

L is a 19 year old man with very high and complex needs including cerebral palsy, hearing loss, sight impairment, global learning disability, non-verbal, epilepsy, doubly incontinent, and self-harming behaviours.

He is assessed as needing 24 hour waking support, 2:1 support when in the community and 1:1 at all other times. He also requires waking night care.

From 2009 he had attended a specialist school as a weekly boarder. Additionally, and based on assessed needs, he received respite in the school one weekend a month during term time, a block of 2 weeks in the summer holidays and 3 nights a week during all the other school holidays. This amounted to just over 60 nights of additional support at school over and above

Since 2016 he has been assessed as being fully Continuing Health Care ("CHC") funded and hence the responsibility for meeting his needs fell to the Local Health Board ("LHB"). .

Issues arose when it was time for L to move on from school to college which is on the same campus. A re-assessment took place by an experienced CHC assessor which concluded that he needed the same level of support as had been in place since 2009. However, following presentation at the LHB "Funding Panel", an opaque process in relation to which family and interested others are not given any information or provided with any opportunity to take part, with no formal system for appealing the decisions made, that package was summarily reduced. They family were informed via a phone call that the respite had been reduced from 60 days to 45 days. No extra support hours were provided to cover the additional time L would now be spending at home.

L's parents, and carers, had made it clear that they would not be able to safely manage his needs if his respite was reduced. They sought urgent legal advice. L qualified for legal aid.

A letter was sent to the Health Board setting out the issues and concerns of L's parents and seeking a reconsideration of the reduction in respite as the reduction would result in L's complex health care needs not being adequately met. A response was asked for within 14 days.

As this deadline lapsed without a response a Pre-Action Protocol Letter Before Claim was sent to the Health Board threatening to bring proceedings for judicial review on the following grounds:

1. A breach by the Health Board of its duties owed under the NHS (Wales) Act 2006, specifically failure to meet all reasonable requirements for services for the care of L who is clearly a person

- suffering from an "illness", contrary to section 3(1)(e) of the NHS (Wales) 2006 Act.
2. Failure to consult on the planning of the provision of services, the development and consideration of proposals for changes in the way services are provided and decisions to be made by the health board affecting the operation of those services contrary to section 183 of the NHS (Wales) 2006 Act.
  3. Failure to make the necessary arrangements for the care of L irrespective of the setting contrary to section 4.5 of the CHC Framework guidance
  4. Failure to plan, specify outcomes, procure services, and manage demand and provider performance for all services that are required to meet the health care needs of L, contrary to section 4.9 of the Framework guidance
  5. Failure to consider and provide support for carers including active engagement with and involvement of carers when making decisions about provision of services to or for carers or the person being cared for and breaching the duty to consult with carers with regards to the planning, commissioning and delivery of local services that affect carers or the individuals they look after, contrary to section 4.3 of the Framework guidance.
  6. Failure to demonstrate a clear rationale for decision and a failure to clearly explain the rationale and the care package to the individual and/or their representatives and confirming this in writing contrary to section 4.12 of the Framework guidance, and failure to give an opportunity to be heard at the final decision making stage contrary to the long established principles of natural justice (per R (*Montgomery*) v *Hertfordshire CC* [2005] EWHC 2026).

The LHB then responded; they set out their rationale behind the decision to reduce respite. However they then stated that given the complexity of the case and in acknowledgment of the additional information we had provided (NB the parents were not permitted or able to contribute to the panel meeting where the decision was made) the LHB had reviewed its original decision and agreed our request to re-instate the previous package.