

System Learning: Young Person K CSPR

- What is the focus?**
Safeguarding children and young people with complex health needs and autism
- What is the ask?**
 - That our work embeds an understanding what the child’s daily life is like.
 - That we clearly identify the risk to the child or young person when working with families where their engagement is reluctant and sporadic.
 - That we encourage critical thinking and challenge.
 - That we take stock of how we effectively respond to changing risk and need
 - Escalate blockers to sharing information in a timely and appropriate way
 - That we organisational leadership and culture across our health economy for good outcomes

Situation
K was a 17-year-old girl diagnosed with autism and a learning disability who died from a serious infection caused by her PEG tube receding into her abdominal cavity causing peritonitis and a fatal sepsis.

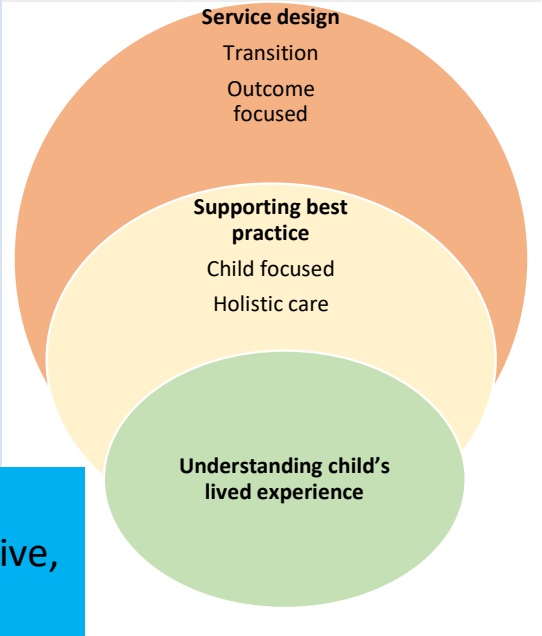
Background
K lived at home with her mother. Concerns about the PEG tube had been raised by the training college over a period of 18 months prior to her death. An urgent referral was made by the GP 10th March 2021 to have the PEG replaced as it had been cut very short and had a split, however she died on 16th April.

Assessment
K had a high level of vulnerability and was unable to express her needs verbally. No assessment of mum’s capacity to meet K’s needs taking into account her own vulnerability, isolation and reluctance to ask for help for fear of having K removed from her was carried out routinely as part of holistic care planning.
Consideration of transition from child to adult and the impact this would have on K and her mother was not evident.

Recommendations

- Prioritising vulnerable young people for treatment with referrals made at the earliest point before it becomes urgent to plan care
- Assessing parent capacity to safely manage care
- Failure to respond to repeated attempts to contact needs to be seen as a safeguarding risk
- Key worker programme to be rolled out to children with complex needs and known vulnerabilities
- Ensure EHCP are holistic and include assessment of risk and potential impact
- MASH to audit thresholds for children with complex needs
- Extend the remit of school nurses to 16/17 year olds with EHCPs
- Transition arrangements to commence at 14 across all agencies
- If another pandemic or civil emergency ensure that vulnerable children continue to be seen at home.
- SSP to review training in communication with disabled children, cultural competence and social isolation

- Practice tips**
 - Pattern of the sole carer not answering phone should be seen as a risk and an alternative contact should be recorded on the records and shared in any referral on.
 - Start transition to adult services at age 14 for all children with additional needs.
 - Consider a safeguarding referral where parental engagement is sporadic and contact with main care unreliable
 - Prioritise home visiting for vulnerable children and young people. Always ask to see areas of the home where the child/young person spends their time such as bedrooms.
 - Assess parenting capacity and parent's own needs when planning care.
 - Where a child is likely to need hospital treatment or intervention make a referral early to allow time for planning for their additional needs/autism



Proposed SYSTEM improvement action
Transition planning for children must begin at 14 across all services. Planning must be collaborative, in partnership with other services and include risk assessments of the impact of change.