Blowing our own trumpet!
Bury parents lead on personalisation
Acknowledgements

A big thank you to all the children, young people and parents taking part. Thank you for giving up your time to tell me all about your lives and how they have changed for the better as a result of this project. Thank you for embracing the opportunity you have had - it is your enthusiasm for this work that is making it so successful. Your love for your children shines through!

Thank you to Sue and Debi for introducing me to families and professionals in Bury. Thank you for inspiring me through your energy, creativity and the commitment you give to your work.

Thank you to Bernie Garner (Disability Development Manager, Children with Disabilities Service) and Janice Cameron (Project Lead Short Breaks, Children with Disabilities Service) not only for giving me time to listen to their points of view, but also for having the vision to put your trust in parents by commissioning the Bury personalisation pilot.
Contents

Acknowledgements........................................................................................................ 00

About the report........................................................................................................... 00

Executive Summary..................................................................................................... 00

Section One: How it all started.................................................................................... 00

Section Two: The process............................................................................................ 00

Section Three: Changing Lifestyles............................................................................ 00

Section Four: Reflections............................................................................................. 00

Section Five: Moving Forward...................................................................................... 00
About the Personalisation Project in Bury

Bury Council invested in the Parent Forum to help them develop personal budgets in children's services. Prior to the project, the relationship between parents across Bury and the local council was often experienced on both sides as a relationship of ‘us and them’. With the aim of setting up a more constructive dynamic between families and Bury Council, the Disability Development Manager invested in the Parent Forum through an Aiming High for Disabled Children programme that included Skill Building Workshops, a Sharing Knowledge Course and the recruitment of a Parent Participation Worker. This investment allowed parents to develop the confidence to work in partnership with Bury Council.

At the end of Aiming High, the natural progression was to take families through the ‘next stage’ of self-direction. The Parent Forum was therefore commissioned to introduce Personal Budgets to a small number of families, at the same time as helping professionals understand and appreciate the advantages of self-directed support for children, young people and families. Fifty families already in receipt of a Direct Payment were invited to take part in the project. Fifteen of those families expressed an interest and signed up for the project.

Following the success of this first group, a further fifteen families were invited to extend the programme. This group has gone through the same process as the one described in this report. As this report is being finalized, a further group of families is embarking on the road to self-direction.

The Personalisation Team

Led by Bury Parent Forum in partnership with Bury Council, the Personalisation Team described in this report includes an associate consultant (Sue Harries); Debi from the Parent Forum; Janice and Bernie from Bury Council; and support planners from neighbouring Parent Forums e.g. Rochdale & Calderdale. As the work is developing the team is expanding with parents from the first pilot working with the forum as support planners and/or community connectors with families new to personalisation. (See Appendix 1 & 2 for more information about Bury Parent Forum and their Personalisation Team)

The report

Bury Parent Forum commissioned ibk initiatives to carry out an evaluation of their work around Personal Budgets in order to share their successes and outline their model of family leadership.

Ibk initiatives is a parent led social enterprise working to promote the inclusion of disabled children, young people and their families in their local communities; and to challenge a disabling world that denies their right to an ordinary existence. This perspective informs our analysis and shapes our recommendations for developing this work further. Pippa Murray from ibk initiatives carried out the evaluation and wrote this report.
The evaluation
The evaluation included:
Face to face interviews with parents, young people, workers from Bury Parent Forum & workers Bury Council (Children with Disabilities).
Telephone interviews with parents
Analysis of DVD
Attendance at training session
Observation of siblings group
Analysis of feedback from parents collected by the forum as they went through the process

The language we use
After much debate about the language we should use – for example, children with disabilities, disabled children or children with impairments. This work is all about taking down the barriers facing children and young people with disabilities. We hope that one day impairment will not be seen as their defining feature and that this leads to a greater understanding of how to support them so that they can participate in their local communities as a matter of course:

“We dream for our children and for your children – for our children’s children and for your children’s children. We dream that children who are labelled today, will one day be included without the slightest surprise, debate or controversy.” (Sheffield Parents, 1996)
Throughout this report we refer to children and young people with disabilities as children and young people.
Executive Summary

(The support I have now gives me) ...more independence and more freedom. Without mum and dad! (M, 15 year old girl)

Over the past year Bury Parent Forum have successfully supported children, young people (aged from 5 – 18) and their families to extend their links in their communities through shaping their own support. The defining feature of the support created is that it centers around the aspirations of the young people and it improves the well-being of the family as a whole. The ideology lying behind the project is that families are the experts in their own lives; they know best what works for them; and they should be in control of shaping the support they need.

The support from Bury Council includes a Personal Budget allowing families to employ Personal Assistants and to purchase items that allow them to take part in activities and enhance family life. However, as this report outlines, the way Personal Budgets were introduced to families has been so much more than giving them a sum of money. This Personalisation Project is transforming family life by helping parents adopt a radically different view on what is possible for their children. This new outlook, frequently referred to by parents as a change of hearts and minds, is allowing families to build on the natural support of family and friends. As a consequence, children and young people are feeling confident enough to want to include themselves in their local communities; families are creating the support that enables children to be included; and parents understand that the main problem they face to an ordinary experience of family life lies in the barriers their children face to being included in their local communities. All the parents we talked to told us their new outlook on life helps them feel more relaxed and better able to deal with their busy and demanding lives.

The success of the initial pilot has led Bury Council to further commission the Parent Forum to work with a further 30 families to give them the benefit of this new way of working. There is a buzz of excitement - from families and professionals - about the project:

“ I've got so many friends at football now. The people come and talk to me!” (M, 15 year old girl)

“And it was learning that we could make the support fit our family! We didn’t know that was possible. It has been ace! It is absolutely fabulous! I don’t know what else to say about it!” (Parent of twin girls, aged 15)

“My daughter is a lot more confident in saying what she wants now, what she would like to happen. And it has helped us understand not to do for her, that she can do a lot of this stuff for herself and then it is on her terms and conditions and then she is much happier. She is happier and more opinionated now!” (Parent of teenage girl, aged 15)

“Professionals are referring families to us regularly now. We are also getting feedback that families are more focussed on positive solutions, are less stressed and are not asking for so much help from professionals.” (Parent Facilitator, Personalisation Forum Team)

“Parents are coming up with things we would never have thought about before and social workers have never come up with.” (Disability Development Manager, Bury Council)
Section One: How it all started

In line with the national agenda promoting personalisation in Children’s Services, Bury Council wanted to give children and families eligible for support from social care the opportunity to try out a Personal Budget. In order to do this they commissioned the Parent Forum to introduce personalisation to those families already receiving a Direct Payment.

Inviting families already receiving a Direct Payment was seen as a quick win as it was simply a matter of extending the possibilities of how those families might spend the money they had been allocated.

Very few of the parents involved had heard about personalisation so the concept of shaping their own support and being in control of how money was spent was new and exciting:

“I got involved as I wanted to learn and to push myself. I wanted to gain more knowledge so that I can give my son a good life.” (Parent of 5 year old boy)

However, some families had not been in receipt of any services from the Local Authority as they had tried things out but felt there was nothing on offer to meet their needs:

“It was the freedom of choice that attracted me. We didn’t fit into the system so we didn’t use anything. The girls went previously to an after school club but didn’t enjoy it. They weren’t keen on the people. My daughter had a favourite member of staff when she went there. The staff changed all the time and it was somebody different every week. She was bored if her favourite wasn’t there. She was happy if he was there but otherwise she was bored. She stopped going as it was so hit and miss.” (Parent of 15 year old girl.)

