Alder Hey Children's NHS
NHS Foundation Trust

10 Steps Transition Pathway to Adult Services- The 'Alder Hey way' Complex Young People

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Safeguarding Children
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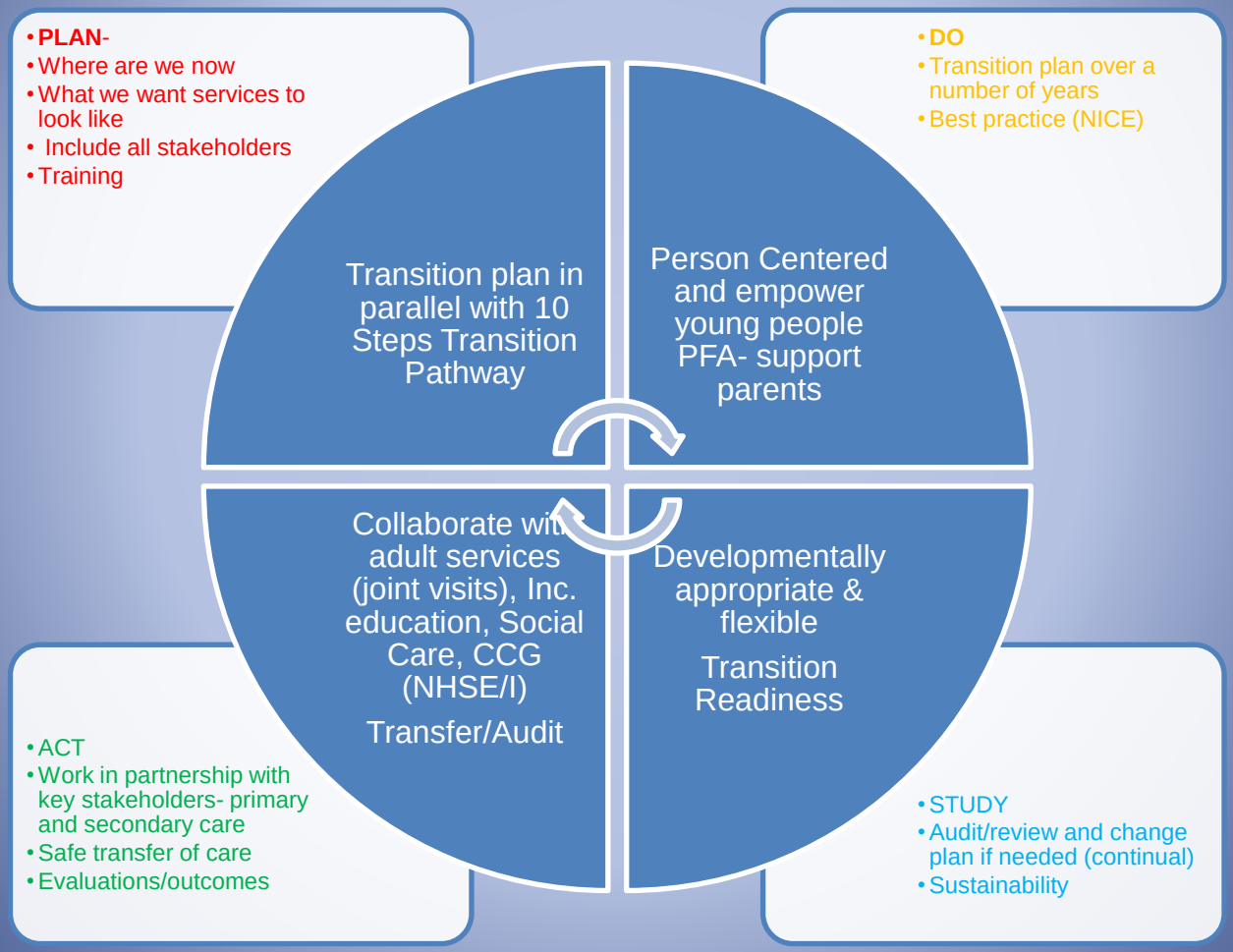
Objectives

Introduction to the Alder Hey 10 steps Transition Pathway & the Alder Hey Transition Exception Register (TER)	Implementing QI methodology
Working collaboratively with other organisations to keep complex YP safe, until we coordinate safe transition	An understanding of barriers challenges and possible solutions A young persons story

