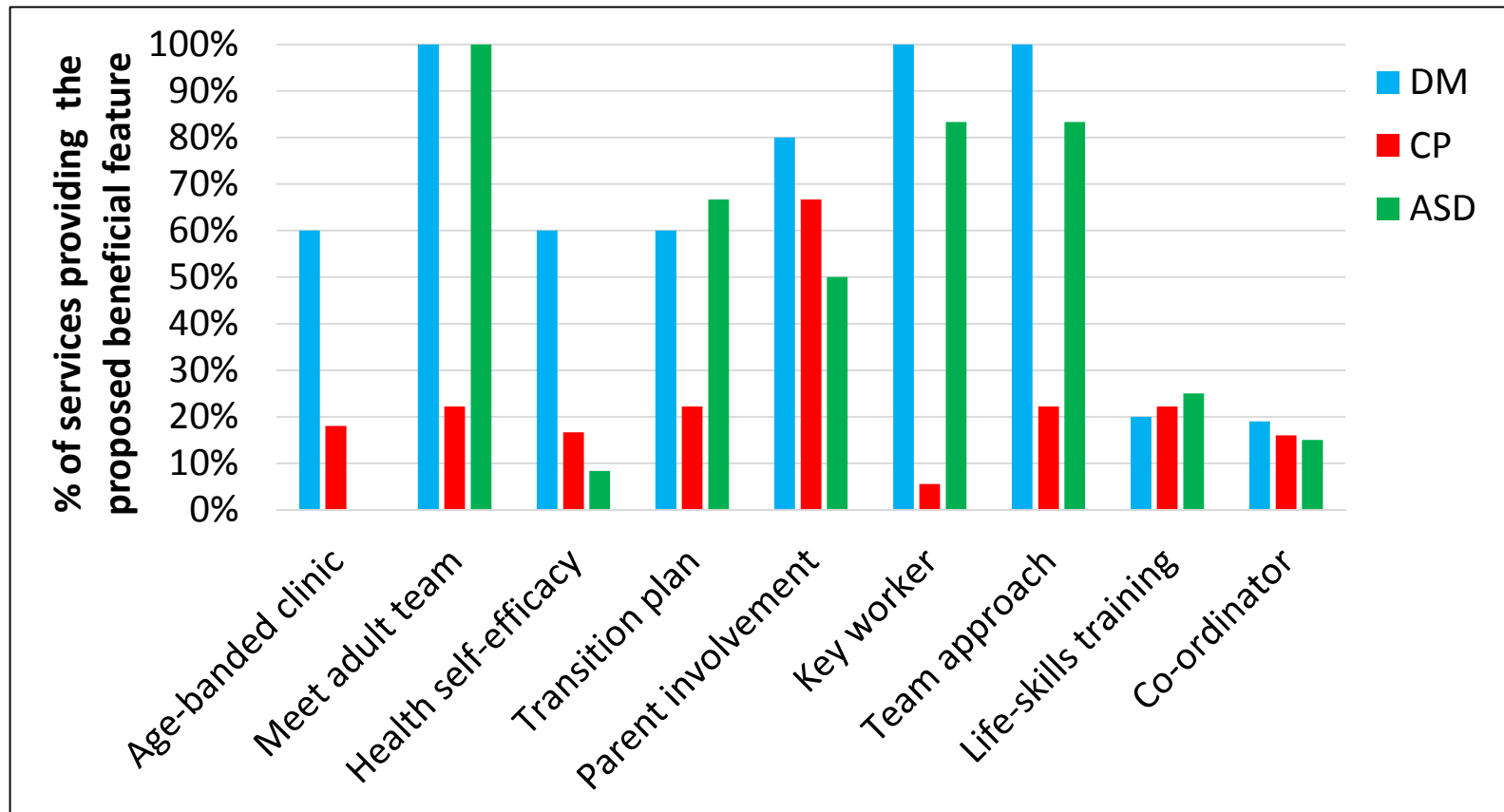
Meet adult  
team before  
transfer

Appropriate  
parent  
involvement

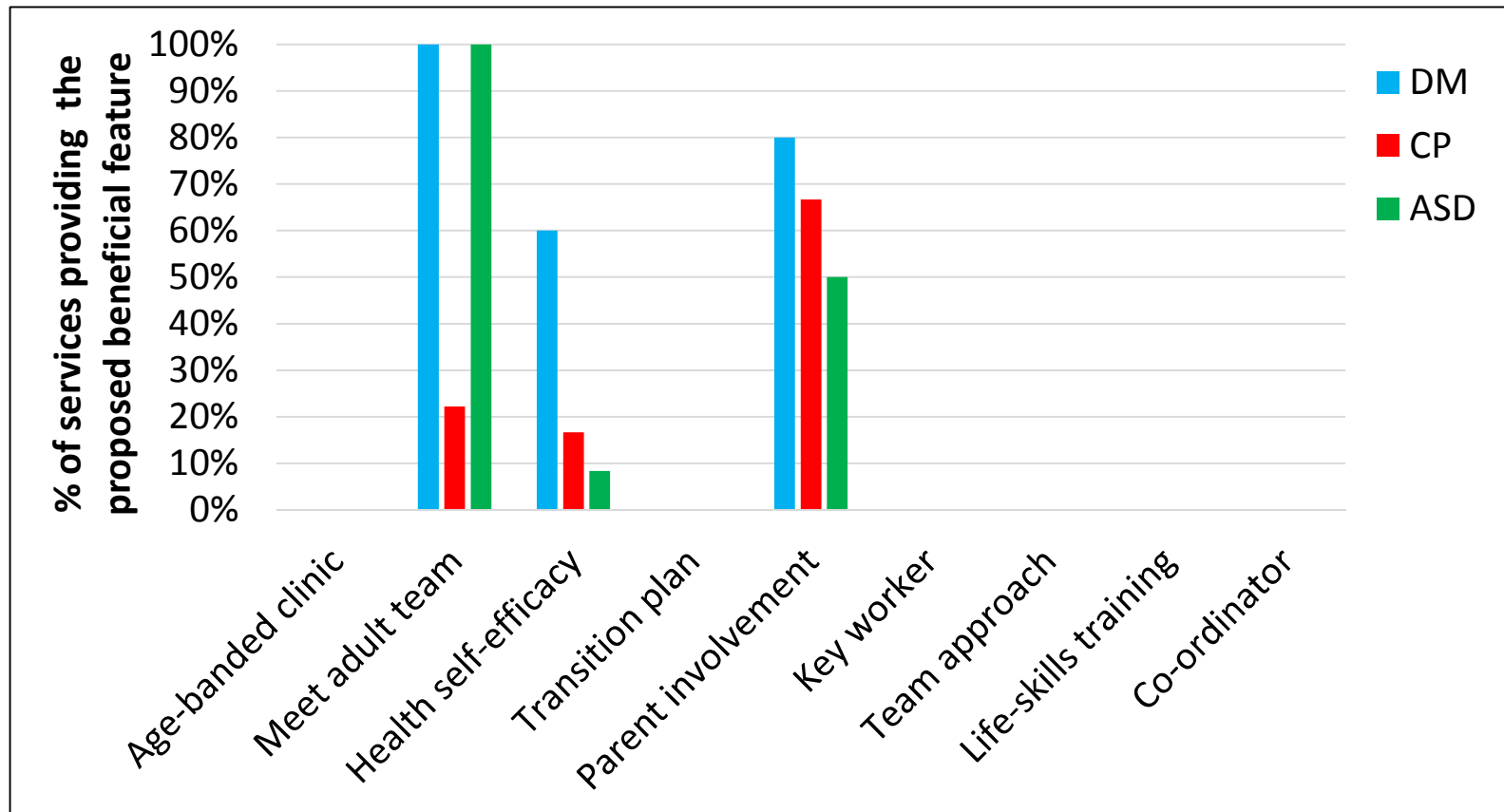
Key worker

Promotion of  
self efficacy

# Proposed beneficial features : Patchy



# Proposed beneficial features : Inequity



# What are the implications of the research findings for adult services?

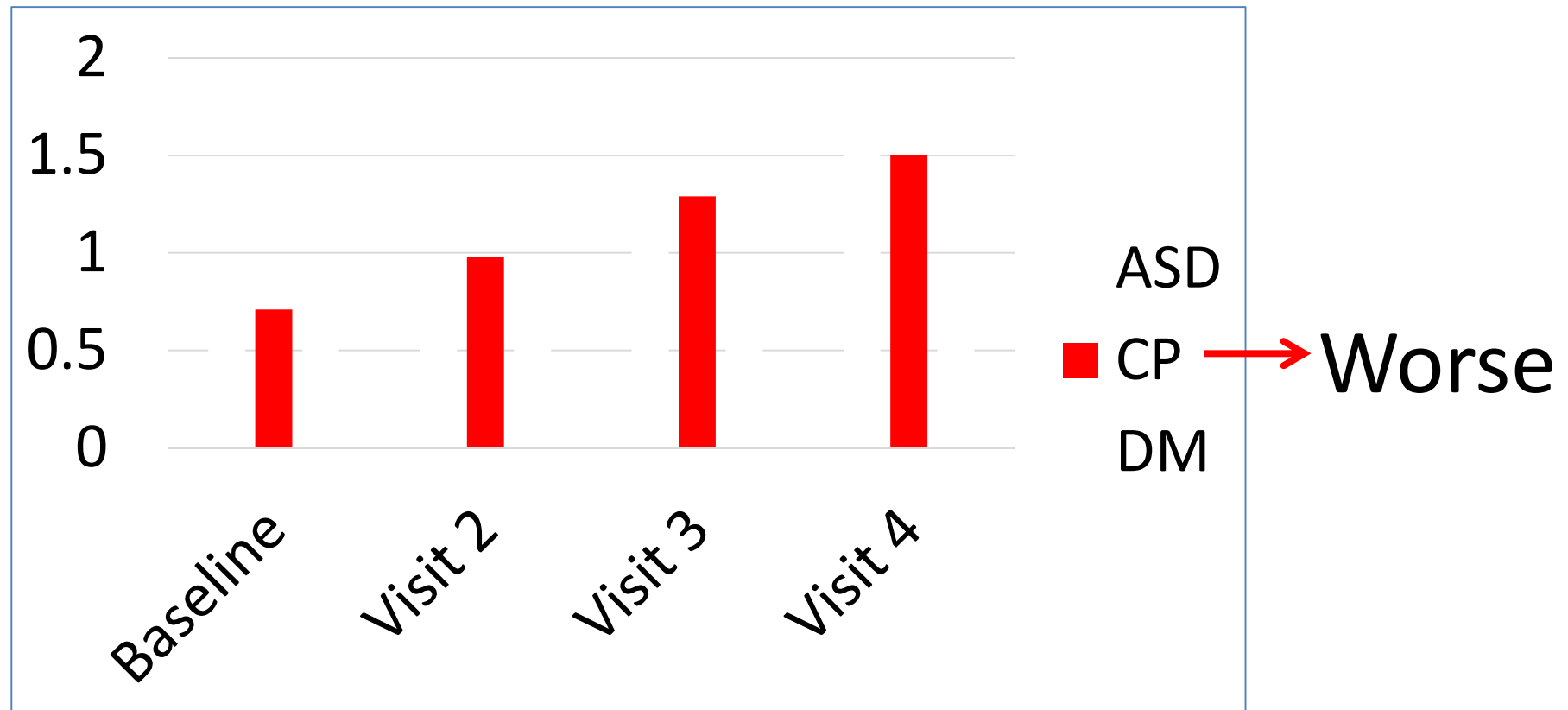
---



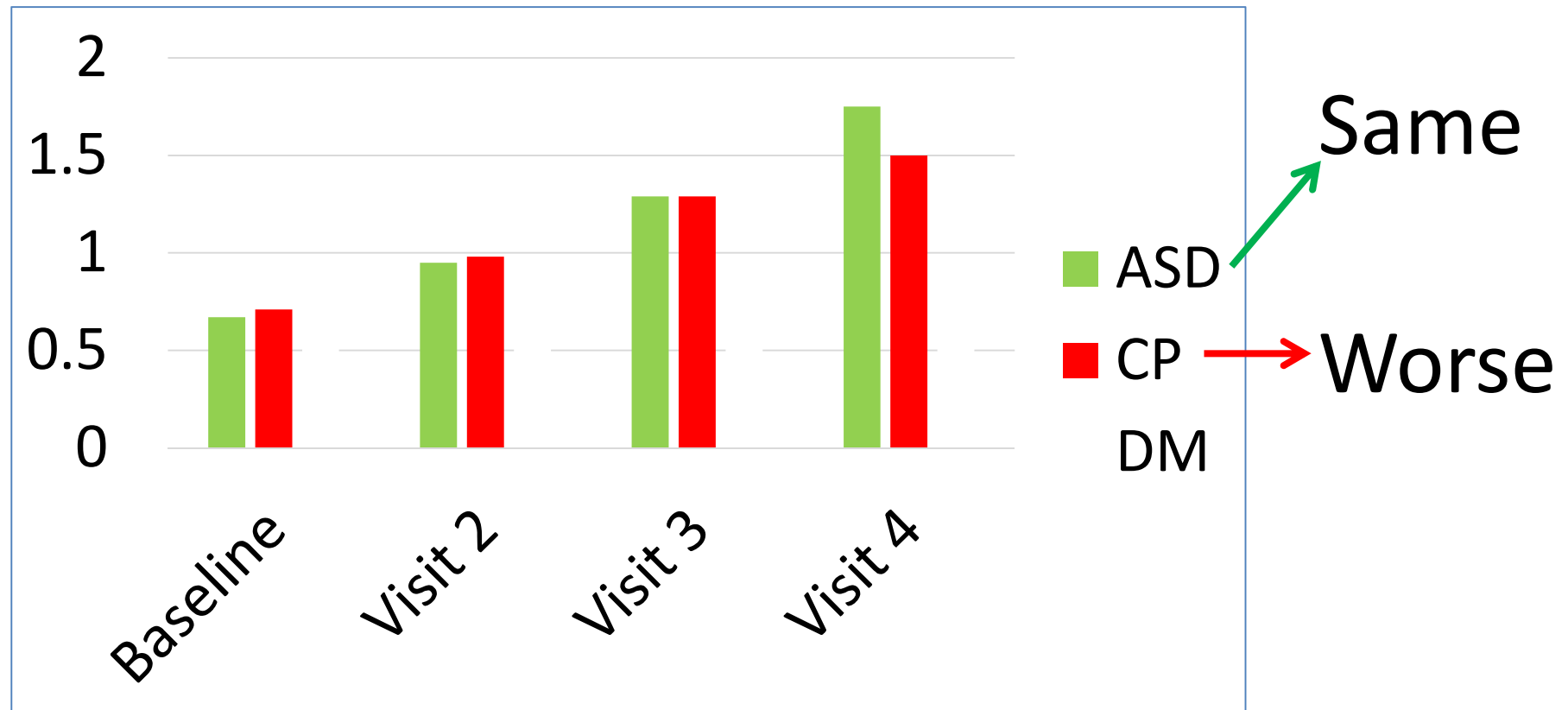
1. Adds to the evidence base
2. Adult services should be the master of DAH and we are now closer to knowing what it looks like BUT we need buy in from senior managers
3. **Compliments NICE guidance while providing an opportunity to focus efforts**



