



CYSUR 3 2021

Concise Child Practice Review



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Circumstances Resulting in the Review

Child A was described as a wonderful, headstrong girl. In October 2020, the Ambulance service attended the family home of the 16-year-old and sadly found her to be deceased. The condition of her body was indicative of chronic neglect, and there were significant concerns about her immediate living environment. The post-mortem examination indicated Child A was severely obese and immobile; extensive inflammation and infection had led to her suffering and ultimate death. Child A had been shielding since the onset of the pandemic in March 2020 and was last heard in the background of a phone discussion with her school on 17th July 2020. A return to school had been planned for September 2020, but Child A's mother reported various ailments that prevented this return.

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Child and Family Background

Child A was the fifth of six children born to their parents in rural Wales. She loved being active and it was said that, with the right opportunities and support, she could have been a future Paralympian. Child A was born with spina bifida (SB), one of the most complex permanently disabling conditions. She had significant bladder and bowel difficulties, paralysis of her legs and was wheelchair-bound. Child A had numerous appointments over her lifetime with specialist services across England and Wales; however, many were also missed. Her parents assisted her daily with complex and intimate care until she had surgery which facilitated self-catheterisation. By the age of 12, professionals and her family had supported her in her independence in school and via sports. As a result, disability services discharged Child A in 2017.

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Improving Systems and Practice

- The Health Board should further embed the Was Not Brought Policy and consider cross-border involvement
- The Local Authority should review case closure practice guidance for Integrated Disability Services (IDS) and IDS Early Help to ensure all closures involve contact with other professionals and clarity on the process of re-referring including for transition needs to adulthood, when required
 - The Local Authority should review the IDS Early help offer to ensure it has sufficient resource to deliver an effective service
 - Consideration should be given to the 'The Eyes' on policy implemented by the school Child A attended is rolled out across the Local Authority area as a model of good practice

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Key Themes: Care and Support

Child A wanted to live a "normal life". However, her condition was lifelong, and transition planning would be required as she neared adulthood. Child A was not subject to a care and support plan, which could have supported this transition planning. The complexity of Child A's needs raised questions for services to consider how a child with chronic disabilities who is not subject to a formal care and support plan, which requires consent, can be care-coordinated and supported. This becomes particularly challenging in the context of rural areas with limited resources, and services spanning England and Wales who each manage specific elements of a child's disability. The review also considered the challenges Child A's parents experienced in managing her care, and reflected that a carer's assessment could have been completed to explore this.

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Improving Systems and Practice

- Care and support assessments should be consistently offered and subsequent plans should be outcome-focused
- A joint review should be undertaken by the Local Authority and Health Board of the processes and pathways in place for children with chronic disabilities
- Practitioners should communicate directly with children, regardless of barriers, and listen to and record their views
- The Health Board must raise awareness, implement and embed the updated All Wales Weight Management Pathway for children, young people and families published by Welsh Government in 2021
- The Health Board should review the availability of and access to lymphoedema services for children in the area

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Identified Good Practice

- Some professionals were able to establish trusting relationships with Child A's family, which supported engagement
- Child A and her parents received advice regarding the initial treatment for lymphoedema, when the parents sought medical attention for her deteriorating skin, and the condition improved
- Child A benefitted from advances in urological care which can prevent avoidable premature death for children with spina bifida
- School supported Child A to explore career options and completed her Special Educational Needs Review in July 2020 by phone
- Some evidence of good information sharing and recording of Child A's voice could be seen in agency records
- Child A's transition to secondary school was supported by robust transition planning to accommodate her physical needs

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Key Themes: Weight and Spina Bifida

Child A's weight had been a longstanding concern, and obesity is often associated with spina bifida due to the limited ability of paraplegic children to burn calories. Contextually, it is known that 25% of school-aged children in Powys are overweight. There were accessible weighing scales within a few hundred metres of Child A's school, however, awareness of how this could be used was not held by all health practitioners. There was practice knowledge of Child A's increasing weight, but an absence of monitoring and review.

Child A and her parents engaged well with professionals with whom they could build trusting relationships and found the input of one dietitian to be an asset to the whole family.