Quality Improvement



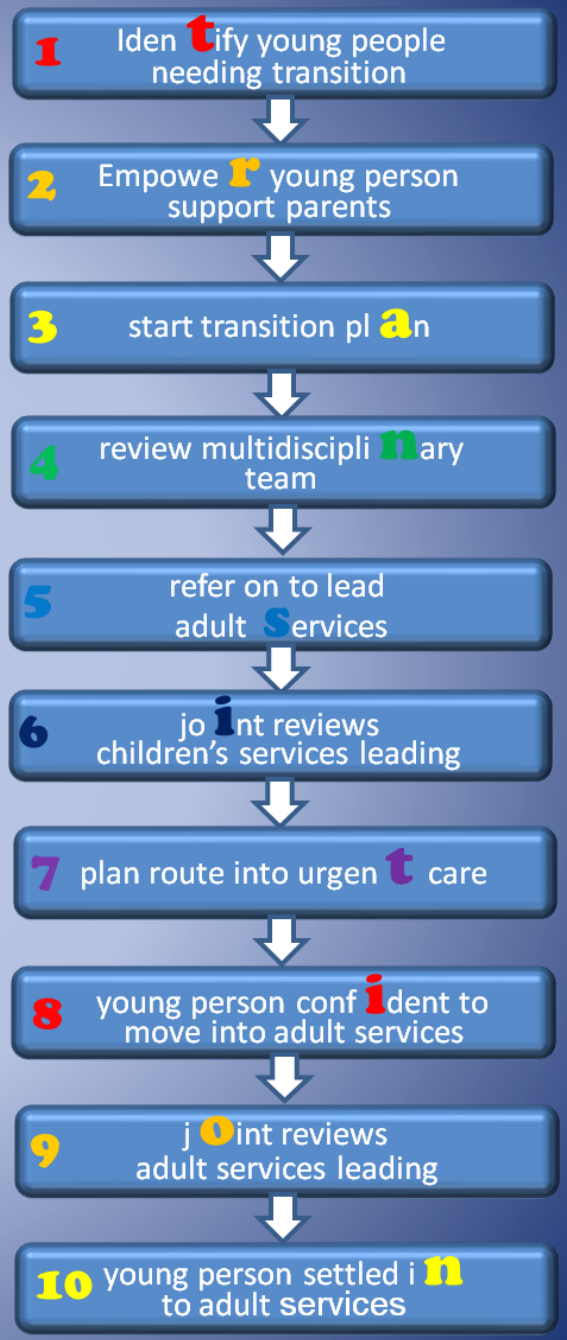
Improving engagement with adult services

- Developed a networked approach to transition across Liverpool & North West
- Identified named Executive Lead in all Trusts
- GP engagement
- North West Multi-Agency Transition Network (AHFT)
- LCCG – Identified gaps in service provision
- NHSE/I – CHC transition planning- equity/standardised
- AHFT representation at the national transition network

10 Steps Transition© Pathway

Generic transition pathway

- Basis of Transition Policy
- Toolkit – Transition MAP
- Auditable standards
- Best practice guidance- 'What good looks like'
- Role of lead consultant, keyworker & GP
- Multi-Agency transition training
- Website www.10stepstransition.org.uk



