Comisiynydd Plant Cymru Children's Commissioner for Wales

Keith Towler

Mr William Powell AM
Chair – Petitions Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

5 March 2013

Your ref: P-04-452

Dear William

Thank you for your letter dated 6th February 2013 outlining the petition received by the Petitions Committee from Dr Tymandra Blewett-Silcock which calls "on the National Assembly for Wales to urge the Welsh Government to ensure that funding is made available to ensure that the vital equipment and services required by tube-fed children and young people are made available to them".

It is unacceptable that any child or young person is disadvantaged or not receiving vital equipment or services due to ongoing disagreements between a local health board and a local authority. This is a clear breach of their rights under the United Nations Convention on the Rights of the Child and United Nations Convention on the Rights of People with Disabilities.

In 2012 the Welsh Government published the Children and Young People's Continuing Care Guidance which outlines how assessments, decisions and agreements should be made to provide a package of continuing care for those children and young people who need it. Within this guidance it is clear that a health assessor must undertake a detailed and holistic assessment of a child or young person, the decision of which is taken to a multi-agency forum to agree a care package (including the funding arrangements). This guidance also states that where a child or young person is not found to have a need for continuing care a rationale must be explained to the child and parent/carer. In this case, their needs should be met via a case management system using existing universal or specialist services. The assessment should be undertaken as a holistic approach with the views of the child and family given due consideration.

While the guidance is not prescriptive in relation to funding arrangements between local health boards and local authorities it does call upon these parties to develop procedures for dealing with disputes that arise out of lack of agreement over funding responsibility. Crucially it is made clear that regardless of any dispute "the interests of the child must be paramount and no child should be denied access or have access to appropriate health care delayed as a result of a dispute".

I would hope that this recent guidance would ensure that these children and young people would no longer face such disputes and I am committed to monitoring the effectiveness of this guidance in meeting the complex needs of children and upholding their rights.

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It is important that each child is treated as an individual and receives a timely and holistic assessment of their individual needs. This assessment needs to be taken forward to a multi-agency forum to ensure that these needs are met without delay or stress for the child and their parent/carer whether this is by the local health board or the local authority.

If you have any further queries please do not hesitate to contact me.

Yours sincerely

Keith Towler

Children's Commissioner for Wales