

P-04-452 : Equal Rights for Tube-fed Youngsters.

Petition wording:

We call 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.

For example, equal rights for tube-fed youngsters in the Caerphilly County Borough Council currently fall between 2 defined categories of need. The Aneurin Bevan Health Board say as they are not Continuing Health Care (CHC) children – 'only tube-fed' – they cannot fund the vital equipment and services we need. Caerphilly Social Services also say they cannot help as these children 'have significant health needs'. These definitions exclude and therefore discriminate against Tube-fed Youngsters and we demand an investigation into this practice in Caerphilly. Whilst our Youngsters do not 'qualify' for help from either Health or Social Services in the Caerphilly Borough we still have a Youngster with 24/7 care needs – the same as a newborn – often with disabilities due to a life-threatening illness.

Additional Information:

Our Youngsters need a 'label' in order to be able to automatically access funding for vital equipment and services. At present inter-departmental financial wrangling takes place on request for anything for a Tube-fed Youngster and this should not involve Parents / Carers. We just need the help for our Youngsters as quickly as possible. We ask that a quick, common-sense, long-term solution be achieved for our Youngsters and for the sake of the health and wellbeing of their Parents / Carers.

Petition raised by: Dr Tymandra Blewett-Silcock

Date petition first considered by Committee: 29 January 2013

Number of signatures: 142