

# Moving from Paediatrics to Adult Care- Journey towards improving outcome and quality of care in Children with Epilepsy and Learning Disability

Inyang Takon (1), Jill Conium (2), Nicki Astle( 2) , Nivi Bajaj (1),  
1. Consultant Community Paediatrician, East and North Hertfordshire NHS Trust  
2. Specialist Epilepsy Nurse, East and North Hertfordshire NHS Trust

## Background

- Children with Epilepsy and Learning disability commonly have their seizures persisting into Adulthood. Referral of children to the Adult team can be met with various challenges including delay in children receiving their first Adult Clinic appointment. The best Transition clinic model should involve Paediatric and Adult Epilepsy Teams, Psychology and Social Care reviewing the children jointly and addressing their wider needs.
- Many children with Epilepsy seen within Children services have never had their mental health needs identified and addressed within children services.
- There is lack of guidance on exact model for Transfer of care from Paediatric Epilepsy Services to Adult Services.
- The Epilepsy Team in East and North Hertfordshire is made up of Consultant Paediatrician in Hospital and Community Paediatrics, Two Epilepsy Nurse Specialists, Service Coordinator and an Administrator. Children with Epilepsy are seen within Specialist clinics in the Hospital and Severe Learning Disability Schools.
- Children with Epilepsy and Severe learning disability undergoing transition are referred to the Adult Learning Disability Psychiatrists when they turned 18. Recent audit showed that a significant number of children had not received their appointment for the Adult Clinic between 6 months and 1 year after discharge from Paediatric Services

## Audits

- Two audits were carried out within the service between 2014-2016.
- A brief audit involving a telephone interview of Nine parents of children who had been discharged from Paediatric Epilepsy Clinic in the preceding year was carried out in 2014. The interview was done by the Epilepsy nurse using 10 standard questions however free text responses and comments provided more insight into parents concerns.
- Retrospective case note reviews of 72 children attending Specialist clinics in 3 Special schools in East and North Hertfordshire were reviewed to assess the standard of care for children with epilepsy and learning disabilities according to NICE guidelines.

## Results

- Children with Epilepsy had a Joint clinic review in the Special school clinics by the Consultant Paediatrician and Specialist Epilepsy Nurse in 100% of the cases seen.
- 80% of the children had a review with the Paediatric Neurologist. Behavioural difficulties were common in the children seen with very few children having access to the mental health service needed.
- Thirty-one (43%) children had used more than 3 AEDS reflecting the refractory nature of their seizures.
- Thirty children (41.6%) had anxiety concerns, thirty seven children (51.3%) reporting mood disturbances. Twenty four (35%) of the children had a diagnosis of ADHD/ASD. Fourteen children (20%) were on medication for sleep. Access to CAMHS and other mental health services was very poor( 23.1%)
- The results highlighted the various challenges facing families of children with Epilepsy and Learning Disability and these challenges continued at Transition.

## Review of Patients by Mental Health Team

Seen by CAMHS	Patient Nos	Percentage
Yes	17	23.61%
No	51	70.83%
Blank	4	5.56%
Grand Total	72	100.00%

## Steering group

- A stakeholder meeting group was set up in 2014 to discuss the challenges identified in the audit and discuss setting up a Transition Epilepsy clinic.
- Group consisted of Consultant Learning Disability Psychiatrists, 2 Community Paediatricians with Interest in Epilepsy, Adult Epilepsy Nurses, Adult LD Nurses, Social workers, Transition Nurses and GP Commissioner. Meetings were held over 18 months
- A comprehensive handover tool covering all aspects of the Child's care and needs was agreed by the team.
- Decision was made to commence Transition Epilepsy Clinics between Paediatric and Adult Epilepsy Team.

## Actions

- 3 Transition Clinics a year are now being held in the Special schools in East and North Hertfordshire. Clinics are attended by Paediatrics and Adult Epilepsy Team( Consultant Paediatricians, Specialist Paediatric Epilepsy Nurse, Adult Epilepsy Nurse, Adult LD Nurses, Transition Nurse, Special school Nurse and the family). Transition clinic has now been running for 2 years.
- Verbal feedback from families who have attended the Transition clinics has been excellent. The clinics have been running successfully since 2016. An audit is in progress this year to assess Parent and patient experience of the Transition clinics and the effectiveness of the service.
- The handover tool /document is used in the clinic and contains comprehensive information about the child's epilepsy history and management. The information in the document prevents parents having to repeat the history when they are seen in Adult services.

The screenshot shows a medical form titled "School leavers with learning disability: Health summary (special needs)". The form is divided into several sections:

- Personal Details:** Includes fields for Young person's name, Date of birth, Gender (Male / Female), Child/young person's address, Current school / college, Main carer, and Address of main Carer if different to Young Person's address.
- CHILD/YOUNG PERSON'S DIAGNOSIS AND HEALTH:** Includes a section for "List all diagnosis below:" with numbered fields 1 through 6. It also has a "General health:" section with fields for Height, Weight, Blood pressure, and H.C.T.
- FAMILY STRUCTURE (including details of full or half siblings):** Includes a table for recording family members with columns for Consanguinity, Name, Age, and Occupation.
- MEDICAL HISTORY:** Includes a section for "Has the child/young person had previous hospital admissions, accidents, operations or severe illness?" with a Yes / No field and a space for "If yes, please describe".

The form is displayed on a computer screen with a Windows taskbar visible at the bottom.

## Further actions

- The Paediatric Psychologist attached to the Diabetes service sat in with the Epilepsy team for some clinics. This provided some insight into the pattern of non medical concerns seen in the Epilepsy clinic. Initial findings showed that there is a huge need for having the Psychologists within the Epilepsy clinics and Transition clinics.
- Business case to provide dedicated Psychology support to the Epilepsy Team is being discussed.
- Service will look at model for children in moderate learning disability schools.