10 Steps Transition© to Adult Services Our journey so far

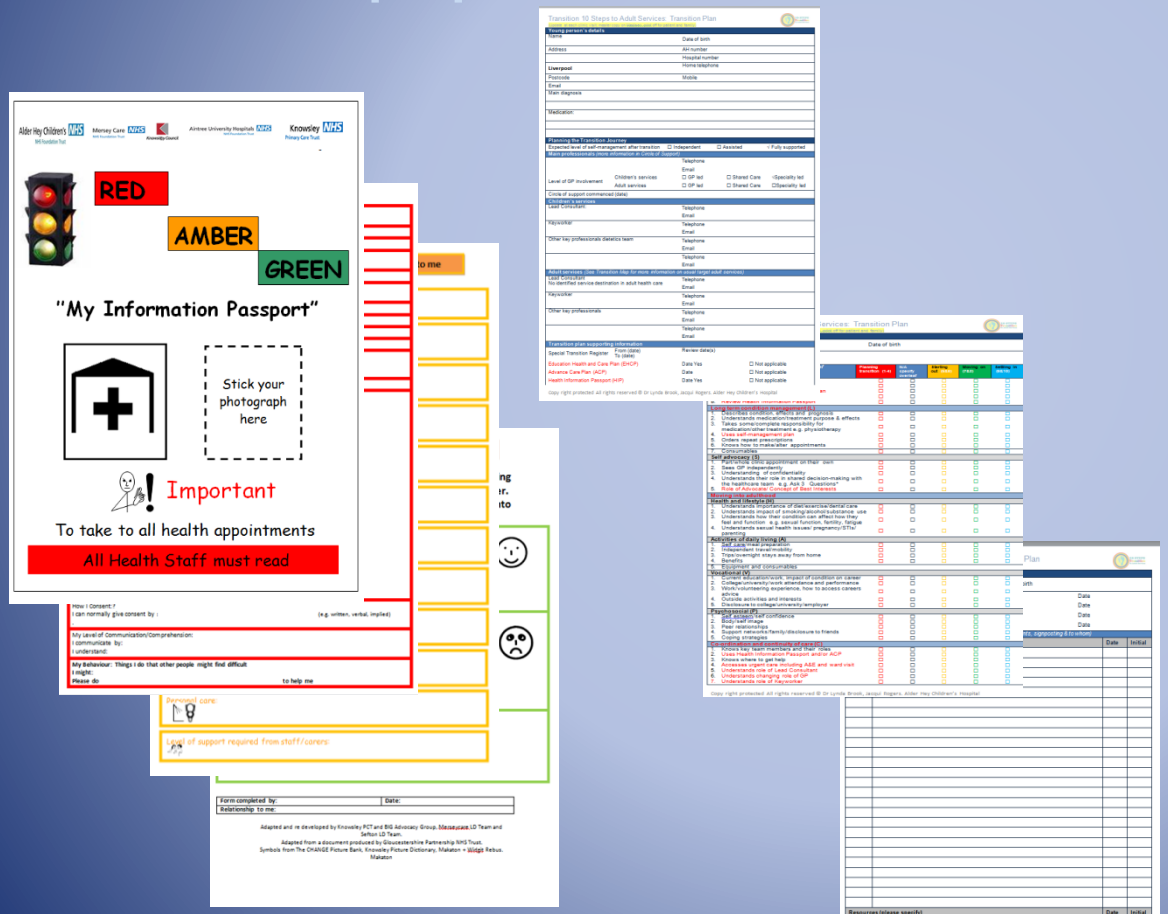
- 2018 – AHFT review – limited resources-
  - Transition team- focus on Complex YP
  - Transition of all specialties- Delegated to Divisional Clinical teams- supported by managers
  - Transition Team available - support difficult transitions & training
  - Extensive & intensive work with adult partners & commissioners commenced

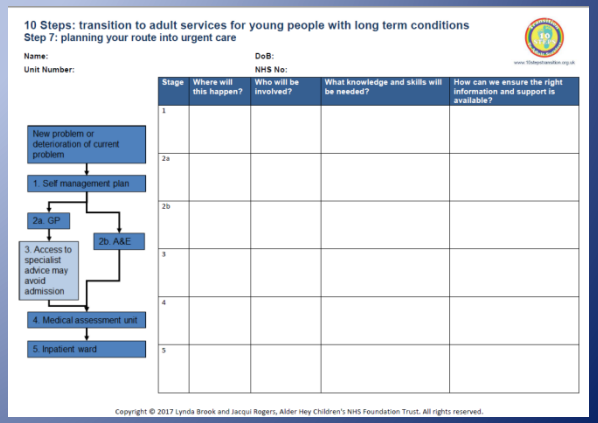
Our Young Adults who are ‘stuck’ in paediatric services

- Under the care of 3 or more speciality services
- **Three or more of the following**
- Oxygen dependent
- Life limiting or life threatening condition
- Life sustaining technology dependent
- Severe or profound LD
- GMFCS 4 or 5

Complex transition CQUIN ‘Cohort 1 & 2’

- Transition preparation documents for complex young people





Planning for emergencies

7 plan route into urgent care

Essential step for safe transition

Anticipate and plan for changes in the young person's condition

Young people need to know

- What to do if they become unwell
- Which hospital they will be taken to/unplanned presentation

GP and emergency services need knowledge and skills to support the young person

Complex YP-Health Information Passport

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Challenges & Barriers: Young adult with complex neurodisability

- Lack of equivalent service profiles in adult sector – transition to GP
- Risk of being “stuck” in children’s services
- Risk of rushed unsupported transition especially if admitted to adult care in an emergency
- Collaborating with adult services
- All YP have Comprehensive Transition preparation & a plan, HIP and route into urgent care

AJ's story

- AJ was born in 1995
- Complex life limiting degenerative neurological condition
- 1997 AJ's sister RJ was born
- Both well known to Alder Hey
- AJ celebrated his 18 birthday - just 4.5 stone
- AJ at just over 18 years became unwell
- Called epilepsy nurses for advise
- AJ deteriorated rapidly
- Emergency 999- Requested to be taken to Alder Hey
- Taken to local adult A&E as 18 years old

