Transition to adult health services

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Todays session

- The transition process
- Roles and responsibilities
- How parents and young people can prepare
- Differences between children and adult health services
- Issues of consent / mental capacity

“Forewarned, forearmed; to be prepared is half the victory”

Miguel de Cervantes

SEND Code of Practice

- Local authorities must ensure that the EHC plan review at Year 9, and every review thereafter, includes a focus on preparing for adulthood. Planning must be centred around the individual and explore the child or young person's aspirations and abilities, what they want to be able to do when they leave post-16 education or training and the support they need to achieve their ambition. Local authorities should ensure that children and young people have the support they need (for example, advocates) to participate fully in this planning and make decisions. Transition planning must be built into the revised EHC plan and should result in clear outcomes being agreed that are ambitious and stretching and which will prepare young people for adulthood.
- Preparing for adulthood planning in the review of the EHC plan should include: support in maintaining good health in adult life, including effective planning with health services of the transition from specialist paediatric services to adult health care. Helping children and young people understand which health professionals will work with them as adults, ensuring those professionals understand the young person's learning difficulties or disabilities and planning well-supported transitions is vital to ensure young people are as healthy as possible in adult life

Transition to adult health services

- Support to prepare young people for good health in adulthood should include supporting them to make the transition to adult health services. A child with significant health needs is usually under the care of a paediatrician. As an adult, they might be under the care of different consultants and teams. Health service and other professionals should work with the young person and, where appropriate, their family. They should gain a good understanding of the young person's individual needs, including their learning difficulties or disabilities, to co-ordinate health care around those needs and to ensure continuity and the best outcomes for the young person. This means working with the young person to develop a transition plan, which identifies who will take the lead in co-ordinating care and referrals to other services. The young person should know who is taking the lead and how to contact them.

- For young people with EHC plans, the plan should be the basis for co-ordinating the integration of health with other services. Where young people are moving to adult health services, the local authority and health services must co-operate, working in partnership with each other and the young person to ensure that the EHC plan and the care plan for the treatment and management of the young person's health are aligned. The clinical commissioning group (CCG) must co-operate with the local authority in supporting the transition to adult services and must jointly commission services that will help meet the outcomes in the EHC plan.
- In supporting the transition from Child and Adolescent Mental Health Services (CAMHS) to adult mental health services, clinical commissioning groups (CCGs) and local authorities should refer to The Mental Health Action Plan, Closing the Gap: Priorities for essential change in mental health. This action plan identifies transition from CAMHS to adult services as a priority for action. CCGs and local authorities should have regard to any published service specification for transition from CAMHS. They should use the specification to build person-centred services that take into account the developmental needs of the young person as well as the need for age- appropriate services.

Adult social care

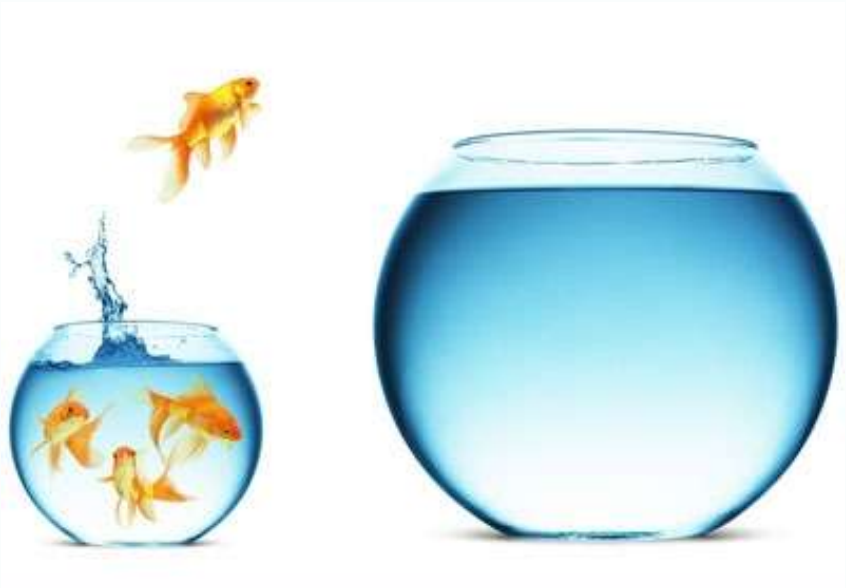
- Transition to adult social care
- Young people with SEN turning 18, or their carers, may become eligible for adult care services, regardless of whether they have an EHC plan or whether they have been receiving care services under section 17 of the Children Act 1989. Under the Care Act 2014, the local authority must carry out an adult care transition assessment where there is significant benefit to a young person or their carer in doing so and they are likely to have needs for care or support after turning 18. Transition assessments for adult care must take place at the right time for the individual. There is no set age when young people reach this point and as such transition assessments should take place when it is of 'significant benefit' to them.
- The statutory guidance 'Transition Guidance for the Care Act 2014' explains 'likely need' and 'significant benefit' in more detail. It also provides further information on local authorities' roles and responsibilities for carrying out transition assessments for those turning 18 and, where relevant, carers who may be eligible for adult assessments.

