



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

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

4th February 2014 Response

Thank you for following up our Petition !

Unfortunately, we still have no start date for our Direct Payments – 3 ½ years later.

I have reached the stage where I would like to just say 'forget it' but am not lucky enough to be in that position – I need the help Direct Payments is supposed to offer families like ours.

Since it was agreed that we would act as a 'test case' family for DPs for a tube-fed child in the Caerphilly Borough (even though this is not an issue in any other Borough in Wales) we have had several delays.

It is hard not to take this personally and I would like to think this is not due to retribution from the women in the offices we have to deal with on a local level. Only when a male Manager is consulted do we seem to get a common-sense, fair resolution that sticks to what we had already agreed on months before.

Discussions and agreements we make at meetings are never documented so we have no proof of anything when the issues outlined below happen - but at least we have our personal advocate to witness these 'games' now.

Recent Issues:

- An Overnight pay rate threat of ~£38 for a 10hr shift as 'Poppy did not need overnight care' ie. a waking member of staff was unnecessary.
Obviously we need a standard hourly rate for a waking member of staff – this would have also reduced our 'pool' of hours to less than we were having before our DP request.
- The Option 2 'Hours per Week' Package we had chosen months before was then queried and we were told we would have less than we had agreed to.

At this stage I had to threaten that I would go back to the Press if they continued to play these games.

Only then did we have the agreed Package we had discussed and chosen months before finally 'approved'.

I am a shy person – speaking up like this takes its toll on me and my family.

Now, further delays finding an appropriate Employers Liability Insurer have been encountered with the Anuerin Bevan Health Board's Legal Department currently undecided if this cover is enough to 'cover health tasks'.

We are totally powerless as a family – I have just requested a start date of 3 February to accrue hours for this inconvenience.

Total incompetence doesn't even begin to describe this whole process – it is devastating for families and is a stark reminder of the 'life' we now face !?

We need an Independent 'Manager' to intervene in Health and Social Services 'Joint' cases like ours – obviously not being returned back to the local teams where you once again face the kind of games only experienced at school.

Best wishes,

Dr Tymandra Blewett-Silcock
Director