“We were getting vouchers to use an established service, but it wasn’t working. We wanted something better. We were unhappy with the workers and the lack of flexibility. We were dispirited as my son was not getting what he needed.” (Parent of 9 year old boy)

And other families using traditional services discovered that having choice and control allowed them to shape the support around their daughter’s needs and wishes:

“For me, having been someone in receipt of services previously.... E used to have to fit into what we were being offered. We were almost grateful for the service we received and we had services that didn’t really fit E or fit our needs as a family. But we didn’t want to appear ungrateful so we were thankful. But now we can have a service purely centred around what E wants and needs. It is wonderful.” (Parent of 15 year old girl)

The project has been oversubscribed from the beginning. Bury Parent Forum had agreed to work with 10 families to help them convert their Direct Payments to a Personal Budget. However when 15 families expressed an interest the Personalisation Team decided to divide the parents in two groups and move forward with all those wishing to take part. In the event 14 out of the 15 families completed the process. The family dropping out of the process had to leave due to illness and want to come back to the work they have started. Of the remaining families, all 14 have been delighted with the process and the change in lifestyle they have achieved as a result.
Section Two: The Process

Designed to build capacity within families and communities the initial process created by the Parent Forum Personalisation Team included:

1. Home visits to families receiving a Direct Payment
2. Introductory evening for all families receiving a Direct Payment
3. Home visits to meet the family and gauge the level of information required (Home visits were then arranged as needed)
4. 3 empowerment workshops
5. PATH (Planning an Alternative Tomorrow with Hope)
6. Community Support Planning Day
7. Ongoing support from the Personalisation Team
8. Presenting support plans to panel

Home visits

Workers from the Personalisation Team visited families at home to explain what the project was all about and the benefits they might get by switching from a Direct Payment to an Individual Budget. These initial home visits set the foundations for a relationship of trust between the family and the Personalisation Team and was the first indication to families that this was a family centred way of working. All the families taking part in the project appreciated the fact that workers visited them at home at times suiting them rather than meetings having to take place within traditional working hours. As the work developed the Personalisation Team, who are all trained as person centred planners, used their experience, knowledge and relationship with individual families to gauge the need for subsequent home visits.

Following the introductory evening, Debi and Sue arranged a home visit with those parents choosing to sign up to the project. The main purpose of this initial home visit was to listen to any worries parents had about the project and to understand the perspective parents were coming from:

“We weren’t sure what it was all about. We signed up because we weren’t very happy with the support my daughter was getting. We didn’t know what person centred planning was and had never heard of a PATH.” (Parent of 15 year old girl)

“When Debi and Sue first came to see us it sounded like a lot of work. The training, the PATH night, the meetings... it sounded like a lot of work, a lot of time, and I haven’t got time. ...I felt nervous before we started. It felt like it was going to be a huge amount of work and we were so tired already. We only went ahead at that point because we had hit rock bottom and needed to do something.” (Parent of 15 year old twin girls)

Being able to get to know Debi and Sue prior to the training beginning was the first indication families had that the support offered by the forum would be tailored to their needs. Meeting the families before the training also allowed Sue and Debi to hit the right note during the first empowerment workshop. This tailored approach to home visits was a key factor to the success of the project.
Introductory evening

All parents in receipt of a Direct Payment for their son or daughter were invited to an introductory evening where the project was outlined and parents had the opportunity to meet with Sue Harris and Debi Walker from the Parent Forum alongside Janice Cameron and Bernie Garner - representatives from Bury Council Children’s Services - and Gerry Kelly from In Control.

In addition to receiving information about the project and the change in lifestyle it promises, parents had their first taste of the challenge involved in this new way of working. As the process was outlined many parents raised the issue that they were very short on time so the expectation to come to four training sessions, particularly because they were held at a weekend, was too much. While Sue and Debi took account of the difficulties of settling on the best day to run the training, they were adamant that there were no short cuts and that attending the training was integral to the process:

“We had to spell out what we expected from parents from the start. Because they had asked to come on board, we knew they were making some commitment. And the commitment they made was to the four days training. If they don’t want to do the training that is fine, but they would not be on the project. This work is all about changing hearts and minds and you don’t do that unless you do the hard work. ... This is about a value change, it is about changing lifestyles and you don’t see that until you have done the course. But families have to have the commitment to change and we had to help them see that before they signed up.” (Personalisation Team Member)

Being clear about the need for an active commitment and engagement from parents is central to the process of transformation. Although many parents found this hard at the beginning, by the end all could understand why the training was so important.

As part of the discussion around commitment, facilitators encouraged both parents to get involved. This is because the impact can be lessened if only one parent attends the training:

“We don’t make it an absolute rule, but we do strongly encourage both parents, where both parents are around, to come along. Because otherwise you have got mums going home all fired up and that doesn’t mean anything to dads if they haven’t been there.” (Personalisation Team Member)

Upskilling & empowering parents

In spite of initial worries about the amount of time the training sessions demanded, parents reported that by the end of the process they understood the training sessions were a vital component of the success of the work:

“Without the particular training we have had on the pilot it would have come across as another review and planning, ticking boxes and going through the motions.” (Parent of 9 year old boy)

Parents appreciated the opportunity to meet other parents in a similar situation, hear their stories and to learn and reflect together on their experiences:
“We needed the training not just to make things happen and to think differently, but it was also good not being so isolated, having ideas collectively, getting feedback from others. All of that gave me confidence and inspiration.” (Parent of 14 year old girl)

Having both parents attend the training was also appreciated by the families:

“I found the training really supportive. My husband and I had different ideas about personalisation. We have been able to come along together, meet other families and discuss our ideas. Doing that at a slow pace has allowed us to come to a mutual understanding. It has allowed us to dream and aspire for the future. We haven’t had the headspace to think about it before. It’s allowed us to do all of that.” (Parent of 16 year old girl)

Parents reported that the key benefits of the training included:

- Learning and reflecting with other parents
- Being challenged, in a supportive and positive way, by the Personalisation Team
- Changing hearts and minds
- Being given a positive view of their child
- Thought provoking
- Understanding that each family needed something different
- Understanding the difference between deciding about your own care and having care done to you
- Gaining trust and belief in Personalisation Team
- Having ‘serious fun’
- Feeling positive & energised

In order to understand the process, commissioners attended the first series of workshops. They reported that it was a huge learning process for them, in spite of the fact they have been on similar training sessions before. They also said it helped them realise the importance of having parents deliver the training:

“The training that Deb and Sue take the parents through gives them a different way of thinking and that’s what changes families. We can’t do that, and social workers can’t do that. The fact that the training is delivered by local parents helps families build up their resilience... workers giving training can’t achieve what Deb and Sue do” (Disability Development Manager, Bury Council)

**Seeing things differently**

All parents reported that the workshops helped them to see things differently. It was not just their view of what was possible that was challenged. Several parents reported that the workshops helped them see their sons and daughters differently and increased their confidence to take a different approach:

