



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

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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.

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Report from a 2011 – 2012 project

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

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BACKGROUND TO THE PROJECT

1. What is the personalisation agenda?

A SCIE report on Personalisation & Independent Living¹ 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*
- *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.

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

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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.

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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

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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.

- o 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	...place greater priority on pro-active planning to achieve more positive outcomes and reduce the time and resources spent reacting to negative

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COMMISSIONERS (LOCAL AUTHORITY AND NHS) – BARRIER AND SOLUTIONS	
BARRIERS Some commissioners...	SOLUTIONS Commissioners need to...
	concerns or cases where the person has been served notice. This leaves very little time for proactive planning to improve outcomes
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
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
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
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
F	...are not aware of what improved outcomes can be achieved through supported living for people with complex needs and

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COMMISSIONERS (LOCAL AUTHORITY AND NHS) – BARRIER AND SOLUTIONS		
	BARRIERS Some commissioners...	SOLUTIONS Commissioners need to...
	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	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 <ul style="list-style-type: none"> - 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 to the Court of Protection, a lengthy and costly process	...ensure care managers understand there is no need for the Court of Protection provided safeguards are clearly linked to a good process of 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	...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

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

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COMMISSIONERS (LOCAL AUTHORITY AND NHS) – BARRIER AND SOLUTIONS		
	BARRIERS Some commissioners...	SOLUTIONS Commissioners need to...
	achieve such transformation	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	...find someone to talk things over with then find someone to support them to

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	which was demoralising and time consuming	persist in seeking personalisation for their relative. Seek training in participating confidently: see Appendix F
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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: <i>Appendix E – interview with Glos's joint commissioning manager</i>
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).

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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.

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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.

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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 FOLLOW

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APPENDIX A

SIGNPOSTS TO WRITING ON PERSONALISATION

The following are publications which guided the work of the project. The sources can be tracked down through the references which are given as footnotes at the bottom of each page.

1. A SCIE report on assessment and eligibility thresholds ³

This report said that *“Above all, finding the ‘right’ assessment methodologies and eligibility thresholds have to be seen not as ends in themselves, but as means to address individual needs and to achieve the best outcomes for people”*

2. Dimensions’ personalisation and families project ⁴

In 2008, learning disability care provider Dimensions decided to transform itself in line with the personalisation agenda. Natalie Valios reported in Community Care the publication of “Making it Personal” charting their journey from traditional care to personalisation –

“Most of the people we support do not live on their own and have neither had an opportunity to choose who they live with, nor who provides them with support. The sort of world we are moving towards is one where people who are supported by a provider will expect to have choice about these most fundamental aspects of their lives.

This is a long way from where we started out and, to be honest, is still some way from where we are.”

3. Winterbourne Commissioning Lessons: Alison Giraud Saunders and Bill Love March 2012 ⁵

The abuse by staff at Winterbourne View hospital, revealed last year, raised important questions about services for people with learning disabilities who display challenging behaviour. Last month (February 2012) the Department of Health wrote to strategic health authorities and local authorities setting out actions they should be taking ahead of the publication of a review into the scandal.

When individuals with learning disabilities and behaviour described as challenging are supported well, they enjoy a good quality of life within their local communities.

³ SCIE Report 57: Crossing the threshold: The implications of the Dilnot Commission and Law Commission reports for eligibility and assessment in care and support Published: March 2012

⁴ <http://www.communitycare.co.uk/Articles/03/05/2011/114404/good-practice-dimensions-journey-to-personalisation.htm>

⁵ Commissioning Excellence March 2012 Authors: Alison Giraud-Saunders, chair, National Family Carer Network; Bill Love, head of learning disabilities, National Development Team for Inclusion.

http://www.ndti.org.uk/uploads/files/comm_excellence_march_2012.pdf

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However, they are at greater risk of experiencing service failures that can lead to placements in inappropriate settings.

Such placements are expensive (often more than £150,000 per year) and can offer little or no therapeutic benefit. Around 24 adults per 100,000 of the general population present serious challenges to services at any one time.

Better commissioning improves outcomes for individuals, their families and services while potentially reducing costs. It also helps prevent scandals such as Winterbourne that damage both patients and the reputation of local commissioners and services.

TOP TIPS FOR COMMISSIONING *(from the NDTi – as above continued)*

1. Effective individual planning could prevent most secure or out-of-area placements. This involves:

- Working in partnership with families, children's services, education, health and social care to identify people whose home life and support is at risk of breakdown
- Genuine person-centred planning alongside individuals, their families and services
- Commissioning preventative support such as training, behavioural support, respite care and long-term provider development.

2. Developing local support and services to meet individual needs takes time and leadership. It begins with commissioners and procurement teams understanding best practice. Specialist knowledge is needed to identify need, develop appropriate support and service specifications and oversee contracting and monitoring processes. Effective commissioning for this group requires:

- Development of specialist community support services that deliver person-centred support to individuals and their families as well as training and guidance to staff teams
- Working with local service providers to enhance their skills and develop new services
- Assessing evidence from service providers about their skills and experience. This will include looking at staff training and supervision, management understanding and the experience of other individuals, families and commissioners
- Designating people within commissioning teams to build and maintain best practice knowledge. This will include outcome-focused contracts and reviews, and attention to safeguarding
- Ensuring that the skills required for local services are reflected in workforce planning.

3. It might still be necessary to commission out-of-area placements until local, less-restrictive alternatives are in place. Ensure there is a clear timescale for periods of assessment or rehabilitation and an agreed discharge plan. Contracting should be based on the delivery of person-centred outcomes, rather than inputs. Ensure that deprivation of liberty safeguards and Mental Health Act rights are observed.

4. Any crisis in support is likely to be a time of great distress and confusion for the individual, but it is essential to find ways to engage them in decision-making about

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short and longer term plans. Despite their knowledge and skills, families and supporters may not always be in a position to act as advocates when they are under great pressure. It takes great skill and experience to play an advocacy role in monitoring and challenging specialist services effectively. Commission independent, skilled and experienced advocates.

5. Families must be supported to play a key role in immediate and long term decision-making. Commissioners should ensure that independent support and advice is available to them. Engagement of families should be part of the review process.

6. Given the evidence of potential negative outcomes, the commissioning of secure or out-of-area placements should never be done in isolation and without high levels of senior oversight and accountability. Ensure that any decision to place someone in secure accommodation is multi-disciplinary and genuinely involves the individual and family. Information about any such placements (including planned outcomes, length of stay, costs, evidence of provider competence, date of review and responsible person) should be reviewed and reported regularly as part of local governance. Close working relationships should be forged between those with responsibilities for commissioning and for safeguarding, and between commissioners, local HealthWatch and the Care Quality Commission.

7. In addition to robust plans for individuals, joint strategic needs assessments and health and wellbeing strategies must reflect the needs of this group. This requires a good database of information about individuals and their current and future support needs.

4. SOCIAL CARE INSTITUTE FOR EXCELLENCE At a glance 10: Personalisation briefing: Implications for carers ⁶

KEY MESSAGES

Personalisation for carers means:

- tailoring support to people's individual needs and being part of the discussion about support for yourself and support for the person you are looking after
- not having to take on all the responsibility and all the managing of care and support – the local authority/Northern Ireland health and social care trust should ensure that you are sufficiently supported
- recognising and supporting carers in their role, while enabling them to maintain a life beyond their caring responsibilities – you should have your own needs assessed and have choices about your own support
- ensuring that people have access to information and advice to make good decisions about their care and support
- ensuring all citizens have access to universal community services and resources such as health, transport and leisure
- making services more flexible so you can agree outcomes and find solutions right for your situation

⁶ <http://www.scie.org.uk/publications/ataglance/ataglance10.asp>

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- if needs change over time, personalisation should enable you and the person you are looking after to change the way you are supported.

4. Adult Social Care Management Induction Standards ⁷

The Skills for Care adult social care Manager Induction Standards (MIS) launched in 2008 were refreshed in 2012 to ensure they remain fit for purpose bringing them up to date with increased personalisation in social care. These can be found on their website (see below)

5. Community Care Journal's Annual Review of the State of Personalisation

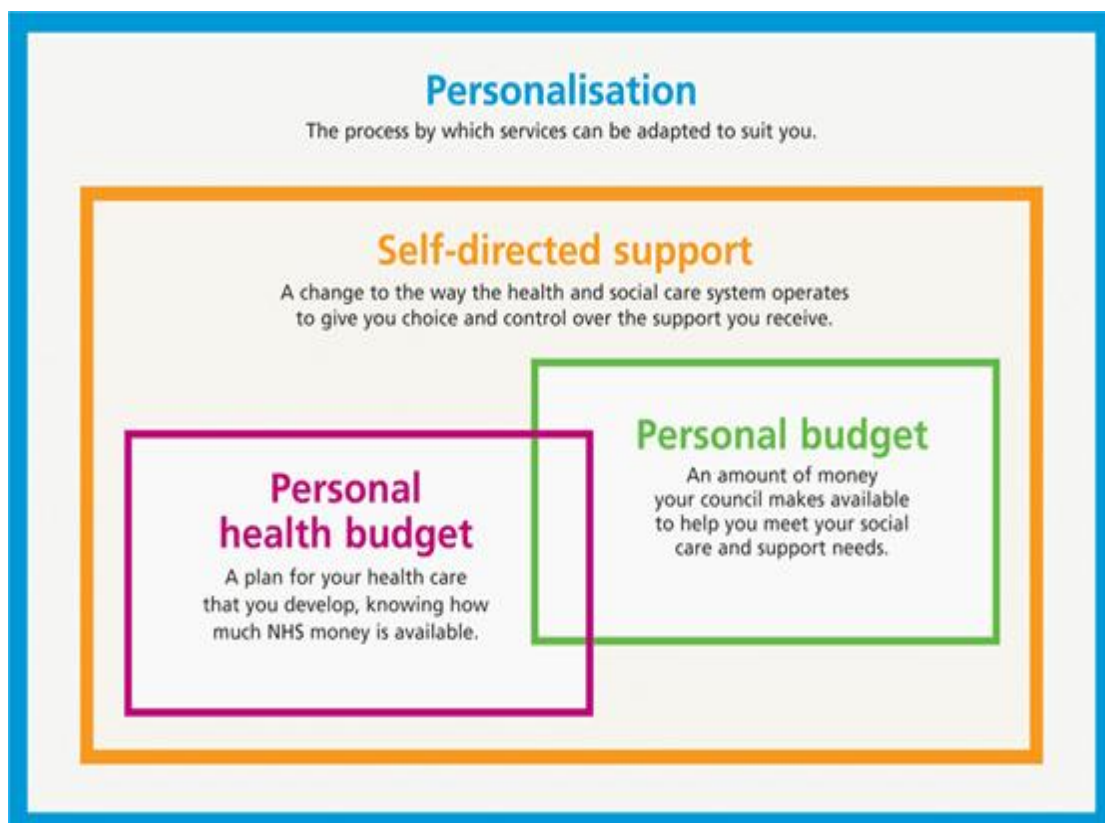
<http://www.communitycare.co.uk/the-state-of-personalisation-2012/>

“The difficulty is that much of the implementation of personalisation has come during a period of cuts. The irony is that good service delivery doesn't have to be more expensive but it definitely has to be less complicated and more transparent. We need to focus on co-producing support plans with people, especially those who rely on managed budgets, rather than embedding bureaucratic systems that alienate everyone, including social workers, who would prefer to be delivering a better system for all, rather than one which discriminates in favour of those who have more family support and louder voices”

6. Dept of Health - Health and Social Care Personal Budgets

This diagram is taken from the following DH website –

<http://www.personalhealthbudgets.dh.gov.uk/About/UnderstandingPersonalisation/>



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APPENDIX B

TEMPLATE FOR A VIABLE PERSONALISATION PLAN

What is a 'Viable Personalisation Plan' within the terms of the Personalisation project? To enable someone to improve their life, they will need a personalisation plan. In the project we used the term 'viable' as the plan needs to go beyond identifying an empowering lifestyle for an individual: it needs all key people signed up to the actions if it is to be implemented

1. ✓ **Outcomes plan** *developed through a continuing person centred planning/ review process*

Sought outcomes identified

- where & how to live: sought characteristics of a 'sharee' where potential for this
- being healthy & safe
- education or employment
- leisure
- family life / close relationships
- access e.g. transport

to include all non-negotiables or 'must-be-dones' – things that can't be compromised

2. ✓ **Decision Making plan** – *how decisions will be made to enable the plan to be implemented*

- IMCA service engaged / general advocate appointed
- Mental Capacity Act assessments done / Best Interest Decisions taken
- Court of Protection / Deprivation of Liberty Safeguards process in hand
- Clarity about use of Mental Health Act e.g. Community Treatment Order / Guardianship / Section 117

3. ✓ **Funding plan**- *who will pay for what*

- Funding agency/s confirmed and amount (or approval to purchase at best value)
- Clarity about how funding will be channelled to get the best effect for the individual e.g. Individual Service Fund / Personal Budget / Individual Budget / Direct Payments
- Financial contribution confirmed & benefit maximisation plan

4. ✓ **Buildings-based plan** – *where the person will sleep at night – where will they call home?*

- Housing Provider selected (or Care Home)
- or scheme agreed for adaptations to current /other home e.g. Assistive Technology/Disabled Facilities Grant

5. ✓ **Support Plan** - *for living at home, going out and about and staying well*

- Individual support plan agreed including required characteristics of support staff & lessons from how people were supported previously
- Provider selected
- Agreement on engaging with informal support in place
- Plan in place for support with finances / Appointeeship

6. ✓ **Outcomes Monitoring plan** – *ensuring changes are maintained/ continue to be appropriate*

- how delivery of the outcomes will be monitored
- who will lead the monitoring and at what frequency
- who will be involved in the monitoring and review process and how

Developed by Jayne Lingard, project manager, in consultation with East Midlands Commissioners

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APPENDIX C

INDIVIDUALS INVOLVED IN THE PROJECT

The project aim was to achieve greater personalisation for 26 people: 20 identified by local authorities and NHS commissioners in the East Midlands and six by families who had approached the CBF for help on matters related to a lack of personalisation for their relative.

The situation of each person as explained to the project team is outlined briefly then the key action and changes during the project. After information about each person's there is an extract *in italics* from the project manager's *verbatim notes made* during conversations with care managers or family members.

