10-Steps - Transition to adult services

An innovative pathway for improving transition to adult services for young people including those with multiple complex long term conditions

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10-Steps – Transition to adult services

- Development of the 10-Steps Transition Framework
- Transition one step at a time
- Key findings through development and implementation
- Discussion and next steps

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CQC Inspection May 2014: "Requires improvement"

- Some young people past the age of 18 continue to visit Alder Hey
- No overarching vision or strategy
- Lack of overall responsibility or leadership for transitional services
- Reporting arrangements to the Trust board were unclear
- Lack of clarity regarding responsibilities of nurses and doctors for transition in learning disability

Improving Transition at Alder Hey 2014/15

- **Transition CQUIN**
  - For complex long term conditions, technology dependency, severe learning disability and palliative care
  - CAMHs
- **Trust Transition Team**
  - Nurse Lead for Transition
  - Clinical Lead for Transition
  - Executive Lead for Transition
- **Trust Transition Policy**
  - Supporting training programme.
  - Link to an overarching **Transition Framework Agreement** across Merseyside and Cheshire.

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Developing the 10-Steps framework

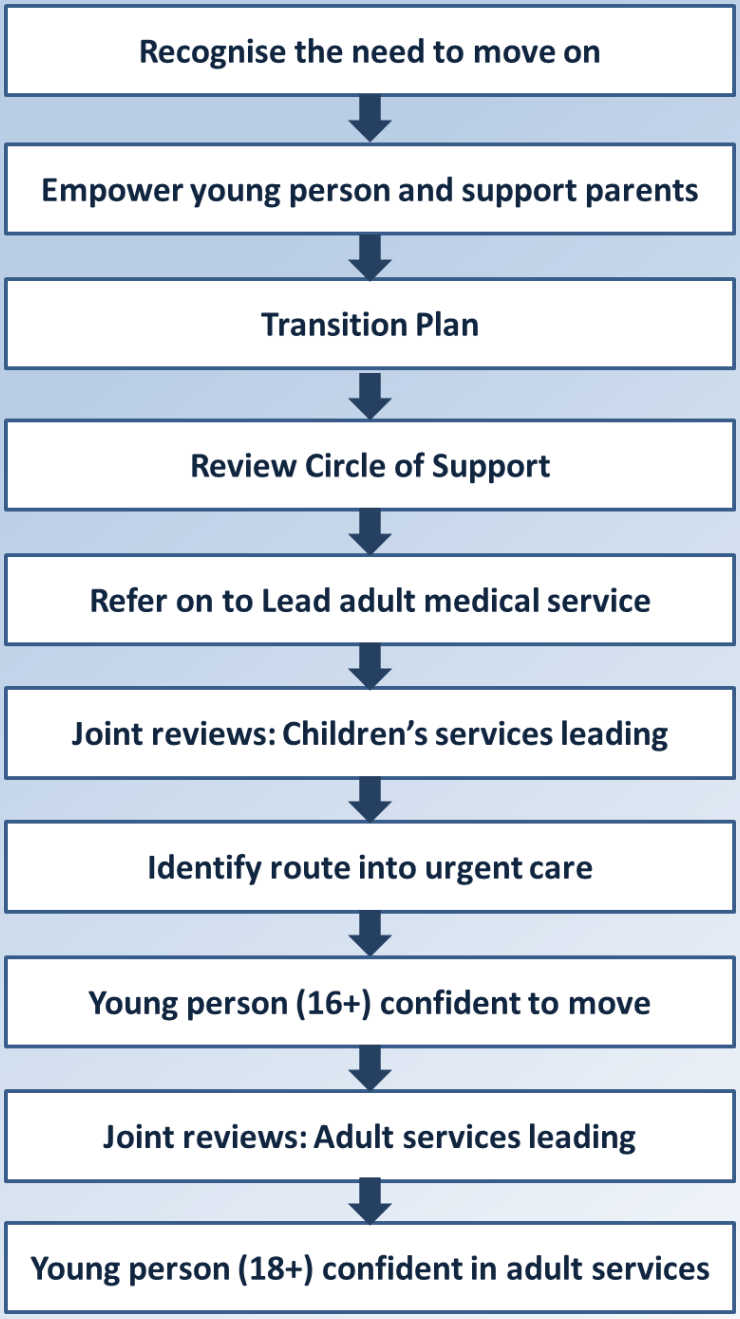
- To develop a simple generic transition pathway
  - Based on best practice evidence
  - Person centred
  - Ensuring co-ordination and continuity across the transition
  - Access to urgent care
  - Role of the GP and primary care team
  - Flexible to adapt for highly complex patients
  - Simple and clear enough to be equally applicable for more simple transitions

