

P-04-452 Equal Rights for Tube-fed Youngsters - Correspondence from the Petitioner to the Clerking Team, 26.09.14.

Hi there,

Thank you for this information.

I have read the letter 3 times and I still think that Mark Drakeford has misunderstood our position ?

We are looking to get more joined-up thinking for families who fall between Social Services and CHC definitions - ie children that are 'only tube-fed'.

His reply hints at us now needing CHC and this is not the case - we have always found it difficult because we (and many other families) do not fit either criteria to get the help we need.

This has been solved on a Direct Payment level for us as we now receive these - after a nearly 4 year battle in the CCBC and only when we involved the Press. Our Direct Payments have been underway for 6 months now and they are a wonderful solution to the help we needed !

The next time we need any equipment etc we will still be in exactly the same position as before - without Policy reform - Social Services saying Health should pay for it and vice versa with no solution having to fight to get something (vital equipment) we wish we could afford so we didn't have to ask - that is what this Petition is all about - to solve this 'lack of categorisation' for tube-fed children. I hope I am understanding his letter correctly ?

Regards, Tymandra

Dr Tymandra Blewett-Silcock

Director, POPSYP (Parents of Partially Sighted and Blind Youngsters)