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Health Inequalities—Case Study

The Learning Disability Epilepsy Team, July 2024

Identifying the issue

The Learning Disability Epilepsy Team support adults with a Learning Disability (LD) and Epilepsy. People with a Learning Disability experience significant barriers to healthcare, which is further amplified when there are additional health needs such as Epilepsy. It is estimated that between 15 and 30% of people with LD also have epilepsy, far more that the general population.

Despite this, people with LD often experience poor access to high quality epilepsy care. This may be due to mainstream epilepsy services failing to offer reasonable adjustments or in some cases failing to understand the complexities of the person's learning disability. Historically, those with a Learning Disability and Epilepsy were managed under the care of a Consultant Psychiatrist despite it being evident that mainstream services were not meeting their unique needs.

The experiences of people with LD and epilepsy within healthcare sit against a backdrop of huge health inequalities among people with LD. People with a learning disability have worse health than people without a learning disability and are more likely to experience a number of health conditions (Learning Disability - Health Inequalities Research | Mencap).

On average, the life expectancy of women with a learning disability is 18 years shorter than for women in the general population. The life expectancy of men with a learning disability is 14 years shorter than for men in the general population (NHS Digital 2017). Evidence suggests that people with learning disabilities and epilepsy have a substantially increased risk of mortality, particularly where seizures are ongoing (Robertson et al., 2015).

Making the Change

The LD Epilepsy Team was established within Humber's LD service around 30 years ago, but was highly innovative in its time and is still recognised as being a unique model nationally. The core team consists of a Specialist Nurse and a Clinical Lead with expertise in both LD and epilepsy. The team is supplemented by a Consultant Neurologist who runs a dedicated LD epilepsy clinic, offering people within the service access to high quality consultant-led epilepsy care which is adapted to meet their unique needs.

The service is person-centred, with a strong focus on building positive relationships which enhance the care experience of those with a Learning Disability and Epilepsy. The team takes a highly flexible and responsive approach to delivering care. Examples of this approach include:

- Managing the appointment system to allow patients to be seen "out of sequence" if people experience difficulties getting to appointments or need to be seen earlier to prevent distress.
- Offering appointments either by telephone, virtually or in person, depending on individual needs.
- Conducting appointments in various community settings and family homes to supporting access and engagement, in some cases even seeing patients who were unable to get out of their vehicle in the clinic car park.
- Offering a consultation service prior to referrals being accepted, which ensures the person is on the right pathway and reduces waiting times and inappropriate referrals.
- Appointment lengths vary, and may be as long as required.

The team has a strong culture of working collaboratively with family members and carers to understand the unique needs of each individual and the team recognise the importance of being an 'inquiring practitioner'. This results in a holistic approach to managing the person's epilepsy which integrates psychological and social aspects of care, including the offer of non-drug approaches such as medication management and vagal nerve stimulation. Where other non-epilepsy needs are identified, the team also make onward referrals for support and care, working collaboratively with Social Workers and other professionals on complex cases through a holistic multi-disciplinary team (MDT) approach. Navigating the healthcare system can be challenging for this patient population and their carers, but as The LD Epilepsy Team are embedded in the Community Learning Disability Team it allows for seamless MDT working on a routine basis.

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Impact

- We have a unique offering in our area for those with Learning Disabilities and Epilepsy, to access specialist & tailored, specialist support.
- The flexibility in access the service offers, results in increased engagement and improved outcomes for individuals and their families.
- Prioritising based on need, allows for proactive and positive risk management.
- Having this pathway lessens pressures elsewhere in the system such as hospital admissions and Primary Care.
- This model optimises care for individuals, through correct diagnoses, care and treatment.
- Stopping over medication of people with a learning disability and autistic people (STOMP) is a national NHS England work programme and is always considered by the team, and therefore medications are reduced where appropriate.
- All transitions in care and treatment (which can be a challenging time), are smoother with minimum impact, as the team are integrated with numerous other teams of professionals.

Learning

- Being **responsive and dynamic**, and **operating with minimal constraints** has increased the teams' capacity to **meet the unique and complex needs** of the patient population.
- Practitioners having **autonomy** has allowed the service to **organically develop and be responsive** to needs over time.
- **Working collaboratively, and not in silos** has supported **better outcomes** for individuals.
- **Involving families and carers** has **improved experiences** and outcomes for individuals.
- **Innovative models** are sometimes needed to meet the needs of some groups, where the traditional medical model is not suited. A **pilot approach** can be helpful to test ideas.

Feedback

"… thanks for your service anyway – it is much appreciated…" (Consultant Neurologist A)

"…you are a star and have gone above and beyond this week to sort all of this thank you…" (Consultant Neurologist B)

"…thank you so much for your reply and the information. I'll speak to the GP. Much appreciated as always…" (Carer)

"…As you say – whole person work is key. Thanks for being so incredibly thoughtful and for knowing so much…" (Colleague feedback)

"…has always been an essential clinician to my relatives care due to their complexities and ensures that other professionals are aware of any changes to their Epilepsy or medications…" (Carer)

Next Steps

- A Standard Operating Process (SOP) for the Service has just been approved and is accessible via the intranet.
- Moving forwards, the service will be developing an audit tool, which will allow the team to audit the service against required standards on a rolling schedule.
- The team will continue to deliver training to other professionals in the year ahead, e.g. Humber Neurology colleagues in October 2024.