NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

1 Guideline title

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

1.1 Short title

Transition from children's to adult services

2 Remit and background

The National Institute for Health and Care Excellence (NICE) has been asked by the Department of Health (DH) and Department for Education (DfE) to develop a guideline on transition from children's to adult services that covers both health and social care.

This guideline will provide recommendations to improve practice, aimed at improving outcomes for young people using health and social care services and their families or carers. The guideline is based on the best available evidence of effectiveness, including cost effectiveness. It is relevant to young people using health and social care services, their families and carers, care providers (including independent and voluntary sector providers), health and social care practitioners and commissioners (including people who purchase their own care). It is particularly aimed at professionals and managers in health and social care services, in both children's and adult services.

The guideline will also be relevant to all people working with young people who are receiving health and social care services, in particular those working in education and employment agencies, youth justice and housing support.

NICE guidelines provide recommendations on what works. This may include details on who should carry out interventions and where. However, NICE

guidelines do not routinely describe how services are funded or commissioned, unless this has been formally requested by the Department of Health.

This guideline will complement a range of condition-specific NICE guidance and quality standards. For further details see section 5 (related NICE guidance).

3 Need for the guideline

3.1 Key facts

3.1.1 This guideline covers both health and social care services. It aims to improve the planning, delivery and experience of care of young people in their transition (move) from children's to adult services.

3.1.2 The timing of planned transition in services reflects wider cultural and developmental changes which lead young people into adulthood. This means that young people experience several transitions which may happen simultaneously and take place over time (McDonagh and Viner 2006). For young people with health and social care needs, their move from children's to adult services complicates their overall transition into adulthood. Transitions between care settings and services are significant points at which people are particularly vulnerable to losing continuity in the care they receive (King's Fund 2010). Adolescence is also a time of enhanced risk of psychosocial problems (Patten and Viner 2007).

3.1.3 There is much existing policy and practice guidance on how young people should be supported as they move between children's and adult services. Transition in this context means more than transfer (Paul et al. 2013). Transition should be purposeful and planned with young people and their families and carers at the heart of the process. Young people and their families and carers need to be involved in decisions that affect them, and should be able to access appropriate information and advice. It is also important that they

know about and understand changes in the services or support available to them, and are introduced to new service settings and practitioners. The preparation should involve both children's and adult services (Department of Health 2011, Joint Commissioning Panel for Mental Health 2012, Council for Disabled Children 2011, Parker et al 2011).

3.1.4 Although there are agreed principles of good transitional care, there is evidence that these principles are often not reflected in practice, and that transition support is often patchy and inconsistent (Beresford and Cavet 2009, Clarke et al. 2011, Gordon 2012, Singh 2010, Hovish et al. 2012).

3.1.5 Research shows that young people who have experienced poorly managed transitions felt insecure and anxious about them. They reported feeling as though they were being punished for reaching a certain age, and as if they were approaching a ‘cliff edge’ (Fegran et al. 2013, SCIE 2012, Singh et al. 2010). Consequences of poor transitions include broken relationships with health and social care practitioners, disengagement with services and deteriorating health (Watson 2005, Singh 2009). Poor transitions in health and social care services might also have negative effects on other transitions such as education, employment and long-term independence. Similarly, poor education and employment can also impact negatively on the transition from children’s to adult services.

3.1.6 Poor management of transitions has been reported across all services, including those for young people with a single long-term condition such as diabetes (Gordon 2012) and people with learning disabilities (Kaehne and O'Connell 2010). Particularly vulnerable groups are identified as those with complex health and social care needs (Crowley et al. 2011), child and adolescent mental health service users (Singh et al. 2010), young people leaving residential care (Beresford and Cavet 2009) and young people with life-limiting

conditions (Children and Young People's Health Outcomes Forum 2012).