Developing the 10-Steps framework

- Initial development
  - Literature review
  - Interviews with adult specialists and GPs
  - Experiences of working with young people and their families over 10 years
  - Extensive engagement and consultation with professionals from children's and adult services, young people and their parents over 10 years
    - Aintree 2009
    - Transition in palliative care (2010 – 11)

Developing the 10-Steps framework

- Consultation and further development
  - Briefing document for professionals, outlining plans for transition, and identifying work streams
  - Initial awareness raising meetings across Clinical Business Units within Alder Hey
  - Series of one-hour ‘Transition Roadshows’ with key clinical teams across the Trust
  - Online transition survey
  - Tackling Tricky Transitions away-day



10-Steps© framework

- Generic transition pathway
- Basis of Trust (and Network) Transition Policy
- Supporting materials
  - Auditable standards
  - Best practice guidance

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10-Steps© portfolio

- What good looks like: Young person friendly guide for what to expect
- Empowering the young person and supporting parents
- Role of Lead Consultant, Keyworker and GP
- Transition map – specialty by specialty transition pathways
- Special Transition Register – to actively support and monitor young people who remain under children's services beyond normal transition age.
- A Transition Policy for children's and adult services with auditable standards
- Competencies for multidisciplinary transition training at universal, core and specialist levels

Recognising the need to move on

- Education, empowerment and development of self management skills for long term conditions, begins in childhood and is life-long.

Standards

- All young people will be aware of transition before their 15th birthday *
- Identification of markers for complex transition and notification of these to the Transition Steering Group if appropriate
- Regular cohort-planning meetings with commissioners and adult service providers

* Except in

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Empowering young people, supporting parents

Standards

- Access to a developmentally appropriate generic health education and empowerment programme
- Access to developmentally appropriate information and advice regarding the young person's condition and its management
- Routine copying of letters and summaries to the young person together with time for explanation and discussion
- Opportunity to be seen alone in part of consultation

Transition Plan

Standards

- Access to a personalised transition plan (hand held or App)

Reviewing the young person's Circle of Support

Standards

- Identification of Lead Consultant
- Active involvement of the GP
- Support from speciality and/or transition keyworker

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Referral to adult services

Standards

- At the latest before young person's 16th birthday*
- Lead Consultant to liaise with other paediatric consultants and Lead Consultant in the adult sector
- Detailed summary of the young person's medical records for each specialist medical service in the adult sector

* Except in

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Joint reviews in children's and adult services

Standards

- At least one joint review with children's services leading
- Adult professionals will introduce young person to adult team
- At least one joint review with adult services leading
- Active monitoring of high risk groups' attendance

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Planning emergency care

Standards

- Clear plan for access to emergency care including self management and the role of the GP
- Opportunity to visit adult A&E and inpatient facilities
- Carers (or parents) continue to provide “everyday care” for complex patients when appropriate

Moving to adult services

Standards

- Young person, adult and children's services agree and communicate
  - the date after which they will be admitted to adult services if they require inpatient care
  - the date after which their outpatient reviews will take place in the adult sector
- All young people previously cared for by Alder Hey children's hospital will be in adult services by their 19th birthday*

* Except in

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Special circumstances

- Conditions diagnosed or recognised during the transition age range
- Life threatening illness
- Services delivered in a specialist centre for children but at a DGH for adults
- Conditions requiring ongoing treatment at Alder Hey beyond the age when transition is normally completed
- Stable conditions requiring infrequent review

