Why do you think people with Learning Disabilities from Black Asian, Minority and Ethnic Communities do not access personal budgets?
Introduction

BILD’S mission is to improve the quality of life for people with a Learning Disability. We achieve this by turning policy into practice and developing the values, knowledge, skills and competencies of those who provide support. We work in partnership with people with learning disabilities and family carers to make sure that high quality person centred support is developed, shared and evaluated.

It is widely acknowledged that barriers exist which can prevent individuals from Black, Asian, Minority and Ethnic communities from gaining equitable access to advocacy services, hence, also, from gaining equitable access to health and social care (Kate Richardson  Dr Rorie Fulton 2009). The aim of the project is find examples of Excellence in Advocacy.

BILD has received funding from the Department of Health to discover how well the process of accessing services through individual budgets as part of the personalisation agenda, is working for people from Black, Asian, Minority and Ethnic (BME) communities with learning disabilities.

The project is led by Sondra Butterworth. We have called the project The PAST Project: Personal Advocacy Story Telling. Our main aim is to share the stories which we hope will enable Advocacy groups, people from BME Communities and professionals involved in personalisation and individual budgets to learn and develop better ways of working and engaging with people who have learning disabilities from a variety of BME communities.

Consultation Events.

Three consultation events took place in Birmingham, Liverpool and London. The aim of the events was to hear stories and to share experiences. Each event was co-chaired by 3 Self Advocates.

Siraaj Nadat in Birmingham  Terry Kelly in Liverpool  Richard West in London

This report includes a brief summary of the events, links to the presentations, the documents we used and the web sites of the organisations involved in the events.

This report also include a summary of the discussions and comments made by the people who attended the events. A more detailed report and a training resource will be included on the BILD web site.

If you would like to download copies of the programmes for these event please click on the links below.
How did we prepare for the events?

We decided what would be included in the programme for the events. We created a flyer and sent it out to all of our contacts.

We also send out an information and consent document so that everyone who attended would understand why we wanted them to attend the event and what we were going to do.

We made contacts with different individuals and organisations who we thought would be able to assist with the events. We worked in partnership with organisations in each region.

The Birmingham Event

The first of 3 consultation events was held on 23rd March 2010 at the Nishkam Centre in Birmingham. The event was supported by Chris Sholl, the Regional Valuing People Programme Lead for the West Midlands, who was also Co-chair.

We wanted people to network and to share experiences at all 3 events. We encouraged people to include their details on an ‘X-change form’ and to let us know if they would like to share information, resources or to become involved in further projects.

At the events there were presentations and discussions. People were asked to share their stories. The first story recorded was from Siraaj Nadat, who told us how important his religion is to his life. and how his parent. Siraaj told us about his achievements and his work. Siraj’s story will be included on the BILD web site. . Keith Smith interview Naomi Madden from ‘Grapevine’ who are working with young people from Black, Asian, Minority communities in transition.
Links

Birmingham event programme
Valuing People Now
Grapevine
Information and consent form
Questionnaire
Giving Us a Voice presentation
X-change form
The Liverpool Event

The second event was held in at the Kuuma Imani Centre in Liverpool. This event was in partnership with Liverpool Citizen Advocacy. Joe Monaghan was Co-chair with Terry Kelly; Val Hall from Liverpool Citizen Advocacy and Clare Roberts from In Control supported the event and contributed to the development of the programme and the organisation of the event.

We heard presentations from Liverpool Citizen Advocacy and from Merseyside People First. We heard personal stories from some people who attended. Some of the stories were recorded and will be on the BILD web site.

Terry Kelly and Joe Monaghan chaired the Liverpool event.

Ian and his support worker were interviewed by Clare Roberts.

Andrew Chan told his personal story and Karen Bellion told us about the work of Merseyside People First.
The third and final consultation event was held at the Resource Centre London. This event was chaired by Richard West, who opened the event by sharing his personal story. Richard is a self advocate but he is also a carer. We heard personal stories from some people who attended. Some of the stories were recorded and will be on the BILD web site. A group of self advocates came to the event from Cardiff and Newport People first. They told their personal stories and told us about the activities they are involved in.

