Challenging BEHAVIOUR foundation

making a difference to the lives of people with severe learning disabilities

The Challenging Behaviour Foundation

Personalisation for People with Learning Disabilities & Behaviour Described as Challenging

A report from a project run between summer 2011 and 2012

The Personalisation Project was run by the Challenging Behaviour Foundation (CBF) from summer 2011 to summer 2012. It was commissioned by the East Midlands regional Joint Improvement Partnership and Strategic Health Authority in the East Midlands. Funding from the Department of Health also enabled the inclusion of some families living in other areas of the country

personalise

verb customise, individualise, make to order, make distinctive, give a personal touch to

'LITE' VERSION=small font/no appendices. PRODUCED FOR THE NCAS CONFERENCE 26/10/2012

The Challenging Behaviour Foundation www.challengingbehaviour.org.uk Tel: 01634 838739

The Challenging Behaviour Foundation (CBF) is a charity for people with severe learning disabilities and behaviour that challenges. The CBF provides expert advice and training, campaigns on a national level, and runs pilot projects to develop new models of service provision.

Personalisation for People with Learning Disabilities and Behaviour Described as Challenging

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BACKGROUND TO THE PROJECT

1. What is the personalisation agenda?

A SCIE report on Personalisation & Independent Living[1] says

- *it is important to define personalisation in terms based on the principles of independent living*
- *this should include service users and carers having choice and control and the freedom to live their lives in the way they want to*
- *many users and carers have positive experiences of personalisation and there are examples of good practice*
- *however, the number of people receiving truly personalised services remains very low and cuts to services may make this situation worse*
- *more needs to be done to ensure that everyone involved in service provision understands personalisation*
- *there needs to be better coordination of resources and services*

[1] SCIE Report 55: People not processes: the future of personalisation and independent living. Published: February 2012

- *there needs to be more co-production with service user and carer organisations*
- *a stronger vision based on a return to the principles of independent living is needed to ensure that personalisation delivers better outcomes for service users and carers at the same time as ensuring resources are used as effectively as possible*

The following reports provide the specific case for personalisation for people with learning disabilities and behaviour described as challenging

- The Mansell Reports on "*Services for People with Learning Disabilities and Challenging. Behaviour or Mental Health Needs*" (1992 and 2007)
- The National Team for Development and Inclusion report "*Guide for commissioners of services for people with learning disabilities who challenge services*"(2010)
- The Tizard Centre report on "*Developing better commissioning for individuals with behaviour that challenges services - a scoping exercise*" (2010)
    - Appendix A provides further signposts to writing on personalisation

2. How was the project set up?

The East Midlands regional Joint Improvement Partnership and Strategic Health Authority agreed to work in partnership with the Challenging Behaviour Foundation to enable more people with learning disabilities to have homes of their own. This was facilitated by the Deputy Regional Director for Social Care in the East Midlands as part of the regional Joint Improvement Programme.

As well as enabling access to housing for people with behaviour described as challenging, the project aimed to address unnecessarily high costs of services for people without reducing the quality of people's outcomes.

3. How much did the project cost and how was it funded?

The project cost approximately £60,000 and was funded by the East Midlands JIP and SHA and the Department of Health. The CBF provided input from their family support team and their chair of Trustees. The Tizard Centre also provided supervision time and research support to the project.

4. Who was the project team?

The project team included a project manager employed by the CBF (0.6wte for 12 months) and commissioned time from two housing consultants (Housing Options) and a certified behaviour analyst/ positive behaviour support expert (PBS consultancy). They were selected by the CBF with input from Valuing People team in the Kent area.

Monthly detailed supervision sessions were provided jointly by the Chair of Trustees of the CBF and Peter McGill of the Tizard Centre. Research assistant time was provided by the CBF to enter and analyse data arising from the project.

Regular updates were provided to the regional Joint Improvement Programme Board.

