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PRACTICE

GUIDELINES

Supporting young people in their transition to adults' services: summary of NICE guidance

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In spite of a wealth of guidance,[1] young people making the transition from children's to adults' services are often inadequately or inconsistently supported.[2-4] This can lead to disrupted care.[5] It can also mean they disengage from services, which can be costly, both for them and for care providers.

Transition is a process and should not be conflated with transfer, which is a discrete event. Simple transfer may result in poor understanding of the young person's treatment needs by the new adult team. Healthcare transition is a gradual, purposeful, and goal oriented process. It can be difficult and often coincides with other transitions such as development into adulthood, which adds complexity. Transition should start well before transfer and enable patients to understand the service changes they can expect. See linked infographic on supporting young people in their transition to adults' services.

We summarise the most recent recommendations from the Institute for Health and Care Excellence (NICE) aimed at improving the transition process and outcomes across health and social care.[6]

Recommendations

NICE recommendations are based on systematic reviews of best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the guideline committee's experience and expert opinion of what constitutes good practice. Evidence levels for the recommendations are given in italic in square brackets.

The guideline was founded on strong evidence about what young people want from services, and what they think would help practitioners work together effectively. This summary focuses on a subset of the guideline recommendations. It offers practical advice to clinicians on ways to improve young people's engagement with services. It also describes what clinicians and others can do to coordinate transition support.

Principles

- Offer transition support to:

  -Focus on what is positive and possible for the young person rather than on a predetermined set of transition options

  -Identify the support available to the young person, which includes but is not limited to family or carers.

[*Based on a good quality systematic review, good quality qualitative studies, a moderate quality survey, expert witness testimony, and guideline committee consensus.*]

- Involve young people and carers in service design, delivery, and evaluation related to transition by:

  -Co-producing transition policies and strategies with them

  -Planning (box 1), co-producing, and piloting materials and tools

  -Asking them if the services helped them achieve agreed outcomes

  -Feeding back to them about the effect their involvement has had.

[*Based on good quality systematic review and qualitative evidence, mixed quality qualitative studies of people's views*

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Infographic on supporting young people in their transition to adults' services

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What you need to know

- Allocate a named transition worker, which is a role not a job title; this should be someone who is involved in the young person's care
- Develop a transition plan with the young person that describes what care will be provided and by whom
- Develop a personal folder, held by the young person, describing their preferences, care needs, and history
- Offer support for a minimum of six months before and after transfer
- Transition planning should be developmentally appropriate
- Education and employment, community inclusion, health and wellbeing, and independent living should all be addressed

and experiences,a moderate quality survey, expert witness testimony, and guideline committee consensus.]

Allocate a named worker

- Help the young person to identify a single practitioner, who should act as a "named worker," to coordinate care and support during transition. This person could be supported by an administrator. [*Based on evidence from a good quality systematic review, good quality qualitative studies, moderate quality mixed methods studies, a poor quality evaluation, expert witness testimony, and guideline committee consensus.*]
- The named worker should be someone with whom the young person has a meaningful relationship and, depending on the young person's needs, this person could be:
  -A nurse, youth worker, or other health, social care, or education practitioner

  -The named GP

  -An existing key worker, transition worker, or personal adviser.

  [*Based on evidence from good quality qualitative studies, moderate quality mixed methods studies, a poor quality evaluation, expert witness testimony, and guideline committee consensus.*]
- Named workers should:
  -Oversee, coordinate, or deliver transition support, depending on the nature of their role

  -Be the link between the young person and the various practitioners involved in support, including the named GP

  -Arrange appointments with the GP where needed as part of transition

  -Help young people navigate services, bearing in mind that many may be using a complex mix of care and support

  -Support the young person's family, if appropriate

  -Ensure that a young person who is also a carer can access support

  -Act as a representative for the young person, if needed (provide support or advocate for the young person if needed)

  -Proactively engage primary care in transition planning

  -Direct the young person to other sources of support and advice, such as peer advocacy support groups provided by voluntary and community sector services

  -Think about ways to help the young person travel to appointments, if needed

  -Provide advice and information.