Ola Odeyemi and Maame Oforiwaa are both Self Advocates. They both told their personal stories about family life and their experiences of work.
Cardiff and Newport People First attended the event. They told us about some of the activities they are involved in. Shahid Asfar, Brian Thomas Saul Webbe, Ean Johnson Ope Abidogun, Shabinah Ahmed and Karen Jeffreys attended the event.

Ola Oneyemi and his support worker Rowland were interviewed about how well they work together.

Richard West told us his story. He told us about his achievements. He told us that he is a carer for his partner and how he has difficulty understanding how to access a personal budget.
We heard about an event they held which included dance. This story was drawn by the Graphic Facilitator Yvie George.

We heard how Cardiff and Newport People First have made a video of their stories.

This story was drawn by the Graphic Facilitator Yvie George.
Links

London event programme

Foundation for people with learning disabilities National Advisory Group on Learning Disabilities and Ethnicity (NAGLDE)

Cardiff and Newport People First video ‘Hidden Lives’
What did we learn at the events?

At all of the events everyone was asked one question ‘Why do you think people with Learning Disabilities from Black Asian, Minority and Ethnic Communities do not access personal budgets?’ Everyone was asked to discuss the question and to tell us their thoughts.

1. Concerns and anxieties from the BME Community
   Many people had concerns and anxieties about professionals coming into their homes.

2. Information
   This included written information from the Local Authority which some people felt was too complicated.

The responses to this question were collected together from all three events and the comments were put into 4 main themes:
3. **Cultural issues**
   Some people felt that there was not always an understanding of their culture, such as religious beliefs and how this has an effect on personal life such as prayer time.

4. **Service provision**
   This included the assistance or help from Social Care organisations or Health Trusts. Many felt that the service provided in the community is not always appropriate to the needs of people from BME communities.

'Why do you think people with Learning Disabilities from Black Asian, Minority and Ethnic Communities do not access personal budgets?’ The responses are shown in the table below.

The majority of responses were based around Service Provision and Cultural Issues.

<table>
<thead>
<tr>
<th>Concerns and anxieties from BME Community</th>
<th>Information</th>
<th>Cultural issues</th>
<th>Service provision (Local Council)</th>
</tr>
</thead>
<tbody>
<tr>
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<td>60</td>
</tr>
</tbody>
</table>

Some of the comments included:

1. **Concerns and anxieties from BME Community**
   - Hate crimes.
   - Fear and anxiety about Social Workers involvement in family concerns.
   - Anxiety about managing a budget.
   - Lack of confidence in managing budget and being an employer.
2. Information  
- Information not available.
- Information not accessible.
- Too complex.
- Lack of information in community languages.
- Information is too difficult to understand and is not culturally appropriate.

3. Cultural Issues  
- Language barriers
- Families prefer to have help from people in their own community
- BME community may not understand the nature of Learning Disability.
- Cultural belief about ‘outsider support’ – and information not delivered in a culturally sensitive way.

4. Service provision  
- The system is too complicated.
- Lack of community support which is culturally appropriate.
- Lack of cultural knowledge among Social Workers.
- Lack of community provider support which is culturally appropriate.
- Trust and mistrust of ‘the system’ and lack of engagement with ‘the system’.
- Ongoing support and funding to people once they have applied for a personal budget.

In response to the question ‘In your opinion, what needs to change?’ The comments we put into 6 main themes.
Main Themes

Responses included:

1. Research
   a) Obtaining a database providing information about BME communities.
   b) Share research findings.
   c) To support research / do research that explores the experiences of specific groups that provides an understanding for professionals and others in order to provide support / services resources.

2. Partnership working
   a) Professionals should develop networks with BME leaders and groups
   b) Advocacy groups working better in partnership with professionals
   c) One stop shops lead by Advocates and link with services
   d) Working with religious leaders
   e) Creation of forums to promote inclusion and provide information and support from peers in success stories.
3. **Training**
   a) Training for transition workers in schools
   b) Training for advocacy groups
   c) Training for social workers

4. **Service provision**
   a) Simplify systems
   b) Social services improve attitude
   c) Build trust

5. **Information provision**
   a) Make information accessible
   b) Target community groups with key information
   c) More accessible information.
   d) More promotion of services for Learning disability within community group.