INFORMATION ABOUT THE PROJECT

5. What did the project set out to achieve?

The aim was for 26 people with learning disabilities and behaviour described as challenging to have a personalisation plan for all aspects of their life in place and ready to be carried out by the end of the project. The project also wanted to learn about what barriers and solutions there were to developing personalisation plans, in particular, to see how people could access housing, what might be stopping this (the barriers) and how the barriers could be overcome (the solutions). A further aim was to see

if better quality outcomes could be achieved at a lower cost than some of the high cost services typically being commissioned.

6. What was the plan for the project?

In the East Midlands, the plan was for 5 Local Authority areas to together identify 20 people for inclusion in the project. Those areas were Leicester; Leicestershire and Rutland; Northamptonshire and Nottinghamshire. People included in the project would be people whose lives needed to change radically to be more personalised but whose complex needs were presenting a challenge to their commissioners.

The CBF would provide a project manager (0.6) to liaise with people's care managers to see what help they needed from the project team's housing consultant (11.5 days) and positive behavioural support consultant (15.5 days) and whether there were any barriers needing other kinds of help.

It was planned to send a joint letter from the CBF and the commissioner to people's families to tell them about the project. It was also planned to hold meetings across the East Midlands where care managers would share ideas about the barriers to personalisation so the consultants could offer training and advice.

The project manager would contact the care managers every month to discuss how personalisation plans were progressing. The result was to be a "viable personalisation plan" for each person, ready to be implemented

- See Appendix B – Viable Personalisation Plan Template

In addition, six families (not from the East Midlands) had contacted the CBF to discuss personalisation. The project planned to support them to contact their relative's local authority or NHS commissioner to pursue personalisation for their relative, with the availability of free advice from the project manager and consultants. The project team would help them decide what questions to ask, what to say in meetings and to write letters.

7. What did the project do?

In the East Midlands, meetings were held for lead managers from each organisation to discuss how to identify 20 people for inclusion in the project.

It took a lot longer than anticipated for the organisations to each identify 5 people from their area. 18 were identified in all, some did not proceed. Due to significant challenges in making contact with some care managers, it was only possible to engage with 10, who were working with 14 people in all (some care managers worked with two people). Some of the people identified did not need the help the project could offer as they needed direct family work or person-centred planning neither of which was part of the project design or resources. Some care managers felt that the available MDT approach was more suitable than the support offered through the project.

The project team had regular contact with 10 care managers and in-depth contact with seven. Capacity was identified as a barrier to progress. The project manager discussed plans for each person with care managers to see what input was needed from the consultants and whether other issues needed resolution. Time spent talking to care managers was kept to a minimum as they were so busy. Sometimes they did not have time. Not infrequently, appointments had to be rearranged. Discussions led to the conclusions that person centred approaches do not appear to be embedded throughout services in the East Midlands

- See Appendix C for information about individuals involved in the project

The housing consultant made home visits at the request of two care managers and offered telephone advice to others. Several care managers said they did not need housing advice at present. One area said they had well-developed housing infrastructure so did not need help.

The positive behavioural support consultant carried out in-depth analyses of service users' behaviour for some care managers, providing detailed reports. The aim was to advise care managers as to whether the commissioned service was delivering the sought outcomes, whether it could be supported to deliver improved outcomes or whether a different service was needed.

- See Appendix D – Two positive behavioural support reports

Outside of the East Midlands, the six families had contacted the CBF because they were concerned their relative's services were not meeting their needs and they had poor quality of life. They were supported to write a letter to their commissioners to tell them about the project. In each case a letter was also sent from the CBF, at the same time. Both letters offered support with commissioning from the project team

When none of the commissioners replied, the CBF rang them up to ask why not or advised the families on how to do this. Families were then supported to continue trying to engage their commissioners in a discussion about personalisation for their relatives. This was not found to be easy: SWs kept changing and did not appear to prioritise the discussion about personalisation. Formal complaints and safeguarding referrals did not appear to have any positive effect.
By the end of June 2012 all of the 14 people in the East Midlands had a partially developed personalisation plan. The six families in other areas reported that significant advances had been made towards personalisation for all their relatives.