The extracts were chosen as they highlight different barriers to personalisation and illustrate complex issues. PBS = Positive Behavioural Support SW = Social Worker Sarah = PBS consultant Steve = Housing consultant

Person	Situation	Action and Change during the project ⁸
Person A	In hospital 55 miles from home area. No discharge plan. Hospital said A was creating too many challenging incidents to consider discharge. No input from local psychiatrist so care manager had to rely on the opinion of the hospital.	The care manager invited the person's cousin, former support workers and current hospital staff to a person-centred planning session then referred A to the supported living team to start to plan a move to a home of A's own.
<p><i>The biggest barrier is the independent hospital: they assume authority; it's very hard to get information from them – you are not part of the link so it is hard to plan ahead. I'm not sure what the role of the independent hospital becomes – they are just managing someone: if the person challenges, they can do the holds and techniques. But their approach reduces our input. At the reviews we are shown a complete sheet of incident reports but there is no exploration of the triggers. I know 'A' can be disruptive or aggressive – there is usually a reason for it – can be about various things. I'm not at all clear what service the hospital is being asked to provide. We have not had the formulation meeting – this should happen when someone goes in as otherwise people get stuck. They get medicalised - warehoused. I am trying to fight A's corner – but they can tell me – look at this incident form! 'A' was going to spend a day with a cousin but they stopped it because of bad behaviour – 'A' must have thought this was a punishment - A is in a medical 'box' – the social care side of things are on a back seat.</i></p> <p>What is the positive note in this situation? A's SW has a good understanding of challenging behaviour and is determined to get A out of hospital and living a full and active life with plenty of contact with A's cousin</p>		

⁸ The project team does not take credit for all actions and changes

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Person	Situation	Action and Change during the project ⁹
Person B	Young person. Living at home with parent, using day service and short breaks. Lack of consistent approaches between the three settings and time spent on transport is particularly difficult	A person-centred planning meeting was arranged. It was suggested that the PBS consultant could attend a multi-disciplinary review to identify a PBS plan for B. However, the care manager became too busy to participate in the project.
<p><i>B's [single] parent has been given the information about the CBF but has both a lack of understanding and is suspicious of professionals so is unlikely to make contact with the Family Support Service. The parent would not approach the CBF as regards themselves as an expert in 'B's care and [thinks] professionals should be listening to them. I don't anticipate agreement [from the parent] for 'B' to leave home, which is likely to be seen as the best option following PC planning. Will CoP will be necessary? I hope it will not have to go down that route.</i></p> <p>What is the positive note in this situation? B's person centred planning is being led by an experienced and skilled facilitator</p>		
Person	Situation	Action and Change during the project ¹⁰
Person C	We are not able to report on this person	Details not reportable
<p>What is the positive note in this situation? C's SW is determined to get significant improvement in C's living situation and will continue to work to ensure this happens</p>		
Person	Situation	Action and Change during the project ¹¹
Person D	Living in a care home where staff allow the person a lot of 'private time' in the bedroom, seeing that as respecting 'D's choices. Quality of life apparently very low though strong family involvement with regular mutual visits and stopovers at family home	The care home was invited to participate in PBS planning training. The person-centred plan was revisited and the home asked to account for how they were meeting the person's needs.

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¹⁰ The project team does not take credit for all actions and changes

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Parent is extremely happy with how things are and does not want 'D' to move....things have really improved recently. Not sure why 'D' is so much happier. Parent thinks it is the new management of the home. It was chaotic before. Now manager is firm with staff but welcomes their ideas: good leadership. 'D' used to have own lounge, bathroom and bedroom away from everyone else. Now 'D' eats with the others. The manager says they have had parties and 'D' is engaging. Not just tolerating people. Has been on a programme of reducing D's medication. Five years ago, parent thought D was being over-medicated. This has gradually come down.

I need to look at whether the service is value for money as it is high cost. 'D' can be unpredictable so when the need for 2:1 varies. 'D' takes private time which requires no staff at all – but is having private time getting in the way of 'D' doing more valuable things?

What is the positive note in this situation? The care home has improved due to a change in management. Staff are open to learning about PBS. The Local Authority has commissioned more PBS consultant time to enable this.

The project has been a catalyst to enable to SW to look more closely at the support that person D is receiving. SW has identified that the home promise a lot but it is less clear what is actually being provided. The home is very poor at providing evidence about how they are using the staffing levels that have been commissioned. It is still felt by the SW that, despite some improvements, person D could be receiving a much better quality of service for the amount of money being paid. Indeed, the SW feels that a better quality of service could be provided at a lower cost than the cost at the current residential home.

The next stage in this process is that we have commissioned an independent assessment from the PBS consultant involved in the CBF project. The aim is that this work will help us either to negotiate a better value and quality service from the current provider, or, if this does not seem possible, look for alternatives.

Person	Situation	Action and Change during the project ¹²
Person E	Person E in same care home as person D. Not benefitting from funded 1:1 time to go out: home says that E is not in the mood when outings are offered i.e. E is choosing not to go out. No family.	Health input requested on mood swings. Care home had PBS consultant input. Person-centred plan revisited and home asked to account for how they were meeting the contract for service.

I have talked to the PCP facilitator about how to take forward PCP to explore E's non-engagement with activities & outings.... Not sure how long this will take. I am currently doing a reassessment of needs and support plan. I have not yet had a response from E's advocate about how much she has met with E. Last contact was

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6 weeks ago. I wanted the advocate to get to know 'E' before progressing to person-centred planning because there is no family contact. Is there a volunteer visitor programme for people with LD and no family? I'm not aware of one....

I referred E to the Community Nurse 3 weeks ago: E lives in another local authority so though not far away, health colleagues don't cross boundaries so I have to refer to a nurse in another team.

How does the cost of E's service translate into direct benefit for E? The 'Care Funding Calculator'(CFC) exercise was done prior to my involvement but I haven't seen a copy – I could check with the person who did it.

What is the positive note in this situation? The care home has improved due to a change in management. Staff are open to learning about PBS. The Local Authority has commissioned more PBS consultancy time to enable this.

Person	Situation	Action and Change during the project ¹³
Person F	Young person living in a large institution 80 miles from family. No evidence of progress. Family and LA unsure what outcomes are being aimed at or achieved.	PBS consultant studied documentation and undertook in-depth liaison with the care home. Found that family and care manager's understanding of the purpose of the commissioned service was completely different from that of the provider. Home visit made by housing consultant. Family considering supported living with reservations about provider reliability and competence.

Resources for PCP have been agreed by head of service! So I can now buy in a person-centred planning service using the transitions budget. I have gone back to the NHS commissioning lead (as F is 60:40 NHS:LA joint funded) to talk about sharing the funding but have not heard anything yet. I think there has been a conversation about this with the other NHS commissioner who covers our patch. [NB The commissioner never did engage with the SW about funding person-centred planning and there seemed to be no process for this kind of negotiation in the commissioning process = only about the costs of the care package]

Have had a report from the project's behaviour support consultant – it is very interesting! She has looked at all the assessments F's current placement have done: they have done loads! But they have no plans to intervene in F's behaviour. The placement's aims and our expectations (F's parents and me) seem to be completely different. There appears to be no plans or desire to support F towards greater independence and adulthood, which is what we thought the service was for!

However, the parents are resistant to talking about alternatives. For F, a barrier to personalisation is the parents – no matter how personalised I am in my work – if the parents want things different.... It is about their journey – they find the idea of F not needing institutional care a distance away from the home area quite difficult...

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What is the positive note in this situation? The SW is considered and has worked hard to engage the family. The SW has made good use of the project team and will continue to work to get F's life on track

Person	Situation	Action and Change during the project ¹⁴
Person G	Living at home with parents. Much conflict over person's needs as a person with autism e.g. keeping certain items in certain places. Family feeling oppressed yet no confidence in alternatives to living at home.	PBS consultant looked at G's assessment and advised care manager. Housing consultant made home visit to parents. Whole situation still fraught but everyone better information about choices and options

Some of G's behaviours are related to autism and need to be accommodated, not changed. The parents do not agree that their lifestyle needs are incompatible with G's and think G should change. They do not have an understanding of supported living but in any case, they do not report injuries thought to be sustained from G: without this being out in the open, funding for supported living will not be viewed as a priority

What is the positive note in this situation? The SW was keen to learn about how this situation can be improved and will continue to support the family towards a better future

Person	Situation	Action and Change during the project ¹⁵
Person H	At school in neighbouring County. Wants to have own home in that county after school is finished and not return home – person seen as having capacity to make that choice.	Housing consultant offered availability to discuss housing options. Project manager discussed complications over funding and how to take that forward. Care manager became too busy to participate in project

Need to work out how to start to plan for H's future life in the neighbouring authority when H leaves school in summer 2013. 'H' understands that .. this means living away from H's family – it is an informed choice. H's perception of the future is not realistic, however, thinking self needs less support than actually needed by H - so will need a support provider who can offer skilled subtle and sensitive support that appears more like friendship/good neighbour than controlling support workers. Housing advice would be welcome at this stage.

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¹⁵ The project team does not take credit for all actions and changes

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In terms of choosing a support provider – there is a need to be very clear about who is procuring the service. If the neighbouring authority is going to be funding this in the future, they may want to procure. I will discuss this with my manager’s manager who already knows all about H and H’s family.

What is the positive note in this situation? There had been good person centred planning for H and a great deal of effort was made to allow H to be self-determined in planning the future

Person	Situation	Action and Change during the project ¹⁶
Person J	Living with parent whose health is not good and person’s challenges include assaulting parent.	Care manager did not want input from project as MDT already fully involved.

J’s parent is unhappy with medication and disputes regime with psychiatrist. Has been known to take J off the meds and instead administers herbal remedies. Psychiatrist reviewing meds. Community Nurse currently exploring all possible physical problems which could be behind J’s behaviour difficulties, which is parent’s theory. There was a strategy meeting in the past when parent was suicidal. Enabling parent’s role as carer can become the focus of planning. - No, I don’t think PC planning is needed to bring the focus back to J rather than parent.

LATER - the situation is all going ‘pear-shaped’. Parent is sacking all of the health personnel –parent said if professionals interfere anymore, they will run away with J. MDT is saying J needs to move to supported living - should live and receive services from one base as moving between support settings is difficult - should not be going between home and short breaks – this is perpetuating the challenges and difficulty. J’s parent says they will not have any services and will pay privately for any help. I am going to call an MDT meeting asap to think where we stand legally.

Would prefer to bring parent along with the team i.e. rather than going to court. Health colleagues want to bring in an IMCA and displace parent’s role in decision-making as parent is saying that J can move at the earliest in 3-4 years. Parent has a good relationship with the day services supporter and also with me – I can offer support as parent doesn’t see me as part of the problem i.e. does not associate me with the health community service staff’s approach who want to move J. So there are mixed messages.

What is the positive note in this situation? The family is being supported to try to make their plans work

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Person	Situation	Action and Change during the project ¹⁷
Person K	Living in assessment and treatment unit. No plans for discharge in place	Care manager did not want input from project as MDT already involved and plans now starting to be put in place for a bespoke service though lack of clarity about who was leading this
<p><i>K needs to move out and be more independent but is very challenging – wrecks buildings – actually removes bricks from wall. Providers not prepared to take on contract until K has fewer seclusions. We are looking to reuse a former NHS service property for K but I do wonder - is there a competent provider for K?</i></p> <p><i>Another complication is that K is a 100% health funded person and the [LA] managers want us to stop working with 100% health funded people. The SDS pathway and assessment framework attributes a budget but not for people who are health funded. A Continuing Healthcare assessment has been done recently by me and the nursing staff at the ATU – and also the NHS commissioner. Getting that together is not a quick process.</i></p> <p><i>6 WEEKS LATER I've not heard anything further about K – the person who is the lead in the provider Trust has been given my contact details. The person in the provider Trust had heard that a bungalow may be available. This has only just happened and they were going to talk to the NHS commissioner. I am waiting to hear what is happening – things are in process – it takes a little while – if the bungalow plan falls to pieces then housing advice from Steve would be useful.</i></p> <p><i>Project manager explained the project is designed to provide technical support to the person's commissioner - I am not the commissioner – health is doing it independently of me as they are responsible for K's care and will be taking on this role. In fact I am being excluded from the process and am waiting on health processes - K needs to be moving. I have told them what they need to be doing before I can move K or commission a bespoke service.</i></p> <p><i>Health is coming up with a bungalow which would be good for K – to be near K's psychiatrist and nurses and also– close proximity to parent although K would not visit parent – they would visit K. My commissioning role not clear as K is 100% health – I will clarify and come back to you.</i></p> <p>What is the positive note in this situation? The commissioner is determined to find a local solution for K</p>		

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Person	Situation	Action and Change during the project ¹⁸
Person L	Living in assessment and treatment unit. Provider will not take person due to high level of challenging incidents and need for seclusion.	Person was eventually moved to care home with 2:1 staffing. Care manager did not want to think about supported living as would take too long. Did talk with PBS consultant about support planning for L at the care home.
<p><i>ATU wants L to be discharged asap to [named] Care Home. Will be £2,200 a week. .. L's parent is elderly - not got own transport & relationship is important so needed somewhere in County although this on the other side of the City from the parent- a mile from a village in a rural area. But the good thing is there are no main roads which would cause L anxiety ... L can go walking in the surrounding open area.</i></p> <p><i>Is it to be a block or spot contract service? What scope is there for specifying L's service in terms of L's personal outcomes? I'll check that with contracting. Outcomes we want for L – to move back into the community – to have a more normal life. L has been in an institution for many years....</i></p> <p><i>Input from Sarah? We could get some paperwork to Sarah for her to review e.g. my reassessment. A lot has been done by health – but they may not be prepared to share their information. ATU can't pass their care plans to providers. I used to just ask to see nursing notes but now I have to ask for permission. There is a procedure: have to ask in advance – I'm not really clear what procedure I have to go through now. I find the daily notes useful to find out what has been happening. I need to understand L's triggers – part of my assessment work. There's a lot I can learn about L from the notes. You can't just sit and observe easily – it can create problems for other people on the unit.</i></p> <p><i>LATER – Have things improved on accessing daily notes on the unit? No – I've been told again that I have to ask and the nurse has to get permission from their senior. L had a paid DOLs rep as well who would like to see L's daily notes and they were told they had to ask permission. I noticed when I did see the notes that there were a couple of times when seclusions were not recorded or not recorded properly.</i></p> <p>What is the positive note in this situation? This SW is very dedicated and although not using advanced personalisation options is working hard to ensure service users get the best possible service available</p>		

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Person	Situation	Action and Change during the project ¹⁹
Person M	Living in assessment and treatment unit. Not sufficiently settled to be discharged.	Person improved due to change in staffing and plans started to be made for an interim placement where supported living would then be considered. Housing consultant advised.
<p>We proposed our PBS consultant could work with commissioners to secure PBS for M when leaving the ATU for the 'step-through' community assessment service being set up by X provider. Steve will also advise on how a trail to supported living can be laid, something that needs to happen as soon as possible. However, the SW warned there is a serious lack of capable local providers.</p> <p><i>The CPA discharge meeting was this morning at the ATU. I have been to see the step-down unit at X – a new building with only one other service user (out of 6 eventually). So has the discharge coordinator and M's keyworker nurse and the consultant. We all think it's a good option for M. The provider's staff are experienced in working with people with challenging behaviour. X is a good service. We all agree this would be a good starting point for M– not to be there long term – want to get M into supported living and to start accessing the community more.</i></p> <p><i>It is time to develop supported living now. Need to find a good provider. Happy to work with them. The NHS commissioner said the clinical team said M should go straight to supported living. There is a need for clear communication as this plan has got lost. But when I talked to the clinical team today, we all think X home is appropriate – shame M can't move there right now. Provider manager thinks it will be a high staffing ratio – start to build M's independence skills again. MDT will stay involved to get M ready for supported living. The step-down period will be about 12 weeks.</i></p> <p><i>There were plans for M to be assessed by the new provider but it did not happen - put on hold. The provider manager said he needed to have a meeting with the NHS and LA commissioning managers about the commissioning basis. I only found this out last week: apparently the NHS commissioner wants to be clear about the service being step-down - a period of assessment for people moving on from the ATU who might find supported living too difficult on discharge but who will then move on again. Delaying M is not good – M was geared up for the assessment – this could start causing problems. Not fair on M. Have fed this back to the NHS commissioner. The ATU are charging delayed discharge charges from today.</i></p> <p>What is the positive note in this situation? The SW understands this person very well indeed</p>		

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Person	Situation	Action and Change during the project ²⁰
Person N	Living in care home. Many incident reports. High cost placement. Care manager asked for advice on whether value for money was being achieved	PBS consultant provided a report to the care manager which revealed that the provider did not think the person should be living at the care home as it was not suitable for N!
<p>The project manager did not have a dialogue with this care manager as entry into the project came very late and was not typical of the kind of situation the project was set up for. Instead we provided a PBS report on N's placement as requested. There is a full version of the report in a different appendix</p> <p>What is the positive note in this situation? The care manager appeared knowledgeable about people with learning disabilities, welcoming the support of the PBS consultant and will make good use of the report</p>		
Person	Situation	Action and Change during the project ²¹
Person P	Living in supported living. Support staff concerned that person's behaviour out of control – risks to person's health. Care manager asked for report on how to improve matters as risk of admission to assessment and treatment unit	PBS consultant provided a report suggesting further input with the staff team. Staff had really appreciated initial input from PBS consultant and could see way forward but wanted further support with this
<p>We did not have a dialogue with this care manager as entry into the project came very late. There is a full version of the report in a different appendix</p> <p>What is the positive note in this situation? The care manager welcomed the support of the PBS consultant and will make good use of the report</p>		

FAMILIES (NOT IN THE EAST MIDLANDS)

Eight families contacted the CBF's family support worker team coincidentally around the time when the personalisation project was about to start. They had contacted the CBF as they were concerned about the poor quality of their relative's lifestyle and current services. They knew things needed to change but did not know how to get a better life for them. They were referred to the project by the family support workers.

