NICE National Institute for Health and Care Excellence

Implementing the NICE guideline on transition from children's to adults' services for young people using health or social care services

Implementation support

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Introduction

This resource is useful reading for health, children's and adult social care managers and other organisations who support young people with special educational needs and disabilities (SEND) and their families in preparing for adulthood. Drawing on learning from workshops held in two local areas with staff from health, education and social care organisations, it provides:

- information to support the recommendations in NICE's guideline on transition from children's to adults' services for young people using health or social care services
- learning points from the workshops
- links to useful resources.

Why should you put this guideline into practice?

NICE guidelines are made up of evidence-based recommendations for health and care in England. The Care Quality Commission (CQC) use NICE guidelines as evidence to inform the inspection process. CQC and Ofsted now carry out joint inspections of local SEND arrangements, details of which are set out in their Framework for the inspection of local areas' effectiveness in identifying and meeting the needs of children and young people who have special educational needs and/or disabilities (2016).

Key messages

The common elements in effective support for young people at transition are set out in legislation and statutory guidance (Care Act 2014, Children and Families Act 2014 and the

SEND code of practice 2014) and good practice like the guideline. These common elements from the legislation and guidance are reflected in learning from 2 local areas who participated in multi-agency workshops that took place in June 2016. The workshops used the guideline as a starting point to review current practice, and to identify challenges and priority areas for improvement. The key messages from the workshops on providing effective support are:

- **Multi-agency and joint team working:** leading to continuity and better quality of care in transfers between services and support to young people and families preparing for adulthood.
- **Participation and engagement with young people using person-centred support:** leading to better outcomes through flexible, tailored support with which young people are more likely to engage positively.
- **A focus on outcomes beyond 16 and 18 years old:** leading to clear longer-term goals with support suited to work towards them, more evidence-based commissioning and cost-effective provision.

Learning from local areas

Using the NICE guideline as a starting point and with the support of the NICE Collaborating Centre for Social Care (NCCSC), two local areas held multi-agency workshops. They used the guideline, and specifically the implementation challenges section, to:

- identify what was in place and working well locally
- prioritise areas for work to improve support for young people at transition and implement the guideline recommendations.

The two local areas had multi-agency protocols in place, which encourage effective joint working, and were confident in using the new Education, Health and Care (EHC) plans. However, they felt they could do more with the Local Offer (SEND Code of practice section 4) to provide information about local services, engage with young people and gather data on how effective support is in achieving outcomes. Both workshops identified three areas for work in future:

- Multi-agency and joint team working
- Participation and engagement with young people
- Support beyond 16 and 18 years old

Multi-agency and joint team working

The guideline and legislation

The guideline has an emphasis on joint working in and beyond health and social care. It recommends that service managers work with each other to proactively identify and plan for young people with transition support needs (recommendation 1.1.6). The guideline also recommends that each health and social care organisation should nominate a senior executive to be accountable for the development and implementation of a transition strategy and policies (1.5.1). The special educational needs and disability code of practice 0-25 also underlines the importance of joint working (SEND code of practice section 3.56) as does the joint CQC and Ofsted SEND inspection framework:

> *It is important to note that these inspections will evaluate how effectively the local area meets its responsibilities, and not just the local authority. The local area includes the local authority, clinical commissioning groups (CCGs), public health, NHS England for specialist services, early years settings, schools and further education providers.*
>
> The framework for the inspection of local areas' effectiveness in identifying and meeting the needs of children and young people who have special educational needs and/or disabilities, page 8.

Example

Services report that they need better information about each other to give to families and also use themselves so they are confident in how best to link up, share expertise and jointly support young people. Developing the Local Offer (SEND Code of practice section 4) provides a focus for this work. Work completed by the South East London Pathfinders group with the Preparing for Adulthood team sets out the range of services that could be involved in delivering effective local support. This includes young people and their families as key partners, and services including:

- job centre plus
- housing providers

- health, education and social care
- transport and leisure services.

It provides a useful checklist for areas bringing together key groups in transition planning and can be found in Developing the Preparation for Adulthood Section of the Local Offer – A guide.

Learning from local areas

During transition, which is a long process, different joint working models may be needed and a range of partners involved at different points. Strong local leadership was identified as important in achieving joint working; bringing together agencies, young people, families and providers and developing sustainable and effective relationships. The table below sets out points from the workshops along with the recommendations they link to in the guideline.

Guideline reference	Local area learning – multi-agency and joint team working
Recs: 1.5.1; 1.5.2	**Leadership – joint working**
	Identify a senior lead as 'transition champion'. This will promote engagement in strategic and operational meetings, provide a focus for work and visible support at a senior level across organisations, and sponsor transition as a key issue in wider strategic discussions.
	Make links with other key staff including the Designated Medical Officer (DMO) (SEND code of practice section 3.46) and commissioners including for housing and transport.
	Sponsor strategic planning groups with key partners from health, education and social care and encourage input from teams including looked after children, CAMHS and youth offending.
	Work with managers and commissioners to include the option of cross team funding and resource sharing in pathways so teams can more easily joint work and share expertise. For example, children with disabilities and looked after children teams.

