



National Development Team **for inclusion**

## **Families and Personalisation Project 'Better Lives'**

**Key Learning Outcomes Summary for  
Families, Local Authorities & Support Providers**

June 2012





Based on our work with and 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 can work at a very local level to engage, inform and support families to achieve real personal outcomes beyond just a personal budget.

For the last 18 months we have been working with groups of families (including adults and children) in three areas. The programme (Better Lives) has combined information sharing, planning, engaging with statutory services and delivering real outcomes. We believe that the programme has raised some very interesting issues about:

- how statutory authorities are engaging with and informing families
- opportunities for providers to work differently with families
- the support and information needs of families
- Potential for increased local family leadership

Coincidentally, just as the programme started the political and financial outlook had just begun a massive change creating a more inward looking environment and a great deal of uncertainty about the future.

**NDTi Better Lives Project**  
National Development Bank for Inclusion  
**Creating better lives adults with learning disabilities and their families**  


- Do you need more support now?
- Are you worried about the future?
- Are you not sure what the options are?
- Does it all seem too complicated?

We will work with families who include Older Carers to get the support their son or daughter needs to have a good life now and in the future. We will include any brothers and sisters or extended family and friends that would like to get involved with planning for the future.

Even if everything is going well now, you are probably worried about what will happen when you are no longer able to care for your son or daughter. We will get together in a small group for about 10 days over the next year to work towards the changes needed now that will lead to a better and more secure future.

Please come along to an information session to meet me and find out if you would like to get involved.



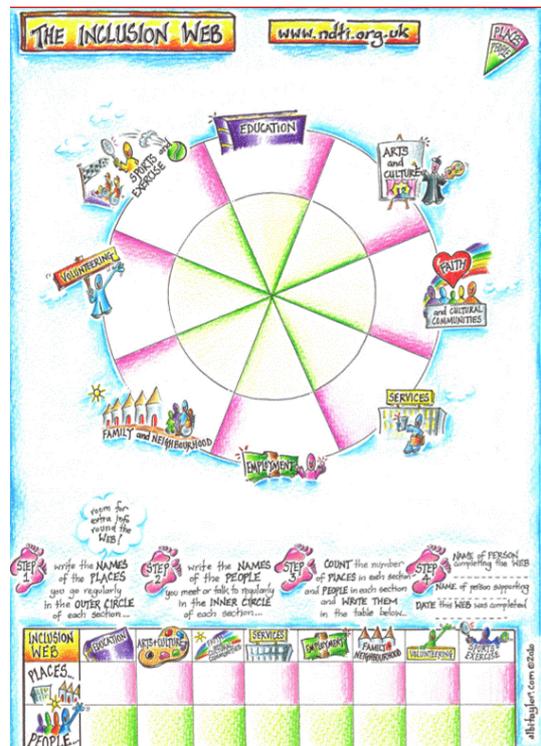
## Project Summary

We ran the programme in 3 locations – Suffolk, Calderdale and Wolverhampton and would like to thank the participants, their families and friends and local statutory and voluntary agencies for their support.

In each site we recruited families who, primarily, were dissatisfied with how things were at the time, who had a vision for things being different and/or were worried about the future. Although each locality had done some information sharing with families, most participants were unaware of or deeply sceptical about personalisation.

Much of the programme was delivered around the ideas, previous experiences and support/care arrangements of participating families. Style included:

- Sessions that informed, raised aspirations and delivered practical tools
- Combined into a workable support plan
- Strengthened natural supports to individual families and within the participating group
- Materials that would be understandable outside the programme





## Sessions/actions included:

- One Page profiling
- Foundations of support planning
- Stories and visions
- Support planning
- Staying in charge of services
- Building community lives and achieving inclusion
- Engaging and negotiating with providers – the Dragon’s Den
- Circles of support
- Individual support and planning sessions with families and their extended networks.

**Better Lives Project**



**Dragon’s Den**

Welcome to the Den. This is your opportunity to persuade us that you have the competence, commitment and characteristics required to be considered as service providers to our families.

We have money to spend, but we are not easy to please. We have spent a lifetime loving, caring and supporting each other and have the highest expectations for the future. In order to survive our fire, please answer the following questions.

1. How do you demonstrate that you work in partnership with families?
2. How are people with learning disabilities and family carers involved in the recruitment of staff?
  - a. How do you select the right staff for each individual?
  - b. How do you ensure continuity of staff?
  - c. What kind of training do you provide for staff?
  - d. What would you do if the regular Personal Assistant was unable to work?
  - e. What is your hourly rate of pay for staff?
3. How would you gather the information you need to support someone well?
4. How do you feel about family carers providing unpaid support alongside your staff of in your premises or transport?
5. How do you ensure that staff recognise and respond to non-verbal communication?
6. What would you do if someone refused medication or to wash/shave/brush teeth?

Thank you for braving our lair – we have much to learn from each other.





## Key learning for working with families

Despite each of the local authorities having people/departments responsible for engaging with and informing families, very few families who took part in the programme were aware of the personalisation agenda and those few knew very little. For example, nobody was aware that personal budgets could be used in a range of ways and Direct Payments were not an option most were willing to take.

