

Transition support case studies 2023-2024

Mapping a transition pathway and developing a personalised transition plan

Organisation

Hull University Teaching Hospitals NHS Foundation Trust (HUTH)

Project team

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Project aim

To develop and implement a personalised transition plan for children and young people with epilepsy for 40% of the caseload and map transition care pathways in line with the National Epilepsy Care Bundle, by May 2024.

Background/rationale

The combined hospitals of Hull University Teaching Hospitals NHS Foundation Trust and Northern Lincolnshire and Goole manage around 600 children with epilepsy, 70% of whom have additional learning needs. Both hospital Trusts are in socially deprived areas and work closely with tertiary centres, as well as with community health services, schools, and the wider multidisciplinary team (MDT). The area had been funded by the ICB to develop transition in epilepsy with the epilepsy nurse specialist leading on this project. The EQIP project formed part of these improvements, with some areas overlapping into the EQIP project.

Hull University Teaching Hospitals were reviewing their patient referral pathway prior to the EQIP from primary/tertiary care, focusing on the first clinic visit, consultant review, and diagnostic outcomes, including functional neurological disorder. A wellbeing questionnaire developed with CAMHS is now used in clinics. Hull has also created and implemented transition booklets for epilepsy.

What was the problem?

All Trusts participate in the Epilepsy12 audit. Hull's epilepsy nurses offer hospital and outreach clinics in special schools and home visits. A specific epilepsy transition pathway with an easy-read version exists for those with learning disabilities.

The project had joint aims - to create a personalised transition plan for each young person aligned with National Confidential Enquiry into Patient Outcome and Death recommendations (covering epilepsy care and its impact on daily life); and, to map the current Hull epilepsy pathway into adult services. The Integrated Care System aims to share learning and undertake joint projects facilitated by the Integrated Care Board (ICB) lead. The team initially focused on transition care for children’s epilepsy services across Hull, and improvements rolled out to Northern Lincolnshire subsequently.

The plan involved auditing current practices, information sharing, and identifying gaps to develop a personalised transition plan applicable across sites. The project initially targeted 40% of the specialist epilepsy nurse caseload (20-30 patients) with the aim to train the wider team and eventually cover 100% of caseloads incrementally.

Hull used the National Epilepsy Bundle of Care transition recommendations, mapping current services against it at a joint meeting with adult epilepsy services.

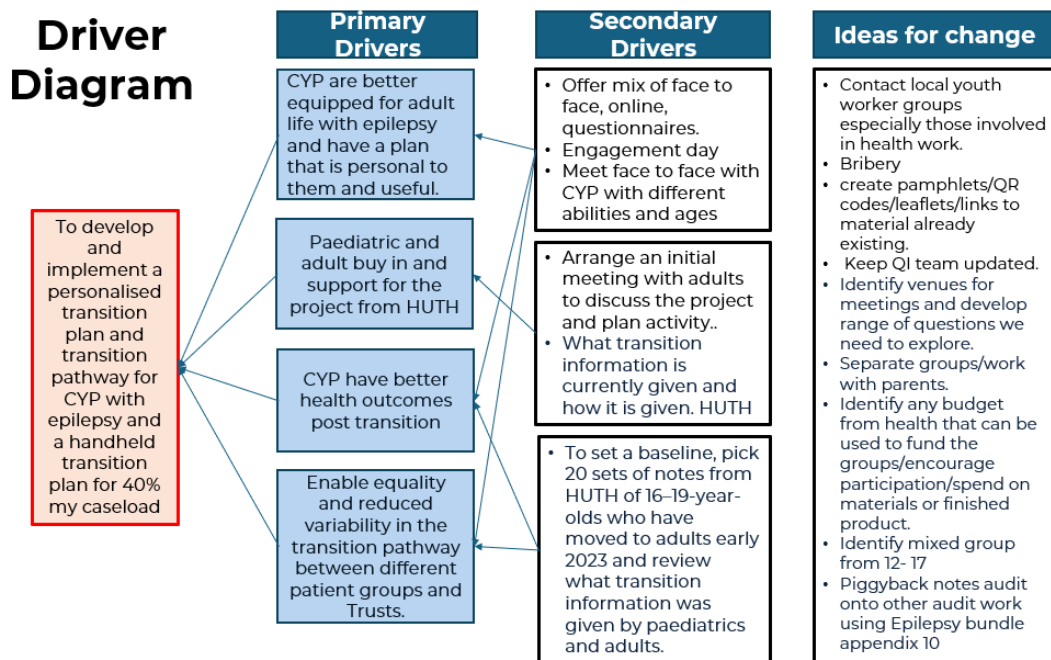


Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team’s theory of what “drives”, or contributes to, the achievement of a project aim.