	Support teams to identity a transition lead and build this role into individual and team work plans.
	Locate staff together to improve general knowledge of services and support. For example, one day a week, secondments or joint training to support with specific advice (including clinicians) and improve general knowledge of services and support.
	Raise awareness with a range of services including drugs/alcohol, CAMHS, sexual health, targeted youth programmes and employment advice as they need to understand and be able to engage with young people with SEND.

In addition to leadership, the workshop attendees identified a number of learning points on multi-agency and joint team working including using the Local Offer, transition protocol and local pathways to check how well support is working and plan more effective joint working in future. The table below sets out points from the workshops along with the recommendations they link to in the guideline.

Guideline reference	**Local area learning – multi-agency and joint working**
Recs: 1.1.5–1.1.7; 1.5.3; 1.5.9; 1.5.10	Share initial assessment information across services and use a single point for initial referral and re-referral to save time and make sure young people and families are directed to the most appropriate support earlier. This can also be used to monitor waiting times for support or intervention after referral/initial assessment as long delays (for example, to occupational therapy) can have a significant impact on the effectiveness of the intervention and long-term advantages for the young person.
	All key services need to be actively signed up to the protocol commitments, pathway formats and to providing information for the Local Offer. Having services like CAMHS or Looked After Children teams signed up increases the range of support/expertise available and demonstrates a commitment to joint working.
	Link up local pathways so teams working with, for example, unaccompanied young people or those seeking asylum can work together on possible pooling of resource or staff skills to meet their needs.

	The Local Offer needs to include and promote good quality non-specialist services who have the skills to support young people with SEND. If there is a gap in local support bring this into discussion as part of the commissioning cycle plan.
	Develop shared transfer arrangements. Young people and families can benefit from early meetings/clinic visits with named staff in each service. Use the Designated Medical Officer (DMO) (SEND Code of practice section 3.46) in planning this support.
	Maintaining the information in the Local Offer needs to be built into a programme of work/job description and have a named lead.

Participation and engagement with young people

The guideline and legislation

The guideline recommends using person-centred approaches (1.1.4) to support young people's involvement in their own transition planning (1.2.11) and in the planning of services (1.5.5). To support them in this process, the guideline recommends enabling young people to identify a 'named worker' who could coordinate their transition care and support (from children to adult services) (1.2.5). The SEND Code of Practice sets out the requirements that need to be met:

> *Young people must have confidence that they are receiving confidential and impartial information, advice and support. Staff working directly with young people should be trained to support them and work in partnership with them, enabling them to participate fully in decisions about the outcomes they wish to achieve. Young people may be finding their voice for the first time, and may need support in exercising choice and control over the support they receive (including support and advice to take up and manage Personal Budgets). Advocacy should be provided where necessary. Local authorities must provide independent advocacy for young people undergoing transition assessments, provided certain conditions are met (see section 67 of the Care Act 2014).*
> (SEND Code of Practice section 2.15)

Example

There is a wealth of resources on developing the participation of young people and on using person-centred approaches at transition. In many of these resources young people set out ideas which would improve their experience of using services and making choices. This is an example from young people with long-term health conditions:

Focus on me the person, not my condition;

Ask about my whole life;

Be friendly and don't make assumptions about how teenagers behave;

Have up-to-date, age-appropriate information;

Help me learn more about my condition so I can make good decisions

Common Room (2015) Talking about rights

Requests like these from young people sound simple to achieve, yet prove difficult to implement meaningfully within a multi-agency framework.

Learning from local areas

Learning from the local area workshops highlighted that participation and engagement of parents and carers was better or better established than the participation and engagement of young people directly. Local areas identified that the revised Code of Practice content, including using the more person-centred, outcome-focused Education, Health and Care plans, brings an opportunity to support young people to have a larger role in planning. In addition, the development of the Local Offer was seen as an essential element in improving participation and engagement.

Learning from the workshops covered three areas of participation: engaging with young people, sharing views and providing information to support young people and families in making choices. They are set out in the table below with the recommendations they link to in the guideline.

Guideline reference	**Local area learning – participation and engagement**
Recs: 1.1.1–1.1.4; 1.2.5–1.2.10; 1.2.11; 1.2.12; 1.2.19–1.2.22; 1.5.4; 1.5.5	**Engagement with young people**
	Build in work with young people with SEND to the wider local participation and engagement programme. Sharing resources and skills across teams can increase staff confidence and encourage better engagement with young people.

