

**Healthwatch Gloucestershire
Review of user experience of support planning
for people with a learning disability**

Phase 2, March 2017



Contents

1	Introduction.....	3
2	Healthwatch Gloucestershire (HWG).....	3
3	Project plan and methodology	3
4	Feedback from people with learning disabilities, collected May 2016 - February 2017	4
5	Feedback from the families of people with learning disabilities, collected January 2016 - March 2017.....	13
6	Feedback from support providers involved in support planning, collected May - September 2016	31
7	A note on quantitative and qualitative evidence.....	32
8	Key findings.....	33
9	Recommendations	36
10	Acknowledgements.....	37

Disclaimer

This report relates to findings between April 2016 and March 2017. This report is not a representative portrayal of the experiences of all people undergoing support planning; only an account of what was observed or contributed during the research by the project coordinator.

1 Introduction

In its document *Quality-checking the Learning Disability Customer Journey*, Gloucestershire County Council (GCC) recognised that, in order to be working within a truly quality-focused environment, as an organisation and provider in its own right it needed transparently to partake in a quality assurance process of its own support and systems for people with a learning disability.

GCC invited Healthwatch Gloucestershire (HWG) to undertake a quality-check of that part of the 'Customer Journey' relating to people's experience of support planning.

In its document, GCC said

the objective of the quality-check will include

- *What is the service users' experience of support planning?*
- *If our objective is to produce a support plan and personal budget for each person which delivers on meeting their needs and outcomes and is co-produced with the person, family and carer, what do people's views tell us about how well we are doing this?*
- *Do service users tend to feel they have choice and control over the process? Do they understand the outcomes they are working on and were they their suggested outcomes?*

2 Healthwatch Gloucestershire (HWG)

HWG is the local independent consumer champion for health and social care giving patients, the public, service users, and their carers and families a stronger voice in how health and social care is planned and provided. It is one of 148 local Healthwatch organisations working with Healthwatch England.

3 Project plan and methodology

HWG drew up a two-phase project plan. It submitted its report on Phase 1 of the project to GCC in March 2016. A public version of this report was published in June 2016.

Phase 2 of the project involved gathering individual's views on their participation in support planning. This involved meeting face to face with people who had been through the support planning process (and their families and carers if appropriate), to find out about their experiences and views. These interviews were carried out in a conversational style, rather than mechanically working through a sequence of questions. People were also invited to contribute via a variety of routes to capture as wide a range of experience as possible; including via GCC, user-led groups, providers' self-advocacy forums, parents and carers' groups, voluntary and community organisations, and HWG membership.

The HWG project coordinator met with the Strategy and Transformation Manager in August 2016 to further refine the objectives of Phase 2. GCC was particularly keen to learn about people's views on whether they were in control of the process and of the plan; and also to ask people "*what do you think could be better?*"

4 Feedback from people with learning disabilities, collected May 2016 - February 2017

4.1 May 2016

I have support workers in Thursdays and Fridays. It works well for me. They are Penderels Trust. They help me with cleaning and shopping.

4.2 September 2016

Feedback from T, who lives in a residential care home in Gloucester. T has learning disabilities and significant physical disabilities.

The registered manager at the home explained: *“T has lots and lots to say. He can understand very well. He can respond, but it takes a while to form a response, and it is tiring.”*

The manager explained that T was getting a computer to use for communication. This was not part of his support plan, though - this was happening separately. The CLDT speech and language therapist had organised this.

We asked T about his support planning. He said

- There was just one meeting for the plan
- It was a new support planner I didn't know
- This was a different person to the assessor
- I said I wanted to carry on living here
- Sometimes it is hard to remember who asked you what - so many people come, with so many questions
- The support planner asked about things I'd like to do - I said about motorbikes. I'm going to Donington
- We didn't have a lot of time. No questions were sent beforehand for me to talk to the staff about, or to think about. No copy of the form beforehand. No information beforehand
- I think the lady who came was in charge of the meeting
- More time would have made it better
- Pictures to use as answers would have helped
- Maybe if it was split up into different sections, to talk about on different days

4.3 September 2016

My last support plan was done in 2013, so I'm overdue. I'm going through reassessment at the moment. I've been told *"you have to fit two of the five criteria in order to qualify"*. But I don't know what these criteria are - my social worker hasn't told me.