The transition process…….

"Transition is a major milestone and the impact of this was not properly shared, we had to learn about the process from another parent; it falls on us as parents to instigate all that happens"

CQC From the pond to the sea

- Information is often poor
- Guidance and protocols often in place but not always being used, and some professionals unaware of their existence
- Parents told CQC they were often the main co-ordinator of care as there was no lead professional
- Process of transition rarely began by 14



The reality – services for your child

- Your child's care may have been co-ordinated by a paediatrician
- If there have been other specialist involvement needed may have been referred by and reports back to the paediatrician
- For many families, children bypass their GPs and have direct access to paediatrician and / or hospital as necessary.
- If your child has needed treatment or care in hospital provisions will have been made to enable you to stay with them and support their care needs

Likelihood of provision of health services as an adult

- GP is likely to become a key part in your young persons care – may not have been involved before
- If hospital care or treatment is needed, there will be no automatic agreement or provision to enable you to stay with your child, or visit them without restrictions
- Depending on the care needed may be looked after on inappropriate adult wards
- Some children's health provision ends at 16 but an adult health team may not agree taking a referral until 18
- May be no expectation you are involved or part of decision making

CQC From the pond to the sea

There is no excuse for the failure of so many providers and commissioners to follow existing guidance that, if followed, would significantly improve the quality of care during transition. Every young person with complex physical health needs, from age 14 should have:

- A key accountable individual responsible for supporting their move to adult health services.
- A documented transition plan that includes their health needs.
- A communication or 'health passport' to ensure relevant professionals have access to essential information about the young person.

• Health services provided in an appropriate environment that takes account of their needs without gaps in provision between children's and adult services.

• Training and advice to prepare them and their parents for the transition to adult care, including consent and advocacy.

• Respite and short break facilities available to meet their needs and those of their families.

– CQC's inspection models will explicitly look at transition in both children's and adult health services – in hospitals, in primary care and the community – which will be factored into the overall rating. This means that good transition arrangements may raise a provider's rating, and poor practice may reduce it. We may take action in cases where arrangements are so poor that they pose a risk to the quality of care experienced by people who use services.

Tips to consider

- Transition planning should begin in year 9…….make sure it does
- Introduce your child to your GP early on…and if they are reluctant to meet with you remind them of their future role
- Request a key accountable individual is identified with you and your child's agreement who is responsible for supporting the move to adult health services
- Ensure that your child's transition plan includes details of their health needs
- Consider and develop a health passport if your child does not have one.
- Ensure children's social care services do not end before adult provision begins
- Find out (where possible) which hospitals and wards may offer support to your child and meet with them before admission or likely admission and agree a plan for support – write this down!

Specific considerations

- If your child is eligible for continuing care – ensure the assessment and decision process for adult continuing health care funding is planned well in advance
- Consider the possibility of the use of personal health budgets
- Find out about your local Healthwatch Service

Young people making their own decisions - SEND CoP

As young people develop, and increasingly form their own views, they should be involved more and more closely in decisions about their own future. After compulsory school age (the end of the academic year in which they turn 16) the right to make requests and decisions under the Children and Families Act 2014 applies to them directly, rather than to their parents. Parents, or other family members, can continue to support young people in making decisions, or act on their behalf, provided that the young person is happy for them to do so, and it is likely that parents will remain closely involved in the great majority of cases.

The Mental Capacity Act

The right of young people to make a decision is subject to their capacity to do so as set out in the Mental Capacity Act 2005. The underlying principle of the Act is to ensure that those who lack capacity are empowered to make as many decisions for themselves as possible and that any decision made or action taken on their behalf is done so in their best interests. Decisions about mental capacity are made on an individual basis, and may vary according to the nature of the decision. Someone who may lack capacity to make a decision in one area of their life may be able to do so in another.

Hang in there

- Preparation is the key
- There are many more drivers to improve the transition process – Children and Families Act, Care Act, Ofsted / CQC Inspection framework

Useful documents and any questions?

SEND Code of Practice
https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

CQC From the pond to the sea
http://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf

NICE clinical guidelines
https://www.nice.org.uk/guidance/indevelopment/gid-scwave0714

SATH transition to adult health service
https://publicdocuments.sth.nhs.uk/pil2398.pdf