

# NICE Collaborating Centre for Social Care

Transitions between children's and adults' services Monday 17<sup>th</sup> February 2014.

## Stakeholder Scoping Workshop Notes

### Break-out group discussions

Nine facilitated break-out groups discussed specific aspects of the draft scope. This paper summarises the themes that emerged.

#### 1. How well does section 4.3.1. (Key areas and issues that will be covered) of the scope address the most important issues surrounding transition?

**Outcomes** - Several groups agreed emphasised that the scope should be outcomes-focused. Some members commented that outcomes should be a key part of organisational frameworks or practice models. There was some debate about whether 'independence' should be a key outcome, with some noting that independence should be understood relative to the individual's conditions and needs.

**Preparation** - preparation for transition was seen as important. Some groups emphasised that children's and adult services should be equally involved in preparation. It was thought that this could aid 'seamless' transitions. The preparation of parents and carers for transition was also important. One group highlighted that parents can become less involved in services after young people reach the age of 16. Some members pointed out that parent involvement can vary on a case by case basis, but it was thought that parents can play a central role in the transition process.

**Primary Care** - The role of GPs was seen as particularly important by several groups. Some members suggested that GPs could be at the centre of the transition process because they can play a co-ordinating role in the transition and commission services. It was also felt that GPs could offer information and support for service users, parents and carers.

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**Transition as a Process** - Almost all the groups stated that transition should not be seen as one discrete change, but as a gradual process which may involve transfer from several different services.

**Client Focused** - All the groups were clear that the process needs to be looked at through the 'lens' of people who use services and their families and carers. This person-centred approach was thought to be the best way to keep services holistic and flexible. Some members commented that there was a danger of looking at transitions only in terms of services and costs. It was also suggested that the approach should move away from being 'risk averse', to one that allows for 'managed risk'. The importance of maintaining confidentiality was highlighted by several groups as a key issue, particularly in relation to potential child protection cases and highly vulnerable adults.

**Mental Health** - Mental health services were seen as playing an essential role in transitions; Child and adolescent mental health services were mentioned specifically. It was suggested that mental health services can play a role in steering service users through the potentially difficult emotional transition into adult services.

**Management and Leadership** - One group suggested that the scope should include management and leadership of services given that these are important factors in transitions: some service users interact with multiple professionals and services, at different times and the scope therefore needs to look at different approaches to management and leadership of the process

**Organisation** - Several groups were keen to emphasise that the guideline will need to exhibit an understanding of team structures and the key people involved in transition. An understanding of how professionals work together, particularly to facilitate good communication and collaborative working was seen as very important.

**Self Management** - There was some debate around the issue of 'self – management' and concern that it might be seen as encouraging young people to manage alone (inappropriately) when they might benefit from services. Some members pointed out that individuals may also need extra support despite a level of self-management and that there was a danger in 'asking too much' in terms of self management. One group said self management is a very broad concept which includes aspects such as independent living, resilience, and preparing for adulthood. Other groups questioned the use of personal budgets and how young people may use these. The risks in making generalisations about individual needs and goals were flagged by several discussions groups.

## **2. What aspects of the transition between health and social care most need to change?**

**Funding** – The groups discussed the challenges in respect of funding, for example different funding streams acting as a barrier to smooth transition, and some ways that services are responding (highlighting for example, the benefits of pooled or integrated budgets).

**Experiences and groups** - Transitions are experienced very differently by different groups. Some conditions are very well-managed in specific settings, other individuals may have undiagnosed or complex health and social care needs which are difficult to transition. One group highlighted that some young people with chronic conditions also have social care and psychological needs which need to be addressed as part of the transition process. Substance misuse was also an area of concern, and some members questioned how this group might be accommodated in transitions planning.

**Eligibility** – Groups discussed the challenges presented by eligibility criteria for services. Young people may not have a social worker and they may not have accessed service for some time. A key issue highlighted here related to young people ‘getting lost’ in the system and failing to access appropriate adult services. There was concern from some members that some young people engage only intermittently with services and therefore may ‘miss’ transition altogether or present at the point of transition.

**Age thresholds** were thought to be a barrier to effective transitions because they impose arbitrary thresholds on young people without account of their suitability for adult services. One group said that adult services expect to receive ‘adults’ who are aged 16 or 17 but there are unclear or variable definitions of what constitutes an ‘adult’ and a child or young person. Similarly, some groups challenged the notion that the age of 25 is an appropriate point to assume full transition into adulthood has taken place.

**Assumptions** - Making assumptions about teenage behaviour and preferences was seen as a barrier to positive and successful transitions. All groups emphasised the importance of service users being seen as individuals and we should not make judgement about how independent service users wish to be or how much parental or carer involvement they require. Another point raised was about teenagers often being profiled as disengaged and challenging to work with. Members highlighted the importance of not making assumptions

**Joint Assessment Process** – Members highlighted the importance of co-ordinated transition across services to avoid young people becoming confused, or being left with unmet needs. One group said that there is a lack of joint-working and there can be confusion around eligibility for services. It was noted that some 16 year olds can’t receive children’s or adult services. There was almost universal agreement that there is a need for more continuity between services.