“I had to look at us differently... I had to look at the kids as individual people, not just the twins. We were just one big lumped together package before. And it didn’t work.” (Parent of 15 year old twin girls)
“It is about her growing up as an independent adult and it takes the focus off disability. You’re not thinking anymore about what she can’t do, it’s about what she can do and what she wants to do.” (Parent of 18 year old girl)

“It helped me focus on my daughter and what she wants out of life rather than what is or isn’t available. I had kind of lost sight of that.” (Parent of 18 year old girl)

Parents described the way their thinking changed from being grateful for accepting what they were given and being grateful for it even though it didn’t really meet their needs. As they went through the training they reported that they started questioning why their sons or daughters shouldn’t be taking part in ordinary activities in the community. Such a change in thinking allowed parents to consider new possibilities:

“I had never considered the idea that having a support worker would make him independent.” (Parent of 10 year old boy)

“I found the training really useful - an eye opener. It was really well presented and gave us an insight into what the personalisation pilot has been about: help and guidance for our youngsters.” (Parent of 15 year old twins)

“This training is one of the best things I have ever done. It is giving me a whole different outlook on life.” (Parent of 14 year old girl)

Discussing and reflecting on the meaning of inclusion throughout the training sessions gave families the confidence to look for opportunities in their local communities:

“The training made me see things differently - like I had never really considered my son going to after school classes with the other kids. I always thought he needed to do something ‘special needs.” (Parent of 10 year old boy)

Another parent said she had never considered the possibility of her son going to a mainstream after school club before, or attending other local clubs and activities. As a result of the training sessions this particular child is now attending local swimming and cycling clubs:

“I started asking different questions as a result of the training. I was asking, ‘Why can’t my son go to after school woodwork? What do boys his age do? So he has joined a cycling club. We actually found a swimming pool near us that welcomes children with special needs. He and his PA go there every week now and it turns out he can swim really well on his back.” (Parent of 10 year old boy)

In addition to this change, parents explained they have also come to understand they can question how public money is spent:

“When we learned that we could have the equivalent of the service she had been receiving we began to ask questions like: If we had the money for this service, what would we do with it? What will give us the best value for money?” (Parent of 15 year old girl)
PATH (Planning Alternative Tomorrows with Hope)

‘PATH - it was fun. I had all my friends and family there. It helped with my independence. I chose who came. I talked about my future and what I like doing. Shopping, bowling, going to the cinema.” (14 year old girl)

All 14 of the families taking part had a PATH event. These took place in the venue that families chose. Most families chose to hold the PATH at home but some chose community venues such as a synagogue, children’s centre, and a hotel.

In terms of who came to the PATH, children and young people were encouraged to say who they would like to be present and every effort was made to include those people families wanted to be there. On one occasion, relatives living on the other side of the world participated in the PATH via Skype; on another a close family member living in Canada sent a DVD that was made especially for the PATH. Some families chose to invite Personal Assistants, practitioners from education, health and social care, along with other key people such as a leader of the Brownies and friends and neighbours. In all cases, those invited had a direct relationship with the focus child, young person and/or their family.

“We had a big PATH party! E invited some friends from school and some disabled friends from some of the groups she goes to. After the PATH her friends were all saying they wanted one too! All the young people, in fact everyone, got something from the PATH.” (Parent of 15 year old girl)

In addition to the two PATH facilitators, the support planner working with the family was also present. This allowed them to understand the future aspirations of the child so that the subsequent support plan would hold the essence of the PATH while working out the detail of what was needed in the present.

All the parents taking part reported that the PATH was a transformative experience. Having been exposed to the new ideas presented through the training, the PATH was the moment when everything began to make sense and the impact this new way of looking at the world became clear:

“It (PATH) was a fantastic evening, inspirational really, everybody was here and all the comments they made about P. And I think everyone who was there is really really surprised about what came out of it. It made us all think in a different way and it made us see P in a different way. I think everybody learned from the evening.” (Parent of 14 year old girl)

As the quote above shows, it was not just immediate family members who found a different way of seeing the world as the result of the PATH. Families reported that all those coming to their PATH were helped to take a positive, can do perspective and this has transformed relationships within the extended family.

A major factor contributing to this positive experience for parents was the role their child had in the PATH. Many parents talked about the way in which their son or daughter had surprised them by the way they embraced the opportunity to take the centre stage and communicate their wishes for the present and their hopes and dreams for the future:
“It was interesting what he came out with! He is very articulate. A few things came up that we didn’t know he valued as much as he did. Like having an underground lab, and making a robotic arm to help other people.” (Parent of 10 year old boy)

And other parents talked about the way in which the PATH allowed them to see their son or daughter was capable of having an opinion and that it is possible for young people to direct the way their lives take shape:

“It took us a long time to persuade M that a PATH would be a good thing to do. She thought it would mean that everyone would be telling her what to do. She couldn’t get her head around the fact that it would be her opinions, her wishes, her wants... she made Sue (facilitator) work for her money. ...Since the PATH, seeing how it was and experiencing that Sue was serious about wanting to listen to her she is so much more confident in saying what she wants, what she would like to happen. And it has helped us understand not to do for her, that she can actually instigate a lot of this stuff herself and then it is on her terms and conditions and that makes her much happier. She is much more opinionated now. She will say, ‘Hang on, I don’t want to do it like that’.” (Parent of 15 year old girl)

“E has always said she doesn’t want to end up in a care home. After the PATH she kept saying she won’t have to! She has really bought into all the ideas lying behind it.” (Parent of 15 year old girl)

Parents pointed out the benefits of a person centred approach, including PATH, as an effective starting point for all services:

“PATH has been the pinnacle of all of this pilot. I think services should be thinking about offering a PATH as a starting point before you even think about giving services or anything. The PATH is what people need, the chance and headspace to think about and aspire for their young people; the chance for the wider family to think about what they want for their relative as well. It has been truly wonderful.” (Parent of 5 year old boy)

Many parents commented on the fact that the skilled facilitation of a PATH can bring families and friends closer together by creating a forum for discussion leading to greater understanding:

“I think it has made a difference in that family members always wanted to be involved but never seemed to find the right avenue. And we never had the right forum for them to say they wanted to be involved. Before people were too scared to say and not sure how to offer help but the PATH has given us a new focal point as a family. It has shown us that everyone is willing and wants to be involved in my son’s life. That is how it has changed us in the short term, and hopefully in the long term it will help us achieve K’s hopes and dreams.” (Parent of 10 year old boy)

“The PATH identified so much from so many different points of view. We couldn’t see how it all fitted together until the PATH. People said afterwards that they didn’t know about our life. Even people who know us really well said they didn’t realise how we live. Because we just live our lives and don’t necessarily talk about things. And all those people came up with really good ideas - things we have never thought of.” (Parent of 14 year old girl)
As the following conversation between mother and daughter shows, having friends and family arrive at a newfound understanding was not only helpful at an emotional level, it also lead to offers of practical support.

Mum: After the PATH, after we had understood how our family and friends can help us we used facebook to recruit support to take M to the football matches. I put a note on Facebook saying M now has a season ticket, does anybody fancy going to a match with her? And everybody did! Too many people!