8. What are the barriers to personalisation? What are some of the solutions?

During the project, the project team came up against several barriers more than once, making us think they were possibly typical of other areas in the country and worth recording. We spent time thinking about how they could be overcome. Not all of the solutions are easy, requiring high level commitment from all parties.

COMMISSIONERS (LOCAL AUTHORITY AND NHS) – BARRIER AND SOLUTIONS		
	BARRIERS Some commissioners…	**SOLUTIONS Commissioners need to…**
A	…have to spend a significant proportion of their time on reactive work, such as responding to safeguarding concerns or cases where the person has been served notice. This leaves very little time for pro-active planning to improve outcomes	…place greater priority on pro-active planning to achieve more positive outcomes and reduce the time and resources spent reacting to negative outcomes such as breakdown of placements and safeguarding investigations, reducing the need for high cost provision, the outcomes of which are unclear
B	…can think a person is ok because there are no safeguarding alerts even though the person's quality of life is poor. They do not routinely include outcomes in service contracts and do not have time to monitor service delivery against outcomes	…develop contracts with clear outcomes that can be monitored; invite families and volunteer visitors to be centrally involved in monitoring and checking regular reviews are held focusing on the outcomes of the service (Q360 is used by Gloucestershire: see Appendix E)

COMMISSIONERS (LOCAL AUTHORITY AND NHS) – BARRIER AND SOLUTIONS		
	BARRIERS Some commissioners…	**SOLUTIONS Commissioners need to…**
C	…do not yet apply a person centred approach as standard and can tend to focus on needs and risks, not outcomes with a lack of developmental aspiration for people e.g. residential care where a person did not go out and about was seen by some care managers as an acceptable life choice	…provide training and resources to enable commissioning staff to frame people's services requirements as outcomes rather than needs
D	…do not view families as equal partners in the commissioning process e.g. do not tell them how much services cost or show them contracts even when asked	…share the challenge of commissioning pressures with families rather than assuming they will demand unrealistic services, harnessing the families' energy and motivation for improvement for their relative
E	…do not have a way to discuss costs with families because standard personal budgets processes relate to all vulnerable adults whereas people with complex needs fall outside resource allocation systems	…engage families in identifying ways to reduce costs and increase quality, explaining to them that the most costly service does not necessarily deliver the best outcomes and invite them to help to find the best value arrangements for their relative
F	…are not aware of what improved outcomes can be achieved through supported living for people with complex needs and think care homes are safer because there are more staff in one place even though the staff to service user ratio is not sufficiently high to offer a personalised service	…obtain information and examples showing how people with behaviour described as challenging have achieved excellent outcomes in supported living, learning about the benefits for people with behaviour described as challenging of accessing supported living so more people could have that choice in future
G	…think people with behaviour described as challenging have to live in a care home or hospital because they do not have the mental capacity needed to sign a tenancy	…*ensure* care managers understand this is not the case. Housing Options can provide support if this is challenged www.housingoptions.org.uk
H	…think that people have to live in a care home or hospital so they can benefit from Deprivation of Liberty Safeguards[2] if they - need to have their house doors locked to keep them safe or - need physical interventions from support staff to keep them safe	…ensure care managers understand that a full range of safeguards can be offered in a person's own home if their need for this is recorded in their needs assessment, all key people in the person's life are in agreement and decisions about it are taken carefully and documented
J	…hold a further misconception that these safeguards can only be provided to people who need them by applying	…ensure care managers understand there is no need for the Court of Protection provided safeguards are clearly linked to a good process of