**‘At-risk’ Groups** - Several groups expressed concern for care leavers and ‘children in need’ in particular. This was on the basis that these groups are particularly at risk of inadequate support throughout transition. Young carers were also seen as being particularly vulnerable in this respect. There was concern about local authorities incorrectly identifying individuals’ care needs and, as a result, failing to fund them for the correct adult services.

**Regional differences** – Some groups discussed geographical variations in services. Feedback suggested that services should meet a basic minimum level across the

board, which would mean that every young person would be entitled to a minimum level of services.

**Professional Training and Skills** – Currently, transitions can seem abrupt because professionals either work in children’s or adult services. Children and adolescent workers need to understand the importance of preparing children for a new ‘adult’ service environment. Similarly, professionals in adult services need to understand how paediatric services work and apply this knowledge in order to help facilitate smooth transitions. Such planning and ‘skilling up’ needs to happen early and staff should inhabit an empowering and enabling role in a young person’s transition.

**Support for Families** - Support for families was thought to be important to address. Groups felt that there is a need to shift away from service-centric view and think about empowering and supporting parents and carers. It was also suggested that there is a need to support the whole family, including siblings. Parents and carers need to have good relationships with professionals and be well- informed about a young person’s conditions.

### **3. What impact may the guideline have on areas of concern/importance?**

**Good Transitions** - Several groups highlighted that available evidence on what constitutes ‘good’ transitions, noting that this should be emphasised as much as problematic areas in the guideline. One group said that there are different levels of support available to people: health, social care, local authorities and the voluntary sector, and the main thing that needs to be improved is organisation of, and access to services.

**Common Principles** – Groups agreed that the guideline should identify and describe the common principles that should underpin transition services to ensure a consistent approach.

**Positive and Practical Guideline** - It was hoped that the guideline may result in an attitude and mindset change among professionals and stakeholders. One group encouraged the scope to be aspirational; to ask, ‘What is possible for young people’?

**Organisation and Planning** - It was hoped that the guideline can influence how professionals organise and plan transitions, and introduce continuity across local authorities, instead of young people experiencing a ‘post-code lottery’. The guideline should drive better communication and planning across and within sectors, along with more communication between personnel such as social workers, nurses, GPs, psychologists and others. Many members emphasised that it should help ensure more seamless provision as a result of improved multi-agency work. One group noted that there are practical ways of addressing this which the guideline may consider, e.g. dual registration in children’s and adults services.

**Measure Successful Transitions** - There is a need for cost-benefit data to show the impact of transition for example, on long-term employment and other health and social care costs post-transition.

**Advocacy and Peer Support** – The promotion of ‘transition support’ from peers and advocates was flagged as a possible outcome relevant to this guideline. It was thought that young people may want to be connected to others who have had similar experiences. It was also suggested that third sector commissioning may help young people to access cost effective services which can help individuals make decisions. Advocates may also be helpful to those affected by the ‘mental capacity act’ and have a limited ability to understand the decisions they are faced with.

**Training and professional competence** – People highlighted the need for the guideline to consider the role of transition-specific professionals, with a breadth of experience who work with all ages. Members also noted the importance of ensuring the guideline is accompanied by implementation support, particularly given its non-mandatory status.

#### **4. Questions for the guideline to address**

The following questions were thought to be important for the guideline to address.

1. What is the impact of the third sector on transition from children’s to adults’ services?
2. Why do people not engage with services that are available, what are the barriers?
3. What happens to young people who are entering adulthood services without support?
4. What is the effect of different health/clinical needs on transitions?
5. How will the transition process affect looked after children, young carers and children in need?
6. How should commissioning processes be influenced?
7. How to address those who seem to be getting lost in the system, due to fragmented service use throughout their childhood and teens?
8. Where are the current gaps in service?
9. What is the impact of joint commissioning and pooled budgets?
10. How will transitions become personalised?
11. How do we prepare young people for transition when parental input is non-existent?
12. What are the long term outcomes of good transitions?
13. How does background and ethnicity affect transition experiences?
14. What does a good transition look like?

## **5. Addressing education, employment and housing.**

Stakeholders were keen to emphasise the importance of the relationship between health and social care, and other sectors, specifically: education, employment and housing, with education thought to be particularly important. In this respect, people thought the guideline should consider:

- Schools' responsibilities to safeguard children throughout transition, as well as to prepare them for adulthood and responsibility, while they are undergoing (or planning for) service transitions.
- How transition services are jointly planned and/or commissioned across sectors
- How schools in particular can end up supporting children who are experiencing health and social care service transition but are poorly supported (or not supported)
- The importance of supporting young people to secure appropriate housing.

## **6. Existing Guidance and Evidence**

Many of the stakeholder groups thought that the current guidance and research on transitions was limited and that there is still a paucity of evidence around this topic. Several members commented that the existing guidance and information is often presented in ways which are not user friendly or accessible.

It was suggested that young service users may be more likely to engage with information online, rather than speaking directly to a professional or visiting a GP. One member mentioned the Department of Health 'You're Welcome' paper which is designed to make health services 'young person friendly'.