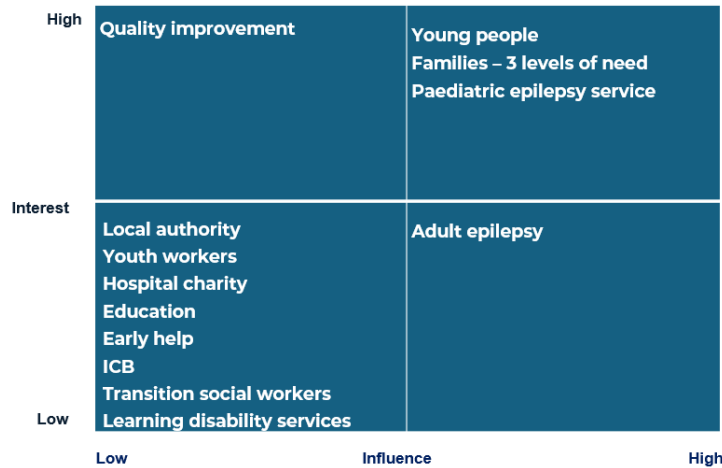


Figure 2: Shows the project stakeholder map, which provides analysis of stakeholders that are of influence/interest to the project. Stakeholders are plotted on the grid to guide the actions you should take for involving and communicating with them.

What was the solution?

Project scope adjustment: The project was delivered in phases across both organisations, starting with Hull University Teaching Hospitals NHS Foundation Trust and later involving Northern Lincolnshire and Goole NHS Foundation Trust (NLaG).

Information and support: The team recognised the need to develop developmentally appropriate information for young people transitioning between 13 and 25 years old. The pathway focused on helping young people understand and manage their condition, aiming for independence by breaking down steps and providing clear health information. Specific guidance included when and how to seek help during the transition, including contact details.

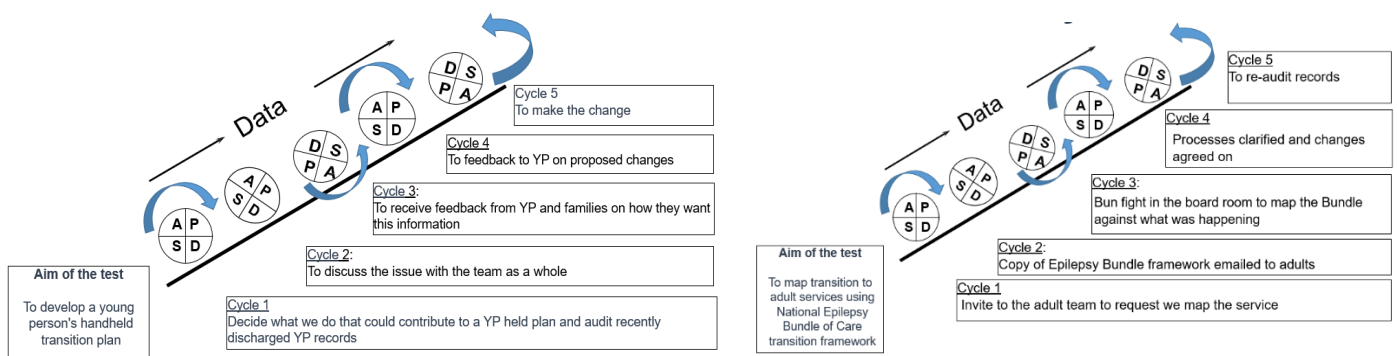
Secured funding and youth engagement: The team worked closely with local youth services to organise a youth engagement event for young people. The lead youth worker provided a central city location for the venue and funding was secured from the hospital charity for incentives to boost attendance such as gift vouchers and catering. This event offered valuable insights into the support needs of young people and the team’s collaboration with the youth worker offered additional support for their engagement activities.

