

Luke's Story
Experiences of Learning Disability Care

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27th September 2023

<https://youtu.be/9dTW93TBTQQ>

Summary of Medical History

- Born healthy, good weight, happy baby, milestones early
- Severe drug resistant epilepsy, 2.5 years started seizures, up to 40 in a 24 hour period. Never had control of his seizures. High risk of SUDEP
- Age six had status seizures- learning and behaviour regressed
- Investigative invasive brain surgery at Kings College, London
- Numerous hospitalisations - some for several weeks
- Induced coma 7 times in life threatening conditions
- Extensive physical health issues, including twisted bowel, leaking bowel, colostomy and reversal, frequent episodes of pneumonia
- Learning disability, haemochromatosis, VNS in situ, bowel issues, autistic traits, dysarthria, pre ictal activity and behaviour changes and confusion
- Anxiety around the trauma he has experienced and physical health issues

Summary of Placement History

- Moved into the full-time care system as an adult
- Multiple placements – 17 in 13 years
- Exposed to a number of recognised failed services over the years
- Endured and witnessed neglect and abuse in hospital settings, including Winterbourne View; considerable trauma
- Witness and contributor to the criminal investigations at WV
- Three other settings judged as inadequate and closed
- Several moves were rapid and not planned due to concerns around the care and safety of the package
- Moved into the community in August 2019 with 24h care support
- Two Independent reviews commissioned by NHS to cover the period from August 2019 to September 2021. This was in recognition of the failings during this period.
- A number of safeguarding referrals around the quality of care

Poor Experiences

- Placement in inadequate hospitals and units- most several hours from home; visits were restricted to two hours
- Providers did not deliver what they had promised
- Accommodation not fit for purpose
- Physical health needs neglected. No annual review for over ten years and no preventative care such as dental, optical, podiatry

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities>

- Long waiting times for specialists

<https://www.england.nhs.uk/about/equality/equality-hub/case-studies/how-one-yorkshire-trust-eliminated-the-elective-care-backlog-for-people-with-a-learning-disability/>

- Lack of consistency of staffing- some arrived on shift and did not know Luke's name, not read PBS

Poor Experiences

- Staff lacked the specialised skills and poor staff training including epilepsy training
- Despite reports insisting for many years on trauma informed training, this did not happen
- Poorly led meetings, no agendas and introductions, reports not sent out beforehand to us, staff at meetings who had never met Luke
- Meetings held, actions agreed but lack of oversight to ensure actions taken, Dates passed without actions; CTR actions not carried out
- Labels given to Luke, inaccuracy of report writing
- Few visits by the provider – clinical lead Glasgow, regional team leader south of England who had never met Luke
- Lack of oversight and assurance visits by commissioners at the time to ascertain the quality of delivery, the safety of the package of care or welfare assessments
- Lack of oversight to ensure agreed actions were undertaken or resulted in improvement

Poor Experiences

- These poor experiences have been Luke's 'normal'
- Many years of not feeling safe and not able to trust staff
- Suffered huge anxiety and trauma from poor care and abuse
- Physical health neglected
- Luke lost a quality of life and many years of his adult life; he lost his freedom and choices
- Lack of normality and ability to form meaningful relationships and friendships
- Missed out on family occasions and events
- Huge impact on us all as a family

Involvement of IST

- Small IST team including clinician, OT, psychology, nursing and SALT; highly skilled team
- Luke in temporary community accommodation in your area
- Referred to IST in September 2022 to prevent his placement breaking down and risk of readmission to a low secure setting
- A number of safeguarding concerns raised around the package delivery
- Restrictions in place – illegal – IST surprised at the restrictions with the low number of incidents
- Person centred- Luke always at the centre of care and discussions; positive language about Luke
- Aimed to understand the needs and functions of the behaviour
- Ensured staff were trained to see the world through the Luke's eyes
- Trauma informed approach and training
- Visited Luke regularly, got to know him, stripped the labels

Involvement of IST

- Went through copious reports; challenged the findings and the evidence base
- Had the courage to make a decision independently
- Attended weekly meetings with ICB, care provider and ourselves
- Updated the behaviour support plan and trained staff in it
- Looked at triggers and compliance with PBS
- Training given to provider, carers and receiving IST
- Robust transition planning back to local area
- Ensured house and environment were suitable
- Review of Luke's health needs; health action plan in place
- Listened to as parents, included in meetings, felt believed
- Very involved in CTR; reports for CTR of a high quality

Impact

- Luke living in his own house in the community since Dec 2022
- Wonderful, consistent and trained staff team with an understanding of a trauma informed approach
- PBS is followed. The few incidents are reviewed
- Luke feels safe for the first time in many years
- The local ICB, IST, LD community team and ourselves are working together
- Regular MDT meetings which we are involved in
- Perception of Luke has changed
- Positive language used around Luke – strengths noticed
- LUKE – INSPIRATION, BRAVE, RESILIENT, KIND
THOUGHTFUL, WONDERFUL SMILE

IST

- Small IST- big rural area, growing demand for services
- Investment in IST and growing the team for prevention – saves financial burden later through admission to expensive hospital placements
- Larger IST will enable high quality training for providers and staff
- Need staffing for 24/7
- Recognise the need for physical health checks and the impact on mental health for LD and A. Prioritise LD and A on waiting lists