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Before we began work, we asked 8 families the following questions and 6 responded. They were asked to score their current level of satisfaction with the following three aspects of their relative's life from 0 (dissatisfied) to 5 (satisfied)

Current level of satisfaction June 2011	Name of person and family's score from 0-5 with 0 low and 5 high						Ave (out of 5)
	Z	Y	X	W	V	T	
with my relative's current support and service arrangements	1	1	0	1	0	0	0.5
with future plans for my relative	1	0	0	0	2	1	0.66
with the communications I have with the commissioner for my relative (via a care manager, social worker or nurse)	2	1	2	1	1	0	1.16

The project engaged in detail with the six families. We wrote to four of their Directors of Social Services in tandem with the family, to invite them to participate in a project on personalisation. We said there would be free consultancy on housing and PBS. We received no response from any of the local authorities. Other more persistent approaches at operational level received a response but we were disappointed with the priority given.

The following information is extracted from the work with the families which was lengthy and characterised by conflict with or a lack of response from their relative's commissioner.

Detail of the people and their families are anonymised. The intention is to illustrate the risks and realities of seeking decent services for people with challenging behaviour. The local authority commissioners were two London boroughs, two in the South of England, two in the Midlands and one in the North-West.

Person	Situation	Action and Change during the project ²²
Person Z	Living at home with parents having left an out of area placement due to the safeguarding concerns of the parents. The out of area service cost £4,000 a week. Now receiving limited support which is poor quality and Z exhibiting signs of distress. LA not responding to family's concerns	Project manager advised parents on how to re-commission the support. PBS consultant advised on some aspects of support plan. Housing consultant offered but parents not ready for Z to move to own home.
<p><i>Z (aged 22) came back home (about 3 years ago) from a disappointing experience with an out of area residential placement, where Z was for a six month period. Since then Z has been supported to live with us (parents) by a support provider who supply 2 care workers (2:1 support) between the hours of 09:30 - 15:00 Monday to Friday. We also have a direct payment of 16 hours a week to pay two friends to spend time with Z for 8 hours whilst my wife and I have some time to ourselves. The quality of care provided by the support</i></p>		

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provider has recently started to deteriorate, due to the service manager leaving and there being a number of changes to the care workers working with Z and the new management regime.

We currently have no idea what the cost of this service is which was set up as an emergency and it is only now that we are speaking with our SW about ‘shopping around’ for a more appropriate service linked with a longer term plan for Z’s future. The current financial constraints are constantly being thrown back at us to help manage our expectations as to what provisions can be sourced. We would like to know about other opportunities that we are unaware exist.”

The family were given information about personalisation and links to various websites to see the wider context of their family situation. They were encouraged to compare the likely former cost of their son’s previous placement (£300kpa) and how much his current care is costing (C£45kpa). They asked the local authority for a full person-centred review of the situation and a longer term plan for Z. The family dealt directly with a more senior person and the SW who had repeatedly mentioned financial constraints was replaced. The LA told them to approach a number of providers to come up with a new service plan for Z but were not given any information on how to do this. The parents made great use of the project to ask lots of questions on how to commission a service and kept in touch to check out their thinking every step of the way. The project provided Z’s parent with CBF information sheets and additional information on how to select a support provider for people with complex needs. They selected a provider with whom they are now happy

Z’s family learned a lot about what choices they have when using a personal budget. At present they do not want to proceed with planning for F’s future home as he was offered a local college placement including independence skills training. They would like to see what progress is made with this before planning a much bigger in with Z’s life. Z is now well-supported and longer term plans for supported living on hold as family is happy with current arrangement of Z being supported to live adult life as part of the family. The family have been very proactive in making these arrangements which have been endorsed by the Local Authority though they have not supplied any advice or support about how to spend the direct payment

What is the positive note in the situation Z’s parents developed a great understanding about what makes for good support and the local authority respected the family’s expertise on and plans for Z

Person	Situation	Action and Change during the project ²³
Person Y	Living in own home. Removed inappropriately to out of area hospital though problems were clearly due to inappropriate support.	Now returned home. Some marginal advice from the project around PBS.

²³ The project team does not take credit for all actions and changes

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We are unable to say more about this situation as extensive and complex legal proceedings are incomplete. We plan to share learning about this scenario once these are complete.

What is the positive note in this situation? The new service provider showed some initial interest in the PBS advice

Person	Situation	Action and Change during the project ²⁴
Person X	X, aged 36, had lived in own home. Was removed under section in May 2010 to a secure hospital 130 miles away when became agitated. Cause was clearly inappropriate support.	Family had wanted support to press for X to return home and the PCT coincidentally started to engage with the family shortly after X's parent contacted the CBF. Plans were being made to discharge X.

X had been living for several years in a rented property with a long term 'friend' whose family was good friends with X's family and with whom S had been at school. The support provider management changed and new staff were recruited who did not speak English well. However X is a person with highly particular communication needs: after X has said certain phrases, X needs supporters to respond with certain set responses. X could not understand the new staff and eventually was accused of being racist due to the difficulty of understanding the accents and pronunciation of the staff and X shouted at the staff about this.

X's continued agitation affected X's housemate who became afraid of X's uncharacteristic shouting. The relationship between their two families broke down. Whilst X's parent was away on business, a psychiatric assessment was carried out and it was decided that X should be removed to a hospital under Section 2 of the Mental Health Act. When X's parent returned, X had not been yet removed. X went to stay at the parent's house that night as a local assessment and treatment bed could not be found. X's parent reports that X was happy and relaxed, showing no signs of disturbance and went with X's sibling to collect the sibling's child from school (X's niece/nephew). X was driven to the hospital the next day in an ambulance even though X's parent could have driven X as they followed the ambulance in a car but was not allowed.

X's parent wrote that "The hospital 130 miles away was the only option at the time and we were assured X would be returned to the local area within the timescale of the section – 28 days. 17 months on, X is still there. Whilst there, X has been made to stay in rooms with other people due to low staffing levels e.g. when X had finished eating X was not allowed to leave the dining room until everyone else had finished. I have been concerned about the use of restraint and a lack of activities and a loss of independence.

I was concerned that no plans were being made for X's discharge. We have had to fight and challenge the PCT all the way for an organisation of our choice to be commissioned to provide support for X. We have just in the last week been given the assurance that the organisation of our choice will be commissioned. Despite their opposition, the PCT never came up with any other choice of providers!

²⁴ The project team does not take credit for all actions and changes

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We now have the long task ahead of us of securing a new house for X and the organisation recruiting and training staff.”

What is the key positive step in the situation? X’s parent managed to remain resolute in advocating for X to return to supported living and turned to the CBF for help with this.

Person	Situation	Action and Change during the project ²⁵
Person W	<p><i>My 23yr old relative W was given 28 days’ notice to leave a residential care home located an hour’s drive from our family home. There had been on-going quality and communication issues with the home for some time which led me to be concerned for W’s welfare and that of the other residents.</i></p> <p><i>The options offered were either W could be placed somewhere else or come home. When I asked what support W would get at home, I was told 1 hour morning and evening. Yet the residential placement cost well over £90kpa with 2-1 support in the care home, a day centre 5 days a week and waking night staff. I work as a teacher and my partner works shifts. The only other person at home is W’s 15 year old sibling.</i></p> <p><i>If the LA offered a personal budget of 75% of cost of the residential placement to purchase support then I may consider having W home to live.”</i></p>	<p>The project has supported W’s family to try to arrange supported living at home. We are still waiting for this to proceed over a year after the first request. In the meantime W has moved to a care home near the family home.</p> <p>There have been many changes of SW and at one point we found out the case was closed. The project team have spent time with the family advising on W’s needs and the best way to proceed in their discussions with the Local Authority.</p> <p>The family have felt compromised – if they became angry with the lack of service, they were labelled as difficult and demanding. But the team can confirm that W has received a very poor care management service.</p>

A new care home was opened near the family home and coincidentally came to the notice of the CBF project team. The family suggested it to the local authority who initially refused to consider it. After intercession from the project team, they agreed to fund a placement there if the provider brought the price down to less than the previous placement. This created weeks of delay. No outcomes focussed support plan was devised when W was placed there. The family asked to see the contract so as to know what service to expect from the care home e.g. activities and staffing levels but were told they were not entitled to see it.

When W moved to the new care home, the former care home refused to participate in any transition planning, not allowing the new staff to visit her and did not provide any records.

²⁵ The project team does not take credit for all actions and changes

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In June 2011, before the emergency move, the family asked to talk to the local authority about options for supported living. Promises were made to do this but not until after the emergency move. Since then, four SWs have come and gone; the family is still trying to have this conversation. The only real contact with the LA has been a statutory review (arranged and delayed twice) and a safeguarding investigation after the home asked for 5 working days' notice of visits and would not let W's parent beyond reception.

Incorporating advice from the housing consultant, the family has significantly extended their home to create an independent tenancy for W and has tentatively spoken to a support provider who say the extension is perfect for supported living as it has independent access from the family as is self-contained. The housing benefit officer is rejecting the plan, claiming it is a contrived tenancy. The social care department say this is nothing to do with them and will not support the parent to discuss plans with the housing department.

W needs an outcomes-focussed support plan and personal budget from the local authority to take W's plans forward and is still waiting for this in September 2012 despite repeated promises from senior managers.

What is the key positive step in the situation? It was good that W was able to move to live at a care home so near the family. However, this is only an interim step to personalisation as W's care home does not meet W's needs well and do not seem to place a value on family involvement.

Person	Situation	Action and Change during the project ²⁶
Person V	V is 32 years old. With no explanation, V was given 28 days' notice to leave the place where V was living. V's sibling believed the placement was supported living so challenged this as V had tenancy rights. It transpired it was legally a care home. The home did not use V's communication tools and appeared to be annoyed by the sibling's frequent questions about V's wellbeing and activities as well as reminders to use the communication aids.	V was moved by a care manager to a new care home a little nearer the family but not local to them. The family wanted V to be offered supported living nearby so V could visit them frequently and informally with support staff using the bus which V likes very much. Instead V visits once and sometimes twice a week but the family have to do the transport which can take up to an hour each way.
<p>V has no speech and although V can make some simple choices, is not independent to remain safe and well. The family were unhappy about how arrangements were made for the move of homes and made a formal complaint listing the following concerns:</p> <ul style="list-style-type: none"> • <i>At an emergency assessment meeting arranged by V's appointed care manager it was made very clear by the family and V's advocate that a PCP transition process was needed to support V with the move. However, throughout the process no such plan has been agreed or put in place.</i> 		

²⁶ The project team does not take credit for all actions and changes

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- *It was my understanding that V was a tenant in a supported living arrangement. I did not receive a copy of V's notice letter so I remain uninformed as to why V was required to leave the previous address.*
- *I was invited to contribute to V's assessment. However I felt pressurized and unsupported by the appointed care manager who didn't give me enough time or make reasonable adjustments to help me understand, make amendments to and return a detailed assessment for V. In fact V's assessment was submitted without the care manager talking to me or making amendments that I had suggested (including correcting factually incorrect points) and without my signature.*
- *I had to make my own arrangements to see two new potential care providers with no support from Social Services. I had no preparation to help me think about what I was looking for when visiting so I could make a useful contribution to the decision-making process*
- *I felt pressurised and forced by the appointed care manager into making decisions about V's future placement that I wasn't comfortable with. V and our family were effectively excluded from the decision making process to choose a place that met V's needs. This is contrary to the Mental Capacity Act.*
- *Whilst a placement was found for V I was asked if he could come to live with me and our parent, to whom I already provide support and care. Different amounts of support were mentioned on two occasions – 5 and then 7 hours each day. No time was spent with me talking through what support I am able to offer my sibling or what the impact of having to live with me would have been. This suggestion raised my anxiety and placed additional pressure on me which in my view was negligent practice.*
- *We are not happy in particular about the confusion V has experienced. V self-injured on the first night at the placement (injuring V's nose) and we believe that this could reasonably be due to insufficient preparation and communication with V. We do not believe there was multi-disciplinary input in preparing V for the move. We believe a proper assessment should have been made about the impact of the move on V and then plans made of how to reduce the negative effect on V.*
- *There has been very poor communication from the appointed care manager throughout and since V moved to the new care provider on the Sunday 2nd October 2011, I have had no contact from care manager or anyone from Social services. [letter was written on 31st October]*

No response of any kind was received to the complaint. The sibling subsequently made a request for referrals of V “to see specialist clinical psychologist or behavioural analysis for a comprehensive assessment of V's self-harming behaviour to determine the triggers and referral to speech and language therapist (SaLT) to look at enhancing V's communication skills and communicate V's needs.” This request was made on 12th September 2011. This resulted in a SaLT making contact in January 2012. On 12th July 2012, in response to an enquiry by the sibling to the SaLT about progress, an email was received which said “Communication passport- We are still working on a rough draft at CLDT - nearly finished.”

V's placement at the new care home was regarded by the family as a suitable stop-gap but the local authority has responded to none of their requests to discuss supported living. The family has made a further complaint about this and received no response to this second complaint, which included a complaint about not getting a response to the first complaint.

V has been the victim of several assaults at the care home from another resident. Yet a

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meeting to review V's new placement in the first week of October 2011 was postponed due to the compassionate leave of the SW then by an emergency case and did not take place until almost the end of January 2012.

What is the key positive step in the situation? W has had an advocate throughout this time and V's sibling has received support from the CBF and has remained committed to V receiving the right quality of support

Person	Situation	Action and Change during the project ²⁷
Person T	<p><i>"I contacted the CBF as T was displaying physical aggression and destroying property. I had called the police as T's behaviour is unpredictable and 'out of the blue' and likely to go on for some time once started. T sees a psychiatrist and has a large cocktail of medication – including Antipsychotics – to 'manage' behaviour. We came to live in this area from another country a year ago but although we are British subjects, we have no support from Social Services other than a week in respite care. The SW said they will not have T for any more respite until a behaviour support plan has been created to help staff manage T's challenging behaviour as a member of staff was accosted. Recently the OT said T's case was being closed as there is no SW – I just don't know how to get help."</i></p>	<p>What happened? Update July 2012</p> <p>We supported T's parent to ask the local authority for supporting living for T. Whilst the SW was pleasant, it has led to no services other than occasional respite.</p> <p>T's parent was offered respite support of 90 mins once a week for 10 weeks to allow the parent to attend a work skills course. This has now ceased. The person who came to support T did not go out with T as the support worker said they did not know T well enough. They sat in the house with T and sometimes did painting and colouring.</p>

Unfortunately we have been completely unable to support this family to get any services at all for their relative. After 15 months of trying we are now supporting the parent to place a complaint about the social work service which has not completed a support plan. The parent has notified the SW of the need to leave the relative in the house alone when going on errands due to challenging behaviour in public which has included accosting 3 women and beating them on their backs (after they have cowered) using clenched fists for 20-30 seconds.