Family and young person engagement: The team created and developed short questionnaires, formed a small focus group, and held clinic discussions. They collected a total of 18 completed anonymised questionnaires from patients aged 13 and above in clinics and face-to-face meetings with young people. Families of children with autism and learning disabilities were also contacted through face-to-face meetings, phone calls, and home visits.

Transition pathway mapping: With support from the Trust’s quality improvement manager, the team mapped the transition pathway, considering special educational

needs, complex disabilities, Dravet syndrome, and other epilepsy specific transition needs. They identified issues such as inaccessibility of technology and low levels of education among some young people and their families. Regular meetings took place with the quality improvement manager and long-term conditions lead from the ICB.

Engagement with adult services: The team organised an MDT meeting with adult consultants, epilepsy nurses, and a business manager and agreed on developing a checklist of key care metrics for transition and a hospital passport for children with complex needs. They addressed referral acceptance for all patients with learning disabilities and improved tracking to prevent patients from being lost to follow-up. Continuous liaison with adult services continued to define and implement the new pathway details.



Figures 3 and 4: Show Plan, Do, Study, Act (PDSA) cycles of change ideas listed within the driver diagram being tested to develop a young person's handheld transition plan and mapping of transition pathways.

What were the challenges?

- Trust mergers:** Both Hull University Teaching Hospitals NHS Foundation Trust and Northern Lincolnshire and Goole are undergoing a reorganisation and merger. Therefore, more time is needed to allow for systems and processes to become embedded.
- Lack of patient groups:** The Trust does not have access to existing children and young people patient groups or forums to gather feedback on service improvements.
- Focus on transition plan vs pathway:** There were times of uncertainty concerning whether to focus on the transition plan or the pathway aspect of the project, as they seem quite separate outputs.
- Post-transition discharge issues:** The team identified that a quarter of patients were not seen by adult services after transition discharge.
- Mapping process:** The team initially conducted a mapping exercise to review processes and timing, leading to changes. However, the process mapping meeting was rescheduled and time allocated was adjusted to ensure engagement from adult services.
- Patient engagement:** Patient engagement exercises included questionnaires on information preferences, with options such as letters to parents/GP, transition

booklets, or simpler letters. The response rate was lower than anticipated, partly due to administrative issues, and there was uncertainty about whether responses came from parents and carers or the children themselves.

7. **Collaboration with adult and learning disability services:** Ongoing discussions and collaborations with adult and learning disability services involve changes to processes, referrals, and support. Further challenges include agreeing on pathway details, referral numbers, and ensuring effective communication and coordination between services.

What were the results?

- Patient questionnaire feedback (18 responses).

Patients were asked how they preferred to receive information, with options including:

- A letter to parents with a copy to the GP.
 - A letter written solely to the young person.
 - A transition booklet.
 - A simpler letter to the GP.
 - A comment box was also included for additional feedback.
- Most children, young people and families were satisfied with the current method of receiving information, although some responses may have come from parents rather than the children themselves. 17% of questionnaire respondents wanted a transition plan written to the young person.
 - Explored software for converting letters to an easy-read format for children and young people.
 - Discussed tangible outcomes such as personalised patient letters and a short booklet with information on transition and personal goals.

Audit and focus group: A retrospective audit was conducted on 20 records of young people who had gone through the transition process in the past 6 to 18 months, including the outcomes from focus group sessions:

- 65% had a handheld transition plan in the form of a GP letter, but the plans were not SMART due to unclear outcomes and goals.
- 25% attended a first appointment with a member of the adult neurology team present, but there was no follow-up appointment.
- 0% had documented consent for sharing information.
- 0% of children and young people with learning disabilities or autism spectrum disorder had a completed hospital passport.
- 100% of focus group participants provided feedback on their need for a written transition plan specific to children and young people.

Changes to transition plans: The approach became more holistic and personalised to the needs of children, young people and their families. Transition plans were developed for different cohorts e.g. epilepsy, epilepsy and special educational needs and disabilities (SEND), epilepsy and complex disability, complex epilepsy. Young people were

enthusiastic about being involved in the changes and expressed a desire for more frequent engagement.