3.2 Current practice

3.2.1 Young people in transition from children's health and social services may be referred to a number of different adult services (or may no longer need services). Young people with long-term conditions will move on to adult healthcare services. Young people in need of continuing social care might move on to intermediary support services, and may also have long-term aspirations of independence from services. For some young people, transition involves a period in which they access services which are designed to meet the needs of teenagers (adolescent services).

3.2.2 There is current evidence of service gaps for some young people, in particular those with mental health needs, those leaving specialist residential schools to move back to their original communities, and young people with palliative care needs (Singh et al. 2010, Beresford and Cavet 2009, Children and Young People's Health Outcomes Forum 2012). Service gaps are caused by a lack of relevant adult services, or because young people do not qualify for adult services. For this reason some young people move from specialist children's services into primary care, often relying on provision by voluntary agencies. There is a reported lack of information about services, and poor integration between services (Crowley et al. 2011, Kaehne and O'Connell 2010, SCIE 2012, Hovish et al., 2012).

3.2.3 Examples of good practice mirror guidance in this area. Young people appreciate it when they receive an introduction to adult services, information on what to expect, and when they are involved in the preparations for their move. A good transition requires not just the efforts of children's services. Adult services also need to be involved in the process (Beresford 2013, Singh et al. 2010, Fegran et al. 2013). Young people have said that a good

transition process depends more on support from practitioners than what transition model they receive (Gordon 2012).

3.3 Policy, legislation and guidance

Principles for good transitional care are increasingly being recognised in policy, legislation and guidance for young people. Some key documents are listed below (not intended to be an exhaustive list).

3.3.1 Policy

- Guidance for commissioners of mental health services for young people making the transition from child to adult mental health services Joint Commissioning Panel For Mental Health (2012)
- You're welcome - Quality criteria for young people friendly health services Department of Health (2011)
- Transitions in mental health care Young Minds, the National Mental Health Development Unit, the National CAMHS Support Service (2011)
- Special Educational Needs (SEN): A guide for parents and carers Department for Children, Schools and Families (2009)
- Healthy Lives Brighter Futures Department of Health (2009)
- Aiming high for disabled children - better support for families Department for Education and Skills (2007)
- A transition guide for all services Department for Children, Schools and Families and Department of Health (2007)
- National Service Framework for Children, Young People and Maternity Services Standard 4: Transition: Getting it right for young people – Improving transition of young people with long-term conditions from children's to adult services. Department of Health (2006)

3.3.2 Legislation

- Children and Families Act 2014 House of Lords and House of Commons (2014)
- The Care Bill House of Lords and House of Commons (2013)

3.3.3 Statutory guidance

- Planning transition to adulthood for care leavers Department for Education (2013). This is provided within the Children Act 1989 and the Children Leaving Care Act 2000
- Implementing fulfilling and rewarding lives Department of Health (2010). This is provided within the Autism Act 2009 and covers the transition into adult services for young people with autistic spectrum disorder.

4 What the guideline will cover

This guideline will be developed using the processes and methods outlined in The social care guidance manual. This scope defines exactly what the guideline will (and will not) examine and what the guideline developers will consider.

Transition in this guideline is defined as a purposeful and planned transition from children's to adult services. This is consistent with the definition of 'transition' in the National service framework for children, young people and maternity services (Department of Health 2004).

This guideline will focus on general principles across all services. However, where evidence is available, recommendations may also be made for specific subgroups, for example young people with mental health problems and young people with long-term conditions.

4.1 Who is the focus?

4.1.1 Groups that will be covered

- All young people using children's health or social care services at the time when they are due to make a transition into adult health or social care services, including young people:
  - with mental health problems
  - who have disabilities, including physical and learning disabilities
  - with long-term, life-limiting and/or complex needs
  - in local authority care

- This guideline will cover young people (aged up to 25) going through a planned service transition. Young people transfer from children's to adult services at different ages, depending on their condition and the health or social care services they are using. This transfer is part of a wider transition period that prepares young people for and supports them after transfer. This guideline will cover both planning for and support after the transfer from children's to adult services.