I live independently with some support. My support has been reduced. I used to have 13 hours of support but it's been reduced to 2 hours. They won't let me have this in one session - I have to have two one-hour sessions, one on a Tuesday and one on a Thursday. This isn't what I wanted to happen. Most of this time is taken up with medical appointments, but I need support with cooking so I can make healthy meals. I don't do any cooking. At the last meeting she said *"if you can put a meal in a microwave, that's healthy eating. There are other people who need more support than you"*.

I used to live in supported living in Cheltenham but then they decided this was a 'move-on' placement and I needed to live more independently. So I moved to where I live in Stroud but I'm really lonely here, I haven't made any friends and I want to go back to Cheltenham. When I said this to the social worker, they said I couldn't go back to supported living because I was too able. They said I should look on the internet for another tenancy. I got a single Enablement session to do this. We didn't find anything.

My Mum is at the assessment meetings, and sometimes the support worker/manager, and sometimes my friend through Building Circles. They haven't offered me an advocate.

They don't explain to you what the difference is between a FACE assessment and a support plan.

My biggest problem is that I want female support. I had a male support worker, and he was fine, but I still wanted female support ideally and then he took offence. Also, he would ring up on the day, and say *"I'm coming at such-and-such a time"* which didn't always fit with me. So now, the manager is coming instead. He rings me up at the beginning of the week and we make a plan.

You get told *"if you go to the Drop-in, they can help you write a shopping list"*. But there is not a private space at the Drop-in where you can do things like this without other people listening in.

I've been diagnosed with depression and I see a male CPN at Weaver's Croft once a month.

4.4 January 2017

I don't think I am in control. It's too confusing. It needs to be easier to understand. I feel they don't do much to help, they make me more confused. If they gave me information, Easy Read information, that would definitely help.

The meetings are quite long - I find them too long. If the meetings were shorter, but have more of them, I think that would help. I would get to know the person.

My support is not the way I want it to be. I've been in respite for a while now at Cathedral View, 5 months, and I find it all a bit much sometimes. I find it confusing, sometimes I'm there and sometimes I'm at home. I don't understand why I'm there. My home is in Dursley with Mum and Dad. I'd like to see Mum and Dad, but when I ring up, sometimes they say 'no'. But nobody will sit down with me to explain. It worries me. If someone would explain, it would help me.

I don't dislike it at Cathedral View, I know the staff do their best, but it's not like being in your own home. At the weekend, we just stayed in and watched telly because, when Z [another service user] is there too, we can't go out much because of how she is. When she's not there, we can do more, and go out more.

4.5 January 2017

I don't always understand what they're talking about when they come out to meet me. They come and say they're doing a meeting. But they don't really tell you what they're coming for and they don't explain it easily either.

I don't feel that I can speak up in those meetings.

4.6 January 2017

I had a meeting and I didn't like it, it was boring, I told them to go away, I didn't want to see them.

4.7 January 2017

They did try and make it easier to understand, but sometimes they're telling me a bit too much. It takes me longer to understand. It feels better after Mum has explained it, after the meeting.

4.8 January 2017

Support staff talk to me about the meetings afterwards to explain what it was about, and that helps.

4.9 January 2017

I get these 'off' days and then it is extra hard if I'm feeling like that and it's a meeting.

4.10 January 2017

I haven't had a meeting about my support plan for a long time. I live with my family and I work at the Treasure Seekers shop. My family support me and that works well for me. My life is the way I want it to be.

4.11 January 2017

I live in a care home. I've been there 13 years. It's not too bad actually. The meetings at the care home are alright. I really don't know whether I'd be able to change anything about my support if I wanted to.

Sometimes, when I'm not feeling up to it, I'm forced to go out, even though I don't feel like it. I do know it's better to go out and be with people, to be in groups and that, because you vegetate when you are by yourself. They sometimes get a bit annoyed when I don't want to go out.

I like art and craft groups when I'm feeling up to it. I like studying boats and tall ships and I'm interested in wildlife and Royal Family history and music and cooking.

4.12 January 2017

The people who come to meetings with me are someone I've met before, and that helps with questions.

I don't know whether I'm in control or not. They ask the questions.

I think there is enough time in the meetings for me.

I think I would be able to change my support if I wanted to. It's working well from my point of view.