M: And I put another note up at Christmas saying if you don’t sign, you don’t get to go!

Mum: And we also had family and friends come over at Christmas and M got her list out and they signed up for dates that suited them. And everyone chose what they wanted to watch. But they were only the people that M was happy going with. She wouldn’t have gone with them otherwise. It just sort of caught on and now people ask to have their name on the list. “make sure you put my name on the list, I am in!”

M: Not only that, but I now have loads of friends when I get to football....

Mum: Yes, because she has a specific seat. She’s inside, she sits in one of the boxes and the people come and talk to her.

M: Yes, I have that many friends inside the football ground now.

As this conversation shows, the process of the PATH generated ideas, positivity and commitment that made parents feel good about their family life and helped raise their hopes for the future. It allowed families to talk about their hopes and dreams with others and this small step was seen to open the door to a more positive, richer, stronger family life where the family was part of a wider community:

“I thought the PATH was great, far more emotional than I expected it to be. It was absolutely lovely hearing family and friends, people close to K and his life from all different backgrounds saying all their hopes and dreams for my son. People got emotional. There were tears. And it gave you a real snapshot to see that K can achieve so many things in his life. He will achieve. But also seeing that his hopes and dreams aren’t so difficult to achieve as we had previously thought. I just thought the whole thing was powerful. Such a powerful tool. All the family went away talking about it. Everybody wanted to be involved, wanted to take on a role to help improve my sons life so I couldn’t speak more highly of it. I think every youngster should have a PATH regardless of their additional needs.” (Parent of 5 year old boy)

Teenagers and their parents were particularly appreciative of the opportunity the PATH gave them to think of a positive life as a young adult:

“The PATH day has made a huge difference to our family because E is growing and developing. She is 12 years old now and we have never had the chance to think about E growing into a young lady. And it gave people the opportunity to sit back and share experiences and opinions of her and think about what we could do. It has allowed us to think creatively.” (Parent of 14 year old girl)
“The PATH has made us more positive about the future and knowing that M can have an independent life for herself and that we are in control of it and that her future is there for the taking. It made us think differently.” (Parent)

Like their colleagues around the country, representatives from Bury Council working with Children’s Services showed a painful awareness of the gap between children and adult services and reported that they saw great potential in using both the process of a PATH and the support it generates to allow for an easier transition for young people and their families:

“...through the PATH we are really focussing on the needs of the young people and so hopefully - we can’t measure this yet as it is too soon - some of the kids that go through this as children won’t feel such a change in the way things are done when they move into adult social care. Because they are already building their social network they won’t need adult care in the same way. Already the young people on the first pilot have got so much more going for them. Their lives could be changed for ever. That is our hope.” (Project Lead Short Breaks, Children with Disabilities Service)

This hope was backed up by the young people who told us they are enjoying their new found independence and have no intention of returning to being silent and compliant. To prove this point, one young woman was able to be very assertive during her interview as she reflected on the process of PA recruitment:

“I never want that to happen again because I didn’t like them [prospective PAs] coming to the house...We have to do it differently next time.” (M, 15 year old girl)

And of course, the parents agreed they will take their daughters wishes into account next time!

Community Support Planning Day

Following on from the PATH event, the community support planning day gave families the chance to actually plan how to make some of their hopes and aspirations come to fruition. For most families, the Community Support Planning event was the day where they felt the practicalities begin to come together and understood the difference being involved in the community could make to their lives. This was particularly true for families who had previously chosen specialist services. Indeed, the power of the process of the workshops, the PATH and the support planning day meant that all families chose to forego specialist services in favour of support to take part in community activities. As with the PATH, parents were encouraged to involve extended family members to come along to the support planning event to help them make decisions about activities and lifestyle. And each family was teamed up with a Community Connector and practitioners who helped them think about things that are available in the community.

“The Community Support Planning day is a celebration event. We invite families, friends, support providers, professionals, and people from community groups. We have all the PATHs up on the wall; we have community boards; laptops on with internet access; people ringing around here and there; people feeding back to the rest of the group; people sharing what they are doing, what they have found out. It is a vibrant, buzzy day where all the ideas families have talked about before are explored to see if we can make them happen, and the best way of making them happen.” (Personalisation Team Member)
The celebratory feel to the day allows for aspirations to rise higher at the same time as taking a very practical approach where things actually get done:

“I liked the community support planning day because I learned about things I had never considered possible before. Simple things really now I look back ... like having someone to help me out on a day trip in the summer holidays.” (Parent of 10 year old boy)

“...very dreamy! Thinking about my own place.” (M, 14)

“The community support planning day was interesting and exciting. It was really fun to see how we were actually going to put things into practice.” (Parent of 12 year old girl)

By the end of the day, all families had a clear idea of what they were going to do to get the most out of their Personal Budget and the resources (financial and other) they would put in to get the lifestyle change they aspired to.

Support from Sue and Debi

The majority of parents reported that the key to the success of the project was the support given by Sue and Debi - known as the 'personalisation workers'. As reported earlier in this report many families were anxious about taking a new approach and only got through that stage because of the way in which Sue and Debi responded to their worries:

“And Sue had said a million times ‘I promise you we won't leave you, you are not in this on your own’. And I think that is what helped... we had such fab support, and we weren't left on our own... and Sue and Debi were there all the way through. They were supportive.” (Parent of 12 year old girl)

“Seriously, we couldn't have done it without them. It was being on the end of the phone if we needed them and they were so honest and nothing was papered over or fancified and it was black and white: if you want to get to there, we have to do this first. We have to do that bit to get there where we are. And they did a lot of the work around what fitted in with our family. Like at weekends, we are busy during the week, and at night time it was hard to get to meetings because of the situations we are in with the kids...” (Parent of 15 year old twin girls)

“When I have had a question pop into my head I've just been able to pick up the phone and it hasn’t mattered if it has been evening, weekends - they have always been there to support us. I don’t know how we could have done it without them”. (Parent of 18 year old girl)

Many of the comments from parents highlight the need for support that is flexible and responsive. For example, parents told us they appreciated being able to contact Sue and Debi in the evenings and at weekends asking them about their small worries as well as their larger concerns. Most of all parents valued the fact that Sue and Debi knew what they were going through as a result of their personal experience and always gave the impression of having as much time as parents needed:

“The most important help has been from the personalisation workers who have guided us and shown us how personalisation can work for us. Without their help, for example if we had just had a social worker, it wouldn’t have been as helpful. It has been really useful seeing and understanding where you can use your money because otherwise you would end up using it for what you have always used it for because you don’t know what is
available and what is best. So to have personalisation workers has really helped give a
different point of view, different aspect on how to go about it.” (Parent of 12 year old girl)

Following the community support planning day, Sue, Debi and the support planners from
the Personalisation Team helped all families finalise their support plan and get it into
shape to present to those responsible for managing the social care budget.

Presenting support plans to panel

In contrast to a traditional model where a group of social care professionals sit behind
closed doors and make decisions about the best way to spend money allocated for family
support, the personalisation project allowed for a radical change in relationship between
parents and LA representatives.