[2] Under the Mental Capacity Act 2005; came into force in April 2009

COMMISSIONERS (LOCAL AUTHORITY AND NHS) – BARRIER AND SOLUTIONS		
	BARRIERS Some commissioners…	**SOLUTIONS Commissioners need to…**
	to the Court of Protection, a lengthy and costly process	assessment and consensual decision-making
K	…appeared not to know about positive behavioural support and how this can transform people's lives. They stated they did not have time to attend training	…learn about positive behavioural support and how to commission services from providers who understand and offer this
L	…appeared not have confidence in service providers' ability to deliver services in ways that could transform people's lives, though providers, when seeking new business, frequently stated with confidence that they could achieve such transformation	…offer training, information and support to providers to enable them to learn how to offer positive behavioural support services, incentivised through procurement practices to invest in staff training in positive behavioural support. This needs to include the most senior provider managers
M	…assume that complex needs automatically means 2:1 yet having 2 staff who do not offer skilled support may increase rather than reduce behavioural challenge	…seek advice on setting up personalised services from a positive behavioural support expert who will analyse and understand each person's risks; prescribe their support in detail; identify commissioning options such as a service with a higher hourly rate for skilled and sensitive 1:1 support (rather than 2:1) to enable the provider to invest in training and staff development

Talking to families in depth over the period of the project yielded the following additional barriers and solutions. We talking in depth about their ambitions for their relative and thoroughly explored the situation of eight young people and adults with severe learning disabilities.

FAMILIES – BARRIERS AND SOLUTIONS		
	BARRIERS: Families (not East Midlands)…	**SOLUTIONS: All families need to…**
N	…appeared not to be listened to and things only began to happen when we contacted very senior managers and even then things moved very slowly	…receive information and support to ensure they know what response they should expect from their relative's commissioner so they can persist in asking for this
P	…did not have the necessary experience or understanding to commission effective services using direct payments on behalf of their relative. The introduction of personal health budgets is likely to bring a further challenge	…prepare a one-page profile about their relative and recording what support has worked and not worked through their life so far, ask for help from supported living providers in designing a service for their relative which the commissioner can then consider
Q	…needed to persist to engage their relative's commissioner which was demoralising and time consuming	…find someone to talk things over with then find someone to support them to persist in seeking personalisation for their relative. Seek training in participating confidently: see Appendix F

The relationship between NHS and Local Authority Commissioners was crucial to the personalisation plans of many people.

NHS/LA Interface BARRIERS AND SOLUTIONS		
	BARRIERS:	**SOLUTIONS: Commissioners need to…**
R	…there is often uncertainty on the part of officers about how to proceed when someone needs both local authority and NHS funding	…develop close operational working relationships to jointly commission individual support for people with complex needs and stimulate and support the local market. Gloucestershire's pooled approach to commissioning is to be commended: *Appendix E – interview with Glos's joint commissioning manager*
S	…there is a lack of clarity about 100% health funded people: in some areas the LA has no involvement; in others, joint planning depends on personalities and relationships	…develop clarity around LA responsibilities when someone is 100% health funded so NHS bodies can negotiate clear working agreements with their partners
T	…people who are in hospital may stay there due to a lack of dynamic planning	…ensure admission to NHS care does not fracture the relationship with social care commissioning

All of the above tables are the main points taken from the project's detailed log.

- Appendix G is a the detailed project log of barriers and solutions

PROJECT PROGRESS

9. What were the biggest barriers to the success of the project?

The project was designed and agreed through the East Midlands JIP in 2010 before cuts were made in public sector spending. Many people who had been involved in discussions to commission the project had left by the time the project started in summer 2011. This was after the first major round of local authority and NHS management reductions which left many managers unsure what their jobs were or whether they would lose theirs in the next round of cuts. All public sector organisations were working hard to deliver immediate changes to reduce costs and planning medium and longer term changes (to which this project had the potential to contribute).

It appears that because there were fewer managers to organise things and because they were heavily involved in their organisational changes, it took a long time to start the project. The project manager found it took a long time to get replies to emails or to find times to talk to people on the telephone as they had many other things to do.

The project plan was to identify the list of people during July and August and start individual planning work in September. Some areas did not confirm their list of people until October and then could not meet with the project team until November or December. One area was at risk of not referring anyone then referred two people in February though their situations were not in line with the original project aims. The delays in identifying people and starting planning, along with the capacity challenges faced by care managers very much limited the impact of the project.