  [*Based on evidence from a good quality systematic review, good quality qualitative studies, moderate quality mixed methods studies, a poor quality evaluation, expert witness testimony, and guideline committee consensus.*]

Support before transfer

The following guideline recommendations relate to all children using health or social care services.

Begin planning for adulthood from aged 13 or 14 at the latest (box 1). Transition planning should be developmentally appropriate, taking into account each young person's capabilities and needs.

- Consider working with the young person to create a personal folder that he or she can keep and share with adults' services. This should be in the young person's preferred format. It should be produced early enough to form part of discussions about planning transition before transfer). It could contain:
  -A one page profile

  -Information about the young person's health condition, education, and social care needs

  -Preferences about parent and carer involvement

  -Emergency care plans

  -History of unplanned admissions

  -The young person's strengths, achievements, hopes for the future, and life goals.

  [*Based on evidence from three moderate quality systematic reviews, expert witness testimony, and guideline committee consensus*.]

Support after transfer (box 2)

The following recommendations seek to ensure that the overall plan for supporting a young person is revised if the young person is not in contact with services after transfer.

- If, after assessment, the young person does not engage with health and social care services, the relevant provider should refer back to the named worker with clear guidance on re-referral (if applicable). [*Based on evidence from one good quality correlation study, one good quality survey, and guideline committee consensus*.]
- If a young person does not engage with adults' services and has been referred back to the named worker, the named worker should review the person centred transition plan with the young person to identify:
  -How to help the young person use the service, or

  -An alternative way to meet the young person's support needs.

  [*Based on evidence from one good quality correlation study, one good quality survey, and guideline committee consensus.*]

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Box 1: Timing and review

- Ensure the point of transfer is not based on a rigid age threshold
- To be able to plan appropriately, use existing information technology systems to identify young people (≤25 years) in transition
- Meet to review transition planning annually or more often if needed*
- Produce the young person's personal folder early enough to inform discussion—for example, three months before transfer

*For young people with a child in need plan, an EHC (education, health and care) plan, or a care and support plan, local authorities must carry out a review as set out in the Children Act 1989, the Children and Families Act 2014, and the Care Act 2014.

Box 2: Recommendations for follow-up

- Follow up young people who do not attend meetings or appointments by contacting them (and their family, if appropriate) or their GP
- Refer back to the named worker for follow-up of young people who do not engage with adult services after assessment
- Where there is no adult service to refer to, send a detailed discharge letter to the GP and give the young person information about other sources of help

Implementation

The lack of incentive for children's and adults' services to work together and the different funding streams are the greatest barriers to effective transition. As a result of this, transition (rather than transfer) is often initiated by individual practitioners rather than being an integral part of the care pathway. Adults' and children's services need to share responsibility for supporting transitions. To help this, a practitioner from the relevant adult service(s) should offer to meet the young person before transfer. This could happen through adult services' clinicians being seconded to work on children's teams (or vice versa), or through joint appointments, joint clinics, or practitioners paired to work together.

Clinicians and managers should review local policy and practices to ensure that they support a gradual and person focused transition. This could include policies on consulting alone to ensure young people have the opportunity to discuss their care separately from their parents. It could also include a review of policies on admissions and discharge, and managing non-attendance.

It is particularly difficult to support transition when no equivalent adult service is available or when eligibility thresholds are different. The process can be made easier by adults' and children's clinicians undertaking a joint review of service provision to establish protocols outlining what to do in such circumstances, and engaging clinicians and commissioners to plan ways to fund service gaps.

The members of the guideline committee were Caroline Bennett, Bryony Beresford, Teresa Culverwell, Kathie Drinan, Thines Ganeshamoorthy, Charlotte Gatherer, Helena Gleeson, Debbie Kinsella, Clare Lamb, Eugenia Lee, Swaran Singh (chair), Julie Turner, Alun Williams, Philippa Williams, and Carrie Wilson. The NICE Collaborating Centre for Social Care team members were Amanda Edwards, Beth Anderson, Martin Knapp, Kristin Liabo, Palida Teelucknavan, Marija Trachtenberg, Nadira Sharif, Isabel Quilter, Joanna Lenham, Kim Rutter, Paul Ross, Claire Stansfield, and Zenette Abrahams. The NICE social care team members were Fiona Glen, Jane Silvester, Justine Karpusheff, Nick Staples, Peter O'Neill, Sarah Richards, Leonie Gregson, and Jaimella Espley.