Parents presented their plans to a small group of professionals who they had already met
at either the training sessions or the community support planning day. Each family was
able to put forward a written support plan alongside their PATH to representatives from
Bury COUNCIL. They were then able to tell them directly about the support they need and
the plans they have made. This included plans for the spending of Individual Budgets as
well as plans for support and activities outside of the money allocated by the Local
Authority.

By the time they reached this stage families were confident and excited. They were keen
to share their new perspective, their hopes for the future and to show how they were going
to work towards their hopes and dreams. The vibrancy the parents brought to the panel
meeting was a novel experience for Local Authority workers accustomed to 'panel' being
full of conflict and difficult decisions:

“I don’t usually feel emotional at those meetings, but it was so moving! Hearing about the
PATH from the family, the stories they were telling us about what they didn’t do before but
what they are doing now. They told us this was happening, that was happening and he is
so much happier. And now I realise I can never second guess what a family might want or
what would work for them.” (Disability Development Manager)

“And I think the whole concept of ‘panel’ has changed - for families and us. I think families
had this vision of a horrible ‘panel’ of nameless, faceless people making decisions on their
behalf. But now we have met them we are people to them. They presented the PATHs to
us and saw that we were touched by them. They must have thought ‘what a soft bunch!’
(Project Lead Short Breaks, Children with Disabilities)

In addition to those sitting on the panel gaining a direct connection with families, having
parents present their own support plan to those with responsibility for the spending of a
particular section of the public purse, allowed for direct dialogue between parents and local
authority representatives. Advantages included Local Authority representatives realising
that parents were happy to invest their own money into some of the ideas outlined in the
support plan and to use any natural support available to them:

“One family wanted an ipad and there wasn’t enough money available to them through the
individual budget. They were spending on other things as well, and by the time they got to
the ipad they were coming to the end of the amount allocated. It wasn’t a problem. They
just topped it up with their own money. They could understand we don’t have a bottomless
pit.” (Disability Development Manager, Children with Disabilities)
On the rare occasion where it became evident that a family did not have enough money, either through their own resources or those allocated to them by the state, to meet their needs the amount could be discussed and increased appropriately. Such occasions were highlighted well in advance of the panel session by the personalisation workers who have the skills to work with families and professionals.

Another advantage was that the thorough preparatory work of the Personalisation Team, the high quality of the Support Plans put together by families and the team, and the direct communication at the panel meeting allowed for an instant decision about the support plan which significantly lessened anxiety on behalf of the parents. It is likely that this brings long term benefits and efficiencies to health and social care services.

Prior to parents coming to present their plans, commissioners would have had no way of knowing about the different ways in which families were improving their child’s quality of life. The direct meeting between parents and commissioners allowed for both parties to become human to each other at the same time as making the process of decision making and budget allocation simpler and easier:

“We saved so much time and money because families brought their own support plans. We could ask questions when we didn’t understand something, and parents could explain things to us. Because of that, we got all the information we needed to make a decision. Before doing it this way we would ask the social worker lots of questions they wouldn’t be able to answer. And they would have to go back to the families and then come back to us. And that could happen a few times. We couldn’t make decisions because we didn’t have the information we needed. This is a much more efficient way of doing it.” (Disability Development Manager)

We reflect on this and other efficiencies made through the personalisation project in a later section of the report. Before doing that however, we describe some of the lifestyle changes produced through the work.

**Section Three: Changing lifestyles**

Personalisation is about giving children, young people and their families greater choice and control in order to increase their opportunities for active citizenship. Without exception, young people and families taking part in this project report that choice, control and active citizenship - as individuals and as families - has increased dramatically. This is true regardless of background, age, impairment or level of support needed by the child or young person. At the end of the process when families were reflecting on the changes they have made to their lives, all of them talked about the transformation of family life:

“For me, having been someone in receipt of services previously, E had to fit into what we were being offered. We were almost grateful for the service we received. We had services that didn’t really fit E. or fit our needs as a family but we didn’t want to appear ungrateful so we were thankful. But now we can have a service purely centred around what E. wants and needs. It is wonderful. ...It is just going to make a huge difference to us as a family” (Parent of 12 year old girl)

Although it is too soon to assess any long term impact the project has had, both parents and children were eager to express their delight with their new lifestyles:
“I have more independence and more freedom. Without mum and dad.” (15 year old girl)

“It has made my life so much easier” (Parent of 10 year old girl)

“It would have been good to have had this when I was younger.” (18 year old girl)

As this report has described in earlier sections, the transformative power of this work lies in families being introduced to a new way of thinking about the possibilities open to disabled children and young people. Parents described this change as a move from a ‘can’t do’ to a ‘can do’ approach:

“It gives us control, or rather M. control. It makes M. the focal point. It is about her growing up as an independent adult and it takes the focus off disability. We are not thinking anymore about what she can’t do, it’s what she can do and what she wants to do.” (Parent of 15 year old girl)

In the short space of time parents have had since presenting their support plans and putting things in place children and young people have enthusiastically embraced their new lifestyles. This has lead to children and young people taking part in after school activities with their friends and trying out new clubs which allows them to meet more people:

“Our starting point was ‘What do other children his age do?’ and ‘Why can’t my son go to woodwork class after school?’ So now he goes to a cycling club one evening after school, has a swimming lesson at a local pool on another evening, and his PA takes him to that, and is going to a day camp during the summer holidays.” (Parent of 10 year old boy)

“She is looking at swimming, we have to go to the Jubilee Centre at Bolton - they apparently have a fab pool there - that’s something we didn’t know about. It is warm, all the facilities are there, it’s too cold in other swimming pools.” (Parent of 15 year old girl)

“In four weeks time I am getting a football wheelchair and Grandad is making me a banner ‘Bolton Bullets on the move.’” (15 year old girl)

And Mum adds:

“The wheelchair is nothing to do with the budget. The wheelchair football association got half the funding through a sporting event they are involved in and we paid the other half. The wheelchair has nothing to do with the budget but we wouldn’t have even thought about it if we hadn’t gone on the training and done the PATH” (Parent of 15 year old girl)

These activities are carried out with the support of a Personal Assistant, paid for through the Personal Budget, or with the support of family and friends. More families have felt confident enough, and found the support they need through a local service provider, to employ Personal Assistants. Families report being surprised by the benefits this brings when it works well. Some parents have gone away for the night, leaving their son or daughter at home with a Personal Assistant while others have taken a Personal Assistant on holiday with them:

“We took her away with us for a week. We would never have done that before. But it worked out really well. We didn’t do everything together but we did lots of things together
and we all had a good time. It made it a more relaxing holiday for the whole family.”
(Parent of 16 year old girl)

“...it was my birthday and we said we are going away for one night. Mum and Dad are going to come and babysit and move into our house for Saturday and Sunday and we were going away with a big group of friends to the Lake District. M had been invited to a party that night and I didn’t think she would go without us to take her. But she did go! Grandad took her and she had a beano. And that is a huge step for M! Massive! M. didn’t go to a lot of things because she didn’t want to. She didn’t want to join in. She didn’t, but she does now!” (Parent of 15 year old twin girls)

Young people reported they were delighted to have Personal Assistants taking them out and about as it gave them the opportunity to be out and about with another young person, having an ordinary experience of the teenage years:

“Rachel is my mate. When I grow up I want to learn how we become mates” (18 year old girl)

Many of the families taking part in the pilot had modest requirements. As we have outlined earlier in this report families were looking for an improved quality of life and a reduction in their stress levels rather than a large sum of money:

“We are not asking for the moon. P loves being outside, she loves the sea. We are buying large wheels for her chair so that we can go on the beach and walk through the forests with her. We have also bought this ordinary but amazing double swing hammock to go in the garden. She is completely safe there and can spend time sleeping out there when she needs to. We also bought her a blow up paddling pool which she uses as a sand pit. Again she is completely safe, and that means I can relax a bit more. We are finding it is the little things that make the biggest difference” (Parent of 14 year old girl)

As parents addressed their fears about the future and began to put steps towards independence in place, they realised that when they took things slowly the future became less scary:

“...she is part of a group called the VIP dudes - visually impaired youth group and they do a lot of work in school with her and they have added her onto their list of dudes and they organise things over each of the school holidays and this time they are going to Slatterys to meet John Slattery and he is going to teach them how to make a cake. I have offered to go, but they have said there is enough volunteers thanks very much! And that is a new thing. I am not going on that, but two of them she has gone on and really, really enjoyed herself. You went on a car maintenance course didn’t you. These are all huge steps. (Parent of 15 year old girl)
The children and young people are taking part in a wide range of clubs and activities that are mainly new to them. These include:

**Rifle range - Rivington Rifle Club**
*Playing football wheelchair*
*camping*
*car camping (with grandparents)*
*going to posh restaurants (with PA)*
*staying with grandad on Friday nights*
*camera club (school)*
*swimming*
*pamper club (after school)*
*cycling club*
*woodwork club (after school)*
*drama club*
*gym*
*dog walking (as volunteer or with family)*
*trampolining*
*music group*
*skiing*
*homework club at library*
*water sports*
*brownies and guides*
*fundraising*

In addition to PAs, clubs and activities several families have used their budget to buy equipment such as ipads to encourage communication and learning; and a portable ramp to access their own house at the same time as enabling them to visit friends.

In many ways it is not what children and young people are doing that is important. Rather it is the fact that they are extending their horizons; following their interests; developing their passions; widening their friendship circles; discovering their own voice; increasing in self-confidence; finding direction; improving their communication skills and means of self expression; and all this amidst the usual ups and downs of family life. These are all things that the children, young people and families on this project cannot take for granted.

“Getting involved with this project has changed all our lives. Now that we have bought into this way of looking at things our futures are going to be different. We will do things now to give E. choice and control. She will make the decisions.” (Parent of 15 year old girl)

“People keep making decisions for me. They're making choices for me. I want to do it for myself.” (15 year old girl)

As the above quotes show, the real value of this work is in people feeling strong and confident enough to create their own pathways through life. This confidence is leading them to create their own solutions to the challenges they face. In doing this they are strengthening their position in the community which makes their communities stronger. That is the lasting legacy of this work.
Section Four: Discussion and Reflections

This personalisation pilot is clearly very successful. In addition to the dramatic changes of lifestyle outlined in the previous section, there are a number of other outcomes which demonstrate the potential this particular approach has to offer. In this section we look at some of the changes that have taken place as a result of the work.

**Economies & efficiencies**

Prior to the project parents were unsure as to the benefits personalisation would bring them. Some parents reported that they were fearful that personalisation was a cover for cutting packages of care and the amount of money awarded to families:

“Even after the first couple of sessions, I still felt unsure... and I was massively worried because we had been let down badly in the past and my dad said ‘this all sounds beautiful, but it had better work’. And that was my worry - would it work? Was it just another way of making cuts.” (Parent of 15 year old twins)

Parents and professionals commented that they considered personalisation as they have experienced it so far to be an economic and efficient way of providing state support:

“I think that in the present climate, this has to be a much more cost effective way of working. We are spending the same amount of money as we had before but we are spending it differently and getting so much more value from it.” (Parent of 14 year old girl)

“We have a finite budget, and I am very clear with families that if everything rocketed from doing a PATH and having a personal budget it would blow our budget. But actually that hasn’t happened. Rather than the budget being blown we have had families coming to meet us half way.” (Disability Development Manager, Bury Council)

It is impossible at such an early stage in this work to say what the long term impact on finances will be but there are strong indications that, even with no cuts in the individual packages of care, this way of working could allow Bury COUNCIL to use its available resources more efficiently. Examples of such efficiencies include: none of the families taking part have been in touch with social services since they got involved with the project; the process of parents presenting their own support plans to panel means that any questions about the plans can be resolved immediately; a PATH produces good quality, comprehensive information needed for an initial and core assessment; and the process of moving from children’s to adult services is simplified. There is little doubt that, as this work develops, other areas of efficiencies will emerge. Present financial systems make it impossible to put an exact figure on the amounts that are saved, but common sense tells us they are significant.

**Personalisation is about so much more than having a budget**

As we have outlined earlier in this report parents too attribute the improvement in their lives to the workshops and the PATH which has enabled them to adopt a radically different approach to their lives. Parents have said again and again that they appreciate the money they are given, but the money is not the main thing. Indeed, most families who were previously on a Direct Payment did not receive any additional funding, but all of them report a huge increase in their quality of life.
“The name says it all - personalisation. It made us feel that it was about our child and not just a form filling exercise. You can really develop an idea of what you want for your child, how you can develop things for your child. It is not just about getting a sum of money at the end it is also about building bridges and we have definitely done that. ... all I can say is that I am looking forward to going forward in my life and particularly supporting my child.” (Parent of 5 year old boy)

It is this changing of hearts and minds alongside a modest sum of money that has given parents enthusiasm for this new way of working.

“We make it clear in the training that the change lies within each parent. It is not about Debs and me doing this for you. You have to do it for yourself. And we go through the thing about social services not being set up to care, that is a process, it is not about care. Caring is in the community. We really emphasize the fact that if you think you want to make changes it has to start with you. You have to do it first and then it will catapult everyone else. I have seen that change. When other people see that change they will want to be part of it because it is positive energy.” (Personalisation Team Member)

It is this compassionate insistence from the parent facilitators that allows parents to move from seeing themselves as passive receivers of services to active agents with all the skills they need to shape their own support. And as they go on they learn that it is not about the money and services but rather about life and love:

“We tell parents that they are more likely to get their child a job than any careers officer because they care. And you can’t buy care. But you can find other people who care. They will be in your communities and they are the people who will help you.” (Personalisation Team Member)

This uncompromising stand and the accompanying skillful approach of the Personalisation Team Members generates a tough love that encourages parents to realise that they have the power to create an exciting future for their children.

**A new relationship between parents and Bury Council**

Officials from Bury Council reported they have a history of a difficult relationship with parents of disabled children that is characterised by a relationship of ‘them and us’. At the worst end of the spectrum several complaints have gone through to judicial review in the past few years.

