



Challenging Behaviour - National Strategy Group (CB-NSG)

Monday 27th June 2022 via Zoom

Workshop 2:

Transition into adult health, education and social care services

Workshop Facilitator: Isabelle Garnett, Dave Atkinson and Wendy Ewins

Time: 11.25-12.35 am session, 14.20-15.30 pm session

The aim of the workshop is to:

- Explore the importance of transition (across health, education and social care) for people with learning disabilities
- Identify the challenges around transition for people with learning disabilities and their families
- Agree solutions to these challenges and share good practice

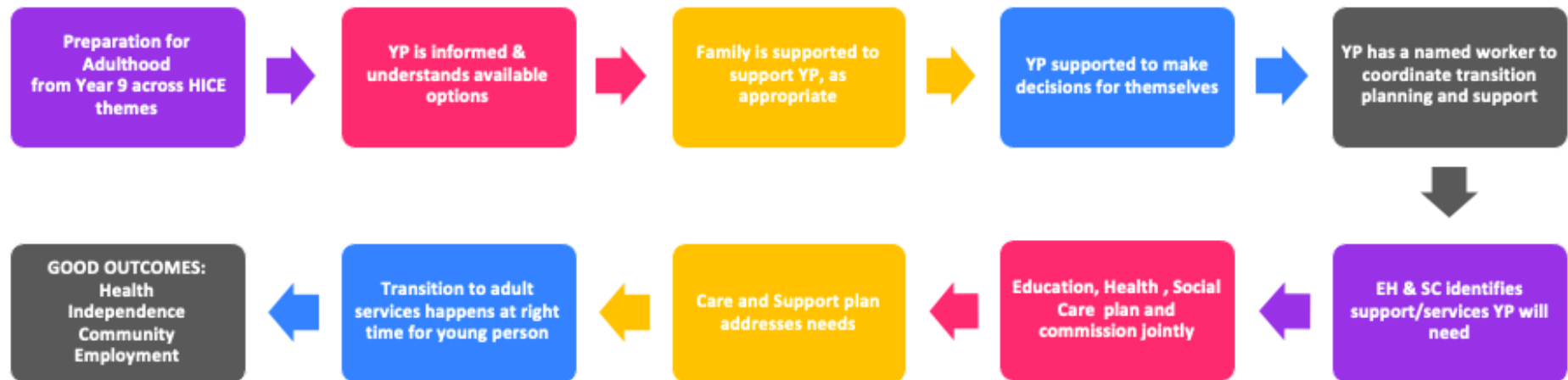
The objectives are to:

- Discuss experiences of transition from child to adult health, education and social care services.
- What works well (including best practice examples) and what are the challenges?
- Discuss how the NHS Quality Standards can be used to capture good practice and work to improve transition?
- Gather feedback on questions that can be used within the quality standards to capture information around transition between health services.
- Identify actions to improve transition for people with learning disabilities, working across health, education and social care.

Background

The flow chart below illustrates what a good transition to adult services should look like:

Good practice transition pathway



Sources:

- NICE Quality Standard 140 'Transition from children's to adults' services' (2016)
- Special educational needs and disability code of practice: 0 to 25 years Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities (January 2015)

However, we know families too often do not experience it this way.

Key relevant findings from the Getting it Right project in the Black Country so far:

- Transition is tough for families
- Transition from child to adult social care is the hardest to access information and support on. The majority of Black Country families completing the Getting It Right survey felt unprepared for their child's transition
- Families made the following suggestions for how anxiety around transition could be reduced:
 - Access to better information
 - Planning well in advance of relative's transition

Additional issues from family carer experiences:

- EHCPs go up to 25 but Health and Social Care services tend to discharge around 18th birthday - even though transition should happen at the right time for the person (NICE guideline 43 1.2.3)
- Families experience transition as 'falling off a cliff edge' - continuity / non-existence of services
- Available funding/ existing services do not meet the person and their families' hopes and aspirations
- There is a lack of clarity around the mechanisms which will fund the person's ongoing support needs as an adult - services fight about who funds what and families have to fight for the person's entitlements

The national learning disability improvement standards for NHS trusts and Benchmarking

The standards were published in 2018 and require all NHS Trusts to measure how they are doing and develop improvement plans. To assist with this, a national benchmarking programme has been commissioned from the NHS Benchmarking Network. Trusts provide data and position statements, in relation to a large number of metrics. Additionally, the experiences of people with a learning disability and front-line staff are anonymously surveyed.

Participating Trusts receive a report which details their performance, metric-by-metric; and are able to access to an online toolkit. A national overview report is published each year (www.nhsbenchmarking.nhs.uk/nhsi-ld-project-documentation-outputs)

To date, systems, structures and experiences specifically relating to transitions have not been examined. Each year however, there is opportunity for supplementary questions to be included the benchmarking exercise, for instance last year, a brief sub-set of questions explored issues related to access to cancer pathways. Transition could be an area for supplementary questions in the next round of benchmarking, and it might be useful to identify specific areas to be explored, within this workshop.

Workshop agenda

- 1. Welcome and introductions (5 minutes)**

- 2. Presentation to give the background and context for this work (15 minutes)**

- 3. Group discussion: (30 minutes)**

- 4. Actions (20 minutes)**

(To be completed after workshop)

What is needed	How it will be done	Who will do it	When it will be done