AJ's story

- No one knew AJ or how to care for him
- No paediatric cannula or catheter's –taxi
- AHFT - Bed – NWT's
- Central line- unsuccessful
- Osteotomy performed
- AJ sedated and ventilated
- Traumatic for AJ, his family, professionals in ED
- Transferred to out of area paediatric ICU

AJ's story

- Didn't look like AJ
- Family advised to say goodbye at 11am
- AJ had a cardiac arrest at 2am
- Traumatic, not dignified or peaceful
- Things could have been so different – with a plan
- Return phone call
- Plan RJ: ALCP-HIP-Transition plan and on Transition Exception Register

Transition Exception Register

- Register of young people who require support from children's services beyond their 18th birthday
- Assurance that the young person's healthcare needs continue to be met in the most appropriate setting
- Identify and actively manage delayed transition-6 months

  - Discussion with adult providers and commissioners
  - Ensure appropriate services are identified or developed
  - Reassuring for YP and families- TER letter

Letters to families- sometimes in emergency situations

- **NWAS- Schools**

Complex Young People & Executive engagement

- 2018 – 2020
  - Difficulty engaging- Transition Exec (2019)
  - 2020 - Executive meetings convened quarterly – included adults & commissioners
  - Operational leads identified in adult trusts
  - Operational meetings 6 weekly – report to Executive meetings
  - Intensive work programme commenced (COVID)

Barriers & Challenges

- Adult acute care concerns
  - Adult acute care – will accept YP
  - Lack of Community infrastructure to keep YP well at home- concern
  - If YP admitted will get stuck
  - Need to confirm safe adult community offer
  - Intensive work programme in parallel – acute and community adult service providers

Progress to date

- 2022
  - Standard operating procedure – 10 steps
  - Identified 12 PCN's – Liverpool & Sefton
  - ICCT coordinators identified in PCN's
  - Each YP transitioned to identified ICCT – coordinate community care *Inc.* GP- MDT's
  - Acute care transition in parallel
  - 15 complex YP transitioned

Steps 1 & 2

Identify young people needing transition

- AHFT identify young people with very complex healthcare needs requiring transition to adult services

Empower young person, support parents

- AHFT empower young person and support parents to prepare for adulthood and the move to adult healthcare

Steps 3 & 4

Start transition plan

- AHFT start transition plan for community and hospital care updating at each review

Review multi-disciplinary team

- AHFT review the young person's multi-disciplinary team and circle of support social care and education, (EHCPs and CHC)

Steps 5 & 6

Refer on to lead adult services

- AHFT refer young person to Integrated Care Team in appropriate Primary Care Network

Joint reviews children's services leading

- AHFT facilitate joint review with young person, their parents, ICT coordinator and clinician from children's and adults services. Propose date for transfer of care (Tracker)

Steps 7 & 8

Plan route into urgent care

- Discussed at both joint reviews. Paediatric ED transferred to adult services

Young person confident to move to adult services

- Transfer of care from children to adult services

Steps 9 & 10

Joint reviews adult services leading

- ICT coordinator facilitates MDT with young person, their parents, and clinicians from adult and children's services & GP

Young person settled into adult services

- AHFT discharge young person to GP and adult services

Home management plan & Route into urgent care

Step 7 (When in adult services)

- The route into urgent care will be discussed with the YP, family as part of the Transition MDT which is coordinated by ICT Co-ordinator and GP
- In the event the YP deteriorates at home the family will contact the GP who will access the appropriate community service to visit the YP at home, preventing avoidable hospital admissions
- In the event of an emergency that cannot be managed safely by the GP or community services, the family will call 999

Next Steps- Implementation

- Sign off SOP
- 15 young people transitioned
- Coordinated and planned transition for all complex YP to continue all cohorts
- Repeat work stream with other adult trusts and localities outside of Merseyside
- Address Transition Trust wide

