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**[1]
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.
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. **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		

[1] The project team does not take credit for all actions and changes

Person	Situation	Action and Change during the project[2]
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.

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 themself 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.

What is the positive note in this situation? B's person centred planning is being led by an experienced and skilled facilitator

Person	Situation	Action and Change during the project[3]
Person C	We are not able to report on this person	Details not reportable

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

Person	Situation	Action and Change during the project[4]
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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[4] The project team does not take credit for all actions and changes

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[5]**
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 6 weeks ago. I wanted the advocate to get to know 'E' before progressing to person-

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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**[6]
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[7]
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[8]
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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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[9]**
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

[9] The project team does not take credit for all actions and changes

Person	Situation	Action and Change during the project[10]
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

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?

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.

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.*

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.*

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.

What is the positive note in this situation? The commissioner is determined to find a local solution for K

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

Person	Situation	Action and Change during the project[11]
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.

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.

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….*

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.

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.*

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

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Person	Situation	Action and Change during the project[12]
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.

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.

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.

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.

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.

What is the positive note in this situation? The SW understands this person very well indeed

[12] The project team does not take credit for all actions and changes

Person	Situation	Action and Change during the project[13]
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!
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 **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		

Person	Situation	Action and Change during the project[14]
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
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 **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		

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.

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)

[13] The project team does not take credit for all actions and changes
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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**[15]
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 recommission 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.
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 provider has recently started to deteriorate, due to the		

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

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[16]**
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.

[16] The project team does not take credit for all actions and changes

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[17]**
Person X	*X, aged 36, had l*ived 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

[17] The project team does not take credit for all actions and changes

assurance that the organisation of our choice will be commissioned. Despite their opposition, the PCT never came up with any other choice of providers!

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[18]**
Person W	*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.* *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.* *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*."	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. 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. 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.
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		

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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.

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[19]**
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

[19] The project team does not take credit for all actions and changes

		take up to an hour each way.

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:

- *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.*
- *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) t 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 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[20]**
Person T	*"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. "*	**What happened? Update July 2012** 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. 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.

[20] The project team does not take credit for all actions and changes

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.