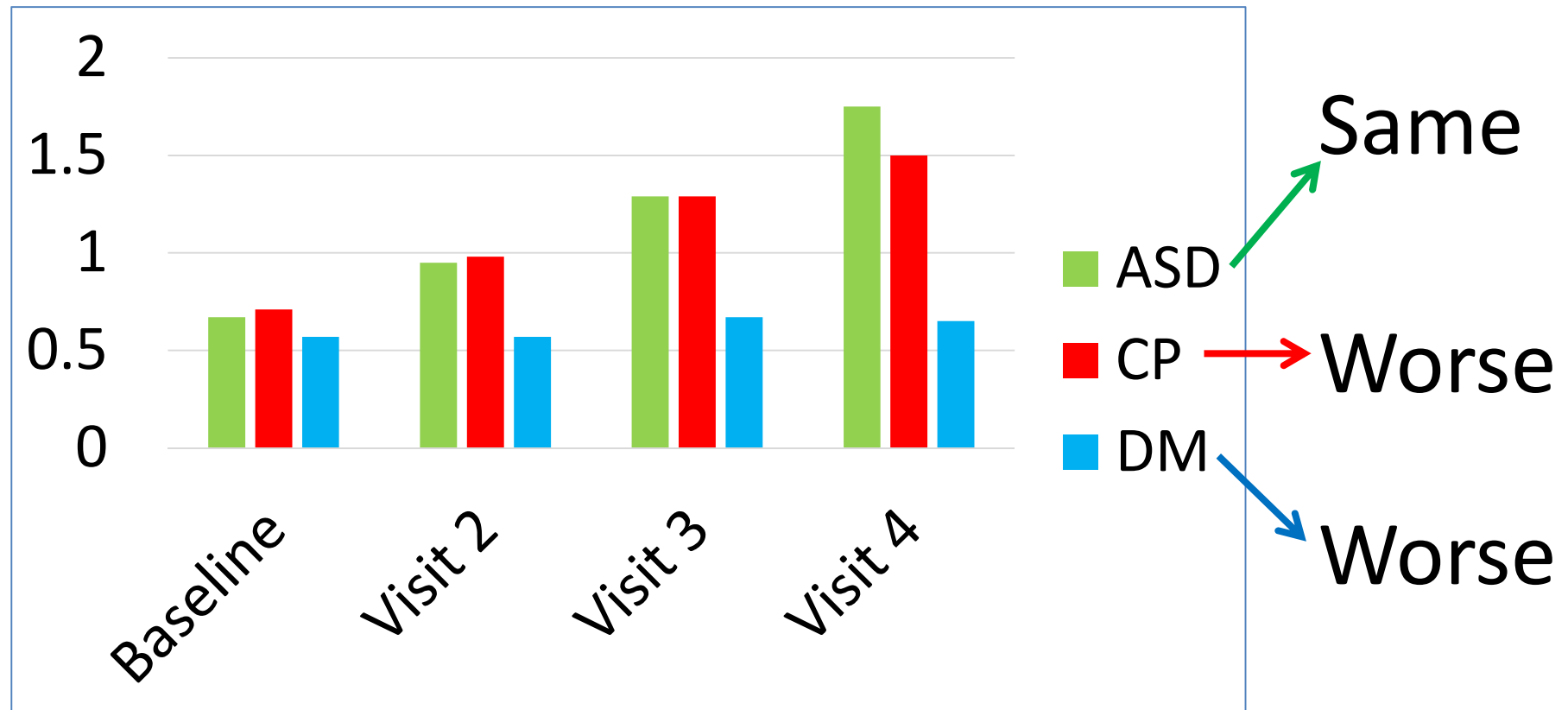
# Satisfaction with services : Mind the Gap



# Satisfaction with services : Mind the Gap



# Satisfaction with services : Mind the Gap



# What are the implications of the research findings for adult services?

---



1. Adds to the evidence base
2. Adult services should be the master of DAH and we are now closer to knowing what it looks like BUT we need buy in from senior managers
3. Compliments NICE guidance while providing an opportunity to focus efforts
4. **Optimal outcomes as well as monitoring remains a challenge**