Of course, each family or group should be asked about what works for them but these are our observations.

### **Before families are able to make an informed decision about the best way to use support they need:**

- An opportunity to explore the support they currently have and to think about what's working and not working now
- An opportunity to think about changing needs over the next couple of years
- An opportunity to openly and honestly share hopes and fears and to have them acknowledged and respected
- Information about the whole range of ways that support can be delivered and frank discussions about the pro's and con's of these
- Examples that families recognise as being 'like theirs' doing things differently. Ideally, this includes being local to them
- Opportunities to meet and speak with people who have personal budgets, their families and personal assistants to find out more
- A chance to explore hopes and dreams for their relative in a person centred context
- Support to think about the impact of changes to the way their relative is supported on their own lives (years spent caring and 'battling' with services meant that some parents had almost lost the concept of a life of their own)
- Clear information about personal budgets, how you get one, how you can spend it, and the support available to make it happen



### When they have decided to go ahead:

- A reliable source of independent information and practical support
- Real choices about the available options
- Well informed local staff who understand and promote personalisation

### If they choose a personal budget/direct payment...

- A good package of policies and procedures
- Practical training on recruitment, person centred thinking tools etc
- Access to quality training for the staff they employ themselves
- Option to buy into recruitment and supervision package for their employees
- Support to set up shared staff pool for emergencies

### If they want to 'buy' from a provider...

- A well developed market-place of providers who are able to respond to their needs in a person centred way
- A coherent approach throughout the local authority and independent providers that enables people to match 'like for like' when researching the available support
- Peer support to find their way through the process



## Key learning for Local Authorities

Local authorities have made various attempts to inform families about personalisation over recent years. Despite this only one of the families was well informed and this was because they had attended a family lead course. Families reported that it took 2-3 months (of a full day each month) before they began to grasp what a personal budget could do to transform their lives. An interest in Personalisation clearly has to be nurtured over a long time! The following key actions and resources will support families in making informed choices alongside their relative.



- Start by understanding and accepting that current engagement with families is probably not working for many families and the only way to address this is by making significant changes
- Understand that personalisation represents a huge shift away from the approaches and ways of working that they have been using with families for decades. A day's training or an hour meeting will probably not change thinking or address fears. There needs to be well considered investment.
- Families listen to other families, so support local people to develop information and skills and reward them for their involvement
- Invest in creating some local 'success stories' to demonstrate good practice with large and small budgets, hugely ambitious and very small goals and outcomes
- Independent organisations are sometimes good at supporting families with the support planning process because they often have the time and community connections to be imaginative
- Support your provider network to develop 'offers' around personalisation using Individual Service Funds and 'pick and mix' packages
- Provide a comprehensive support package, including policies and procedures, access to training and fast, reliable help when things go wrong – people need to know it is ok for things to go wrong occasionally and they won't lose their budget, but must ask for help
- Even though they may not recognise it, existing family networks may not reflect the experiences and needs of families engaging with personalisation. Engage with and invest in emerging, formal and informal, family networks and support circles.



## Key learning for Support providers

Support providers can play a big part in offering choice and control. It seems that many people, for a variety of reasons, do not currently want to manage their own package of support, indeed for many older carers the thought of this brings much anxiety for who would take over the management when they are no longer around to do it?

Families involved in the Better Lives programme knew little about the existence of service providers or the range of support available for their relatives – for example national and local providers, staff run or individual/family run. They really appreciated the opportunity to get to know staff both by working alongside them on some sessions or by interviewing them during the Dragon's Den. Families can be an excellent 'critical friend' encouraging service to look at their practices from recruitment and training through to pay and conditions, and of course a flexible approach to meeting their self determined outcomes. We suggest that the following could be of mutual benefit to families and providers:

- Make it clear to families how they can use their personal budgets within your service
- Offer low cost support products for people who want to manage their own budgets but would like some additional help with parts of it for example:
  - Recruitment support
  - Supervision
  - Low cost access to training
- Get to know families in your area, for example:
  - Co-facilitate and fund support groups with local family support organisations around transition, older families, behaviour or other key issues
  - Enable your person centred planning facilitators to support families to develop imaginative plans
- Share your success stories *and* be honest about challenges and difficulties
- Offer the opportunity to make small changes and build on them slowly so that people can have a gradual transition from the familiar to something new
- Create opportunities for adult siblings and wider circles of support to be involved in information and planning sessions

- Include family members on your Boards and your management structures to ensure that you are meeting the needs of families as well as the people you are paid to support.
- Understand and be open with families that an investment of time in talking about services, answering questions and helping people think about support packages will, for good providers, result in new work, but they are under no obligation to buy.

For more information about the project please visit our website at [www.ndti.org.uk](http://www.ndti.org.uk)

We are committed to rolling out the programme into more areas. If you would like to talk about commissioning a Families & Personalisation 'Better Lives' Programme please contact Bill Love at [bill.love@ndti.org.uk](mailto:bill.love@ndti.org.uk)