Parents taking part in this project reinforce this by talking about having a sense of alienation and a reluctance to get involved with professionals in social care:

“We were fed up with what we didn’t have. When we asked for any help we always got a duty social worker and I got fed up telling our story over and over again. I actually said to the last duty worker that came to see us that I wouldn’t waste my time telling the same story.” (Parent of 15 year old girl)

Happily, both parents and professionals report encouraging signs that indicate this project is going someway to repairing the relationship between families and Bury Council. Families have nothing but praise for the people commissioning this work. Simple acts such as commissioners attending the training session and parents presenting their own plans
for sign off by the Local Authority has contributed to a warming of the relationship between parents and staff at Bury Council. This trust is continuing to grow as parents experience an increased sense of well being and staff acknowledge that putting families in the lead brings totally different results:

“Parents are doing things we would never have thought about before and social workers have never come up with. (Disability Development Manager, Bury Council)

“...and social workers are used to hearing a lot from some of the families, they might have come back for additional support for whatever reason, but they have gone away with the personal budgets and they are just getting on with their lives.” (Service Manager, Children with Disabilities)

“Professionals are referring families to us regularly now. We are also getting feedback that families are more focussed on positive solutions, are less stressed and are not asking for so much help from professionals.” (Personalisation Team Member)

Reaching different cultures, engaging new families

The initial cohort of families involved in this project include families from black and minority ethnic communities. These families have taken their experiences and learning back to their communities and there has been a subsequent increase in requests for support from families in those communities. In one case, a family from the Jewish community has started up a brokerage agency in order to make it easier for Jewish families to recruit Personal Assistants and manage the role of employer. She is giving talks about personalisation to families with disabled children.

“I have set up an organisation and have put together a data base of PAs. I have 17 PAs on that list already. I have put two ads in a community newsletter and am still getting calls from parents asking for information about Direct Payments and from people wanting to be PAs. I have already matched a PA with someone wanting some help with their child in the morning. Many families don’t know what a Direct Payment is. It has made my life so much easier, I want to help other families get the same.” (Parent of 10 year old boy)

The work of this parent has resulted in several Jewish families coming on to the second group coming into the project. Bury Council have previously struggled to engage with families from the Jewish community.

Creating positive futures

Many parents expressed a very natural concern about what will happen to their son or daughter when they die:

“We need more help and we are very worried about the future for our son. What is going to happen to him when we die?” (Parent of 14 year old boy)

“...and I think we had hit rock bottom and we needed to do something. I was really concerned that the girls were getting older and we hadn’t got anything. And my main concern was if anything happened to us because we had put nothing in place for the kids to help them and guide them. I have had health problems in the past and it opened my eyes. We are not always here are we?” (Parent of 15 year old twins)
This fear for the future was probably the strongest motivator for parents to make something different happen as both they, and some of the young people involved, expressed an abhorrence of the traditional system of care:

“I don’t want to send my son to a residential place when he is older. I am glad we got involved.” (Parent of 10 year old boy)

As the project developed and both parents and young people embraced the new ideas presented to them, they realised that they did not have to accept a traditional service but could shape their own support:

“E always said she doesn’t want to go into a care home. Now she knows she doesn’t have to.” (Parent of 14 year old girl)

Several young people now have their sights raised and are adamant that they are going to follow their interests and develop their natural talents:

“She doesn’t want to go to college to do disability studies or special courses. She wants to go to college to learn about catering or IT - the kind of courses everyone else has a go at.” (Parent of 15 year old girl)

“She has started talking about ‘my future, my independence’ This seems like a small thing but actually it is going to change all our lives. We have hope for the future now. (Parent of 15 year old girl)

Involving the whole family

In much work with families, it is likely that mums and disabled children are at the forefront. Sadly, it is rare for brothers, sisters and dads to be involved. This presents families with difficulties and makes the job of parenting even more difficult. The holistic whole family approach of the personalisation process in Bury allowed dads and siblings to find their own place:

“The impact on Dads has been great for me, I didn’t expect that. The fact that 2 or 3 dads presented their support plans to panel was brilliant. We very often have comments about dads not being present; dads at work; dads not in the family home any more; but these dads were very involved. It gives a different perspective.” (Project Lead Short Breaks, Children with Disabilities)

“The siblings are amazing! Just watching the group is fascinating. One of the other girls with a disability is in this group and it doesn’t fluster them one bit. How can we make this happen elsewhere? So that has been really good and we want to go on letting that evolve in whatever way the young people want it to evolve. The energy they have.” (Personalisation Team Member)

Education and health

Although this work was commissioned through social care, there is clear evidence from families that the benefits gained are sometimes closely linked to outcomes usually understood to be the remit of health or education.

In one instance, a family took the support plan and PATH into school. The class teacher was so inspired by the materials that she has adapted the child’s curriculum to include several elements laid out in the PATH:
“It has made a difference to school. We took the PATH into school and they were brilliant - they looked at it and said ‘we can do this’ and ‘we can do that’ - things like getting out in the community and self help skills. They were all up there on her PATH. The teacher looked at it all and included a lot of it in her curriculum.” (Parent of 14 year old girl)

This same child is now taking an ipad into school to help her make choices and express her wishes. Although the ipad was not bought through a Personal Budget, it came as a direct result of the process.

“The idea about the ipad came from support planning day. Sue had one there and we were looking at it, talking about it, and someone said their company had a charity so there is no harm in trying to see if they would buy us an ipad. So we did and they gave us money for the ipad. We then bought an expensive app with the budget, and she hasn't looked back.” (Parent of 12 year old girl)

This child was not the only one whose education is benefitting from equipment bought through a personal budget. Another young woman, who is unable to get into school regularly as a result of a chronic health condition, is able to keep in touch with school and continue with some learning programmes through her newly acquired ipad.

Another family has purchased a puppy for their daughter with their personal budget. They did this as their daughter loves animals and needs to walk more to improve her mobility. The young girl is now walking her dog, with the support of her family, friends and her PA, every day and as a result her mobility is improving.

These, and other similar results, indicate the pressing need to involve health and education in this work. This could only improve the benefits for children, young people and their families.

Section Five: Moving Forward

The overwhelming success of this personalisation pilot leaves the Parent Forum and Bury Council with the question: how can this work be extended, developed, embedded and sustained?

Rather than provide a list of recommendations, this section highlights key areas for discussion between the Parent Forum and Bury Council. These questions are simply given as a starting point for a conversation and we anticipate many other topics will emerge through this discussion and lead to an action plan to progress and sustain this work.

The only recommendation we give is that the author of this report facilitates a meeting with key people from Bury Parent Forum and the Children with Disabilities Service.

1. Developing Family Leadership

The workers at Bury Parent Forum have done a magnificent job at establishing a model of Family Leadership. Their energy has created the potential for further development of the personalisation project; establishing a young people’s forum made up of disabled young people and their brothers and sisters; and extending the newly formed Dad’s group.

What is the shared vision for the future of this work?
The personalisation project is entirely dependent on two highly skilled parents with a natural flair for the work. How can their commitment and expertise be used to best effect in making this work sustainable?

How can we develop the existing mechanisms for ‘pass it on’, and help more parents become facilitators, trainers, community connectors, and peer mentors?

How can this work be developed, extended and made sustainable?

2. Build up leadership in young people - disabled young people & their brothers & sisters as role models

Many of the young people taking part in the project discovered they had a voice and a role to play in their communities. How do we nurture this and give these young people opportunities to become role models and leaders in their local communities?