4.13 January 2017

I've not had a meeting for a long time. There wasn't any information.

My family were at the last meeting. I feel I can speak up in meetings if my family are there.

I live in supported living. It's good. I get to do the things I want to do. My support plan helps me to do those things. I look after children at work at Kingfishers. I've been doing this for a year.

4.14 January 2017

My support plan - I have an advocate. There was a review of my support plan in lots of detail last year. Then OPENhouse help me make a weekly plan.

There was a long wait between the assessment and anything happening - and then there was another reassessment. Less waiting would be good.

The person who comes is different every time. You don't know the person. They do their best but the meetings are long. They are in control - they are asking you all the questions, and you are thinking - "*what is this question about?*"

The information in the FACE assessments are very wordy, the support workers at OPENhouse explain things and help me to understand.

My support plan means I live my life the way I want - I've got goals, OPENhouse help me put them into my weekly timetable.

I've been with OPENhouse 9 years. I started down in the main house, then moved to the flats, then back to the main house for a bit, then back to the flats, and now I'm in my own place with OPENhouse floating support.

4.15 January 2017

It is a long time since I had a meeting with a social worker.

18 months ago they put my support hours up, because my support worker put all the evidence together to show that I needed extra support with my physical needs.

Also, my Mum got involved because I was very unhappy in the flat where I was living - I had neighbours from hell.

The support planner was new to me, but my last social worker was awful so I'm glad it wasn't them.

I felt that I was in control of the plan.

I feel that OPENhouse is much better than my last support.

4.16 January 2017

Having a support plan for here at the house is really helpful, and it helps me with the future as well. Someone came along to help me with it.

I am in control of what's in my support. I'm really grateful I've got it.

4.17 February 2017

I had a support planning meeting a long time ago, with Christine Brown and Leon, Dan and Helen.

I don't want meetings all the time, it gets on my nerves. Just a couple of times to see how I'm getting on.

I like information with pictures.

4.18 February 2017

I live in supported living. I have meetings with support workers in my house because I get really worried about things. Sometimes this is helpful. When I get agitated, I get pains in my tummy, like someone is squeezing it. My doctor says "*eat more fruit*" but the support workers keep cooking me the same food, they're not cooking the right food, and I'm losing weight.

I've got a shower in my bathroom but the step is too high - I can shower myself, but getting in and out of the shower is the problem. I'm waiting for a wet room - but I've got to wait ages.

At my support planning meeting it was my Mum, and Bo, and somebody else, and Kevin the support planner. Kevin was quite good - he didn't speak too fast, he explained. He asked about what activities I liked doing, and any hobbies.

I could put things in the support plan that I wanted. My Mum said what she wanted to say as well.

4.19 February 2017

I have a plan where I live in supported living. I had a support planning meeting not long ago. I hadn't met them before. At the meeting there was Sally the care manager from Phoenix, Amy the big boss and me. I felt I could make my choices heard in that meeting.

I've started doing voluntary work, getting out and about - this is quite a new thing for me. The support I get in my supported living is the way I want it to be. I think it is OK - there isn't anything different that I think it should be.

4.20 February 2017

The support I get helps me live my life the way I want. I've lived in the same place for 25 years.

I feel listened to in meetings about support. If I wanted to do something different, I would be able to make that happen.

I think that my support could be better.

4.21 February 2017

My support plan means I live my life the way I want. I am proud of doing things for myself. I live in a flat.

I feel I can speak up and say "*this is the way I want things to be*". I don't want things to change.

I feel that I do get enough information. I can read and write.

I am happy as it is.

4.22 February 2017

I get 4 hours' support a week. This feels like nothing. I did get 13 hours 2 years ago.

I suffer with mental health challenges and, when I'm going through a really trying time, 4 hours doesn't feel enough at those times. In these times I feel it would help if they had more time to listen to me. So sometimes it takes me longer to get through it. I'm lucky because I've got a very supportive psychologist, Tracey Morgan who will come to my house, or if we are doing more intense therapy I see her at the Memorial Hospital.

I'm having a review of my support plan at the moment. I'm petrified they are going to cut my hours. I was worried they were going to cut them last year too.

When they come and do the assessment, I think they come to their own conclusions about "*this many of your hours is for this purpose, and this many of your hours is for that purpose*" - and this isn't sometimes what I would like to use the hours for.

