



Parents of Partially Sighted and Blind Youngsters
Reg Charity 1104560 www.popsy.org.uk

P-04-452 Equal Rights for Tube-fed Youngsters ePetition Oral Evidence Paper - 16 July 2013

Continuing Health Care

A severely disabled child – blind, in a wheelchair, tube-fed and with a degenerative terminal condition - does not 'qualify' for a Continuing Health Care (CHC) definition in the Caerphilly Borough.

Caerphilly Social Services vs the Aneurin Bevan Health Board

The Aneurin Bevan Health Board say it is not their responsibility to help a family whose child does not have 'health' or 'nursing needs', i.e. is not a CHC child.

Social Services tell us that as our type of child has 'significant health needs' they cannot help either.

When a family then meets with both parties and asks "Well, who will help us then?" there is still no resolution.

We understand budgets are under pressure but so are we.

Joint Funding a '3rd Category Disabled Child'

When an Occupational Therapist assesses your child as urgently needing a Medical Bed or Fully Supported Specialist Chair, or Bath Seat for their health, safety and comfort Parents should not be involved in the financial wrangling over who will pay for this type of equipment or service if their child apparently does not meet either criteria for funding.

There is obviously the need for a 3rd Category of Disabled Child – a '50% 50% Funded Child' – costs automatically being jointly funded to avoid delays in vital equipment or services.

The Children's Commissioner in Wales has also supported this joined-up thinking - questioning the type of wrangling we experience as constituting a breach of a disabled child's Human Rights.

Legislation to help Families at Breaking Point

Families with a severely disabled child find it difficult enough to cope on a daily basis as it is. We are often suffering financially hardship as well as being stressed and depressed due to our caring role – please take away one more worry by making legislation to 'define' our type of child.

Our family is not unique and having set-up the POPSY Charity I have had the privilege of getting to know many other families with disabled children who do not fit either (existing) category and who are also experiencing major equipment and respite problems.

Our Personal 'Battle' and lack of Advocacy

No family wants their child to be disabled - we do not want to have to ask for help but sometimes we have to. When we do we should not be made to feel as if we do not deserve this help or are not entitled to it.

As our daughter cannot ask or communicate her wishes we have not been able to get an Advocate to help us in our 2 Year 'battle' for Direct Payments to help us care for her and improve her quality of life.

I had to ask Ms Catherine Lewis, ex-Special Needs School Governor, to help us and she has been good enough to attend our meetings over the past 7 months – witnessing just some of the games played with Parent Carers in the Caerphilly Borough.

We get one life – just like you – PLEASE help us make it better for hundreds out there who do not have the strength to 'battle' – we represent all of these hard-working people and are here to try and influence legislation influencers and makers like you !

Use Us

If you need any advice or an insider's view on disability or being a Parent Carer just ask – I would gladly help with anything if it means just one family's life is improved !

Dr Tymandra Blewett-Silcock
POPSY Charity Director