

## Personalised care and the economy of being well

I went into the Peer Leadership Academy expecting to emerge with a comprehensive grasp of personal health budgets. Indeed, I learnt a lot about how people with physical impairments made good use of theirs. Each delegate movingly portrayed their own experiences through their #myPHBStory presentations. Something I was surprised to learn was how the work I have been doing within the community aligns with NHS England's emerging model of personalised care.

As a parent of a disabled child, my 'Lived Experience' vantage point is once removed from that of the disabled person I think. From my position it is easy, however, to see the shared objectives of health, education and social care playing out to put the child at the centre of their care plan. When this works well, it's because the various practitioners in education, health, social care are collectively connecting with both child and parents.

What isn't so prevalent in this model, and it's something I work to address, is how parents are supported through **their** journey. In the case of my daughter's Batten Disease, or indeed any childhood condition, it isn't just the child that's affected. Like a pebble thrown into a pool, the ripple has an effect on family and extended family alike.

The support that is available, although invaluable, is often on a compartmentalised and insular level. It seems that different settings work very hard to engage their parent group and, after all the hard work, they then find it hard to relax the grip on their successes. This ring fencing often ends up segregating and isolating the parents further, as they stick to their artificial cliques, cutting them off from the broader SEND parent populace and the variety of support and activities out there in the community.

Over the last academic year, I've worked to develop a peer support model that links up parents whilst at the same time allowing them to remain in their native settings. This possibility becomes most realistic when the onus of responsibility changes and the balance of power moves to **doing with**, instead of **doing to**. This is a shift from being *supported*, to being *supportive*.

When we stop asking what our children's school, children's centre, children's advice centre, early development centre (the list goes on) can do for us and start asking what we can do **in partnership**, together with our local GP practice, with our local authority, with our Clinical Commissioning Group, then a joined up, supportive, network of professionals, practitioners and parents can begin to develop. As lived experience individuals, it seems the onus of responsibility is shared. When that responsibility is taken away from us, something important is lost.

So, when the comprehensive model of personalised care at the Peer Leadership Academy was scrupulously explained, it turned out a key segment of the model was on community capacity and peer support. Rather than personalised care being all about how personal health budgets can be used creatively, actually the point is that they complement a much broader regime of care that NHS England are driving forward through personalised care.

This new form of care is done in partnership. Power is shared and decisions made together. It is collaborative, humble and scrupulous.