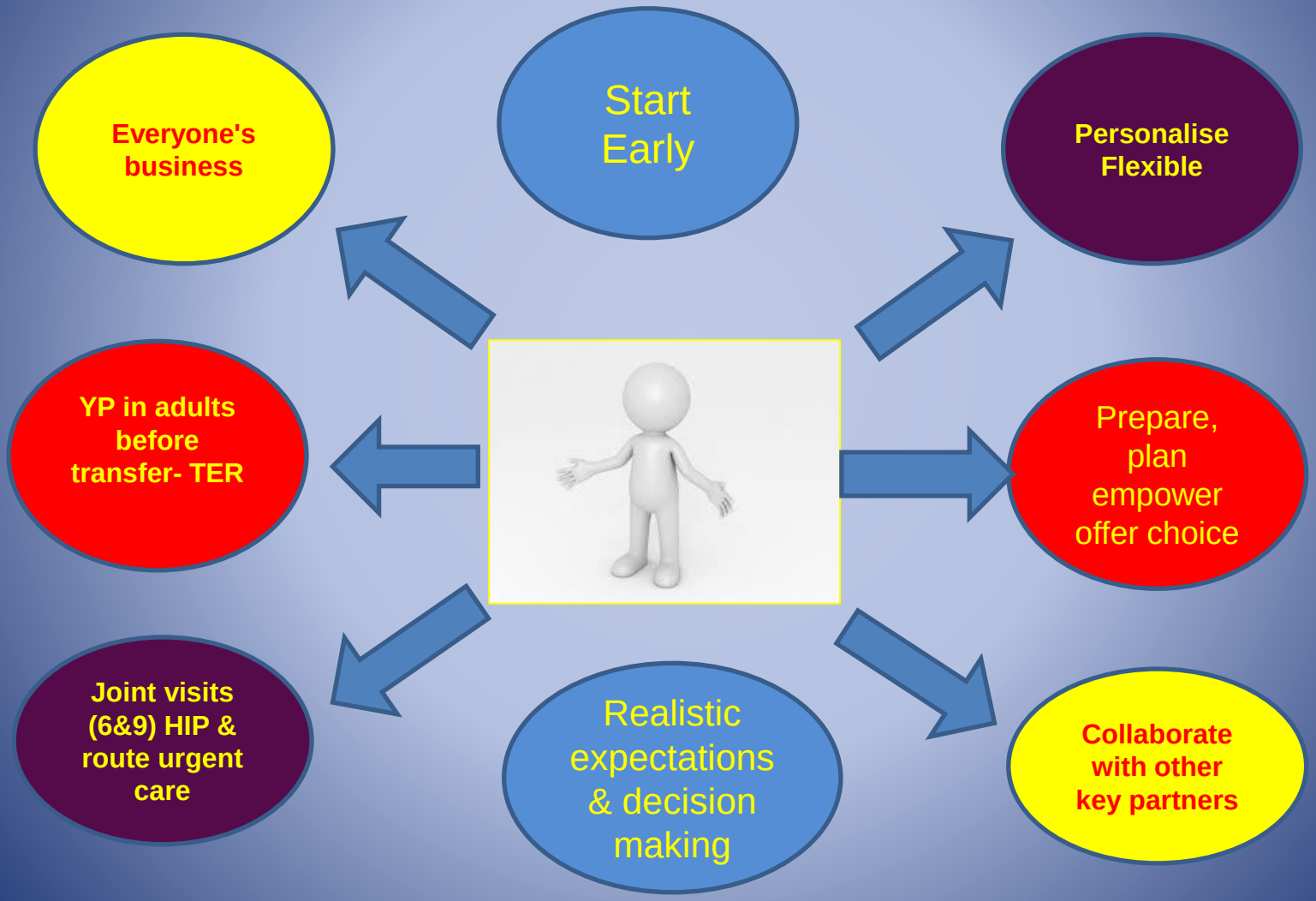
What do adult services need to support transition of our Complex Young Adults

- Cohort Planning- needs of complex YP
- Data intelligence to develop services
- Planning meetings- Joint visits
- Specialities required- Lead Consultant
- Training support
- Emergency care - HIP’s
- Phone a friend option

Conclusion

- The 10 Steps Transition Pathway supports transition to adult services for ‘all’ young people including those with the most complex needs
- Effective implementation of the 10 Steps Pathway with any Transition plan - will ensure safe effective person-centered transition
- Be flexible with age of transition until services, systems, processes and pathways (SOP’s) are embedded
- Be mindful of those who may need to access urgent care and have not transitioned to adult services - NWAS

Advice for success



"There
comms
we hav

"dedicated team w
youngsters eligible
the profile of trans
practice helping te
undertaking audit

"more focussed with an active interest and streamlining integrating the process for benefit of patients, their carers, clinical staff at ACH, community workers and accepting trust"

"It seems coordinated now"

THANK YOU

www.10stepstransition.org.uk

Publications

http://ijnnet.com/current-ijn

https://www.entandaudiologynews.com/features/ent-features/post/10-steps-to-improving-transition-to-adult-services

An Evaluation of the Implementation of the 10-Steps Transition Pathway to Adult Services at Alder Hey Children's Hospital – Fingerprint — Edge Hill University

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