- Some young people may only enter children's health or social care services shortly before their transition to adult services. They are within the scope of the guideline, providing they are using children's services at the time of their transfer to adult services.

4.1.2 Groups that will not be covered

- Young people who are not using children's health or social care services.

- Young people (aged up to 25) entering into adult health or social care services who were not previously using children's health or social care services.

4.2 Settings

4.2.1 Settings that will be covered

All settings in which a transition from children's to adult health or social care services takes place including primary, community, residential, secondary, and tertiary care, and secure care settings (including young offender institutions). This includes transition from specialist care to general practice, including if the GP is the care coordinator.

4.3 Activities

4.3.1 Key areas and issues that will be covered

- Transitional care may be provided within organisational frameworks which specify how services should work together to deliver person-centred care for young people in transition (for example protocols for joint working and

sharing of information). Transitional care is also delivered through direct support such as that provided by transition key workers, transition clinics, young people's support workers in adult services, and information and advice services.

- The guideline will make recommendations that focus specifically on 'what works' for young people in transition, and cover:
  a) Activities to ensure that young people and their carers are involved in, and informed about, the way that their transitions from children's to adult services are planned and delivered (for example, advocacy)
  b) assessment and care planning, including the coordination of care with education, housing and employment services
  c) interventions to support effective transitions (such as the services or support provided by transition workers, peer support groups and transition clinics)
  d) organisational frameworks for transition
  e) training of health and social care staff working with young people in transition, in both children's and adult services
  f) joint working between children's and adult services (health and social care, and with education services where education is leading the transition planning)
  g) changes to adult health and social care services to improve care for young people in transition
  h) factors that help and prevent good transition practice (a key issue because of the current disconnection between existing policy guidance and practice)

4.3.2 Areas and issues that will not be covered

- Developmental transitions and transition support for young people that is not related to their transition from children's to adult health or social care services. Sometimes organisations offer general support to all young people approaching adulthood (for example, careers advice). This type of support is not covered by this guideline, unless it forms part of a support package for transition from children's to adult services.

- Support for young people in the general population, for example, the transition from primary to secondary school for young people not using health or social care services.
- Transitions for young children, for example from early years settings to formal education.
- The transfer between settings of young offenders moving from young offender institutions into adult prisons.
- The effectiveness of specific health treatments or therapies.
- Any service or intervention with no transition component.

4.4 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

- transition readiness (as measured by relevant scales, for example, the Rotterdam Transition Profile)
- self-efficacy (young people's ability to undertake the activities they want to, as independently as possible).
- quality of life (including both health-related and social care-related indicators)
- condition-specific outcomes, including physical and mental health outcomes
- experience of care, for example, accessibility and acceptability of services
- continuity of care:
  - implications for continuity: loss of contact with services, inappropriate referrals
  - promotion of continuity of care: satisfaction, inter-agency communication, clinical outcomes.

Outcomes will be considered for young people and their families and carers.

4.5 Review questions

Review questions guide a systematic review of the literature. They address only the key areas and issues covered in the scope, and usually relate to interventions, service delivery or the experiences of people using services and their carers. The review questions will be used to explore evidence to consider how the outcomes which are important to young people and their families and carers (listed in section 4.4) can be improved. Some possible review questions are:

4.5.1 What are young people's experiences of transitions? What works well?

4.5.2 What are the experiences of families and carers in respect of young people's transitions? What works well?

4.5.3 What factors contribute to successful and unsuccessful transitions, as identified by young people, their families and carers, practitioners and research?

4.5.4 What are the consequences (including costs) of poor transition for young people, their families and carers? Are some groups at particular risk of poor transition?

4.5.5 What is the impact of support models and frameworks to improve transition from children's to adult services? These models include early transition planning, joint working or protocols between children's and adult services, and signposting young people to, or offering them support from, the voluntary and community sector.