Outcomes from collaboration with adult services: Continuous discussions with adult services with a focus on improving transition for patients with learning disabilities and epilepsy. Agreed to change some processes and include a checklist of topics based on the epilepsy bundle for patients with epilepsy, up to the age of 25 in adult neurology services. This includes regular reviews and appropriate support from GPs, covering topics such as employment and relationships.

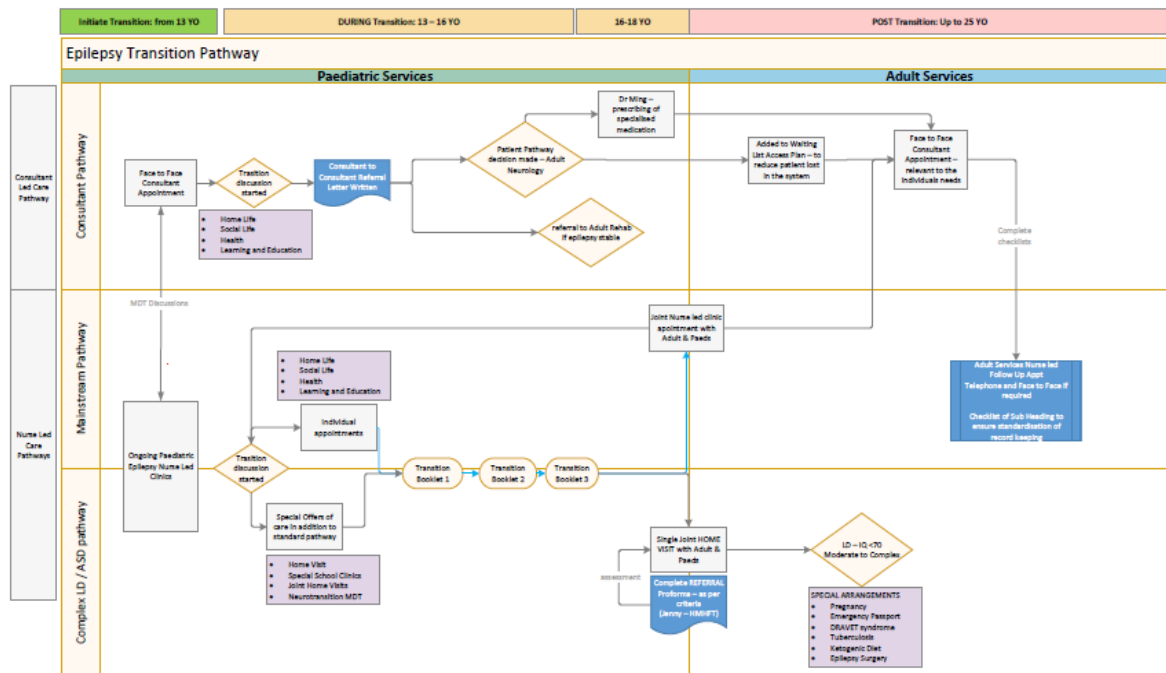


Figure 5: Shows mapping of transition pathways.