I haven't met the support planner who's coming before - I was hoping that it would be the same lady who did it last year, but it isn't. I am getting better, but sometimes, I get anxious about meeting new faces. And I think, how can they make decisions? Based on meeting me for an hour? I think it would be better if you could meet the support planner beforehand. My anxiety levels can be sky-high.

Having a chance to prepare some of the support plan beforehand might be helpful.

Sometimes, people have written in my support plan that I can do something - well, yes, it is something I can do, but I do need some motivational support to help me.

If there is something I'm not happy with, I will say. Sometimes, I feel that I put an opinion across and it is dismissed. That's not just in support planning, that's in other things in my life too. So sometimes I don't have a voice.

Sometimes I feel that the process is dragged out - I did some Enablement at the end of last year, and then that case was closed, and then social services didn't call me until a week ago, and the appointment she made was in a month's time, in April. Why does it have to be so drawn out - why can't it be quicker?

5 Feedback from the families of people with learning disabilities, collected January 2016 - March 2017

5.1 January 2016

I have 2 sons. They are 20 and 21. Both have learning disabilities, and autism. F is 21. He was at Star College last year, and now he is at home full time. C is 20. He is currently at St Martin's Post 19 Centre in Stroud, where he receives 1:1 support.

He tried 2 other special schools before this. He has very limited verbal communication, high anxiety, and sensory issues. C doesn't cope with having more than one person around. His sensory issues are extreme - he is very, very sensitive to vibrations. C cannot use SEN transport - he cannot have strangers in the car. He can cope in the car with me and with his brother, but no one else. If C has an anxiety meltdown, he is in danger, as he will run. He will also take his clothes off.

The transition from children's to adult services when C was 18 was very stressful for me. At this time I had taken him out of Milestones, so he was at home with me.

C had his FACE assessment. The assessment takes a long time. You pour your heart out to these people.

Then another person came, to do C's support plan. He suggested that C could go to the Butterfly Garden, or to Jamats. If he had understood C's assessment, he would have known that these suggestions wouldn't work. When it came to support planning for C, the options available were more limited than for F.

We came up against particular problems over respite care. We used to have a weekend's respite once a month, so we could spend time with F, along with some mid-week respite. When C was under Children's Services, he was at Bettridge School for a while, and C got on well with one of the support workers there who was also a family link worker. He went to her for respite, once a month, until he reached 18 and transferred to Adult Services. She has now retired, so there wasn't the option to continue visiting her.

We looked at the Care Centre, but this wasn't a suitable option for C. Day respite was a problem. With C's anxiety and sensory issues, I said I didn't want a PA to take him out into the community, it was not an option for him to have to be out for this length of time.

(.../continued)

(.../continued) St Joseph's had offered residential care, so we discussed weekend provision here. I know a lot comes down to cost, so I did cost everything up. The school offered to open up its bungalow during school holidays. I knew this could work for C. The only issue was the cost of this. The support planner said it was very expensive, 'way over' the indicative budget. He suggested Matson Day Centre, run by Selwyn Care, instead. But when I spoke to the manager of the Centre, they said that they couldn't provide one-to-one care; that the day centre doesn't have windows, which C needs; and that they wouldn't be able to help him to get out of the car.

This process went on for about a month. I was getting upset. We kept being told that C was very 'lucky' to be being offered this level of provision. It was such a horrible time. I felt at loggerheads with the support planning person. I had to do all the work. I even tried asking St Joseph's if they could reduce the hourly rate.

Finally, we were offered a meeting with the support planning team manager. She came to meet us. She understood straight away. She said "*I know how difficult it is to find care suitable for C. We know there are not a lot of options. I agree with your suggestions for the respite*".

The overnight respite is good. I book respite 6 months in advance, so we can plan our time with F. On Friday afternoons, I take C to the bungalow, and we collect him at 4pm on Sunday afternoon. At first, I helped with the handover on the Friday, to help him settle in. I can go away and feel secure that he's being well supported. They have been able to be flexible occasionally. We have booked tickets to take F to see Coldplay in June, and in order to do this we have booked respite on a Wednesday. This will be good for C, but he will also find it a challenge.

Social care did not give a copy of the support plan to C's lead health professional (Dr Manju, consultant psychiatrist, CLDT). Dr Manju has written to social care to say "*we need to work together on this transition*" and also to emphasise the health aspects of C's sensory issues.