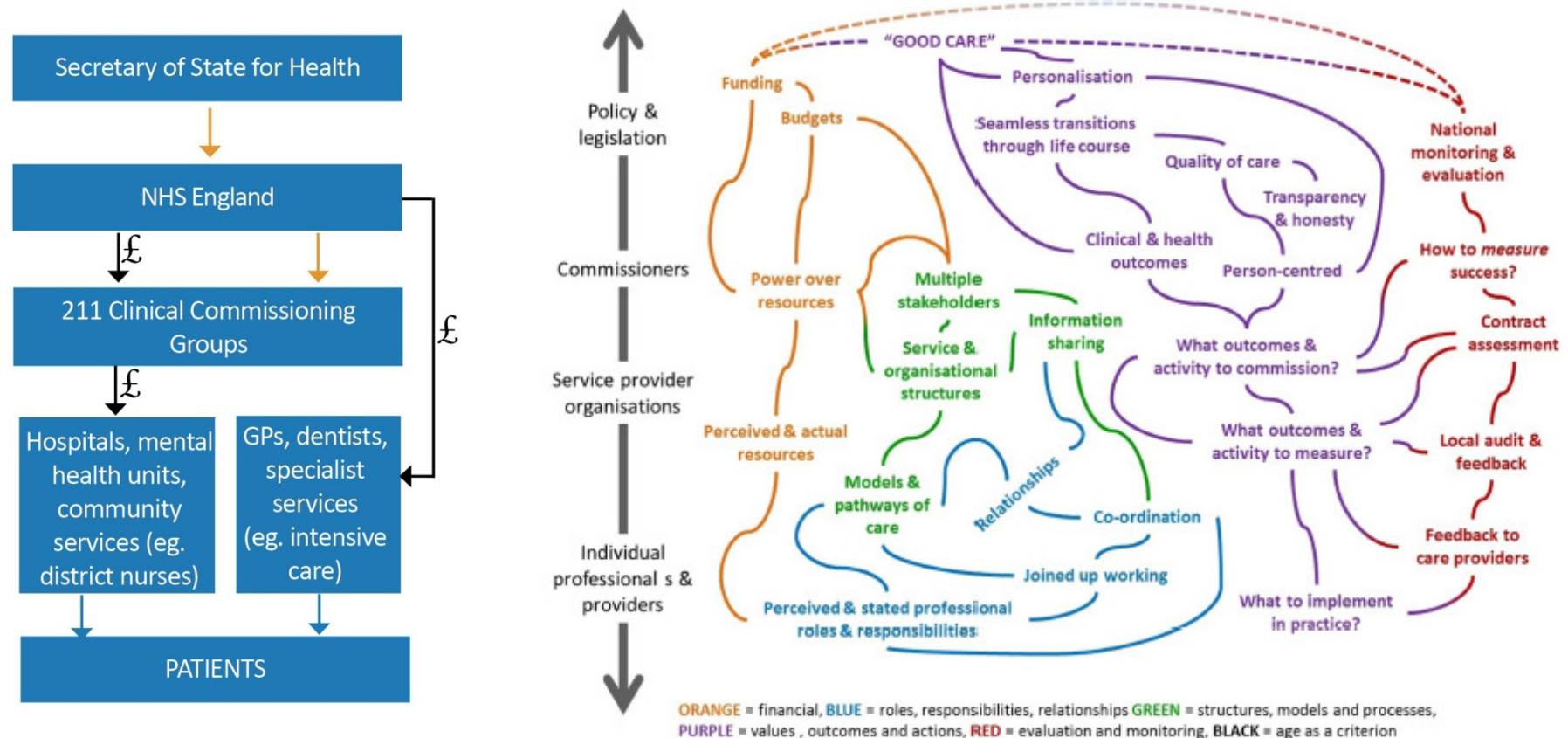
# Commissioning

---



*"I'm right there in the room, and no one even acknowledges me."*

# Commissioning



# So many holes to fill!

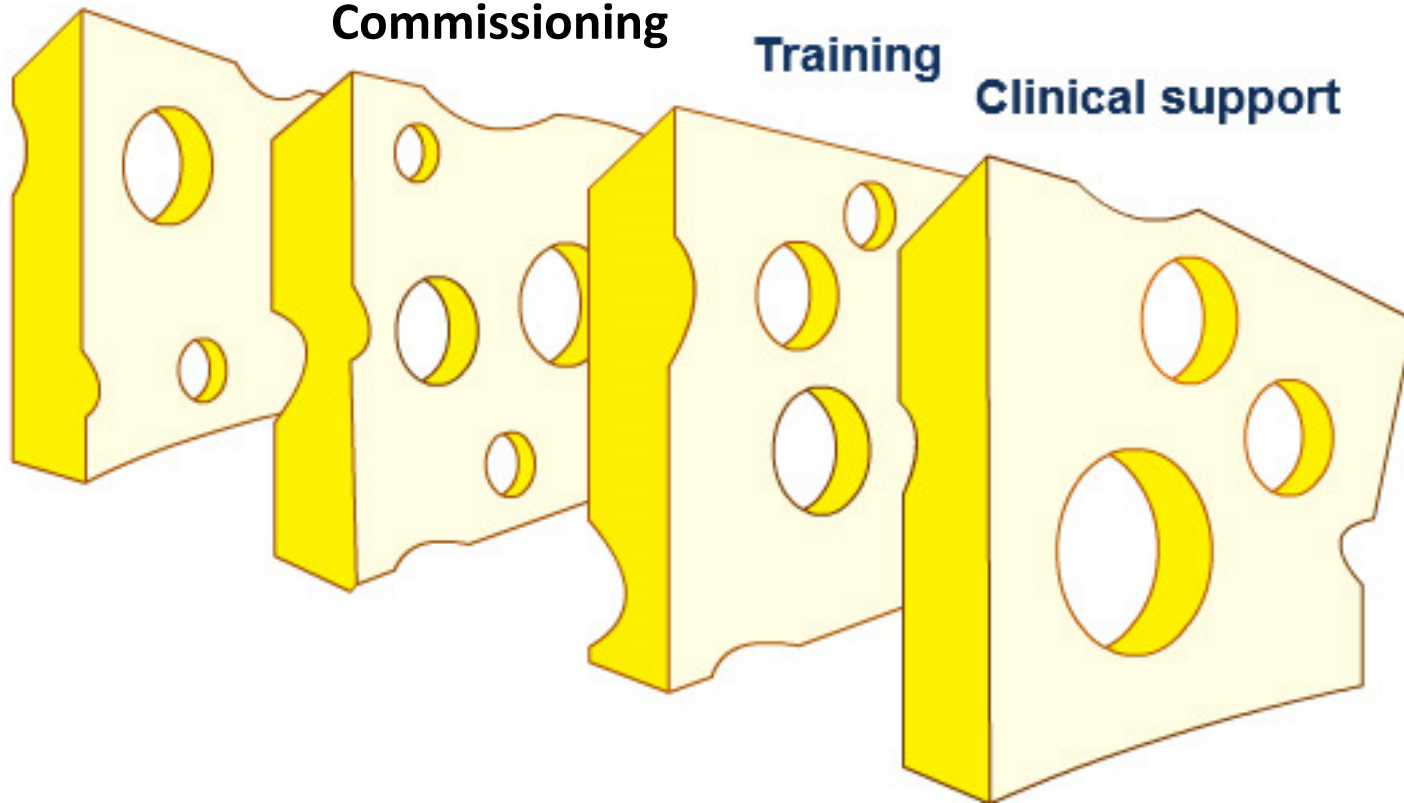


**Culture & leadership**

**Commissioning**

**Training**

**Clinical support**



# What are the implications of the research findings for adults' services?

---



1. Adds to the evidence base
2. Adult services should be the master of DAH and we are now closer to knowing what it looks like BUT we need buy in from senior managers
3. Compliments NICE guidance while providing an opportunity to focus efforts
4. Optimal outcomes as well as monitoring remains a challenge
5. **Commissioning needs to mirror what is happening in clinical services around transition**