Another barrier was that there was very little evidence of person-centred planning in relation to the futures of people referred to the project. It was not possible to provide consultancy around future housing and support arrangements when this had not taken place as it would have meant assuming

that people should move without being clear why (what was not working about the existing situation) and what for (what different outcomes were sought from a different lifestyle). Project resources were already committed and we were not able to divert these to person-centred planning.

The project team met to evaluate whether/ how the project had achieved its aims.

- Appendix H is the evaluation by the project team

10. What positive outcomes were there from the project?

Some SWs engaged well with the project and fed back that they learned a lot about how to provide personalised services for people with challenging behaviour. This was through the opportunity to reflect on their practice and from the input of the consultants.

- Appendix J contains feedback from two care managers

One area found the provision of positive behavioural support advice so useful they went on to commission more time of the consultant for their work with other people.
One area invited the project team to run a workshop on challenging behaviour at their supported living support provider forum. Following presentations on understanding challenging behaviour and on the latest housing issues in supported living, providers discussed how to overcome barriers to delivering aspects of the Challenging Behaviour Charter. Attendees said they found it very useful as did the commissioning manager.

Plans are underway for one person to leave an out of area placement to return to live near family. The cost of supported living will be almost half the cost of the out of area placement.

One care manager learned from the PBS consultant report that the provider of one person's care believes they are not the right provider for that individual. The care manager had been unaware of this, believing there were just quality issues which the provider would address.

Some people now have positive behavioural support plans which they did not have previously.

The project manager has already fed in some of the learning from the project to the DH review carried out in response to the Winterbourne View expose.

11. How does the project relate to the current policy context?

The CQC reviewed 150 services across England and the report found similar barriers to personalisation for individuals and a lack of person-centred processes. The DH review made an interim report in summer 2012 setting out a series of objectives including the following

- *improve commissioning across health and care services for people with behaviour which challenges with the aim of reducing the number of people using inpatient assessment and treatment services*
- *clarify roles and responsibilities across the system and support better integration between health and care*
- *improve the quality of services to give people with learning disabilities and their families choice and control*
- *promote innovation and positive behavioural support and reduce the use of restraint*

The increasing availability of personal health budgets to sit alongside personal social care budgets may well harmonise some of the differences in the approaches to commissioning for people who are eligible for both health and social care funding. One Clinical Commissioning Group (not in this project) which was a pilot site for the personal health budget pilot is joining up their personal budget processes with those of social care i.e. using a joint brokerage hub and being able to pay personal health budgets via the social care personal budget process.

12. What other work is underway to throw more light on this area?

The South East Housing Project is a short term project funded by Department of Health's South-East region led by Housing Options. The aim is to enable commissioning of local and personalised housing solutions for learning disabled people with complex needs.

The barriers identified so far are a focus on process rather than achieving outcomes with a 'disconnect' observed between strategic intentions and the assessment/ care management staff who work directly with individuals and who appear to have many competing priorities.

- See Appendix K for a summary of that project

13. Next Steps

Information from the project will be disseminated to various audiences so that the learning can be shared. The report will be made available to various stakeholders.

The learning from the project will contribute further to the national development agenda following on from the Panorama programme on Winterbourne View. Local authority and NHS commissioners are invited to incorporate the solutions to the barriers to personalisation which were identified by this project as part of their action plans.

The CBF will review its information resources and update these to ensure they help families and professionals in search of personalisation for individuals, with additions to the website. Families are invited to explore the existing resources which are available free to all families and which can be found on the Challenging Behaviour Foundation's website (see back of this report). These are also useful for all professionals including service providers.

The Challenging Behaviour Foundation would be pleased to provide local workshops on Understanding Challenging Behaviour and Supporting Behaviour Change as well as Communication with people with Challenging Behaviour. This training can be customised to be effective to the audience in question, whether strategic or operational commissioners, strategic or operational service managers, hands on staff or families: training@thecbf.org.uk

END OF MAIN REPORT

APPENDICES AVAILABLE ON CBF WEBSITE

http://www.challengingbehaviour.org.uk/