Special transition "Register"

- Registration system for early identification of complex or difficult transitions
- Compulsory if patients are to access Alder Hey after their 19th birthday
- Resource for commissioning and cohort planning
- Permissions to stay on the Register and continue to access Alder Hey reviewed every 6 months after the young person's 18th birthday

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Carer Skills Passport

- Integrated framework of accredited carer training
- Train the trainer framework
- Online, classroom and simulation based teaching
- Parents, paid and unpaid carers trained together
- Core and additional competencies to care for individuals with complex healthcare needs e.g.
  - Moving and handling
  - Suction and oxygen
  - Tracheostomies etc.
- Linked Policy and framework Honorary Contract allowing carers to deliver care across all care settings

Carer Skills Passport

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10-Steps: Implementation

- Active engagement with development and implementation of the pathway through:
  - Face to face meetings, online consultation, newsletter and a one day workshop
  - Development of a Trust Transition Steering Group with identified Transition Leads for each specialty and additional transition champions
  - Identifying all patients of transition age who have accessed the Trust in the last 2 years and their transition status
  - Engagement with adult sector and commissioners

Trust-wide engagement:
Trust transition survey

- 99% understood importance of transition
- 79% knew how to identify young people of transition age and services they require
- 85% understood their responsibilities with regard to transition
  - 25% identified themselves as keyworkers or with a role in co-ordinating transition
- 95% aware of need to empower young person to manage their long term condition

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Professionals with a specific role in facilitating transition

- 87% reported being able to support and empower young people to take responsibility for own health needs
- 97% understood principles of consent and information sharing for young people

But

- 64% unsure how to support and empower the GP to take an active role in the care of a young person moving into adult services
- 54% unsure when and how to escalate issues regarding transition within the Trust
- 30% unable to facilitate a Person Centred transition planning meeting

Issues and concerns identified

- What is working?
  - Non complex transitions
- What is not working?
  - Lack of planning and organisational time
  - Lack of reciprocal service
- What needs to change?
  - Fully developed services
  - Planning and co-ordination
- Need for flexible transition age: 16 – 25 years
- Biggest barriers
  - Lack of reciprocal service
  - Family and professional fears
  - Resources
  - Communication, timing planning

Transition Roadshows: key themes

- Vast majority of staff are aware of the importance of good transition and need for improvement
- Conflicting National Policy recommendations for upper age limit for services e.g. oncology, diabetes
- Paucity of support services e.g. community physiotherapy, specialist respite
- Human Resources legislation making it difficult for adult specialists to in-reach into children's services and vice versa
- Information governance making information sharing difficult

Transition Workshop: key themes

- 43 attendees: 23 subsequently self nominated as trust Transition Champions
- Strong support for overarching Trust Policy linked to a Framework Agreement with other Trusts both Adults and Children's
- Outputs used to inform and refine 10-Steps Transition Framework and draft Trust Transition policy
- Other comments and suggestions
  - Trust Transition Team
  - Joint appointments across children's and adult services
  - Transition APP

Young people of transition age accessing the Trust

- 177 inpatients aged 18 or over cared for by the Trust in the last 2 years
  - 30 inpatients with no evidence of transition (+ 8 unknown)
- Continue to access the Trust due to
  - No appropriate target service in the adult sector
  - Specialised services only available at Alder Hey
  - Lack of a clearly defined transition pathway
  - Failure to “look ahead”: appointments for 1 or 2 years’ time

Implementation

- Engagement with over 250 professionals across the Trust
- Identification of Transition Leads for all key specialties
- Active ongoing monitoring of transition status for young people of transition age
- Improving professionals' understanding and meeting learning needs regarding transition
- Engagement with commissioners and adult services to develop appropriate pathways including for young people with complex neurodisability

Conclusion

- The 10-Steps Transition Framework provides a robust framework to support transition to adult services for all young people including those with the most complex needs
- Implementation of the 10-Steps has the potential to ensure safe effective person- centered transition for all young people with long term conditions
- Further evaluation in parallel with ongoing implementation is planned

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Any questions?

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