6. **Cultural Awareness**
   a) Professionals work with community leaders.
   b) Religious leaders become more involved.
   c) Raise awareness about learning disability within BME community.
   d) Ideally a more culturally diverse workforce if possible.
   e) Workers to develop links with different community groups and key people within them can provide information or assistance with process and spread the word.
   f) Positive action projects to empower people and their carers from BAME groups to ensure diversity within cultures are understood and respected.
Evaluation comments from 3 consultation events

What did you like about the day? People making connections

1. Meeting people, networking, thinking about issues.
2. The opportunity to network and hear what others are doing.
3. To develop links and contacts.
4. Discussing issues in a group.
5. Listens to another group good.
7. People.
8. We learnt a lot about each other. Raised important points. Everyone was friendly.
10. The mix of people and the approach taken
11. Good knowledge and chance to talk with others about issues.
12. Very lively – good keeping to time. Good mix of group work and presentation.
15. The chance to meet people from other organisations Graphic translation. Friendly bunch. Good mix of people (NHS, voluntary sector, advocates).
16. Very informative input from audience, information sharing.
17. Working with my group.
18. The whole event and location, listening to views of others provider agencies.
### What did you like about the day? Activities interaction

1. The friendly atmosphere.
2. It was an interesting topic.
3. Excellent group work. Good feedback sessions. Excellent ideas about how to improve access into BAME to get people to grasp ideas about personal budgets.
4. Facilitation of group work.
5. Excellent table work.
6. Everything was organised properly.
7. Enjoyed the discussion opening and honesty.
8. Virtually everything especially the intensive sessions.
9. Was informal, right pace, enjoyed watching interviews
10. Well organised and kept to time mostly.
12. Washing line idea.
13. Graphic translator was fantastic.
14. Networking / chance to consider important issues in depth.
15. Opportunity to network.
17. Artist was a very nice touch.
18. The graphics.
19. I enjoyed the artists impressions.

### What did you like about the day? Comments about Learning Disability

1. A day focussed on the needs of people with a LD. Co-led and attended by people with no LD that listened to their views.
2. Cardiff and Newport group was inspirational and I look forward to learning more about their group.
3. The day was run by people with LD.
4. Very informative, good insight into their lives.
5. The fact that the person I was supporting got a lot out of it.
6. Cardiff People First.

### What did you like about the day? Topic.

1. It was very informative.
2. Very interesting and very good.
3. Cross section of interest.
4. Themes : good table discussions.
5. General discussion about personalisation.
6. An insight into the lack of support for Birmingham.
7. Interactive, sharing ideas, meeting new people.
8. Interaction and networking.
10. Information sharing being made aware of other services.
### What did you learn from the day? BME Communities

1. New thoughts on how to make link with BAME communities
2. There is no magic wand to get BAME participators.
3. It was good to think about minority groups in the broadest sense e.g. travellers etc.
4. About barriers to enter BAME communities and ideas to improve their social work systems.
5. My home town is not alone in struggling to involve BAME in services.
6. Information that will help me make contact with BAME communities in my area, through my work.
7. More about personal budgets and BRM /BME.
8. Implications of personalised budgets for BAME communities.

### What did you learn from the day? Personal Budgets

1. About personal budgets
2. There is a lack of understanding about personalisation
3. More familiarisation about direct payments and websites to research.
4. More understanding of how personal budgets fit into individual budgets.
5. I learned a lot about single payments.

### What did you learn from the day? Good work

1. That there’s lots of good work being done out there but there’s lots more to do.
2. The Welsh groups (Cardiff and Newport people first) and what can be achieved.

### What did you learn from the day? Personal experiences

1. About individual experiences.
2. About other people’s experiences.

### What did you learn from the day? Networking

1. I have learnt more and networking.
2. Understanding of difficulties experienced networking.

### What did you learn from the day? Learning disabilities

1. I learnt about people with learning difficulties.
3. To work with people with learning disabilities.

### What did you learn from the day? Misc

1. Consolidation of information I was aware of.
2. A lot of ideas and things to make me think.
3. Consolidation of information I was aware of.
4. A lot of ideas and things to make me think.
What did you learn from the day? Service provision

1. I will take this back to my organisation and create more awareness and hopefully there will be more awareness and hopefully there will be more programmes like this in the future.