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Competing interests: We declare the following interests based on NICE's policy on conflicts of interests (available at: https://www.nice.org.uk/Media/Default/About/Who-we-are/Policies-and-procedures/code-of-practice-for-declaring-and-managing-conflicts-of-interest.pdf): BA works for the Social Care Institute for Excellence (SCIE). SCIE is a charity and improvement agency funded by a range of organisations involved in commissioning or providing services for children and adults with health and social care needs. SS is head of mental health and wellbeing and deputy head, division of health sciences at Warwick Medical School, University of Warwick. He is honorary consultant psychiatrist and associate medical director for R&I at Birmingham and Solihull Mental Health Foundation Trust. He is also commissioner for the Equality and Human Rights Commission, UK. KL was employed by the EPPI-Centre at the Institute of Education in University College London while leading the systematic review work on this NICE guideline. Her time co-authoring this summary was spent while employed by the NIHR funded Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South West Peninsula. The authors' full statements can be viewed at: http://www.bmj.com/content/bmj/353/bmj.i2225/related#datasupp.

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Further information on the guidance

Methods

This guidance was developed by the National Institute for Health and Care Excellence (NICE) Collaborating Centre for Social Care according to the methods described in the NICE guideline development manual.[7] A multidisciplinary guideline committee considered evidence gathered from a series of systematic reviews and developed recommendations accordingly. Review data were supplemented by committee members' expert opinion and formal submission of expert testimonies where gaps in evidence were identified.

The committee comprised two young people with experience of transition services, a care leaver who is also a carer, two carers, a consultant endocrinologist, a consultant paediatric and adolescent urologist, two consultant psychiatrists, a clinical commissioner/GP, an education transition lead, an academic specialising in transition, a physiotherapist, a national development officer for transition, and a social worker/transition service manager.

The guideline was subject to formal consultation with external stakeholders. The committee considered stakeholder comments and updated the recommendations accordingly.

NICE has produced three different versions of the guideline: a full version; a summary version known as the "NICE guidance"; and a version for people using NHS services, their families and carers, and the public (https://www.nice.org.uk/guidance/ng43/ifp/chapter/About-this-information). All these versions are available from the NICE website (https://www.nice.org.uk/guidance/NG43). Updates of the guidance will be produced as part of NICE's guidance development programme.

NICE is currently developing a Quality Standard on this topic. This is a set of concise statements to drive measurable improvement in the areas of the guideline where this most necessary.

Future research

- What approaches to providing transition support for those who move from children's to adults' services are effective or cost effective (or both)?
- What is the most effective way of helping families to support young people who have been discharged from children's services (whether or not they meet criteria for adult services)?
- What is the most effective way for primary care services to be involved in planning, implementing, and following up young people after transfer (whether or not they meet criteria for adult services)?
- What are the consequences and the costs of young people with ongoing needs not transitioning into adult services or being poorly supported through the process?
- What is the most effective way to help carers and practitioners support young people's independence?
- Is there an association between transition and subsequent self management?
- What is the most effective way of supporting young offenders in transition from children's to adults' health and social care services?
- What is the most effective way of supporting young people in transition from children's to adults' health services?
- What are the effects of different approaches to transition training for practitioners on outcomes for young people?

How young people were involved in the creation of this article

- The guideline scope was informed by consultation with two groups of young people with experience of transition
- Three young people with experience of transition were appointed as full members of the guideline committee for this topic
- The review protocol included a research question on young people's views and experiences. Qualitative studies of people's views and experiences were also considered in relation to all other research questions
- Thines Ganeshamoorthy was one of the young people on the committee and is co-author of this article

Guidelines into practice

- Do you check the young person is registered and engaging with a GP?
- Does a clinician from the relevant adult service(s) meet the young person before transfer?
- Does the young person see the same clinician from the adults' team for the first two appointments after transfer?

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