Both the local authority and the psychiatrist have been informed of these risks yet the person remains with no service other than intermittent short breaks when the parent goes on holiday and this was once unconfirmed until a few hours before the parent was due to take a plane.

What is the key positive step in the situation? There is no positive step here: the situation is most unfortunate and we remain concerned about the whole family.

²⁷ The project team does not take credit for all actions and changes

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APPENDIX D

TWO EXAMPLES OF POSITIVE BEHAVIOURAL SUPPORT REPORTS

These independent reports by a certified behaviour analyst / positive behavioural support expert were requested by a commissioning care manager within the CBF's personalisation project

The aim was to advise the care manager as to

- whether the commissioned services are delivering the sought outcomes
- whether the services can be helped to deliver improved outcomes

The aim of sharing the reports is to demonstrate how detailed such independent reports can be and how they can be useful to a commissioning care manager

It can be seen that the reports

- highlight which aspects of a service are working well/not working well for the person
- provide constructive information to enable improvement
- would be very useful in commissioning a new service

REPORT 1: BEHAVIOUR SUPPORT FOR MR ANDREW SMITH (PSEUDONYM)

Based on one visit to his care home and t/c discussion with his care manager

Contents

1. Assessment methods:
2. General observations:
3. All about A
4. Defining The Behaviour
 - a. Triggers:
 - b. Course of behaviour:
 - c. Function of behaviour:
5. Proactive Strategies (Ensuring A Good Quality Of Life).
 - a. Physical environment strategies:
 - b. Interpersonal environment strategies:
 - c. Programmatic environment straggles:
6. Reactive Strategies (To Use When Challenging Behaviour Occurs)

1. Assessment methods

- ⤴ Interview with Support Worker 1
- ⤴ Interview with support worker 2 when working with A
- ⤴ Brief interview with Support worker 3
- ⤴ Brief interview with Co-keyworker
- ⤴ Joint interview with Home Manager and Psychologist
- ⤴ Interaction and observation of A for 90mins whilst eating his lunch and in his room
- ⤴ Review of Care home records

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2. General observations

Support staff were very friendly and helpful and A came across as well liked. There was some discontentment expressed about A's support plan and potential strategies that staff thought would work well with A. In particular some staff have tried things or made suggestions which have been rejected by other staff or management.

Examples are:

- ⤴ Having access to certain preferred objects
- ⤴ Paying for his own items in shops
- ⤴ Putting things up in his bedroom

Despite having made formal arrangements to visit the care home, the manager did not meet or greet me and did not introduce herself despite me entering her office twice. She was with the in-house psychologist until I asked to see her mid-afternoon. When we did meet she said there was “nothing she would change” about A's support strategies and therefore I surmise she will not find my input useful. The manager and psychologist said they think their care home is not the right place for A. They suggested a smaller unit that specialises in Autistic Spectrum Conditions or a placement where they have a safe room.

The manager said she thought I would be there to specifically give them strategies regarding A's biting of others. I discussed the need to understand the function of behaviour (i.e. why A presents with certain behaviours) and the need to include proactive strategies (supporting someone so they do not need to present the behaviour).

3. All about A

A has a learning disability, Autism Spectrum Condition and reported seizure activity but no diagnosis. He presents as bent over and has an unsteady gait. No exercises or aids or adaptations were utilised to assist with this, although the psychologist reported his GP is aware of his back. During the assessment, A reported a sore toe and was reluctant to walk on it.

A is reported to be possessive over items. He was witnessed taking DVDs from a store cupboard but agreed to return them with support using a light-hearted approach and distraction.

The assessment and intervention suggestions are detailed in the following format

- Defining the behaviour: a description, its triggers, course and function
- Proactive strategies (including physical, interpersonal and programmatic strategies)
- Reactive strategies

4. Defining The Behaviour

According to A's file and the support staff, A presents with the following behaviour challenges

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Self-injurious behaviour

- ⤴ Biting self on arm – can be through skin
- ⤴ Hitting self
- ⤴ Head butting windows and walls and the ground including concrete
- ⤴ Crying

Property Destruction

- ⤴ Ripping his own clothing
- ⤴ Refusing to give back items that do not belong to him

Aggression

- ⤴ Verbal aggression towards others
- ⤴ Kicking others
- ⤴ Throwing items at others
- ⤴ Spitting at others

The psychologist was particularly concerned about A biting staff and the risk this behaviour poses. I did not recall reading any reports of this in his records held at the care home but had discussed one incident with the care manager where this happened when A was at a theme park. This appeared to have a clear trigger (the preferred activity coming to an end) and the staff member reflected independently on what could have been done differently.

The psychologist said that A is not someone she typically works with as her area of expertise is risk management and direct 1-1 working with verbal clients. She therefore does not get involved in A's care planning. Her lack of relevant expertise for doing so was borne out by her discussion of A in terms which were not pertinent to his history nor needs and a lack of understanding about the function of challenging behaviour in a person with A's range of needs.

4a) Triggers

The support staff seemed aware of the triggers to A's behaviours. These included:

- ⤴ Not being understood
- ⤴ Poor interpersonal match and/or lack of interaction with staff. This included reports that staff were using mobile phone or iPods when with A
- ⤴ Another client going into his bedroom
- ⤴ His clothes being messy e.g. saliva on them
- ⤴ Possible sexual frustration

Despite this I did not observe any evidence of or read in his file about actions to mitigate these triggers such as communication aids or adaptations in the home; a training plan for how to interact/develop a rapport with A; strategies to prevent other clients entering his bedroom; investigation of sexual needs.

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4b) Course of behaviour

A's behaviour frequently includes coming out of bedroom and behaving aggressively to the support staff in the hallway. They may then withdraw and direct A outside to the bench in the garden. A will walk down stairs hitting his head on the way on the walls and windows. When at the bench A may take off his clothes and hit his head on the ground or concrete driveway.

There are between 3-5 critical incidents per month where Accident & Injury forms are completed.

4c) Function of behaviour

The Aide to Functional Analysis assessment has previously been filled out and indicates that A displays challenging behaviours to initiate social contact. This appears to be the primary reason and could be understood as reliable way of getting staff support when situations are devoid of appropriate interaction. See Antecedent, Behaviour, Consequence contingency below:

A: Lack of appropriate staff support (e.g. staff remaining in the corridor/poor rapport with A)

B: Challenging behaviour

C: Well skilled/confident/familiar members of staff being called upon to provide intensive support

At times A also appears to display challenging behaviour in order to obtain an activity/object/event (access to tangibles). This occurs when he has been refused an item e.g. staff denying him an additional can of coke, staff preventing him putting pictures on his wall and staff informing him the theme park activity was over. The access to such items may be more reinforcing than they ought to be due to a lack of freely available activities and events (see Proactive strategies section below).

A: Lack of reinforcing activities/objects/events available; staff deny request or terminate access to activity/object/event

B: Challenging behaviour

C: Staff 'give in' and activity/object/event is provided. There is inconsistency in staff response in these situations.

5. Proactive Strategies (Ensuring a Good Quality Of Life)

5a) Physical environment strategies

A has a lovely large bright room which is a great match for him as he likes having space. He needs however to go up two set of stairs which he appeared a little unsteady on which may cause him anxiety. These may also prove dangerous when he is descending them during an incident. There is a lounge and a couple of small kitchenettes. A makes himself tea in one of the kitchenettes. This activity could be expanded to include simple cooking and baking. The house is in lovely grounds with grass and trees. A concrete road runs around the grass and there is a bench in the middle of the grass. The concrete road presents a very serious hazard to A as he will bang his head on it during an incident.

A's bedroom has huge windows overlooking the front and side garden. It is relatively

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sparsely furnished, with a radio and ball pool. Other items are locked away (clothes in a box that staff have key to), pictures very high on the walls; no curtains; no play objects. This is reported to occur because he can't cope with choice. Any toys he had are reported by the manager to be stored downstairs as A uses them as weapons during behaviour challenges. It is my suggestion that regular opportunities to interact with these should be included in a structured timetable. The use of them should come with clear behavioural contracts explaining that they are not A's to keep.

A lives with approximately 12 other residents. They appear to have very varied needs, including personality disorder and no apparent learning disability, mental health problems and Asperger's. There is also a wide age range from approximately 19 years to 50+. I suggest this makes it difficult for staff to build up expertise in working with A especially in regard to his autism.

5b) Interpersonal environment strategies

A receives 1:1 staffing in the home for 14 hours per day, although when he is in his bedroom staff often are in the hallway. This may be because he asks them to leave. This appears to occur with particular staff who do not have a good rapport with A. This then appears to establish itself as a setting event or trigger for challenging behaviour when there is a lack of social engagement. I suggest the development of a training plan/induction for staff on how to interact/develop a rapport with A. A profile of the kind of staff who works well with A should be created to try to establish a good match.

Some staff appear to enjoy spending time with A and use a laid back, humorous approach that appears to work well. He appeared playful, enjoying toddler-type games, such as pretending objects were a telephone, pretending he is a dog and using games to shock, e.g. pretending to pee on the files for a reaction. The staff seemed relaxed and confident but with him but the psychologist suggests that they are cajoling him and appeasing him because they are scared. The appropriateness of the dog game should be questioned as it involves biting objects – I suggest staff reinforce other safer games and pay less attention to this game (differential reinforcement).

5c) Programmatic environment strategies

A's file contained lots of information about things he liked to do but these are only infrequently part of his programme. Examples include swimming, visiting the trains, collecting eggs, horse riding and going to the park. Support staff interviewed said they didn't know he enjoyed these things and therefore never offer them to him. The manager reported A chooses not to engage in activities and wants to spend all his time in his bedroom. This is his own choice.

I suggested to the manager that A may need strategies in place to help him engage in varied activities. This includes 1) understanding what is being offered (e.g. using visual aids), 2) making a choice (e.g. giving limited choices); 3) feeling confident doing it (e.g. with staff that he has a good rapport with). There are various

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behavioural strategies that could be employed such as 'behaviour momentum'²⁸. No visual aids, timetables, PEC's etc were observed to be used with A. Since poor interaction and lack of understanding of A are significant triggers it is suggested that these are explored.

A is funded for 2:1 to access the community however staff interviewed reported he may not always go out, at times due to staffing shortages. The manager disputed this and said there are 10 staff per shift but the rota seemed to show there are 7-8 on shift, with 4 clients requiring 1-1 support due to sickness and shortages. I suggest this is checked.

6. Reactive Strategies (To Use When Challenging Behaviour Occurs)

Studio 3 provides the methodology behind the reactive strategies and it appears useful that staff are not using physical interventions with A. Instead staff withdraw and move away from A and encourage A to go outside away from others. However going outside makes A vulnerable, due to his mobility (going down the stairs) and his engagement in head hitting of the walls and windows. Further being outside brings him into contact with the concrete ground which he bangs his head on. It is therefore suggested to review and risk assess these strategies to consider if they can be amended. This may include moving the bench, him having a downstairs room etc. One staff member also reported that there are sometimes too many people involved. This needs reviewing.

A is then supported to put on new clothes. Previously this has involved staff having to go up to his bedroom to collect some. Recently a support manager proposed the use of a "grab bag" to take out during the incident which contains clothes. This was reported to have been agreed but staff are not implementing the strategy. I suggest this should be put in place and monitored.

REPORT 2 : BEHAVIOUR SUPPORT FOR MR BRENDAN FOSTER (PSEUDONYM)

Based on one training day at his care home and t/c discussion with his care manager

Mr BF lives in a care home for four individuals. He is moving to his own supported living house soon and will eventually have his own dedicated support team. Until then his current staff are providing the support.

I carried out the functional behaviour assessment (FBI) to understand what his challenging behaviours look like, the rates and severity of occurrence and antecedents and consequences in order to gain a consensus on the function of them.

Mr BF displays excessive fluid intake, requesting and drinking large quantities of tea and water - to the extent that he has been hospitalised after an apparent seizure

²⁸ presenting instructions that occasion compliance at a high rate and then taking advantage of the resulting 'momentum' to present a task related instruction that typically does not occasion compliance but rather occasions challenging behaviour.

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caused by low sodium levels - as well as self-injurious behaviour and the grabbing of staff. We established that all his behaviours appear to be a reliable way of gaining staff attention in the form of social interaction.

With support I helped the team identify strategies that would prevent Mr BF from displaying challenging behaviour based on what we had established the behaviour to mean.

This included proactive strategies in the form of environmental strategies and skills teaching strategies. Of particular use were the physical environmental strategies as these can be implemented immediately in his new home. These included strategies such as not having the kettle, tea and coffee on display and not having his chair in the lounge facing the kitchen door. Mr BF appeared to see the sight of such objects as prompts for excessive fluid intake behaviour.

Recognised the lack of social interaction can be a trigger for challenging behaviour, in other words it can be the withdrawal of an environmental event as well as the presentation of an environmental event that acts as a trigger.

We identified the replacement skill of learning to use another method to attract staff attention and increasing his independence skills, through greater staff engagement with Mr BF in his home. On this note we discussed the role of active support and the manager has asked for some more information about this.

Finally we also re-worked their reactive strategies. The staff team were unknowingly responding frequently with high levels of attention to these behaviours so we considered ways we can reduce this and provide the attention when engaged in positive activities. Staff found this area particularly helpful and it helped explain why it is so important to also have proactive strategies.

Nine staff attended the assessment half of the training and seven staff attended the intervention development. All staff reported finding the day very useful as it provided them with ways of working that they had not thought of before. They wrote up their own strategies and have agreed to type this up to form a behaviour support plan.

This was a really good session, working in partnership with a team to use their knowledge and expertise of a person to develop a positive behaviour support plan.

Environmental strategies

Kettle, tea etc to be put away after use so not visual prompt.

Begin introducing de-cafeinated tea.

Staff not to have tea in between his times.

Staff to move out of the kitchen area and engage him in other areas of the home.

Use of visual schedules for AM and PM (implement the one he has at his day service).

Support during transition times, such as handovers.

More social interactions when engaged in positive behaviours.

Use new house new rules to implement new behaviour strategies.

Benefits from laid back male staff -consider when recruiting.

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Skills teaching

Learning to use another method to attract staff attention (achieved through differential reinforcement).

Increasing his independence skills, using task analysis to break down tasks for him to participate in. This will provide greater staff engagement with Mr BF in his home. On this note we discussed the role of 'active support'²⁹ and the manager has asked for some more information about this.

Reactive strategies

- Low key response to challenging behaviour:
- Stop providing attention for the behaviour (even in the form of negative attention e.g. social disapproval).
- Walking away.
- Turning off the tap and gesturing for him to move away, no verbal interaction.
- Use of distraction such as singing.

NB These reactive strategies will only be effective if Mr BF has the chance to receive social attention through other means i.e. through the display of pro-social and positive behaviours.

Both of the names of the people above are fictitious but the reports are real reports which were prepared as part of the personalisation project .

²⁹<http://www.kent.ac.uk/tizard/staff/documents/Mansell%202002%20RDD%20Engagement%20and%20active%20support%20preprint.pdf>

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APPENDIX E

EXCELLENCE IN JOINT COMMISSIONING - GLOUCESTERSHIRE

The project manager spotted a tender for service which looked interesting. Contact with the tender officer led to an interview with their Joint Commissioner who leads a team of health and social care assessment and commissioning professionals. They may have the answer to working across the unhelpful health and social care divide.