# The “Myers Briggs” of Transition



# What are the implications of the research findings for adults' services?

---



1. Adds to the evidence base
2. Adult services should be the master of DAH and we are now closer to knowing what it looks like BUT we need buy in from senior managers
3. Compliments NICE guidance while providing an opportunity to focus efforts
4. Optimal outcomes as well as monitoring remains a challenge
5. Commissioning needs to mirror what is happening in clinical services around transition
- 6. Suggests an opportunity for tailoring transition care**

# What are the implications of the research findings for adults' services?

---



1. Adds to the evidence base
2. Adult services should be the master of DAH and we are now closer to knowing what it looks like BUT we need buy in from senior managers
3. Compliments NICE guidance while providing an opportunity to focus efforts
4. Optimal outcomes as well as monitoring remains a challenge
5. Commissioning needs to mirror what is happening in clinical services around transition
6. Suggests an opportunity for tailoring transition care

# Conclusion

## One-minute elevator conversation

---



### Locally

- Distribute the “Implications” documents
- Implement the DAH toolkit as part of training
- Encourage my colleagues with less time and resource to focus down on the three features described

### Through the YAASG at the RCP

- Disseminate the findings through different channels
- Discuss next steps – research, QI
- The work must go on to fill the holes!



<http://research.ncl.ac.uk/transition/>

# Workshop: Developmentally Appropriate Healthcare

---



Jeremy Parr, Newcastle University

Tim Rapley, Newcastle University

Janet McDonagh, University of Manchester

Debbie Reape, Northumbria NHS Foundation Trust

# Developmentally Appropriate Healthcare

---



Key principle: A young person's *developmental stage* should be the starting point for appropriate provision of services

‘A stage, not an age’

NICE guidance (2016) says transitional care should be developmentally appropriate

# Why is DAH important?

---



Young people experience health transition across different settings within an organisation

DAH provides the context for health service interactions – where and how we interact with YP, and what should be provided for them

Young people are more likely to engage with relevant healthcare that is appropriate for their stage in life – not doing this risks disengagement and poor short and long term outcomes (health, social, vocational)

Poor outcomes lead to costs: personal, family and NHS

---



# Findings about DAH

---



Variation in what DAH meant to health professionals

Some strategies to provide it already exist

No plans about how to provide DAH across Trusts

A need for clarity and consistency about what it developmentally appropriate healthcare means

# Findings about DAH

---



DAH was considered important by clinicians, and:

- Health service commissioners
- Managers
- Chief Executives

# Definition

---



‘Developmentally Appropriate Healthcare’ (DAH) 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.’

# Findings about DAH

---



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 should rest at Chief Executive and Board Level; and with senior managers in both child and adult services
- ii) Ensure that DAH planning engages from the outset adult and child services
- iii) A Trust-wide strategy on and training about DAH

# A toolkit to support delivery of DAH



To support the implementation and delivery of DAH across NHS organisations, we created a free to access NHS Toolkit

4 domains:

- Definition of DAH
- DAH across your organisation
- Having a team approach to DAH
- Engaging young people in clinical practice

# The Toolkit: How to implement DAH in an organisation

---



## Making healthcare work for young people

---

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

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

### What is this NHS toolkit about, and who is it for?

This toolkit gives practical suggestions about how healthcare can be tailored to young people’s needs as they develop and change through adolescence into young adulthood – such care is termed ‘Developmentally Appropriate Healthcare’ – or DAH.

The toolkit is designed to support everyone working in the NHS, from clinicians to chief executives, to promote the health of young people and to play their part in making healthcare work for this age group.

Click on the image below to access the toolkit.





# The Toolkit: How to implement DAH in an organisation



---

## Introduction

Focusing on improving healthcare for young people is important. **The Lancet commission on adolescent health and wellbeing** (2016) states that there are 'tremendous unrealised opportunities' in focusing on the healthcare of young people and that this represents *an investment in the health of future adults*.

**'Developmentally Appropriate Healthcare'** is about making healthcare work for young people *by recognising their changing developmental needs*, and the role of healthcare in addressing these throughout adolescence and young adulthood. This is also an overarching principle in **NICE guidance** on transition from children's to adult services.

# Appropriate Healthcare

Understanding biopsychosocial development and holistic care

*"...awareness of issues for young people in society and young people as a kind of developmental stage around things like mental health, sexual health, confidentiality, consent... seeing that young person in that wider context..."*

Health professional, adult hospital

Adjustment of care as the young person develops

*"It never stops changing. That's the challenge... you see one person one time, and three months later... some other developmental issue has taken primacy."*

Manager, general hospital



## Resources

Farre A, Wood V, McDonagh J, Parr J, Reape D, Rapley T.

**Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies.** *Archives of Disease in Childhood.* 2016;101: 628-33.

---

Farre A, Wood V, Rapley T, Parr JR, Reape D, McDonagh JE.

**Developmentally Appropriate Healthcare: A scoping study.** *Archives of Disease in Childhood.* 2014;100;144-51.

---



## Who is this section for and what is it about?

This section is for senior managers, senior clinicians and leaders. It provides guidance for how Developmentally Appropriate Health care can be supported at an organisational level and through trust-wide approaches.

A parallel piece of work explored in detail the role of Commissioners in commissioning for Transition. One of the key recommendations concerned introduction of Developmentally Appropriate Healthcare.



