

Families and Personalisation Project Some thinking for local statutory agencies

Based on our engagement with and work alongside families, two years ago the NDTi and Dimensions identified a shared concern about how families of people with learning disabilities were, or more commonly were not, becoming truly involved in and benefiting from the personalisation process. Central to this was a desire to understand how we, local authorities and service providers (small & local and large & national) can work at a very local level to engage with, inform and support families to achieve real individual outcomes beyond just a personal budget.

For the last eighteen months we have been working with groups of families (including adults and children) in three very different areas. The programme (delivered under the name 'Better Lives') has combined information sharing, planning, and engaging with statutory services and real outcomes.

Now commissioned by the local authorities, the programme will be running again in two of the three participation authorities, this time with more leadership contributions from local families involved in the first programmes. Over the coming months we will be seeking to roll out to programme in other areas.

We believe that the programme has raised some very interesting issues of national importance about:

- How statutory authorities are engaging with and informing families;
- The support and information needs of families;
- Opportunities for providers to work differently with families;
- The potential for increasing local family leadership.

We will be disseminating information under each of these themes but in this brief paper we aim to identify some of the key issues for how local statutory agencies are engaging with families.

What was happening locally

In the three sites, each of the local statutory agencies had made various efforts to inform families about personalisation, this had usually been in some form of briefing information, short training sessions (similar to that for all social care staff) or meetings with workers. We found, almost without exception, that these approaches had failed to inform and enthuse the families. A days training or an hours meeting will probably

not change thinking or address fears. While some local workers were skilled and positive others were giving incorrect and uninspiring information.

Much of the shared information had been focused heavily on direct payments and personal budgets as the key outcome rather than on them as a method of change. This seems rather like trying to persuade people that they might like to visit the United States simply because it gives them the opportunity to experience spending dollars.

Examples tended to be of individuals and families who had a lot of support, confidence and social capital and who had made big changes. For some people these are useful and very empowering but for others they had simply acted to heighten people's sense of isolation and powerlessness.

Working with families on personalisation had been very focused around the training and information sharing without understanding some people's needs to grow and involve their support networks before they could start dreaming about or planning for the future.

What families told us about how to engage with them to think about personalisation

The first message is, of course, that not everyone wanted the same thing, style or way of working. But there were enough commonalities to guide us.

Families want to start by thinking about their lives and the support that they have now, what was working and not working. Based on this we can then move to thinking about changing needs over the next couple of years.

Working within a small group of other families and with a programme leader who is also a family member, gives opportunities to openly and honestly share hopes and fears and to have them acknowledged and respected.

Information needs to be offered about the whole range of ways that support can be delivered and this needs to come with honest pros and cons for each. Examples need to include some that families can recognise as being 'like theirs' who are doing things differently (this includes a reflection of ages, family structures, learning disabilities and other support needs). Ideally these should be local.

Recognise that how one person is supported will have an impact on the life of the whole family and give an opportunity to talk about the hopes and fears that goes along with this.

People need time. Commonly it was not until about the third day together (by which time we had talked about hopes and fears, aspirations, one page profiles and support networks) that participants began to feel that they were understanding personalisation and what it could offer them.

Building relationships between families and support providers

For some people, their support plan will involve one or more support providers. Families knew little about support providers working locally to them. Most families want more information than leaflets, connections to websites or a broker – they want to engage.

Build engagement. We did this through a series of ‘Dragon’s Dens’ where providers were invited to present to family members about their service and how they would support the individual family members. Families demanded a much greater level of detail than most providers expected including information on recruitment processes, pay and conditions, flexibility and profit levels.

Properly engaging with families delivers for support providers. In addition to immediate and potential individual contracts providers left the process with a much greater awareness about how to gain family trust and confidence, to achieve real partnerships.

Family support organisations

During the programme some families began to think about the support and information that they had received from local family networks and groups. This thinking raised more concerns than positives. While the concerns were not common to all they were enough for us to suggest that local statutory organisations and family networks explore together:

- Are family networks presenting a balanced view of the opportunities raised by personalisation and personal budgets?
- Are leaders aware of the full range of support opportunities and styles?
- Do family networks have current and useful information about person centred planning, support planning, personal budgets and working with support providers?
- Are family networks successfully reaching families of younger people, people in transition and those seeking a more community focused and less service focused outcome for their family member?

Of course, no single approach will be right for all families. The Families and Personalisation ‘Better Lives’ Programme was intended to build a local outcomes focused approach with the participating families. We believe that this showed that it is possible to get families more engaged and to deliver real outcomes for an investment of about £1,500 per participating family. Whatever approach local authorities take, this seems reasonable investment to deliver real change.

For further information about the project visit www.ndti.org.uk or contact Bill Love on bill.love@ndti.org.uk