Questions to Chris Haynes Joint Commissioner, LD Joint Commissioning Team Gloucestershire CC	Answers to Jayne Lingard of the Challenging Behaviour Foundation Personalisation project manager
<p>What decision-making process led you to tender for this framework agreement?</p> <p>Did you have external advice to draw up the tender process?</p>	<p>We have a strategic commissioning plan which includes bringing people back into the county. For at least two years we have had a joint LA & NHS LD commissioning team (Gloucestershire CC and NHS Gloucestershire). We work from a common plan and as lead commissioner I head up the team of 8 people.</p> <p>We have commissioners from both health and social care. Health team members are directly engaged with complex people including people 100% funded by health and both LA and NHS colleagues work with people placed out of county.</p> <p>We sought advice on our tender from NDTi who act as a critical friend to us and we have also had engagement from RIPFA – Research In Practice For Adults. They look at our customer journey and give feedback on it. Both engagements are ongoing as is the framework agreement – providers can bid to join the list at any time.</p>
<p>What confidence do you have in existing providers locally?</p>	<p>The out of county people were placed out a long time ago. More recently we felt the level of expertise available locally had improved sufficiently to bring people back to the area; in addition we had done some pre-market development and made contact with providers who said they would come into the area e.g. Reach.</p>
<p>How will you assess the competence of applicants?</p>	<p>Our Commissioning Support Officer has a procurement background. She carries out initial screening. We have rejected 50% of those who have replied so far - it is a continually open list. Once screened, the scoring is done by the team. Families get involved at the individual placement level: we send providers on our list a pen picture specifying a person's sought outcomes. Providers can then apply to provide care and families help to pick out which provider is right for their relative. The outcomes are identified through person-centred planning which is done for us by Reach, which we pay for.</p>

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<p>Questions to Chris Haynes Joint Commissioner, LD Joint Commissioning Team Gloucestershire CC</p>	<p>Answers to Jayne Lingard of the Challenging Behaviour Foundation Personalisation project manager</p>
<p>How will you monitor and ask them to evidence their competence when services are being delivered?</p>	<p>The commissioners on the health side all have nursing background and have continuing monitoring involvement based on the person's outcomes which are in their individual contract.</p> <p>In addition we do annual "Quality 360". This is delivered in two parts: the first is quality checkers: people with a LD who are trained and paid to go out and talk to service users about how they are doing. Sometimes the service user is someone who challenges, but despite this the quality checker gets a good sense of how it is for that person: their visit offers great insights. The second part is the 360: a request for feedback goes to everybody around that person – <u>everybody</u>. They can opt to respond in one of three ways - a telephone survey , automatic interactive voice survey (via the telephone) or a personal conversation. They are asked how they think the person is doing through simple questions like "is this person doing better or worse than they were doing a year ago?" or "would you recommend this resource to people?".</p> <p>The process is very inexpensive! Most of it is using technology yet it is hugely insightful. Also, if there is a safeguarding or whistle blowing issue, the system automatically puts these into the operations manager's email inbox, cc'd to safeguarding! It's a clever system created for us by Process Matrix. http://www.q360.co.uk/ It's opened our eyes to information we'd never had before.</p> <p>Gloucestershire is the first authority to have such a service in place to keep in touch with the quality of care being provided once the service user/patient is back with us-in county.</p> <p>Alan Rosenbach (Special Advisor-Care Quality Commission) has described the system as 'brilliant'. The system was a finalist in the 2012 Health Innovations Awards</p>
<p>What relationship do you envisage with local specialist NHS LD services? e.g. if the service is in crisis?</p>	<p>The NHS commissions an intensive health outreach team. This team is available if required by an easy referral via health colleagues in our team. The team operates 'out there' - in the community and is shifting more and more to community delivery rather than using the ATU model. They are now planning a new team just for people who are complex and challenging.</p>

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<p>Questions to Chris Haynes Joint Commissioner, LD Joint Commissioning Team Gloucestershire CC</p>	<p>Answers to Jayne Lingard of the Challenging Behaviour Foundation Personalisation project manager</p>
<p>Who finds the housing for people who want to move to supported living?</p>	<p>The support provider is responsible for sourcing the housing. It depends on the individual: some people need individual supported living environments and others share 2-3 bed resources - we are not locked down to a model. But the provider will source the accommodation which could be via a separate arm of the provider. Some of the accommodation has to be specially built (for example we have someone who needs a wood free environment as he eats wood) but the support provider would lead on that.</p>
<p>Is there any piece of work you are particularly pleased with?</p>	<p>One person was placed in Colwyn Bay years ago in a PMLD environment. Because it was so far away he became completely disassociated from his family. Now he has moved back, his family see him regularly and were involved in the planning.</p> <p>R who has a moderate LD was in a private hospital in another county. His medical records stated he would need to be in a private hospital for the rest of his life due to his challenging behaviour. Now he is in a local supported living service for one person: his challenging behaviour was a response to other people with LD. In his own environment he is fine. He is supported by Reach. He has made a terrific DVD about his life and does workshops for us. His family maintained some contact whilst he was away: now they are delighted about him being in the local area.</p> <p>We use the NDTi inclusion tool with all our providers. This measures what relationships people have. In the hospital, his only regular contacts were with paid carers (with occasional family contact). Now we have re-done his inclusion tool: all the quadrants are starting to be filled up. If you met R now you would not believe that he had ever been so complex and challenging. He would certainly make a good ambassador! His service is now half the cost of the hospital service.</p>
<p>Are you planning to disseminate your work?</p>	<p>We have been talking to CQC about the quality tool. We have not done much about our out of county placements work.</p>

Gloucestershire welcomes enquiries about their local model

Margaret Willcox, Director of Adult Social Care Margaret.Willcox@gloucestershire.gov.uk
Sue Morgan, NHS senior manager sue.morgan10@nhs.net

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Gloucestershire used this company to help them develop their quality monitoring system.

Would you really like to know what's happening in each of your care homes?

Are you waiting for Panorama to let you know you have a problem?

Would you like to have a system of quality and outcome measurement that lets you sleep at night?

If you answered 'yes' to any of these questions, then Quality 360 is for you - an efficient tool that measures quality outcomes and performance within care homes, giving you:

- early preventative alerts to issues you need to know about in any home
- safeguarding and whistleblowing alerts that you hear about first
- an independently verified baseline of quality measures
- outcome measurement tied into assessments
- summary quality reports on each care home which can be updated
- a tried and tested system that is cost efficient and effective

How does it work?

Quality 360 is built to tap into the knowledge of the formal and informal network of support that surrounds each individual. Each person is surveyed using a field tested outcome assessment. This is accomplished through independent experts skilled in the use of telephone surveys, web-based surveys and on-request personal interviews.

The combined information is triangulated and built into a report which measures the effectiveness of not only how the service users are doing, but how the care home is performing.

Want to know more?

Send an email to info@q360.co.uk to arrange for an online demonstration and start back on the road to a sound night's sleep.

Q360

www.q360.co.uk

Further information about this way of monitoring services can be found at <http://www.q360.co.uk/>

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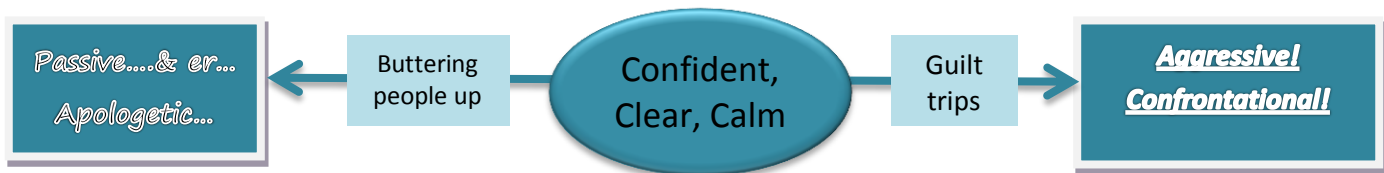
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APPENDIX F

FAMILIES PARTICIPATING CONFIDENTLY

The personalisation project worked with six families not from the East Midlands. They contacted the CBF's family support workers because they were concerned their relative's current arrangements were not meeting their needs.

The project learned that families have to be very persistent if they are to achieve anything and also that they have to be confident



Families Working in Partnership with Commissioners

The project manager aimed to support families to engage in confident and positive communication with the commissioners. It was not easy: families had to be persistent. Some commissioners appeared to think families were unreasonable in asking for personalised arrangements for their relatives. The families' aim to reduce the likelihood of their relative's challenging behaviour and improve their current unacceptable quality of life seemed not to be understood.

The project manager talked with families about what to say to the commissioners and how to say it. They were encouraged to be confident and not apologetic or aggressive. The skills families needed were those which commissioners acquire by working in large organisations, assisted by training on assertiveness, negotiation skills and communication skills generally.

This led the project manager to wonder whether there are easily accessible courses for families to help them engage positively with commissioners.

Family –led Commissioning or Monitoring

The other relationship in which families need to be confident is with service providers when spending direct payments, participating in service reviews, challenging if quality is not satisfactory or posing other queries about the service.

One parent became labelled as difficult because of the persistent challenges made to a care home. The care home was apparently responsible for the following matters in relation to the care of the parent's relative³⁰ -

- An injury to the leg was explained by care staff as being due the relative leaning against a radiator – yet if the radiator was so hot as to cause injury, this was a

³⁰ the relative had no speech and the ability to make decisions similar to a person at 18 months of age

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failure of care. This was raised as a concern with the manager who responded angrily to the parent for raising the matter

- An injury was explained by bed springs sticking through the mattress. A care worker said the parent should buy a new mattress. This was raised with the manager who eventually agreed to replace the mattress.
- The home accused the parent of buying poor quality clothing for the relative: they said the parent was allowing their relative to look like a tramp. Yet the parent had bought almost exactly the same clothes for a sibling who lived at home and the clothes were still in good condition. The problem was the laundering at the care home e.g. wrong temperature, use of bleach. This was raised with the manager
- The parent witnessed a resident being kissed against their wishes by another resident. When this was mentioned to the manager, the family was told to give notice of their visits so a manager could be present
- Soon after the above incident, the home accused the family of causing injuries to the relative on a home visit and a safeguarding investigation was undertaken though found to be without any real foundation

Eventually, notice was given to the relative to leave the home within 28 days. No information was made available to the new placement and no transition visits to the care home by the staff of the new placement were allowed. The manager told the commissioner that the relative was difficult and hysterical and this was repeated to the project manager as a fact by the commissioner.

Families Participating Confidently– Tips for Meetings with Professionals

Confidence does not mean being pushy – it means speaking your truth clearly so you are heard. No-one can argue with your truth – it is an important piece of the jigsaw. Only you hold that piece.

Some people find that in meetings they end up being passive – they are not sure what to say when or how to say it; they worry they might lose their temper, or they think people will be shocked if they say what they really feel. So they end up saying nothing even though plenty needs to be said. How many times have you found yourself thinking “I should have said.....I wish I’d said”.

Some people find they end up being confrontational in meetings - aggressive and pushy - perhaps because they panic when they need to speak in public which might be because they think people are against them. Perhaps they are! But start by assuming they are not.

Some people find that in meetings they end up being manipulative, putting things as though they are asking people for ‘favours’ when there is no need to; being overly familiar even though the relationship is not a friendship; trying to make professionals feel sorry for them to get more help which can make professionals lose respect if it is not true

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Some of us just go blank in meetings! So - before the meeting

- Think through what you need to say before you are in the situation – prepare yourself. Jot down a few ideas.
- Practice what you'd like to say in the mirror or with a trusted person who understands you. Ask them how it sounds. Don't get a rigid script though – there might not be the right moment to say it – but at least try out some of your ideas
- If you think it is going to be a difficult meeting, ask to speak to a professional before the meeting to talk about how it will be run and when you can speak – make sure you know the 'rules' about the meeting

Because there is not always time for everything in meetings, before you go think through

- which things you must say and
- which things you would like to say but that are not essential this time
- what you want to say on your behalf. Don't speak for others unless they have asked you to. If you and your partner or other relative are both going to the meeting, agree how you will avoid this. The closest couple can have different views - try not to find out your differences in the meeting! And you can both put forward your views – with respect for one another

When you speak in meetings, try to make sure you speak

- at the right volume: not too loud, not too quiet
- at the right speed: don't rush, take your time. But also don't take too long!

If you need adjustments to the way the meeting is run to make yourself understood or so you can understand, ensure the person arranging the meeting knows straight away whether this is to do with your hearing, speaking voice or language

At the beginning of the meeting, make sure the person running the meeting (usually called the chair) knows you want to say something at the right time. It is their job to make sure everyone gets a chance to speak. As the meeting rolls on and you want to say something, ask the chair when it will be your turn to contribute

If you find that you keep going to meetings and come away feeling that you have not said the things you wanted to or let your temper get out of control or made a fool of yourself in some way, ask to speak to a professional about the meeting – ideally the chair - and how it could have been better. Tell them you don't feel you are getting your points across and ask for their advice.

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You might need to spend quite a bit of time to develop these skills. Most people do. Here are some websites about being confident – there are lots on the internet. Have a look around for one you like

<http://www.assertiveness.org.uk/>

<http://www.mindtools.com/pages/article/Assertiveness.htm>

<http://www.teamtechnology.co.uk/assertiveness/how-to-be-more-assertive.html>

<http://crucialhabits.com/assertive-communication-skills.html>

Parents Participating Confidently

Medway parents and carers forum run a course called “Parents Participating Confidently”. It is funded by a grant from the Department of Education, which is received by all parent forums. See the next page for the flyer sent out to inform people about the course

“We run two courses a year – one in Spring and another in the Autumn. The courses are designed for no more than 12 people at a time. The parents and carers have to have a young person with an additional support need, in the age group 0-25. We are looking for some of those parents to become trainers themselves.

The proof of the effectiveness off the course is that of the ten committee members we have, 9 attended the course before they joined the committee!”

If you know of any other courses about participating confidently that are available to families – they don’t have to be specific to the families of disabled people, the CBF would be very pleased to hear about them – please send details to – info@theCBF.org.uk

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Here is an example of the kind of course which can help families develop the necessary skills for leading or participating in commissioning support



Parents Participating Confidently Parent Course

Date: Thurs 20th & 27th September 2012
Time: 9.30 am to 2.30 pm (9.15 am for coffee)
Venue: Rainbow Court
Danecourt School
Hotel Road, Watling Street
Gillingham, Kent ME8 6AA

To book a place

or for more information contact
Medway Parents & Carers Forum
at
medwaypcf@googlemail.com

or Phone 07813 123984

Lunch will be provided, so please
advise of any dietary needs at
time of booking.

Why should I take part?

- It is very important that parents are involved in the planning of services for children. Agencies are now involving parents at all stages
- It is also important that you feel fully involved in decisions about your child
- This course aims to help strengthen your knowledge and skills to be able to feel confident in participation

How will I learn?

- In a comfortable and informal setting
- By doing activities and having discussions
- By having fun
- By receiving and giving information

What will I learn?

- What is meant by the word 'Participation'
- What the specific activities are that this might involve
- How to identify the barriers that might make taking part difficult
- New communication skills to enable you to feel confident when expressing your views
- Tips and strategies for coping with difficult situations.

What will I be able to do at the end of the course?

- Understand the different types of participation
- Use the skills you have learnt to prepare for meetings effectively
- Feel confident to give your views
- Be able to express or challenge a different view confidently and positively

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APPENDIX G

DETAILED PROJECT LOG OF BARRIERS AND SOLUTIONS

During the project, we maintained a project log of barriers and in supervision we analysed the barriers to personalisation for people with challenging behaviour and developed hypotheses about what was causing them.