There are a number of ways an organisation can work to improve Developmentally Appropriate Healthcare, and this section will discuss these:

- a. Strategic recognition
- b. Participation, engagement and co-production
- c. Organisational culture and the environment
- d. Using incentives and drivers to support change
- e. Facilitating transition from child health to adult services

## b. Participation, engagement and co-production

- Consider young people's participation at all levels of the organisation
  - How do you share young people's feedback across the organisation?
  - How many young people give you service user feedback? What does it tell you?
  - How can you involve young people in research you or others are undertaking?
  - How are young people involved in the development of new services?
- Work with experts in participation locally and nationally to support a sustainable approach to engagement for the young people you work with, and your organisation
- Use resources outlined here to plan how you work with young people



### Examples from practice

Northumbria Healthcare NHS  
Foundation Trust

**The Child Health Action Team (CHAT)**



### Resources

---

**Children and young people's participation and advocacy resources** RCPCH

---

**Reaching marginalised young people** AYPH

---

**NHS youth forum's tips to involve young people in healthcare planning**  
NHS England

---

**Walk the talk – top tips about providing a youth friendly health service**  
NHS Health Scotland

# Making healthcare work for young people

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



You can freely access the toolkit at:

<https://www.northumbria.nhs.uk/dahtoolkit>

Please take a few minutes to look through it

Then we'll have questions and discussion



**DAH Toolkit business cards are in your packs  
Please give cards or the weblink to your  
colleagues locally, nationally and internationally**



# 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



<http://research.ncl.ac.uk/transition/>

# How do the research findings relate to international transition research?

---



AnneLoes van Staa

Professor of Transitions in Care, Rotterdam University



## KEYNOTE CRITIQUE

How do the research findings relate to international transition research?



AnneLoes van Staa PhD, MD RN  
Prof. Transitions in Care, Rotterdam  
University [a.van.staa@hr.nl](mailto:a.van.staa@hr.nl)



Research Centre  
Innovations in Care



## On Your Own Feet

Preferences and competencies for care of adolescents with chronic conditions

AnneLoes van Staa



# Strengths of this study



1. Prospective data collection; mixed methods approach, broad view
2. Inclusive, generic approach
3. Strong involvement of young people throughout all phases and most WP's
4. Practice-oriented: looking for clues and solutions
5. Comprehensive: involving different stakeholders; exploring new areas such as economic evaluation and commissioning
6. Made painfully clear that YP with chronic conditions and Transition are not "on the radar" and are "not a priority"



# Limitations of this study



1. Study of actual 'beneficial features' in clinical practice was limited: it is not really clear what these really entail
2. Outcome measures in longitudinal study: transfer experiences not included, Mind The Gap / HRQoL ....
3. Follow-up in adult care was limited
4. Still unclear what the costs and benefits of transitional care interventions actually are
5. How much (more) evidence do we need?!





# Basic principles of transition



The basics of transition are simple:

1. Prepare young people and their families well in advance
2. Prepare and nurture adult services to receive them
3. Listen to young people's views



Key message from this research: *Apply a practical, tailored and relational approach!*

# 1. Prepare young people and their families well in advance



---

## What this research adds:

1. Developmentally Appropriate Healthcare is about personal growth and responsiveness
  2. One-size-fits-all approach does not apply
  3. Enhance and encourage self-management & self-efficacy of young people but keep parents involved
-

# 1. Prepare young people and their families well in advance



---

## *My reflection*

1. Make DAH practical: what are the minimum requirements for good DAH?
  2. We need to know more about HOW to enhance and encourage self-management & self-efficacy of young people: interventions such as Ready Steady Go? Split consultations? Peer support?
  3. We need to solve the issue of parental involvement, privacy and adulthood: but HOW
  4. How about social media, video consultations, eHealth?
-

## 2. Prepare and nurture adult services to receive young people



### What this research adds:

1. Transition of care cannot be successful without involvement of adult care providers
2. Meeting adult providers in advance is beneficial
3. Need for Developmental Appropriate HC does not stop after 18
4. Parental involvement is highly valued by young people, but often discouraged and disqualified by adult providers
5. Deterioration of health status, risk of long term complications is real; while actual (quality and quantity of) service provision goes down



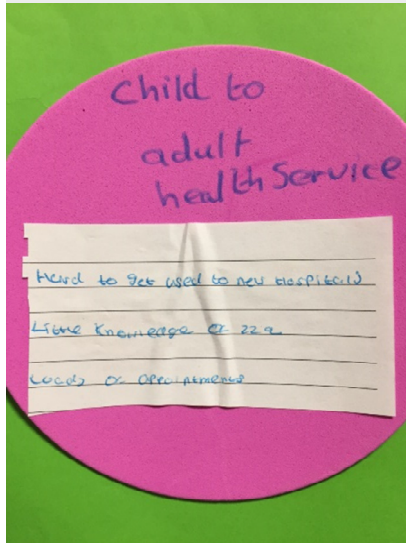
## 2. Prepare and nurture adult services to receive young people



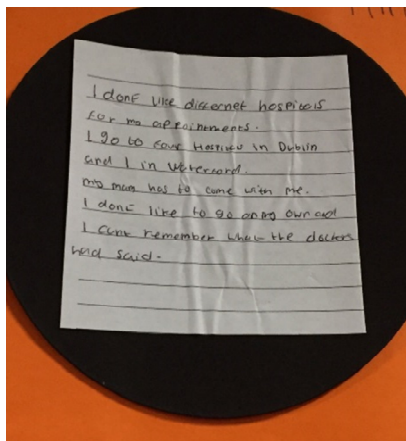
### *My reflection*

1. Collaboration between PC and AC is key: this is not only about transfer, but also about joint policies, protocols and case management
2. Importance of multidisciplinary team approach in adult care: how do we make it feasible?
3. Meeting adult provider in advance (transition clinic): we need to know how often this is needed, how this is best organised (in an effective and efficient way) and it should be combined with multidisciplinary Transition Team Meeting
4. Involving primary care: but HOW?