4.5.6 What is the impact of interventions designed to improve transition from children's to adult services? These interventions include any specific intervention which is there to support transition, for example keyworkers, transition clinics or information evenings, provided by any agency, statutory or voluntary.

4.5.7 What are the factors that help or prevent implementing effective transition strategies and practice?

4.5.8 How can the transition process (including preparing the young person, making the transfer and supporting them after the move) best be managed for those receiving a combination of different services?

4.5.9 What effect does transition training for health and social care practitioners have on the success of transition?

4.5.10 How can adult services be improved for young people in transition?

Please note that these are only examples of areas that may be addressed. The review questions will be agreed by the Guideline Development Group (GDG) at the start of guideline development.

4.6 Economic aspects

The guideline developers will take into account cost effectiveness when making recommendations involving a choice between alternative interventions or services. Appropriate economic review questions will be identified. A review of the economic evidence will be undertaken in line with the methods outlined in The social care guidance manual. Economic analysis, where undertaken, will consider all relevant commissioners, decision-makers, funders, providers, service users and their families and carers who are relevant to the economic review question.

The timing and processes used for managing young people's transitions between children's and adult services have economic implications. Ensuring that young people's needs are met, reducing the risk that their outcomes are negatively affected, sustaining or improving their quality of life, and helping them to achieve education and employment (where these are realistic aims) will all have economic consequences.

Economic analysis will be informed by evidence on service use, costs and outcomes from a broad range of studies. This may include international evidence where relevant.

As far as possible, the analysis will use sufficiently long time horizons to explore long-term impacts on quality of life, education and employment, social care and possibly criminal justice. Outcomes will be expressed in natural units of measurement (such as employment), in utility measures (where these can be calculated) or in monetary terms (again, where these can be calculated).

The analysis will adopt a public sector perspective (that is, costs and outcomes from the perspective of the health and social care system). However, calculations may also be made adopting a societal perspective in order to test the sensitivity of the results to the inclusion of other relevant outcomes (including those relevant to families and carers).

Subgroup analysis might be used in situations where the effectiveness or cost effectiveness of interventions is likely to vary between particular groups of young people. Subgroups could include: young people with learning disabilities; those with complex needs; those who have conduct disorders; looked-after young people and teenage or young parents.

4.7 Status of this document

4.7.1 Scope

This is the final scope, incorporating comments from a 4-week consultation.

4.7.2 Timing

Guideline development will formally start in June 2014 and the final guideline is scheduled to be published in February 2016.

5 Related NICE guidance

5.1 Published NICE guidance

- Antisocial behaviour and conduct disorders NICE quality standard 59 (2014)

- Children and young people with cancer NICE quality standard 55 (2014)
- Autism NICE quality standard 51 (2014)
- Antisocial behaviour and conduct disorders in children and young people NICE clinical guideline 158 (2013)
- Psychosis and schizophrenia in children and young people NICE clinical guideline 155 (2013)
- Depression in children and young people NICE quality standard 48 (2013)
- Looked-after children and young people NICE public health guidance 28 (2010)
- Methylphenidate, atomoxetine and dexamfetamine for the treatment of attention deficit hyperactivity disorder (ADHD) in children and adolescents NICE technology appraisal 98 (2006)
- Obsessive-compulsive disorder NICE clinical guideline 31 (2005)
- Self-harm NICE clinical guideline 16 (2004)
- Eating disorders NICE clinical guideline 9 (2004)

5.2 Guidance under development

NICE is currently developing the following related guidance (details available from the NICE website):

- Diabetes in children and young people NICE clinical guideline (publication expected August 2015)

- Transition between inpatient hospital settings and community or care home settings for adults with social care needs NICE social care guideline (publication expected November 2015)

- Transition between inpatient mental health settings and community or care home settings for people with social care needs NICE social care guideline (publication expected August 2016)

6 Further information

Information on the guideline development process is provided in The social care guidance manual, available from NICE's website. Information on the progress of the guideline will be available on the NICE website.

7 References

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