Transition from children's to adults' services for young people using health or social care services

NICE guideline No. 43

Published February 2016

The problem with transition….

The problems…..

- **"Bridging the gap"**
  - interruption in services
  - poor transfer of care
- **"From the pond into the sea"**
  - the differences between child and adult services
- **"Lost in transition"**
  - no services to transfer to
  - lack of preparation and support during the process
  - do not attend or engage with adult services

The consequences

- poor outcomes for young people
- disengagement with services
- increased costs for the NHS, local authorities and other statutory services

The problem with (a lot of) previous transition guidance…..

The NICE guidance

- National Institute of Clinical and Care Excellence
- Published February 2016
- *Any* young person leaving children's health and / or social care provision

What the NICE guidance can do for you…

- Evidence-based or evidence-informed **guidance**
  - mandatory only if already law / government policy
  - national status & recognition
  - informs and drives quality standards
- A **lever for change**
  - practice
  - service organisation
  - responsibilities
- **Support for existing good** practice and processes
- **Resources**
  - training
  - case studies
  - commissioning
  - evidence reviews

How is transition defined?

- Transition is a planned and purposeful **process** that address the psychosocial and medical needs of adolescents and young adults with chronic physical and medical conditions as they **move** from child-oriented to adult oriented health-care services

  (Department of Health, 2006)

- Taking place within a **wider transition** – from childhood **to adulthood**

What young people say….

NICE guidance: a starting point for positive change

- Joint recommendations between health and social care

The basis of the guidance

- Developmental perspective
  - the notion of ‘emerging adulthood’
- The entire process
  - list-making, packing, the departure longue, arrivals hall & beyond
- The layers of issues
  - practice: staff skills and knowledge
  - service organization and coordination
  - commissioning
  - accountability
- It has to work for simple and complex transitions
- It has to address the issue of no equivalent adult service

NICE Recommendations

1. Person-centred approach
2. Transition planning
3. Support before transfer
4. Support after transfer
5. Staff training
6. Supporting infrastructure

1. Person-centred approach

- Tailored process adjusted to each individual's needs
- Holistic
- Developmentally appropriate
- The young person as an equal partner in the process
- Finding out what young people think and want

2. Transition planning: I

- Named worker (role not person)
  - link between child & adult services
  - input / involvement for a minimum of 6 months before & after transfer
- A 'destination' needs to be identified
  - sometimes that may be the GP
- Timing & review
  - start planning early
  - developmentally appropriate planning
  - (at least) annual meeting to review
  - all relevant services/practitioners involved

2. Transition planning: II

- Involvement of the parent/carer
- Building skills to support readiness
  - peer-support groups, mentoring, networking
  - taking lead in appointments / attending alone
- Holistic: not just statutory health and social care
  - training /employment
  - social opportunities & inclusion
  - relationships
  - independence
  - ….these things (may be) more important than going to a new clinic!

3. Support before transfer

- Service manager to ensure the young person has a named worker
- Personal folder for the young person (e.g. health condition, history of interventions, emergency plan, hopes for the future)
- Identify & make available information about service options
  - many ways to provide information, including 'experiential'

4. Support after transfer

- The destination is <u>developmentally appropriate</u> and is <u>mindful of the differences</u> between child and adult services
  - example: DNA's chased
- Continuity of professionals seen during first few appointments
- If disengagement → re-referral

5. Staff training

- Staff have an understanding of :
  - the developmental stage and characteristics of their patients
    - teenagers
    - young adults
    - ..affects: cognitive skills & abilities, emotional maturity, physical growth, concerns & priorities
    - care needs
  - Communication and learning needs
  - Consent & safeguarding
  - Connected or related services

6. The supporting infrastructure

- Ownership
  - Senior executive (child **&** adult services) accountable for transition strategies
  - Operational-level champion (child **&** adult services) reviewing effectiveness of strategy

- When developing transition provision
  - service mapping / needs analysis for young persons (currently) **not eligible** for adult services
    - …"pay particular attention to young people ….who are being supported with palliative care" (p15)
  - consider pooled budgets
  - wherever possible, **draw on evidence**

Things to bear in mind about the guidance….

- The recommendations had to be about high level principles, approaches and practices
  - …but 'translatable' into specific situations or populations
- Very little robust evidence: constrains the scope and strength of recommendations
  - the need for more evidence
  - the importance of taking opportunities to evaluate innovation and service developments…and share learning
    - successes and challenges

Where can I find it?

- NICE website: https://www.nice.org.uk/
  - search for ng43
    - https://www.nice.org.uk/guidance/ng43
  - includes quality standards
    - https://www.nice.org.uk/guidance/qs140
  - lots of 'implementation resources'

- Don't forget: TfSL guidance