### 3. Listen to young people's voices



- ☐ Had to get used to new hospitals
- ☐ Loads of appointments
- ☐ I don't like different hospitals for my appointments
- ☐ I don't like to go in on my own
- ☐ My mum has to go with me
- ☐ Little knowledge of 22q11
- ☐ I don't remember what the doctor said
- ☐ Each individual with 22q is different
- ☐ Planning helps to develop trust in the change



YEEP 22q11DS; October 2017, Dublin



**22q11 Europe**  
2nd Alliance Meeting  
Dublin, 7-8 October 2017  
Proudly Hosted by 22q11 Ireland

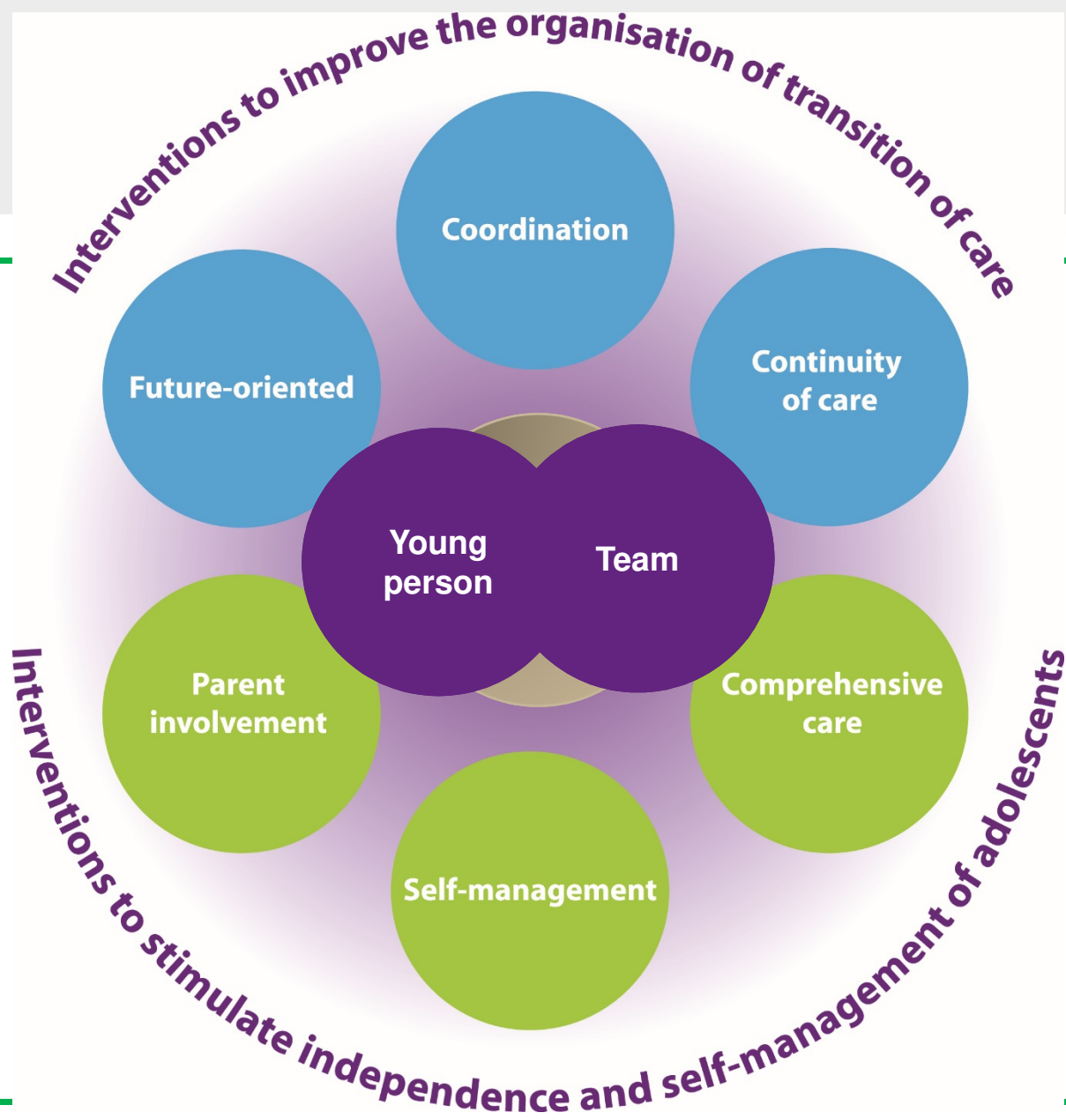
### 3. Listen to young people's voices



---

#### *My reflection*

1. It's not about reaching the top of the participation ladder, but it is about being involved and being heard
  2. Youth panel: inviting young people after transfer for the evaluation of transitional care services ('mirror' meetings) is probably more useful than involving them as co-researchers Long term involvement is difficult to achieve; issues of reimbursement
  3. Not all voices are being heard in our participatory projects....
-





<http://research.ncl.ac.uk/transition/>

# Concluding remarks. Allan Colver

Website: <http://research.ncl.ac.uk/transition>

Toolkit from above or direct  
<https://www.northumbria.nhs.uk/dahtoolkit>

My e-mail: [allan.colver@ncl.ac.uk](mailto:allan.colver@ncl.ac.uk)

Generic e-mail: [transition@ncl.ac.uk](mailto:transition@ncl.ac.uk)

We undertook 'Applied Health Research'. It will have been of little value unless in some way it changes policy and practice.

We are not asking you to feedback on today's presentation.

But we would really value observations from you in due course on the implications of our work and your own work.



<http://research.ncl.ac.uk/transition/>