

Transition of Care Conference Summary

10 November 2017

Young Adulthood – Can we be skilled helpers?

- Kath Evans, Lucy Watts MBE, Amy Frounks

Young people have little knowledge about their rights in the NHS.

Health professionals need to start considering young people.

The NHS youth forum generated questions to raise awareness, prompt conversation and make the way young people feel clear.

We need to make it more accessible for young people to know their rights;

- Platform to engage with healthcare and their rights
- When you know your rights it is much easier to make decisions and take control.

International Nurses' Day 2018 will focus on young people's rights.

It is important to understand what young person, alongside what they need and what they want.

The young adult period of transition is important.

Good communication is imperative;

- Team that understand the person is important
- Coproducing care plans.

Quality is what matters.

Making allowances for young people is important:

- *"Not a protocol. Not a policy. It is about them".*

Important to not define someone as 'hard to reach', instead they are seldom heard.

Communication skills are not emphasised enough in care;

- Focus on the clinical aspects of care, but communication underpins everything;
- Important to empower young people.

Forget to look at people and care holistically;

- Care services still work separately.
- Communication would tie this together.

It is the small/simple things that make a difference:

- Take time to understand a person
- Explain things
- Listen to them.

Transition, doesn't mean a journey has finished, rather it is continuing.

Never make assumptions about what someone wants/needs;

- Ask questions.

Important to get feedback on a young person's experience of transition;

- Transition doesn't end at one person, another will come along
- Service improvement!

Barriers for services taking on advice about transition:

- Time. Heavy caseloads and not enough time
- Attitude
- Getting everyone to be on the same level
- People are so set in routine, no forward planning
- Threshold of services; forward planning would overcome this.

Transition through a patient's eyes

- Hannah Phillips

Growing up is a universal truth, but for patients (children, young people) and families it is a time of uncertainty.

Difficult to not have anyone to relate to, no-one of a similar age.

Very little positive human interaction.

Even though at the same hospital, healthcare team changed at transition and the environment was different.

Asked to sign a consent form at 16 – not even a legal adult at this age!

At the moment there is more bad than good in transition services.

Young people are a lost generation of patients;

- Lost between adult and children services.
- Patients and their families feel abandoned by healthcare transition.

Environments are important:

- Create a positive space to improve young people's wellbeing

Visibility:

- Improve the visibility of young people in healthcare and communication tools

Families are cut out of care at 16.

Denied help at university because GP notes did not "prove" health condition would last longer than 12 months.

Communication is key across **all** services.

It is currently a postcode lottery as to whether transition is good or bad.

Families must be supported during transition. Family is the most important thing to a young people in transition.

"When I was a child I was a human. When I turned 16 I became a number".

The small things matter the most.

How can adult services do to help?

- Consider the small things as these make the biggest difference
- Communication is so important.

Transition is not a module for health professionals.

Need for a young person advocate!

Transition Improvement Project at Great Ormond Street Hospital

- Nigel Mills

The Department of Health, CQC and NICE all say things need to improve. Young people and carers say that things need to improve.

The NICE guidance on transition is not being followed.

Some young people go to adult services at 16;

- Could be because of speciality condition or service structure.

Different pathways/new referrals, some patients may only have a few appointments before transition.

The NICE guidance says transition should begin at 14.

Transition needs to cover everyone.

Great Ormond Street Hospital reviewed:

- National/International approach
- Trust's transition guidance
- Multiple specialities, some with established transition

From 12 years of age children are aware they can have an appointment on their own;

- This links in with secondary school
- Patients are prepared for signing consent forms
- Aware about DLA, PIP and other financial support
- Aware of local service changes. Including losing contact with current health professionals, and aware about the new professionals who will be involved in care.

A&E and adult services are not something that people can be easily prepared for.

The same things are relevant and important for all young people, regardless of whether they have additional needs/learning disability.

Holistic support for children and young people.

Developing support resources.

IT at Great Ormond Street Hospital is antiquated!

- *"We do transition, that [IT] supports it".*

Linking IT:

- Portals
- Developing with other services to link into how services and care can link and integrate.

QNI Transition of Care learning resource and film – an overview

- **Dr Candice Pellett OBE and Sandra Lawton OBE**

Universities are starting to teach transition for the first time.

Transition resources are being followed.

Examples of nurses who have changed practice as a result.

Can't make decision without first having the person involved:

- Planning is important as it preparation.

Relationship building and trust are important.

Imperative to go at young person's pace, speed and ensure they don't have an information overload.

A Parent's perspective on transition of health care services from childhood to adulthood Samee's Story

- Feisal Jassat

When faced with adversity, fly.

It's not just a young people who transition, families do to.

Imperative to listen to the individual's voice.

Peer-to-peer support and empowering a young person is important.

Improving engagement and communication in transition for young people – The importance of multi-disciplinary working

- Carrie James QN, Chris Berns, Michelle Shore, Jordan Jackson

Going to adult services is daunting/scary for a young person.

Health professionals have to understand the difference between child services and adult services.

Gradual and planned transition is important.

Transition is complicated:

- Getting it wrong can be detrimental.

How young people feel about transition?

- Exciting
- Progression
- Change
- Good
- Strange
- Scary
- Confusing.

Things young people worry about include the following (not much focus on health!):

- Education

- Employment
- Changes to care
- Moving to a different hospital
- Learning to drive
- Future
- Coping with grief
- People not listening
- Friendship.

According to the CQC only half of young people receive support during transition.

Young people should be fully involved;

- Transition should incorporate other life aspects (employment, education etc.)

The service in Walsall is commissioned by the CCG;

- Difficult for commissioners to say no if you present strong evidence formulated in a way which is difficult to say no to
- Lead of service needs to have passion to drive service forward.

The way you work with someone doesn't change on the person's birthday.

How can adult services adapt?

- Engage with them
- Need to think differently about appointments/discharge.

NICE Quality Standards and the transition buddy: how to ensure young people are prepared for transition

- Dr Su Madge

The best age of transition is a point of contention.

Practitioners are encouraged to involve patient in their care.

Transition doesn't end at a patient moving services; transition takes time.

Young people go through many transitions outside of healthcare.

Preparing for transition should start early at diagnosis.

It is important to have confidence in transition.

Good relationships with adult services are important, don't make them sound negative.