The parent forum has the beginnings of a successful siblings group. How is this given the encouragement and resources it needs to grow? Should it remain a siblings group? Or should it be a sub-group of an inclusive group that could form the basis of a children’s and young people’s group hosted by the Parent Forum?

3. Using the messages from families to inform strategic direction of services

In addition to the 25 families who will have completed a similar process to the one described in this report, many other families in Bury have a PATH and around 30 also have a support plan. These documents carry a wealth of data that, when aggregated, can be used to inform strategic thinking and development across health, education, social care & the community sector. How can this be initiated? How can this information be used to develop services within the Children with Disabilities Sector?

It is clear from the work carried out so far that, although the intention of this work was not to make financial savings, this looks like being an extremely cost effective way of working. How can we gather evidence that this is a case? What information do we need to put this in place?

It is clear that children, young people and their families are taking part in their communities to a greater extent than they were prior to the project beginning. It is also clear that they have much to offer their communities - as employers; as role models; as community connectors; as neighbours and friends. How do we teach the wider community about the gifts and talents disabled children, young people and their families bring to our communities as a whole? How do we exploit the natural talents of disabled children and show them off in the wider community? What contribution can they make to improving our communities and making Bury a better place to live? And how do we go about doing this? How can you use the information you are gathering to its full extent to create a new vision for Bury Council - moving from disabled children’s services to the wider arena of communities?
One parent from the Jewish community has set up a PA data base and parent support group as not many parents in the Jewish community know about personalisation and individual budgets and what it can do for families. This parent already has 17 PAs on the data base and is going out to speak to various parents groups to let them know what she is doing. How can this work be encouraged and nurtured?

4. Leading the way for new policy direction: SEN Green Paper - support and aspiration

Government policy with regards to disabled children, young people and their families has been set out in the recent SEN Green Paper: support and aspiration. The main thrust of this policy paper, set to become law in 2014, is choice, control and self-direction.

How can the learning from this project be fed into national learning and best practice?

The work in Bury lays out a clear process for children, young people and families to take greater control over their lives at the same time as increasing their autonomy, resilience and happiness. How can Bury extend this pilot to work with young people from the ages of 0-25 across health, education and social care? Could the Parent Forum be the vehicle through which the ‘local offer’ is disseminated to parents? Could the Parent Forum lead a personalisation pilot - funded through health, education and social care - starting with tiny babies at the child development centre that gives families 1 assessment via PATH and 1 plan? What would training for families with tiny babies look like?

There is one young person already on the pilot who needs a joined up budget in health, education & social care - could this be looked at as a quick win and the means of exploring a joined up pathway?
Appendix One: About Bury Parent Forum

Bury Parents Forum started with the Aiming High for Disabled Children initiative in 2008. The forum is designed to enable parents of children with disabilities in Bury exchange views and information, publicise events of interest to other parents and discuss issues and concerns. All workers for the forum are parents of children with additional needs/disabilities. The forum engages with Bury families in order to give them information, raise expectations, design and plan their support, and provide training parents feel they need. The forum hosts a web site with information, news, discussions and events. The forum has also enabled parents to sit on strategic boards in Bury to help them influence policy and decision making. The forum works closely with neighbouring parent forums and has a growing band of associates.

In 2011 Bury COUNCIL commissioned the Bury Parent Forum to take the lead on introducing personalisation to families of children and young people with disabilities.

Appendix Two: Key people

About Sue Harris

The understanding Sue gained from her experience of being mum to a daughter with disabilities lead to her belief that real change will only come when it is informed and driven by the voice of disabled people and their families.

Following the loss of her daughter in 2008, Sue has undertaken a range of independent consultancy and in 2009 she established Sue Harris Associates in order to manage a range of consultancy work.

Sue has directed a wide variety of programmes including personalisation pilots in children’s services, national Circles of Support projects, and promoting family leadership as a means of delivering organisational and cultural change. She has developed and delivered bespoke training courses for third sector organizations; worked in a mentoring and support role to parents and professionals; and delivered training and presentations to a host of organisations and audiences.

Sue leads a team of parent consultants and trainers who are experts in their particular field with considerable experience of delivering change locally, regionally and nationally. Sue and her team also work directly with parents of disabled children – helping them embrace the opportunities afforded by personalisation.

About Debi Walker

Debi started working with families as a result of her own experience of parenting her son with disabilities and a high level of support needs. Debi’s positive attitude and high expectations for her son forms the basis of her work with families in Bury. As her family receives a Personal Budget to meet their support needs, Debi acts as a role model showing other families what is possible.

In the early years of parenting her son, Debi worked on a voluntary basis to set up support groups in schools as well as working as a full time nurse. Also at that time she started on a governing body at a local school gaining diverse experiences to work towards a possible career change. In 2006 she became a graduate of Partners in Policy Making and then started an extensive journey of person centred planning training, developing a particular interest in graphic facilitating/recording.
Over the last four years she has been developing the parent participation role and is now leading the forum and is a director. Whilst still working part-time as a nurse Debi has discovered her passion and skills for helping families find their own way to make the most of their lives. Now Debi is working closely with parents in Bury and other neighbouring forums using person centred approaches and as a skilled graphic facilitator.

About Janice Cameron

Janice has worked for the Bury Council within Children with Disabilities Service for the past 12 years. Four years ago the Government introduced Aiming High for disabled children which was a 2 year funding commitment to develop meaningful short breaks, childcare, transition, parent forums and individualized budgets. Janice undertook the role of Project Lead for short breaks for children with disabilities to develop these services for families within Bury. At the same time she also undertook the training programme on the All Together Better course with other professionals and parents sharing knowledge, learning and resources.

During these two years she developed our range of short break opportunities within Bury together with growing the number of families who used a direct payment as a means of support.

About Bernie Garner

Bernie is employed by the Bury Council as the Development Manager for Disabled Children. She has worked as Manager for the Children’s Disability Service since 2004.

Bernie has over 27 years experience working with disabled children and adults and their families. Her work has been focused on developing and delivering innovative services, both specialist and inclusive, to support disabled people to live within their own communities.

Bernie led the Aiming High Short Breaks development work in Bury from 2008 to 2011. This period of service transformation saw Short Breaks developed that met a wider group of disabled children needs within universal settings. The innovative development of both specialist and inclusive services to support families within their own communities was a focus of the Aiming High for Disabled Children investment by Bury Council.

For the past 18 months Bernie has been developing a new model of Short Breaks delivery for Children with disabilities in Bury. The Short Breaks Service has been designed to enable families and their children to have more control about which services they access and when they access them, so that the services are individual, person-centred and flexible around the needs of the child.

Bernie’s work remains focused on improving the life chances of disabled children and their families. Her work with adults and children with disabilities over her career has been as an advocate, a practitioner and a manager who has worked with families to improve opportunities for disabled children and adults. Bernie is passionate about equality and the need for inclusive ways of supporting anyone who needs additional support to lead a valued life within their own community.
For more information about the Personalisation Project contact:
Debi Walker - admin@buryparentsforum.org.uk
Sue Harris - Susanamharris@aol.com
http://www.buryparentsforum.org.uk

For more information about this report contact:
Pippa Murray - pippa@ibkinitiatives.com
www.ibkinitiatives.com