We also discussed solutions to the barriers. Most of that discussion is captured here.

THEME Barrier Evidence	Analysis / Hypothesis	SOLUTION
COMPETING PRIORITIES		
<p>Although the additional project inputs were modest (PT project manager, 2 consultants), there was a distinct lack of capacity locally to make the project work well i.e. local service managers and care managers</p> <p><i>One senior manager commented on the serious disconnect between what Directors sign their organisations up to and the realities of operational pressures. This simply leads to workers experiencing work pressures. This seemed to be something that was agreed with by others at the meeting</i></p> <p><i>A SW case was nominated to the project by others. She said she would not be able to attend meetings or spend time on the phone. She did once I had explained the value of the project. She talked about the terrific workload pressures for all workers</i></p> <p><i>SWs repeatedly cancelled (& rearranged) monthly tel calls due to other priorities. Rearranged phone calls were cancelled</i></p>	<p>There was much change going on in both NHS and LA organisations. People constantly referred to not knowing whether their job would continue (not care managers)</p> <p>Project-itis (having lots of different projects all happening at the same time) affects the available time which workers and managers have to give to each one as well as the 'day-job'</p>	<p>If there is to be a project, it should be resourced honestly and ring-fenced so that workers can do what needs to be done rather than constantly feeling as if they are failing the project whilst having to juggle higher priority work</p> <p>We need to calculate what input projects will need from on all stakeholders and not make assumptions that people can participate in projects whilst doing their 'day job' whether that is service users, families, workers or managers</p>
Lack of SW capacity/ time due to safeguarding pressures. Safeguarding pressures overwhelming teams (conversations with all managers / SWs)	A senior manager suggested there is a need to rationalise current safeguarding practice and develop clearer thresholds for team managers to apply so that alerts due to poor quality services	More training and support for team managers to help them develop more confidence in their judgement when

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THEME Barrier Evidence	Analysis / Hypothesis	SOLUTION
<i>One SW said that the reality is that people with complex needs do not get attention unless there are specific risks presenting, even though their service outcomes are not as good as they could be</i>	are addressed as such rather than being treated as safeguarding. But need to balance that with intuitive sensing of the need to pursue. Potential conflict between intuitive assessment of risk and the getting it wrong	deciding whether a safeguarding alert requires investigation More training and support for SWs when carrying out investigations to match time spent with the risks
Workers weighed down by bureaucratic procedures	SWs are anxious to ensure they have a complete audit trail in case challenges arise. The litigious climate is diverting workers making them focussed on the needs of their organisation (and themselves) rather than the needs of the disabled people they are serving	National paperwork set – rationalised?
PARTNERSHIP COMMISSIONING		
Lack of information sharing across agencies - A SW planning for someone's discharge was told she was no longer free to look at people's ATU nursing notes without following the correct procedure. <i>The SW was not told what the correct procedure was. The person she was assessing was non-verbal</i>	Some people become bogged down in the rules on information sharing and see confidentiality as an end in itself Others hide behind confidentiality if they want to block access to information for other reasons	Need for regular training and briefing reminders to workers about how information should be gathered i.e. with notification that it will be used in furthering a person's best interests in ways that are related to the purpose and context of how it was gathered – that this might mean sharing information with other agencies to enable the best outcomes
A lack of clarity at operational level in the local framework for joint commissioning for people with learning disabilities and behaviour described as challenging <i>Difficulties were experienced in setting up some local project teams between the LA and NHS – the frameworks for this were</i>	Insufficient capacity in system; differing priorities; tensions in funding arrangements PCTs insufficiently equipped to provide quality case management for individuals. Lack of commissioning expertise in PCTs. Outsourced to NHS providers and not linked to social	Operational joint commissioning teams so that common issues can be resolved, joint solutions reached and a single market shaped Gloucestershire's joint

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THEME Barrier Evidence	Analysis / Hypothesis	SOLUTION
<p><i>generally not in place.</i></p> <p><i>One SW said in a meeting “Managers want us to stop working with 100% health funded people”</i></p> <p><i>Separate streams of commissioning between LA and NHS commissioning and within NHS separation between Continuing Healthcare and MH/LD specialist commissioning.</i></p> <p><i>Whilst people have a right to access a community care assessment, if the LA finds that their needs are continuing care, they discontinue care management responsibility.</i></p> <p><i>Also “When people are admitted to hospital, they are no longer a priority for us (LA SW)”</i></p>	<p>care commissioning processes.</p> <p>Lack of provider support and development framework for providers provided by NHS. To what extent do they have capability in promoting non-medical model lifestyles?</p> <p>A regional market development role would lose the links with contracting for individual patient’s outcomes and links with LAs.</p>	<p>commissioning sounds to work well: a manager employed by the local authority manages 8 care managers who do social care assessments and healthcare assessments of complex people. Cases are allocated according to the presenting information and then discussed as a team. People are assessed as to what degree of CHC funding they are entitled to (if any). The team commissions together, shaping a single marketplace for local people.</p>
<p>Some LAs/PCTs are in effect ‘exporting’ needs. In some cases they are not routinely conducting good quality reviews and ensuring a developmental or future focus</p> <p><i>One senior manager talked about how many safeguarding referrals they have relating to out of area living people in their LA. One PCT had not reviewed one person referred for safeguarding for 7 yrs</i></p> <p><i>One psychiatrist said she had received 35 referrals of people from out of area in a month due to new providers opening up in her area (Cambridge/Peterborough)</i></p>	<p>A commissioner can ‘export’ their person’s needs without responsibility for the impact on the system local to the OOA service</p> <p>The economic relationship between safeguarding and OOA complicated as people placed by NHS or other LAs do not have to provide safeguarding response. The cost of a placement does not reflect the total cost</p>	<p>Need for economic model to show the full costs of OOA placements including safeguarding and DOLs</p>

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THEME Barrier Evidence	Analysis / Hypothesis	SOLUTION
CHC DST PROCESS & TOOL		
<p>Planning for people whose needs could be either or both health and social care are subject to two systems of assessment and funding decisions</p> <p><i>One area said that the needs of people with LD just do not fit the DST format and that the NHS and LA perceptions of aspects of the tool do not match up</i></p>	<p>The inherent tension between health and social care in determining how people's services should be funded is exacerbated by the current tremendous financial pressure on both 'sides'.</p>	<p>Advice from a reliable source on future NHS commissioning process/structures said " <i>The National Commissioning Board will retain funding for high, medium and low secure services. The rest ...will be devolved to Clinical Commissioning Groups whose work will be directed by the Health and Wellbeing Boards and scrutinised by Healthwatch. The relationship with LA commissioning where people are assessed as 50:50 will fall within these arrangements. <u>There will be the option to pool funds for commissioning to avoid incentives for needs to be interpreted as health or social care according to funding pressures</u></i>".</p>
CARE MANAGEMENT PRACTICE		
<p>Many commissioners think that people need to be in a care home or hospital if they</p> <ul style="list-style-type: none"> do not have the mental capacity needed to sign a tenancy or might need to have their house doors locked to keep them safe or might need physical interventions from support staff to keep them safe <p><i>One area told us this in their set up meeting</i></p>	<p>This is not true. Case Law has ruled that none of these things should stop people living in their own home as long as their assessment clearly states they need to live in their own home and that they need to have doors locked and to receive physical interventions. If everyone agrees with the assessment, it is legal to local doors and provide physical interventions with very clear support plans, reviewed regularly delivered by staff who have had appropriate training about this</p>	<p>If everyone who is important to that person agrees with the assessment, they can have their own private home (as a tenant or as an owner).</p> <p>If everyone does not agree, the Court of Protection can look into the situation and decide what is best for the person.</p>

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THEME Barrier Evidence	Analysis / Hypothesis	SOLUTION
<p><i>One person was removed from her home because her commissioner thought she could not have physical interventions (families work)</i></p>	<p>kind of support.</p>	
<p>Lack of clarity about what service is being commissioned and dynamic monitoring once a person is placed</p> <p><i>One care manager was reviewing someone in an out of area placement. The project's consultant found there were no clear objectives shared between service, family and commissioner:</i></p> <p><i>"It appears from my discussions with X that the aims and objectives of the placement from the provider's perspective and from the local authority/parents are at times different. The SW found the expert advice invaluable and said "the outcomes could not be achieved without her support"</i></p> <p><i>Another care manager asked for advice on someone in a care home following many incident forms. She was shocked to learn the care home thought he should move care homes as they did not have the expertise for him.</i></p>	<p>The consultant analysed documents and discussed plans with the OOA placement She said</p> <p><i>"The provider is supporting the person to develop compensatory skills to help him function successfully rather than changing his long standing and persistent behaviour traits and cognitive/skill deficits. His parents appear to expect the provider to be addressing and attempting to change the difficulties that the person experiences. This leads to confusion about the interventions that are being used and the priorities are sometimes conflicting.</i></p>	<p>External independent advice to commissioners from a behaviour analyst/ positive behavioural support specialist is beneficial in commissioning services. Not only does can advice give a clear picture of what is not working in a current placement, it can point the way for what could work in a new service or enable the current service to improve.</p> <p>See Annex X for a sample report to a care manager (anonymised) from a behaviour analyst/ positive behavioural support specialist</p>
<p>Lack of involvement of multi-disciplinary team and lack of expertise in SWs.</p> <p><i>A newly qualified SW whose only previous experience was with physically disabled people did not involve the MDT in her assessment and clearly lacked an understanding of the nature of someone's behaviours: she offered a mother 1 hour of</i></p>	<p>Lack of training and experience – a risk in generic services</p>	<p>Given pressures on workloads, an online Training module for SWs around challenging behaviour and positive behavioural support</p> <p>Availability of behavioural support specialist to advise workers</p>

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THEME Barrier Evidence	Analysis / Hypothesis	SOLUTION
<p><i>support each day for her adult daughter who has 3:q staff to go out. The family felt they had to be pleasant to ensure SW did not avoid them so did not challenge (Families work)</i></p>		
<p>Families all struggle to get timely (or any) contact with their SWs / care managers. Families not kept informed of developments (Families work)</p> <p><i>Examples from all families</i></p> <p><i>e.g. despite giving several weeks' notice of one family's flight details, respite care for person A not confirmed until 2pm the day before. Person still has no long term support plan or allocated SW after one year</i></p>	<p>There appears to be it lack of prioritisation of family's communication need – why? (cont'd)</p> <ol style="list-style-type: none"> 1. Do some workers regard the family as oppressive and think they overprotect their relative or 'keep them back'? 2. Are some SWs simply anti-family and projecting this onto their clients? 3. Is there a cultural/ generation gap between care managers and parents in values, attitudes and style? 4. Has the data protection act led to such individualised case management that workers think they cannot share info with families? 	<p>The person with a LD as a member of a family - agenda to be explored and promoted including family information needs – how to involve families. How to help families see that their point of view is important but needs to be balanced with advocacy point of view for individual.</p> <p>CM's father did SCIE module for SWs on personalisation and found it interesting. Bespoke module for families would be good.</p>
<p>Families not properly involved in assessments or best interest decisions</p> <p><i>W – given notice to leave current placement. Family not involved in assessment or offered sight of it. SW new to LD. (Families work)</i></p> <p><i>Despite family warning LA that things were not going well at his care home, V given 28 days' notice to move. New SW had 3 hrs notice of the meeting to plan the move with no previous knowledge of the person. Did not tell family why notice has been given. SW asked family in meeting whether they wanted relative placed in or out of area! (Families work)</i></p>	<p>Have people with LD become seen as individuals at the expense of being seen as detached from families? What is this driven by? Is it the data protection act i.e. because information can only ever relate to one person and workers have to be careful not to include information about other people?</p> <p>Or is it a symptom of a broader trend towards Individualisation in society?</p>	<p>Need to raise awareness of workers of family involvement as a source of enduring social capital for the individual and as providing a valid natural cultural context or point of reference for the individual which must be valued and respected</p> <p>Need to stop thinking of families as carers i.e. the issue of people's family relationships should not be conflated with issues to do with</p>

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THEME Barrier Evidence	Analysis / Hypothesis	SOLUTION
		families as carers – this is a separate and additional issue.
Lack of choice and control by individual	Being non-verbal is seen as not being able to contribute	Creative person-centred proxies for service user satisfaction measures to be included in service monitoring
Fragmentation of response: <i>one young person (S) has three SWs – a children's worker, a transitions worker and an adult worker. At a review, the adult worker had not spoken to the children's worker before and had not seen the file. One person (T) is being referred to a different team to have a person-centred plan (families work)</i>	Could computer based records be driving this?	Need person-centred and not internal process orientated care management
FAMILY-LED COMMISSIONING		
Families know when things are not right but not necessarily what to do about them Conversations with commissioners are not easy to access <i>(Families work – all families)</i>	Why should they? Commissioners not seeing families as key partners in planning for individuals	On-line Training modules for families using family experiences - how to be persistent when my son's assessment took over 10 months! - starting to think about my daughter in terms of outcomes family-commissioned support using direct payments - the value of advocacy in engaging with my brother's commissioner
Families may have low expectations of their relative's life ambitions <i>R's family happy with OOA placement. Think supported living not possible for her (families work)</i>	Families might be happy with new placements if previous ones were even worse. Some families prefer apparent safety of residential care if they are not able to appreciate benefits	Small numbers of people with complex needs so families don't necessarily meet those in similar circumstances Link families with each

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<i>S's mother does not want to consider supported living for her 19 yr old daughter. Only wanted advice on choosing a local care home.(families work)</i>	of supported living model	other to share experiences More DVD / video footage needed of supported living for people with complex needs to inspire families
Families reluctant to ask for help in case it is seen as an inability to cope and person would be taken away from them <i>Mentioned in EMids network meeting July 2011</i>	Emphasis on safeguarding makes families reluctant to reveal they are struggling, as their inability to cope with the behaviours is interpreted as a threat to the individual rather than a gap in their support	Prevention agenda to be implemented rather than relying on reactive safeguarding responses Need for CBF training on positive behavioural support for families undertaken together with all those who all support a person
Personalisation without preparation <i>Z's family told to find new support provider for Z with no preparation, guidance or support (families work)</i>	Assumption that people understand how to assess providers	Need to think about what training and support families need to do this A printable online guide to commissioning services for families (for people with complex needs)
Families not seen as relevant to commissioning / value for money <i>Email from SW to highly involved sibling: "I do not believe that it is appropriate for families and carers to become embroiled in discussions between the Local Authority and care providers regarding funding arrangements but, nonetheless, you are aware that the Care Home has queried the funding for the current package, specifically for V's daily activities. ... (families work)</i>	The SW appears to have commissioned a service without negotiating a contract before the service began. The family has been querying this before the move to the care home was made and for the four months since the move was made.	Families need to be told what level and quality of service has been contracted and given a clear role in contract and made explicit with the service provider
PERSON-CENTRED OUTCOME PLANNING		