Just a few months after the support plan was agreed, they wanted to do another assessment. It seems so wrong that you spend hours explaining things to someone doing the FACE assessment, and then someone different comes to do the support plan. I asked whether the same person could do both - but we had two different people again. So you just have to have faith, that they have taken note of everything.

It was a very stressful year.

(.../continued)

(.../continued) C was due to finish at St Joseph's - his three years' educational funding was up. In January, we were waiting to hear if he was going to get continued education funding (through his EHCP). We knew that if he wasn't going to get into St Martin's, we would have to look at residential care.

C has weighted blankets but he wakes up in the night every night. He has a 'sensory diet'. I take him to Stroud and back every day. He needs such high structure to his day. Any transition for C - for instance travelling from school to home - is stressful for him, even though it happens every day. He's not being difficult - it's just his sensory needs.

We were worried that they were trying to scale down the support he could have. The social worker who had carried out the FACE assessment rang us up afterwards and asked "*How many meltdowns does C have in a month?*" I replied "*He's well-managed at the moment - so it's about three*".

When we received a copy of the FACE assessment, there were quite a few errors. For instance, the assessment suggested that C had capacity; that he could pay bills; and the score for sensory impairment was put at 0, when on his previous assessment his score for sensory impairment was 4 (severe). Finally the assessment said that he had substantial need, when it should have said that he had critical need. If I hadn't picked up on these errors, it would have made quite a difference to how someone who didn't know C would understand what his needs were.

So when the FACE assessment was amended, the process passed over from the assessor to the support planner. She wanted to meet in February - I said this wasn't good timing, as we were still waiting to hear about whether C would get his education funding. She said "*We need a Plan B - I can do a pen profile*". I wasn't asked to contribute to this before it went out - I've no idea what was on it.

In April, we heard that C had got his funding for Year 1 Post-19 education through his EHCP - which was a huge relief. This meant he could go to St Martin's.

The Post-19 provision is a supportive, calm environment which works for C. Some staff transferred over with him. He's meeting his learning goals, he's being managed well and he's happy, and he's going out into the community for swimming and horseriding. Someone from health and social care came to his school meeting. I asked about funding applications for Year 2 - apparently this will be after his annual review in April 2016. So I'm going to go through this again, which is stressful.

(.../continued)

(.../continued) The support planner is going to try to help to move forward the education decision. I know that social care should be providing life skills. I know social services want to help, but they're taking anything parents can offer to reduce the costs.

I don't think there is enough information about residential care options for families. C is going to need a very structured environment if he does need to live in residential care. Families are told they can't visit a residential home to see what it is like, without social services' consent. I have sleepless nights worrying about this. There are very limited options offered for C. I feel there should be someone independent who can help me.

5.2 May 2016

Our son has learning disabilities and autism. He had an assessment in October, and the follow-up support planning meeting in January. It's now May and we haven't heard anything since then.

5.3 July 2016

There are problems with 'shared care'. If people have 'shared care', you can't see from their support plan how their individual needs for support with different things will be met. My adult son has learning disabilities. He shares a house with other people with learning disabilities. Because their care is 'shared care', if one of the people in the house has an urgent medical appointment for example, then other individuals' planned activities for that time have to be shelved. There isn't additional support available.

5.4 July 2016

My adult son has learning disabilities. When he had had his assessment and was planning his support, I had to ask several times before the personal budget was shared with me. When I had questions about the way that his support would be organised, I was told I should ask for a copy of the service provider's contract. I did so - but I never received a copy.

5.5 July 2016

I've learned that, if you don't know something yourself, services won't tell you. It is really hard to find out about things.

My son is in his early twenties and has autism. When his support was being planned, I wasn't told what the personal budget would be.

When we looked at what his needs were, I found a provider that was able to offer what he wanted; but GCC said "No", this provider couldn't be used, because they weren't "on their list". Instead, they gave my son a really limited choice for his support.

My son really likes musical activities; they help calm him. But his support workers don't seem to have any idea how to find out about these and other activities, and how to get him involved.