The implementation of the Care Bill and Children and Families Bill was seen as a key steer for this guideline and several groups discussed how this legislation will have an impact on transition and that this should be clearly discussed. It was felt that there needs to be a clear link with current policy, legislation and practice. The scope needs to cross-reference existing policies and guidance.

The members thought also that the scope must make an effort to engage properly with service users, parent and carers in the gathering of evidence. Engagement with professionals is also important.

There were also comments that there is already a good deal of guidance available and that this project will have to bring something different to the table if it is to be effective.

Many groups did provide examples of good practices which they had read or heard about and these are listed below.

## **7. Where is there likely to be innovative practice in relation to this topic?**

- The YMCA
- Transition Taskforce
- Surrey Local Authority
- East Sussex Local Authority
- Yorkshire ADHD transition services
- Transition teams – health and social care
- Newcastle University – Modelling Health Outcomes
- Bangor University ‘Bridging the Gap between Children’s and Adults Services’.
- Birmingham Children’s Hospital – Liver Unit
- Sheffield Children’s NHS Foundation Trust – Haematology Unit
- Ealing Local Authority
- Oxford University Hospitals – Renal/Kidney Units
- University Hospital South Hampton – ‘Ready, Steady, Go’ – Transition to Adult Care
- University of Toronto, ‘Good 2 Go Transition Programme’.
- Bristol University
- One group discussed a study in Australia of mental health services for 14-25 year olds (although noted problems related to the differences in context, and in relation to measuring long term outcomes).
- One group suggested that community specialist nurses seem to be offering good support and are co-ordinating care effectively.
- Two groups mentioned good practice in diabetes transition, but it was noted that type one diabetes is a well managed condition in children, but type two diabetes, is less so.
- The role of families and carers should also be taken into account. We can’t make assumptions about capacity to make decisions at 18. Some individuals might want a high level of parental/carer support, other may be more independent.
- VARMM – Vulnerable Adult Risk Management Model which provides a ‘risk score’ and could be used as an example of good practice.
- Many individual studies in ADHD and costs to society/cost effectiveness
- Nick Goodwin – Care co-ordination work.

**8. Equalities – Are there groups whose circumstances or conditions make them especially vulnerable to poor transitions**

- Those moving to a different local authority.
- Young people who go into the Armed Forces (starting from 16 yrs)
- High functioning autism
- Families from black and minority ethnic (BME) communities
- Children with challenging behaviour
- Young people living in poverty
- Parents who do not speak English
- Asylum-seeking children
- Travellers
- Young offenders

### **9. Audience – who is the audience for the guideline?**

- Children & young people
- Families, parents, carers
- Care Commissioning Groups
- Adult services (Health and Local Authority)
- NHS England – strategies clinical networks
- Voluntary sector organisations
- Education – schools/universities
- Occupational Therapists
- Allied Health professionals
- Association of Directors of Adult Social Services
- Association of Directors of Children’s Services
- GPs
- British Association of Social Workers
- The College of Social Work
- Royal College of Surgeons
- Safeguarding professionals
- National Union of Students
- Schools
- The Police

### **10. Which stakeholder groups or organisations is it important to include in the GDG?**



- Children & young people, parents and carers (including foster carers) – This could include those who have passed through transition and those about to transition.
- EPIC rep representative
- Clinical Commissioning Group[s both Primary & Secondary Care
- Voluntary organisations (e.g. national parents org)
- Social workers
- Teachers
- Oncologist
- Local Authority and Health Commissioners
- Mental health worker (CAMHS)
- Housing/employment sector representatives
- Adult social care
- Transition team representative
- Safe guarding worker
- Paediatrician
- GPs
- Adolescent palliative care specialist/Hospice
- Education – school, further education colleges, special education
- Voluntary Sector Organisations
- Community Paediatrician
- Voluntary sector
- Association of Directors of Adult Social Services
- Association of Directors of Children’s Services
- Care leaver teams
- Social care/corporate parents
- Child and Adolescent Mental Health Services
- Childline
- Department of Health transition workshop members
- Psychologist (adult and child)
- Royal college of GPs
- Adolescent health group
- The Association for Young People’s Health
- ‘Speaking Up’
- Public Health Representatives

## **11. Key Points in Summary**

1. The output need to be presented suitably for all prospective audiences, particular service users.
2. The output need to be presented in an equitable way - different languages.
3. Adult services need to be a central part of transition
4. A single point of contact for service users to contact would be beneficial
5. A Person centred, holistic approach is desirable
6. Links with education, employment and housing need to be made.
7. The guideline needs to take the perspective of young people; the focus should be on their needs
8. Methods of identifying individuals who may be getting missed would be useful,
9. Transitions will differ hugely from individual to individual
10. Service users and carers should have control and choice.
11. The guideline should acknowledge current gaps in care
12. The role of primary care is important
13. Transition is a gradual process, not one discrete movement.
14. Good communication between professionals is important
15. Good communication with service users is important
16. The views of children and young people should be central to the development of guideline.
17. The Guideline should influence commissioning.
18. Services need to be interrelated involving multi-disciplinary teams