	Identify and plan support to meet the communication needs of local young people. This includes staff training (for example in using person-centred approaches), and having access to particular skills (for example, sign language), when needed. This can greatly increase the participation of young people in their own plans and in shaping local services and support.
	Sharing information
	Agree with families and young people how their views are shared. For example, views on service planning shared through the Parent Carer Forum; Youth Parliament or on dedicated council web pages can promote the needs of young people and highlight gaps in local support.
	Share information that young people and families provide with services including commissioners. A regular slot at strategic and operational multi-agency meetings can be helpful along, with a clear point of reference for staff to access the information or views when needed.
	Providing information
	In relation to transition, 'information' might include support to assist in accessing information from an advocate or lead worker, support from the local Independent Support programme organisation or from peer support groups.
	Systems like the Family Information Service; service directories; and Information, Advice and Guidance (IAG) should include information for young people and families with SEND to make sure it reaches as many people as possible.
	Include information on general issues, including drug and alcohol issues; pregnancy; child sexual exploitation (CSE) and personal safety; and local community activities in the Local Offer.

Support beyond 16 and 18 years old

The guideline and legislation

The guideline sets out the need (duty if young people have an Education, Health and Care Plan) for health and social care service managers to work together to 'ensure a smooth and gradual transition for young people' from Year 9 onwards (1.1.5; 1.2.1). To meet the challenges of providing support for young people after 16 and 18 years old, earlier joint planning by children and adult services along with a person-centred approach to identifying all available options should be in place (1.2.14). The guideline underpins this in recommending a holistic approach to transition planning (1.2.13) and supporting young people to engage with services when available (1.4.2). The development of the Local Offer will provide opportunities for young people, families and professionals to work collectively in identifying gaps and look creatively at short and longer-term solutions (SEND Code of Practice section 4.3).

Example

Moving from a service, or changes to support, are part of the transition process and can be a challenge and a worry for some young people as they prepare with their families for adulthood. In particular this can be the case for young people who may not be 'eligible' for support from, for example, adult social care services. Parents' concerns at this time, as shown by a report from the University of York from parents of young people with autism, include:

- a lack of progression or meaningful daytime occupation
- the threat of harm and police involvement arising from behaviour problems
- poor or worsening mental health
- parents' own ability to continue the caring role.

University of York (2013) Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions

Learning from local areas

The workshop attendees identified that planning across services was essential to offer the best support to young people and families. This includes making sure individual plans have long-term goals and that service support plans are based on data of local current and future need. For example housing provision, college places and primary care. Key points from the workshops are set out in the table below and the recommendations they link to in the guideline.

Guideline reference	Local area learning – support beyond 16 and 18 years
Service provision and eligibility Recs 1.1.5; 1.2.1; 1.2.13; 1.2.14; 1.2.17; 1.3.1; 1.3.5–1.3.9; 1.4.1; 1.4.2	Make sure staff are confident in outcomes planning and able to work with young people and families to identify a range of potential support beyond statutory services. This also needs to be understood by staff in employment support, independent living and community organisations.
	The Designated Medical Officer could work across pediatrics and adult clinics or GPs to promote using transition planning to ensure young people understand the impact of taking risks. For example, in managing their own condition or disengaging from services.
	Longer term planning (for example five year plans) is needed for services to anticipate young people's needs, including those who will return from out-of-county placements. This planning could include sharing data about young people in transition to help identify those who are disengaging or not going to be eligible for adult support.
	Use transition pathways to provide clarity on what is available from therapy services at 18 and beyond. For example, occupational therapy (advice on adaptations) physiotherapy (consistent support and access to services including hydrotherapy) and speech and language therapy. Consider joint funding these across services if no health funding or provision is available.
	Improve promotion of community and non-specialist support options for young people, for example training and employment opportunities. Promote these through the Local Offer and other information sources locally.

	Share data on consistent gaps with managers and commissioners and work with providers to increase choices of support. For example, agencies who can support direct payment/personal budget administration with families particularly on identifying more flexible, creative support.

Resources and useful links

- Common Room (2015) Me First. For healthcare and front-line staff to develop knowledge and skills in communicating with children & young people.
- National Voices (2015) My life, my support, my choice. Describes success factors in the support of children and young people with complex lives.
- NICE (2016) Baseline assessment tool. Information to review local services and support on transition.
- Preparing for Adulthood (2015) The links between The Children and Families Act 2014 and The Care Act 2014. Information on recent legislation.
- Research in practice for adults (2014) Personalisation and managing the market. Looks at how commissioners can influence market development.
- Social Care Institute for Excellence (2015) Transition from children's to adult services – early and comprehensive identification. One of a range of publications for local areas on the Care Act 2014 in relation to transition.
- Southampton Children's Hospital (2013) Ready, Steady, Go. Provides direct information for young people and families at transition.

Links

- Preparing for Adulthood provide a range of resources, including factsheets, stories and videos about transition.
- The Transition Information Network provides information for young people, families and professionals on all aspects of transition.

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About this tool

This tool is based on NICE guidelines and quality standards published up to April 2016 about transition from children's to adults' services for young people using health or social care services.

You can find out more about NICE guidelines and quality standards on our website.

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