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THEME Barrier Evidence	Analysis / Hypothesis	SOLUTION
<p>Person-centred planning not being done so pc outcomes information not being developed. Why not? <i>“Takes too much time to arrange and we have high workloads - it is not a priority.”</i> <i>“ We have very little admin support to help with arranging meetings”</i> <i>“Finding a date all stakeholders can make is really difficult”</i></p>	<p>PCP seen as inevitably requiring large meetings</p>	<p>Encourage idea of virtual meetings and teams – people do not all have to be in the same place to contribute – care manager as collator of information and views through a series of processes</p>
<p>Lack of confidence and expertise of SWs in person-centred planning - person-centred planning seen as something that is facilitated by an expert <i>“I’m waiting for the pc planner to arrange person-centred planning for my clients” (several SWs)</i> <i>“ Flipcharts, coloured pens, pictures and clear writing, artistic skills - all that kind of thing is not really my strength”</i></p>	<p>This belief and the practice stops pc planning becoming embedded into routine work as there is limited or no funding for expert facilitation</p> <p>Workers challenged and demoralised by being expected to deliver this?</p>	<p>Need to simplify person-centred planning, challenging some of the assumptions of the current approach. Encourage belief that person-centred planning is a way of thinking not a particular methodology.</p> <p>Allow workers time to learn more about complex people so they can see support planning from the person’s viewpoint. Training on co-production</p>
<p>Some families refuse to participate in person-centred planning meetings</p>	<p>Some families more comfortable with being in meetings than others (assertiveness skills). Some are intimidated by so many workers (who are used to being in meetings and forget this). Some families might feel their privacy is invaded – taking about painful private matters in large meetings</p>	<p>Try including families in different ways – not necessarily in big meeting format – give options and don’t judge</p>
<p>Most of the people identified for the project had not got a recently created person-centred plan</p> <p>One person’s family had paid for PC planning but this had no clear way of taking it forward:</p>	<p>It is quite likely that PCP is not being offered unless there are safeguarding or other significant risks to people, and then when there are, it is quite likely that the need for urgent action diverts</p>	<p>Offer person-centred planning on a routine basis</p>

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<p>ambitions were unrealistic and not tracked as characteristics of achievable realities</p> <p><i>Questions asked of all SWs and families</i></p>	<p>workers from initiating and undertaking PC planning work.</p>	
<p>SWs not seeing PCP as their responsibility. PCP has not become embedded in day-to-day practice. Seen as separate from assessment – an optional loop in the planning process</p> <p><i>“we have a team for that”</i></p> <p><i>A SW said she is newly qualified and has not had training in PCP</i></p>	<p>Is this view because specialist workers / teams were set up. If the posts have either ended or been cut, is this seen as the end of</p>	<p>New initiative needed to ensure PCP is integral to assessment and support planning with training for team managers on how to inspire their workers. Need for a PCP methodology suited to a time of austerity, with short-form training for SWs and a simple guide on incorporating PCP into mainstream practice so SWs do not see PCP as a separate process e.g. co-production in MCA Best Interest decisions</p>
<p>SWs/care managers are not using PC planning as a driver for their work due to a lack of experience</p> <p><i>A PCP facilitator said that many SWs have not had any experience of PCP which this has been done by day centre officers and by reviewing officers but not SWs who would be working with people who present greater risks due to their complex needs.</i></p> <p><i>W- New placement chosen by SSD with no discussion of sought outcomes or a PCP.(families work)</i></p> <p><i>Z’s PCP was paid for by family: SSD do not have copy. Appears to be both capacity and capability issues in SW workforce (families work)</i></p>	<p>SWs are not required to use outcomes – is anyone monitoring their work? I saw more than one support plan where recording of needs and outcomes was muddled with little outcomes statements – mostly needs and descriptions of what support should be provided</p>	<p>SWs to be monitored on their use of outcomes as the basis of their commissioning.</p> <p>Training for SS in developing or conceptualising outcomes needed (What is a need, what is a service or support, what is the outcome of that?)</p>

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<p>Lack of commitment by SWs to person-centred planning <i>One PC planner said that some SWs regard PCP as giving away power – their style is more directive and doing to people rather than co-production</i></p>	<p>Is this about fundamental personal values or is it a lack of awareness/inspiration?</p>	<p>Assuming latter, need for inspirational training which helps people to see the value of PC practice/ co-production SCIE briefing on the evidence base for co-production: http://www.scie.org.uk/publications/briefings/briefing31/</p>
<p>Reactive commissioning and lack of outcomes focus when setting up a contract for service. <i>Email from SW to sibling “ the Care Home has queried the funding for the current package, specifically for V’s daily activities ... To date...the Care Home has not confirmed some of the details that have been requested by my commissioning officer. Hence, V has an allocated budget but the service and support the Provider will provide within that budget remains unclear.” This remained unclear 8 months on</i></p>	<p>A lack of practice of outcomes-related commissioning</p>	<p>SWs need to be required to use outcomes to lead the commissioning of a service, asking the service provider specifying to propose how they will achieve the outcomes and this dialogue should form the basis of monitoring the contract (which would include any regular visitor to the person or someone who the person might visit regularly)</p>
<p>LENGTH OF TIME TO SET UP SUPPORTED LIVING</p>		
<p>Discharge from hospitals or moves from care homes where there are problems cannot wait for supported living to be developed due to the length of time it takes to set up supported living - what happens to people whilst they wait? <i>NHS commissioner asked for advice on what can be done about this.</i></p>	<p>What is causing the delay? Housing? COP? What should happen to people whilst they wait?</p>	<p>Develop notion of interim placements whilst people have supported living developed for them. Develop interim services using existing services or short-use buildings, with future support provider recruiting additional staff who will then be the core of a team for the person when they get</p>

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		their own home. LAs and NHS to share the true cost of interim placements - honest relationship with provider
People with LD / autism cannot cope with uncertainty around a crisis or change in their needs	Need to get away from the idea that. Is a disablist view.	Support to cope with change needs to be properly planned and necessary support provided.
PARALLEL OR PARTNERSHIP PATHWAYS: HEALTHCARE MODELS & SOCIAL CARE MODELS		
<p>Lack of availability (capacity) or limited nature of roles (capability or remit) of specialist healthcare professionals</p> <p><i>Removal of person under MHA for 1 years from her own home when problem was lack of positive behavioural support approach (families work)</i></p> <p><i>Lack of monitoring of communication support for people in care homes (two people in the families work both use picture symbols but didn't have any)</i></p>	<p>Is there a clash of social care and medical models? Is there a need to integrate the resources into one model of assessment, care management and monitoring or services rather than having two separate support & care/decision-making process pathways? Pressure on public sector finances funding and assessment process for continuing healthcare funding– does this drive LA and NHS to polarise their approaches?</p>	<p>Hounslow have psychiatrists in the social care team and they are line-managed by Social Care senior manager– what can be learned about this? How is it developing? (Have asked for feedback)</p>
<p>Interface between NHS Provider / Social care Provider: People's supported living services are provided by support provider organisations who might need additional resources when people are in crisis. If the LA does not provide any, they are at risk of being admitted to an ATU. The individual sits between two processes of care and support for which the resources come from different pots. When people go into inpatient care, they lose their benefits and can lose their home: if the additional input could be provided in their own home, this would not need to happen. The</p>	<p>Medical model / social care model – service and care pathways: Do NHS crisis assessment and treatment services and associated specialist services (inpatient units and linked community teams) fit with a disability model of positive behavioural support?</p> <p>Mental Health treatment often cited as need for admission – but is this the best way to support someone if their home address is the best place for them in the long term and there is a need for change in their support plans not in their accommodation?</p>	<p>Individual Health Budgets combined with personal social care budgets – will enable better shared approaches to personalisation</p>

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<p>LA can make a saving if the person stays in hospital for a long time and altogether if they become 100% CHC. NHS staff have no control over LA budgets if they think the person needs additional support.</p> <p><i>A psychiatrist from Cambridge said that her letters asking for a higher level of support for people received no response</i></p>		
<p>NHS commissioned and provided specialist LD services not in tune with the social care model of LD</p> <p><i>SCENARIO 1: P lives at home with parents. Aggression towards his father by P, though not towards people at his day and short breaks services. Parents finding life v difficult. The family is offered intervention from the NHS LD Outreach team who aim to prevent admissions to inpatient services. The parents refuse the service as they have previously not found it useful.</i></p> <p><i>SCENARIO 2: Y: lived in own home with support commissioned by the NHS. Denied access to physical interventions either due to a lack of this being in the service spec or the wrong provider being selected or – worse – the provider being told it was illegal. Removed to inpatient services. PCT pushing for long term hospital placement</i></p> <p><i>SCENARIO 3: The project team was invited to present to a provider forum. Suggested the organiser invited the NHS crisis/inpatient services to discuss service interfaces. This was not usual practice yet there is no other forum where the services reflect on how they work</i></p>	<p>Are NHS commissioned and provided specialist LD services fit-for-purpose in relation to people with challenging behaviour i.e. do they promote the social care agenda and supported living?</p> <p>What is the basis of the typical NHS crisis/outreach team's approach - the underpinning model? What are they being asked to do by commissioners? Is there a service specification or just a number of face-to-face contacts in the whole of the provider's contract – a line on a spreadsheet?</p> <p>Do the teams deploy positive behavioural support? Do they rely on reactive strategies? Do inpatient services offer positive behavioural support? How do they do this despite what we hear about high staff turnover and use of agency staff?</p> <p>Do LD specialist services offer a model of support which does not fit with the philosophy and direction of the personalisation agenda?</p>	<p>Providers need to routinely talk to NHS specialist services – developmental dialogue – how do we work together? Do our models complement each other? The two sets of providers then need to advise together re funding/service model for individual people with the LA or NHS commissioner.</p> <p>It would be good to identify an area where the NHS specialist services work closely with commissioning. This seems to be the case in Glos. Any others?</p>

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<i>together.</i>		
LEGAL FRAMEWORKS – MHA . COP		
Needing a tenancy signed by the CoP will burden care managers / adult social care commissioners, disrupt the payment of housing benefit and potentially delay arrgts <i>Someone in one area had been waiting 9 months to be discharged due to COP delay – their home was ready for them</i>	Are CoP applications increasing? Is it possible that the needs of people with LD are becoming too legalised Recent messages from the COP sound as if reason is prevailing	LA have powers to make a Best Interest Decision provided all are in agreement
A belief that people without capacity need to go to CoP to have security of tenure <i>In one area an experienced SW believed supported living was not possible for someone unable to sign a tenancy without COP</i>	Only if the person having a tenancy is a matter disputed by those around him and therefore needs to go to CoP. – otherwise no need for CoP	As above
A continued lack of clarity on DoLs policy for people without capacity for whom supported living would be a Best Interest Decision option of choice <i>In one area an experienced SW believed supported living was not possible for someone as they need DoL to be safe.</i>	Caselaw has shown that as long as receiving physical interventions and having doors locked is in a person's assessment of need, providing a service with these features in a person's own home is lawful without recourse to the CoP.	Relationship between MHA and MCA needs further exploration e.g. use of CTOs (related to medical model within social care model)Develop the policy through practice – advocates and providers to shape. Practitioner guidance needed
THE COST OF PERSONALISATION		
The high costs of services encourages continued use of residential care even through people suspect that although 2:1 is commissioned, this is not actually delivered. <i>discussions with various workers and senior managers</i>	Commissioners believe that people need 2:1 yet 2:1 staffing could lead to staff relating to one another rather than the person, escalating/provoking negative behaviours. Although the principle of delivering higher quality staff on a 1:1 basis (more trained) moving from a service which relies on 2:1 to one which delivers safely 1:1 would be a massive change in provider culture and practice	RADICAL CHANGE IN COMMISSIONING Implementing this thinking would lead to radical change in commissioning services, improving service quality and virtually halving costs. We should develop a QIPP proposal e.g. for how Sarah would work with providers to help them achieve

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		that change: Sarah would need to work with them over a 2 year period, with intensive training and support at first, moving to mentoring and monitoring. See project plan in email
Cap on Direct Payments – so that people having Direct Payments cannot afford to commission their own service	Peter believes this is something to do with In Control	Needs to be clarified as LAs have a duty to meet assessed needs and cap on hourly rates perhaps goes against this requirement?
R's mother believes barrier to supported living in their affluent area is care worker shortage as pay is too low.	Needs testing before assumptions accepted on this	
LACK OF UNDERSTANDING OF CHALLENGING BEHAVIOUR		
<p>If the person's behaviour presents too much of a challenge, supported living providers not prepared to offer a service. Yet their behaviour is likely to be arising from their current situation which needs to change</p> <p><i>One area reported that a person being secluded in an ATU was regarded as too high a risk by a provider and that they would not take him until he stopped being secluded.</i></p> <p><i>Another person in an ATU was said to be having an unsettled period, yet we knew from another source that there were severe staffing shortages at that time – no link was made by the worker between the two</i></p>	<p>Living on an inpatient unit where only reactive support is provided due to understaffing and the use of agency staff; where the other people there are all disturbed; where the environment is not the person's settled home must surely trigger people's behaviour</p> <p>Use of inpatient units for people with challenging behaviour needs to decrease</p>	<p>More training in understanding challenging behaviour is needed for ATUs which can be dominated by a mental health model, and also for support providers who want to develop services for people with challenging behaviour</p> <p>Inpatient units need to use proactive behavioural support plans for each person with a transparent system to track when these are not being put in place due to a lack of staff – this way it can be seen what potential there is for the person to respond to positive behavioural support.</p>

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THEME Barrier <i>Evidence</i>	Analysis / Hypothesis	SOLUTION
<p>People's challenging behaviour when they have high levels of support continues to be seen as an individual character trait rather than a form of communication <i>Workers cited high numbers of incident forms as evidence that the person is not yet ready to leave where they are</i></p>	<p>High numbers of incident forms probably indicate that the person is not well supported in their current arrangements</p>	<p>Positive Behavioural Support Training needed for all commissioners so they understand challenging behaviour and what building the right support for someone means – not just 2:1</p>

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APPENDIX H

EVALUATION OF THE PROJECT BY THE PROJECT TEAM

On April 27th 2012, the project team assembled to reflect on the project and think about what worked and what didn't work about the project. We also asked why some things had worked and some had not - as lessons for future projects.