2. About keeping safe in the community. How services should be improved.

3. A lot from people attending who use services.

4. Making links and contracts with others.

5. So much information.

6. Use of engagement across all local authority departments “adopt a pol” (politician).

7. That some people still think day services for people with a learning disability are a good thing. Attitudes need to change so people can be seen as individuals.

8. We all have the same problems all over the country.

9. To get out there and outreach communities.

10. More about what is happening nationally and locally (valuing people and BRM) hadn’t heard of ‘Giving us a voice’ before.

11. Information needed to be share more clearly.


13. An increased awareness of available resources and facilities. An insight into how this could be improved within the community.

14. More has to be done to get better access for information sharing.

15. About difference organisations approach to supporting people from BME communities to access ‘personal budgets’.

16. That the problems are shared. That we weren’t doing so bad.

17. Ideas – lots. Finding out what is happening in other areas.

18. I also learnt about with minority groups find it hard to access services.

19. Advocacy rights hub is out there. (Liverpool).

20. Ground work which needs to be done in reaching people from Birmingham.
<table>
<thead>
<tr>
<th>What did you dislike about the day? General comments</th>
</tr>
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<tbody>
<tr>
<td>1. Sound not great - microphones might have been help full (Liverpool).</td>
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<tr>
<td>2. Too rushed.</td>
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<td>3. Room a bit claustrophobic (Liverpool).</td>
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<tr>
<td>4. It would have been good if the group members from Cardiff/ Newport had done more of the presentation. (London).</td>
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<tr>
<td>5. Didn’t think that people with a learning disability in a group had a chance to make meaningful contributions / time to understand issues.</td>
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<tr>
<td>6. A microphone would have been good for everyone to be able to hear. (London).</td>
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<tr>
<td>7. More awareness for the communities.</td>
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<tr>
<td>8. More carers and service users need to be made aware of programmes such as this.</td>
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<tr>
<td>10. Not enough time.</td>
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<tr>
<td>11. No traffic light cards especially for asking speakers to speak louder.</td>
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<tr>
<td>12. Too much listening, would have liked more discussions.</td>
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<td>14. There should be more breaks.</td>
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<tr>
<td>15. There should be public address system (London).</td>
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<tr>
<td>16. Lack of representation from Liverpool City Council. (Liverpool)</td>
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<tr>
<td>17. Room was very stuffy and noisy when the windows were open. Needed a larger room (Liverpool).</td>
</tr>
<tr>
<td>18. Room was to small (Liverpool).</td>
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<tr>
<td>19. A bit too Liverpool focused. (Liverpool)</td>
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<tr>
<td>20. Less consultation, more information. Too much repetition.</td>
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Is there anything else you would like to say?

1. It was very well organised.
2. Would like information about evidence / research about law updated personal budgets with BAME communities.
3. I did ask at the event if you could please email the group photo so we can include on our website please? – b.heard@virgin.net
4. It is a shame there were so few councils that attended.
5. Could the subject BAME be taken to regional networks board for further discussion?
6. I enjoyed the variety of presenters.
7. Congratulations, a really enjoyable day!
8. To set up a lobbying group to keep this issue as top priority for the government as if there isn’t the potential will to change things and make support and serving accessible and available to people no thing will change.
9. Training carers regarding learning disabilities
10. A big thank you for letting me attend and we need more of these programmes for London, a year is not enough.
11. Excellent lunch.
12. It would be good if the day had been filmed and so we could look back on it. It would be good to have all the notes taken throughout the day typed up and get them back.
13. I would like to come again.
14. Outreach working with ethnic community organisations.
15. The meeting was alright and I am doing something about my own problems now and another day I will come back and tell the group what worked.
16. Found it very enlightening and managed to gain some contracts.
17. Thanks.
18. I enjoyed the day it was friendly and it went smoothly for me. This is my first time coming here. Just to say thank you for your feedback.
19. A very informative and enjoyable event. Some good points for the future. I met some contacts that I would like to maintain communications with, would a contact list be available?
20. Keep the fight going.
21. We need to just get on with it and not just talk about it.
22. I enjoyed all the sessions especially the personalised budgets.
23. Well run event.
24. Thank you.
25. Thanks.
26. Yes the graphics worked well. Good idea.