

Personal Budgets

A Poisoned Chalice

I decide to write this article after reading the link from Roy Lilley's blog to Jo Fitzgerald's guest blog at NHS England 'Personal Health Budgets are not all about the money –5 May 2015'

For me and my wife, our experience of personal budgets is that they are a poisoned chalice. Far from offering choice they are meaningless and a burden.

Our 24 year old daughter has Asperger's Syndrome - an autistic spectrum disorder. She also suffers from anxiety and depression. Since leaving fulltime education at age 19 she has not been in any form of work or training, despite obtaining 7 GCSE's at Grades A – C.

At the moment we manage her social care personal budget and based on our experience we would not want a health personal budget. We are her prime carers and do most of the running around to get the system to do what it is supposed to do.

As Jo Fitzgerald's blog points out, whilst it wasn't the personal health budget itself that made her experience easier, it was the ongoing process of developing a care plan centred around her son and her family and the positive trusting relationships that they had with professionals that made it all work.

If you don't have a complete well rounded care plan, positive trusting relationships with professionals and services that meet identified needs then personal budgets are meaningless for the person in need of care and are an additional burden for carers.

In April 2015 the Dept of Health published updated statutory guidance in support of the Autism Act 2010. NICE published guidelines on Autism in June 2012.

The Care Act requires autism specific needs assessments. The guidance expects 'the system' to make reasonable adjustments as required by the Equality Act.

Personal budgets are a waste of time and money and a dangerous illusion of choice if the following are not in place:

1. An assessment process that completes health **and** social care assessments in accordance with the Autism Act, first time – every time.
2. A detailed joined up care plan that has contributors from health, social care, housing, employment, etc as required under the Autism Act and Care Act.
3. A market that encourages service providers to meet identified needs as required under the Care and Autism Acts.
4. An administrative process for allocating and managing budgets that is aligned to the care assessment.
5. An administrative process that is capable of good record keeping and correcting errors.

As you've probably guessed we do not have any of the above in spite of the valiant efforts of our daughter's Social Worker to produce a social care plan.

It means that our daughter gets some care but it is unfocused. Complaints to the system fall on deaf ears. Don't even bother with the Ombudsman service –it is useless.

The end result is that we have an indicative social care budget that is underspent. The local authority has recently deemed that our daughter should now contribute £2 per week towards her care.

Their records do not match those of the care provider (with which we agree). It is probably costing the local authority more than £2 per week to send out incorrect invoices to my daughter.

We are personally experiencing the madness that is described so well in *The Whitehall Effect* by John Seddon.

The administrative burden of rectifying 'failure demand' falls on us and on the local authority.

Meanwhile our daughter is not making any progress.

Jo Fitzgerald's experience must not be used by politicians and civil servants to promote the use of personal budgets for all people. The evidence base is poor.

The personal budgets system is geared towards supporting people who have relatively predictable and stable needs. In our experience it is not capable of dealing with anything else.

It is inflexible and does not make reasonable adjustments.

Reasonable adjustments to a broken and dysfunctional system don't fix the system or meet needs.

Personal budgets can only work well if the underlying systems of assessment, planning, budget allocation and administration are working well.

This is clearly not the case for too many people with mental health problems or autism.