WHAT HAS WORKED?	WHY DO WE THINK IT WORKED?
<p>Strengthening individual commissioning</p> <p>We added value to the work of some SWs who spontaneously expressed appreciation. Although they were hard to get hold of, care managers were prepared to reflect on their work and think through what needed to happen. This seemed to be well received by the care managers who we were able to engage</p>	<p>Their cases were at the right point of needing the project's input i.e. the worker was already planning change or there was a clear need for change due to risks. The workers appeared to be particularly open to learning and they wanted to improve their practice. We possibly talked about areas they had not considered or that they had dismissed. For some workers, new generic team management means their line manager does not necessarily have knowledge/experience around complex needs so the project seemed particularly useful</p>
<p>Improving knowledge of positive behavioural support</p> <p>All workers who spent time talking to or liaising with the Behaviour Consultant found this interesting and useful</p>	<p>One piece of consultancy about someone in an OOA placement enabled the SW and family to see it was not adding value so it could be brought to an early end. The placement cost twice what the future supported living service will cost with the person returning to his family's local community instead of living over 80 miles away. One area has chosen to commission more input which also may be due to learning from campus re-provision where the only advice available to the commissioners was from providers, both incoming and outgoing</p>
<p>Improving Housing Options</p> <p>Housing advisor visited some people's families to talk about supported living. The visits were well received by families</p>	<p>One family moved on particularly significantly in their thinking about what options there could be for their relative as an alternative to residential care. He was impartial and not linked to LA or NHS. They probably found his expertise reassuring</p>
<p>Developing Provider Knowledge</p> <p>The provider workshop in one area was well received by attendees. This was a presentation on the work of the CBF, the project, housing related policy and the theory of positive behavioural support</p>	<p>The project team prepared well and considered the audience's perspective. The audience appeared to like the free expertise on offer - they see CB as a growth area. We had been told to expect 28-30 people as attendance is optional yet there were over 50</p>

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WHAT HAS WORKED?	WHY DO WE THINK IT WORKED?
<p>Multi-Agency/Generational Commissioning</p> <p>The initial inter-agency project set-up meeting in one area stimulated useful discussion. There were representatives from children's services, continuing healthcare, specialist healthcare services, someone reviewing healthcare services, adult care, specialist teams. Everyone could think of at least one case which was 'stuck' and the need for help with it</p>	<p>Meeting attendees saw how each other was involved in the CB pathway and there was a sense that they did not appear to know each other well or communicate systematically: the enthusiasm in the meeting promised to improve collaborative working such as shaping the market</p>

WHAT HAS NOT WORKED?	WHY DO WE THINK THIS IS SO?
<p>Local Ownership</p> <p>The project design relied on a local lead role to drive local progress and engage between local leads meetings in e.g email discussion or attending events such as the DH review or other forums</p>	<p>The project started at a time when public sector spending cuts were about to impact, with huge organisational change being implemented and uncertainties in staff structures. Local leads did not appear to have time to work on getting the best possible impact from the project. One asked us to convey to their senior managers that they needed to understand operational pressures and not agree to initiatives for which there is no capacity. For 6 months, another said they were only 'holding' the role until someone was nominated. That 'someone' was nominated in January 12 though they were only in role until the end of March 12. They had no working links with the NHS, no mainstream role and access to only 1 care manager.</p>
<p>Getting on with the project</p> <p>People were nominated either very slowly or not at all. Took a long time to get nominations and we had to expend a lot of effort to get them</p>	<p>Area 1's local lead manager was off sick, delaying nominations. The person who nominated Area 2's people had no operational link to care management. Area 3 only managed to enable one worker to participate out of a possible five. Area 4 did not appear to have any way of identifying the people and SWs to participate and had no dialogue with the NHS. Area 5 was keen to participate though took a long time to decide which officer would engage with the project</p>

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WHAT HAS NOT WORKED?	WHY DO WE THINK THIS IS SO?
<p>Outcome-focussed plan</p> <p>– a person-centred plan was assumed as the starting point for each person</p>	<p>We were not tasked or resourced to provide support with person-centred planning as it was assumed that previous investment in this would have matured into embedded practice. However, the lack of person-centred plans - ambitious or otherwise - were a barrier for many people either in terms of timeliness or altogether</p>
<p>Developing individual plans</p> <p>There has been very slow progress on developing plans. None are complete</p>	<p>Several workers regarded person centred planning as something only PCP co-ordinators could do and were not proactive in setting this in train. The other observation is that unless there are immediate risks making a person’s life unsafe in some way, proactive planning is not a service priority.</p> <p>We only observed proactive planning for two people. For four others, planning has been good but stretched over time, so though change is being actively planned, their situations have not changed quickly. Some SWs engaged only superficially. Two opted out entirely. Some did not have time due to major changes in team and management structures. Others said other work was more urgent (safeguarding; DOLs; best interests decisions) or they just had too much to do</p>
<p>Wider impact of learning</p> <p>We were not able to set up action –learning sets or explore of issues</p>	<p>People said they did not have the time to participate in action learning sets. We did not get responses to questions presented as email discussions; a well-designed commissioning workshop for one LA was poorly attended. People arrived late for meetings and left early. Difficult to plan phone calls</p>
<p>Support at the right time</p> <p>A lack of or slow person centred support planning processes meant there was a lack of stated sought outcomes for people which we could help realise through advising on the commissioning process</p>	<p>There was not enough resource to offer local consultancy for the full development of a plan so the focus was on advising on how to achieve the identified outcomes of a PCP e.g. “a home of my own”. On reflection, it might be been better for consultants to get involved earlier to encourage more ambition from the outset. However, there would then have been insufficient consultancy resource to then support workers to realise the ambitions. We tried to manage the resource across areas so if one area needed more PBS and another more housing advice, this would balance out. An alternative would have been to allocate a time budget of each consultancy to each person to be used or not</p>

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WHAT HAS NOT WORKED?	WHY DO WE THINK THIS IS SO?
<p>Housing outcomes</p> <p>Project came out of the regional housing agenda, but housing advice was not the priority need in the cases identified. and for others it was direct work to help to engage troubled families</p>	<p>People who signed up for the project moved to other jobs or retired when the project started. Perhaps they did not brief those who took it forward re the housing objective so several nominations to the project did not reflect this</p> <ol style="list-style-type: none">1. Some families did not agree with supported living and needed skilful family intervention to work towards a more open attitude2. Others needed more general skilful direct work with their family which we were not resourced or intended to offer3. Some people put forward were in a care home yet no move was wanted by the workers or the families4. One local authority worker was keen to use a residential care model and was supported by the NHS commissioner in this
<p>Contributing to Joint Strategic Needs Assessment</p> <p>Not aware whether this happened at all</p>	<p>Local leads did not wish to engage in discussion about this in meetings or by email. When asked to confirm that they would make the necessary local links they affirmed that this would happen, but they did not answer a question about how it would happen</p>

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APPENDIX J

FEEDBACK ON PROJECT FROM TWO CARE MANAGERS

At the end of the project, the project manager emailed the 14 care managers and several others who had been involved with the project and asked 6 questions:

1. *What did you find useful about the project? What worked well?*
2. *What could the project have done better? What did not work well?*
3. *What did you learn from the project? How did it help you?*
4. *What barriers do you think there are to achieving personalisation for people with complex needs?*
5. *What solutions do you think are needed so they can be overcome?*
6. *Do you have any other comments?*

Two care managers responded and two others indicated that they would but did not.

Care Manager One

1. What did you find useful about the project? What worked well?

I found it useful discussing the case with people who are working with or have experience of working complex cases. However, what was most useful was having the involvement of the PBS and housing consultants and project manager.

The PBS consultant was able to appraise the work/assessments of the 'specialist' placement and conclude that CD did not require the on-going clinical support and that it could be provided on an outpatient basis. This enabled both parents and SWs to view things very differently re what CD needed and question why he was at the specialist placement. The housing consultant was able to offer a wealth of info on housing which can only be provided properly by an expert. Usually a SW would have to do this.

The project manager offered care management skills around cases which in a climate of LA's where managers are managers and are no longer knowledgeable/experienced about the fields of care they are responsible for.

2. What could the project have done better? What did not work well?

One of the barriers to moving people with complex needs can be parents. I know the project did offer some support to parents on a case by case basis, responding to need when they became aware of it.

Perhaps a day at the beginning of the project getting parents together to outline project and meet the team and then on going meetings? When I speak to CD parents they see their case as very different to others, which obviously it is. However, I think this is why parents/professionals hang on to these specialist placements because they feel no other case is like there's and it needs the specialist provision nowhere else can offer.

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3. What did you learn from the project? How did it help you?

As a worker coming back into LD work I learnt a huge amount on many different levels. I have learnt how very difficult it is to move people from these specialist placements once they are in, even if we all agree it's for the best and it's what the person wants. Having expert involvement helped me break through the 'fog' on knowing where to go next...I've learnt that everyone else is experiencing the same :my case is not unique.

4. What barriers do you think there are to achieving personalisation for people with complex needs?

Medicalisation. Parents/professionals are made to feel by clinical leads that the person needs to be in their placement. I feel that in our case CD would benefit from on-going clinical support but the problem is we don't have the Psychology or the clinical confidence/'sell' the placements have. Psychology is difficult to commission and then provided in an adjacent area which relays to parents that this is an ad hoc service which doesn't work tightly with professionals in our local area. Parent still feel where challenging behaviour is an issue that clinical advice is the decision maker.

We have a huge difficulty getting providers to work in our small county because we don't have the numbers to make it worth their while. Also recruitment for them is a really difficulty. This also impacts on personalisation as we do not have the scope to recruit the people we need to post (through providers or Direct Payments). Also we don't get the people who we know are needed/have the skills to support complex needs on the wage providers are paying. With my case, the family feels a Direct Payment would put more work on them when they are already exhausted by caring for a person with complex needs.

Parents can be a barrier. As much as we advocate for SU's, we are always walking a line where we are taking parents views on board. It may be that a barrier is that SW's listen more to parents than SU's. But with MCA and best interests, family would be the people who we would be accessing. Obviously this can be challenged but in reality I don't think this is done unless there are clear concerns that someone is not acting in someone's best interests.

LA's view is that we have to have independent provider and not workers from LA's (again though, we are laying ourselves open to being led by their agenda and marketing) be it in a placement or living locally. A barrier in my case to using independent providers is that parents feel the risk increases if they move someone into independent living. They feel this because there is no team close by and communication and monitoring is more difficult.

Parents also feel cynical about providers as they have already fallen for the "hard sell" (their words) and that if they move to a core and cluster the provider would have to be very different to the usual elite companies that have most of the 'market'. They are not convinced this is the case. Barrier is gaining parents trust with providers who are not providing what they say they will. There are pockets of providers who are managing to provide excellent personalisation care but they are still in the minority.

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SWs trying to co-ordinate this by themselves within the time constraints of the job and work pressures.

Children may have already been placed in high cost placements away from home earlier on because maybe one aspect or more had broken down. In our area we have no special needs schools in county so children have to go out of county. It becomes the norm by the time they reach adulthood. Independent Service Providers are out of county. These provide specialist care/education for complex cases.

Parents are used to this type of provision and feel by the time a child reaches adulthood that they cannot live locally as provision has never been there.

5. What solutions do you think are needed so they can be overcome?

I have looked at everything, housing, behaviour modification, person centred, talks with clinical leads, PCP review and plans, PCP service spec, working with contracts, exploring other providers to moving CD locally. What stops this happening is that parents are not convinced (even with PCP service spec) that supported living providers will provide the care they say they will and that the clinical support is not as robust if he moves back locally.

We have a health community learning disability team of - OT's, outreach nurses, SALT, Psychiatry (not Psychology - but we can refer to adjacent area) who meet every two weeks as part of our MDT process. They work quite separately in many ways because they have health processes and are not co-located with social care workers.

Ideally they would work together with SWs to support complex cases moving back. But they can't be involved before because the person's GP is not in our LA (funding issue). But if the LA and health agreed a way forward for professionals to have a robust team in place to support people with complex needs moving back locally to supported living, parents may feel more confident than a lone SW talking of the benefits.

A multi-disciplinary team approach both in the transition and the care management would be ideal. And I think this could be done using existing resources differently. I felt it was me negotiating all the processes/systems that health/ social services/independent providers have, within the time pressures of a SW's caseload

If LA provided a specialist in house service to support the high need, complex cases this would erase some of the issues we have. If we could have an in-house service, this would provide a more robust care that parents would feel better about and would be cheaper for LA than his current out of area placement. But this won't happen because the view of LA is that they don't want to provide services in-house. Yet they are willing to pay overpriced placements out of county!

6. Do you have any other comments?

No

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Care Manager Two (who referred the two people in Appendix B)

1. What did you find useful about the project? What worked well?

Once I had information on the CBF, the work was carried out quickly. The report that was completed on the customer addressed the issues and gave solutions. Good feedback on Sarah's input from the staff that are working with the customer.

2. What could the project have done better? What did not work well?

It was difficult in the beginning as I got involved in the project later on so communication did take a while to become fluid. I feel that there would have been several customers that would have benefited from the project but with the time restraints it was not possible to include them.

3. What did you learn from the project? How did it help you?

Having knowledge of the project is helpful and I feel it is something that we could use in the future to support with reviewing complex customer to ensure needs are met in the most cost effective way.

4. What barriers do you think there are to achieving personalisation for people with complex needs?

Not having enough appropriate resources within the County, not having enough skilled experienced providers to meet the needs of complex customers so they are able to have choice on who supports them. Finding appropriate accommodation.

5. What solutions do you think are needed so they can be overcome?

Having more specialist providers that can meet the needs of the customers, in turn this would provide the customers with more choice of who support them.

6. Do you have any other comments?

I found the staff on the project very helpful and knowledgeable. Jayne and Sarah were very professional and Sarah went off and completed the assessment and gave me feedback and the report in a timely manner. The report enabled me to follow up issues that she raised. I feel this service could be beneficial with other customers we support.

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Appendix K

The South East Housing Project

Report from Alicia Wood, Housing Options – September 2012

The South East Housing Project is a short term project funded by the Department of Health South-East region and two local authorities. It is led by Alicia Wood of Housing Options. The aim is to commission and enable local and personalised housing solutions for individuals with learning disability and complex needs.

The Challenging Behaviour Foundation has been a partner in this project providing links to families and disseminating learning.

Three local authority areas are participating and the project is also working with individuals living in two other South East local authorities

There has been mixed progress

Local Authority One

This area has used the project most actively, topping up the project funding with local funds to achieve the following

- Design of a housing assessment process for people with challenging behaviour
- Design of a housing pathway for people with challenging behaviour
- Housing design checklist
- Set up a Challenging Behaviour network for providers, health and social care professionals to develop and share good practice
- Set up a Framework commissioning agreement with 5 providers to deliver specialist support to people with challenging behaviour in a flexible and person centred way
- Set up local housing for 6 people with challenging behaviour by making better use of council property to adapt into a specialist service with individual flats and support
- Worked in partnership with a support provider and private developer to commission a service with 3 individual flats built around the needs of particular young people
- Enabled a young woman with complex needs to return from out of area

Local Authority Two

- Provided advice and information to rehouse a young man with challenging behaviour but this has not resulted in a move
- Provided workshops for social services and health staff

There has been insufficient local action to enable progress with any individuals.

Local Authority Three

- Have established a new internal group to identify individuals who can return to to the local area if the right housing and support is put in place
- Have included development of local housing and support services for people with complex needs within the Council's supported accommodation strategy

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- Have identified a group of local providers with a track record of delivering housing and support services for people with complex needs

During the project, Local Authority Three has not yet brought anyone back from out of area or delivered a new local development for people with complex needs.

Progress with individuals in two other authority areas:

Person 1: The key to progress for person 1 has been concerted determination on part of the person's parents to tackle unproductive public sector bureaucracy and the apparent indifference of officials. They have done this with assistance from external parties including solicitors, the Challenging Behaviour Foundation and Housing Options.

Person 2: Housing Options has met twice with the family and identified the preferred option of the family to be the construction of an annexe to their property. Housing Options has subsequently provided assistance by phone and provided a housing plan for person 2 for use by the family. The plan sets out for the benefit of other 'partners' why the family's preferred option is the right option for person 2. The key barriers to progress have been the PCT being the 'lead' in the person's support package (CHC funding) yet not demonstrating any leadership in funding a solution that suits the person and their family and a lack of coordination between the PCT and the local authority.

Barriers to progress

These tend to be 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 competing priorities.

Why has Local Authority One made more progress than the others?

- A committed commissioner with strong values and action focussed, perhaps made easier by being a smaller council
- They understand the business case for enabling people to access local services rather than being sent out of area. They can communicate it confidently to decision makers "*it will cost us a lot to support people well locally but no more than it does to send them away- in some cases we will make savings and in others not*"
- Getting providers on board at an early stage to develop services through the framework agreement means that the collaborative approach sits alongside the competitive tender process well. Ahead of the tender process, they get providers and practitioners together in a room to discuss how they can bring a particular individual back to the local area.
- They have effective staff leading on this process who have a mix of strategic vision and understanding individual need.

For more information about the services and support which can be provided by Housing Options see their website at <http://www.housingoptions.org.uk/>

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FOR INFORMATION AND SUPPORT ON CHALLENGING BEHAVIOUR

www.challengingbehaviour.org.uk

FOR INFORMATION ON HOUSING OPTIONS FOR PEOPLE WITH LEARNING
DISABILITIES

www.housingoptions.org.uk

FOR INFORMATION ON PERSONALISATION IN ENGLAND

<http://www.scie.org.uk/topic/keyissues/personalisation>

FOR INFORMATION ON PERSON-CENTRED PLANNING

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_115175