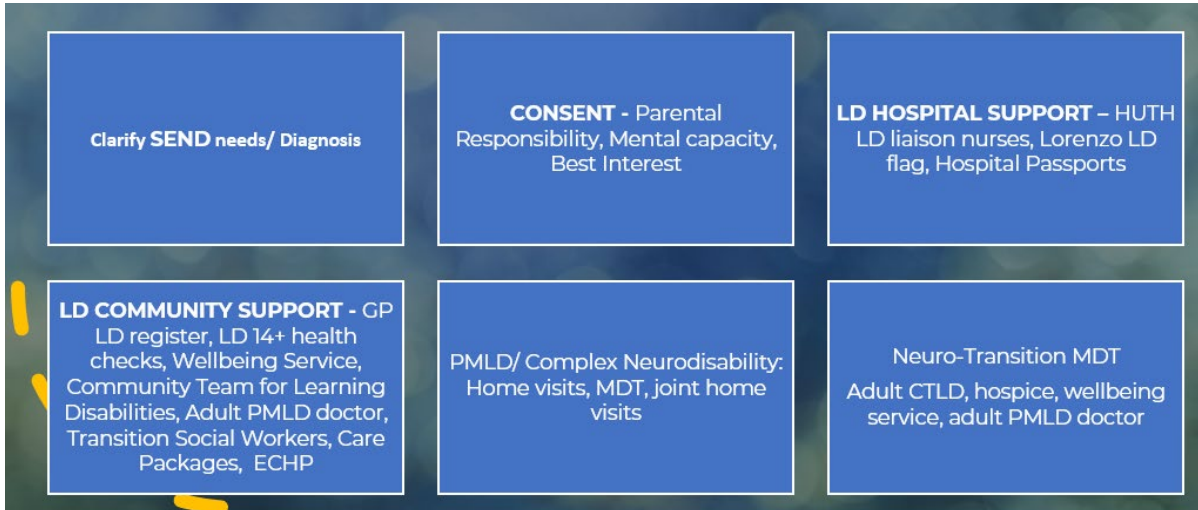


Figure 6: Shows mapping of improving transition for people with a learning disability by engaging with Trust and local agencies, gaining a better understanding of when a patient is given a diagnosis of learning disability. This should provide access to improved primary care and social care support moving into adults.



Figure 7: Images of interactive engagement and a questionnaire that was used at an organised young people’s focus group. Feedback captured from the event included wanting short videos, information on epilepsy they could give to their friends, and to include information within appointment letters to say who they will be seen by.



Figure 8: Shows examples of the Trust's transition tool on the far left, and proposed improvements to the same documents when adopted by the National Epilepsy Bundle of Care.

What was the outcome?

- Enhanced capability to develop individual personalised transition plans with consistently SMART goals on transition clinic letters.
- Increased available resources for signposting children and young people with diverse needs, covering health, lifestyle, education, employment, and community inclusion. This includes the completion of a hospital passport and the addition of a reasonable adjustment data flag on the electronic patient record.
- Increased engagement with other healthcare professionals in collaboration to improve transition heightened the awareness of the wider support network available.
- Implemented changes to transition letters which are addressed directly to the young person and include domains from the National Epilepsy Bundle of Care.
- Amended letter templates to be both staff user-friendly and children and young people friendly.
- Gained a better understanding of adult service delivery and their specific requirements.
- Improved booking rules in adult services and revised adult clinic letter templates.
- Expanded the focus to include additional transition needs for young people with learning disabilities and complex disabilities within the epilepsy service across both paediatric and adult services.
- Mapped special arrangements for children and young people with Epilepsy, including those with Special Educational Needs and Disabilities (SEND), complex disabilities, and specific conditions such as Dravet syndrome, Tuberous Sclerosis, and those on the Ketogenic diet or epilepsy surgery pathways.

What were the learning points?

- Transition is much bigger and more complex than initially anticipated.
- Following an internal audit, the team realised they were not performing as well as they thought.
- Identified many underutilised community resources.
- Engaging more with the wider network and appreciating the challenges of coordination.
- Need to better prepare children young people and families for adult services.
- Increased focus on transition within the organisation.
- Importance of sharing learning within the ICB and regional network, YPEN.
- The team recognised the need for a structured approach.
- It is important to continuously monitor the implemented service improvements.
- Care must be personalised to children and young people and consider their aspirations.
- EQIP helped improve understanding of the need for closer collaboration with young people and for engaging individuals with diverse skill sets.

Communication with children and young people: feedback from youth group and parents

- Young people involved in the engagement activities appreciated receiving the gift voucher incentives.
- Remember to be friendly and make the young person feel at ease. Smile.
- Talk to the young person, even if they cannot answer back.
- Encourage the young person to join in the consultation.
- Use short, simple sentences. Do not rush; pause between sentences.
- Avoid “waffling” and give time for young people to think and consider their options.
- Do not expect quick answers.
- Provide longer appointments where possible and repeat important information on another day.
- Choose a quiet clinic room without distractions and avoid making families wait.
- Use information that the young person will understand.

Next steps and sustainability

- Establish clinics with specific focus on transition with longer appointments times.
- Plan a re-audit for the period 2024-2025.
- Maintain and continue to improve engagement with young people.

Want to know more?

If you wish to know more about this project, please contact:

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