5.6 July 2016

My adult son has learning disabilities. In Healthwatch Gloucestershire's report on Support Planning, GCC said that it produces an Easy-Read support plan document. My son's Support Provider asked GCC Support Planning for the relevant Easy Read material, but they were told it was not available. The Team Leader at his house intends to try again, with the GCC Assessor

5.7 July 2016

I had a call from my son's next support planner, who I've never met, telling me that he will try to say 'Hello' to my son next week when visiting his day centre on other business, so that he won't be a total stranger. I appreciate that, but up until very recently the families of the individuals at my son's supported living house had been told that unlike their first support plan on moving house, when they each had a different planner, this time the same planner would do all of them and it would probably be one of the previous planners who had all met the housemates and families before. Sometimes it does feel as if there's a definite policy to have as little continuity as possible!

He also said I shouldn't worry about the FACE form as he would 'fill in' afterwards from other sources, and he did suggest another 'unofficial' meeting between ourselves afterwards. This has actually been done before, but I felt the information I wanted did have to be asked for rather than offered and I never succeeded in getting all the answers.

I don't think FACE paperwork is too popular with staff either! The 'official line' seems to be that it is used in order to achieve fairness - which I can accept up to a point - but this hardly seems compatible with also saying that a support plan can be written by someone other than GCC.

I am really hoping that this support plan meeting will be different as at least my son has had a new assessment - which 2 years ago he hadn't - so the plan on which his change of address, change of support provider and non-negotiable change of day provision was based was done largely copied and pasted from an out-of-date and now in parts totally incorrect assessment. I think this is actually contrary to statutory guidance.

I think all families felt the need for a LOT more support and answers over the move, and we've spent the following 18 months trying to sort out what should have been dealt with before the housemates moved in. A bit more information and working with the support provider from the outset would surely have saved time and money.

5.8 July 2016

I am responding, on behalf of my Learning Disabled son, to your request for information on Social Care Assessments. He is nearly 30 and has been a recipient of Social Care all his life.

My experience has been that the Social Workers who undertake the Assessments are generally very well informed and thorough. I feel that the field of Learning Disability is specialised and value the knowledge of staff who are experienced in this type of Assessment. I hope that with the current 'All disability' policy we will not lose that expertise.

However over the past few years the policy of de-allocating the Social Worker once the Assessment has been completed, and closing the case once the Assessment and Support Planning process is complete, means that the person is likely to have a different Social Worker every time, and if a problem arises must wait to be allocated a new Social Worker.

In addition the interval between Assessments (supposed to be annually unless there is a reason to re-assess before a year) has been lengthening and Assessments are not always carried out as recommended in Statutory Guidelines (e.g. before/around major life changes). The lack of an up to date assessment was commented on as problematic by the incoming Support Provider.

I also think that the paperwork used by GCC is constraining and that there is insufficient information available to individuals and families about the legal basis of Assessments, what can be expected during and following Assessment, what 'outcomes' are and who determines them, criteria for eligibility and scoring, the RAS system and resulting Indicative Budget etc.

It would help if people could see a copy of the assessment form plus any supporting information beforehand.

5.9 July 2016

My son is 21. He has learning disabilities, and autism. He goes to the Drop In in Cheltenham once a week. Until recently, a member of staff came to collect him. They rang me and said they wanted to get him more confident, so they would meet him at the end of our road. He did this for two weeks and did well, but then they said that they wanted him to walk to the bus stop. This requires crossing a road.

My son has a lot of anxiety. I contacted LiftTraining to ask if they could help with Independent Travel Training, to help him gain the skills and confidence; they have set up ten training sessions for him.

On the Friday, he went to the bus stop; the Drop In rang to say they thought he could manage this from now on, having done it once. I said I wouldn't sign the risk assessment until he had completed his training; I wasn't refusing, he just needed this to be introduced gradually. If it isn't gradual, there is a risk that his anxiety will cause him to shut down, and then refuse to leave the house at all.

While this was going on, there was no acknowledgement that his brother also has support needs (his brother also has learning disabilities, autism, and significant sensory issues) or any consideration of the impact these changes might have on him.

5.10 September 2016

Support planning needs to be clear what it will and what it won't address; and, the bits it won't address, to say who will address them.

There needs to be much more joined-up working with CLDT and other organisations.

The CC promote independence and choice, but they do not facilitate it.

The support planners are not well-enough trained, qualified or informed.

The social workers do a good job.

5.11 September 2016

My daughter has learning disabilities and currently lives in Action for Children's place in Ebley. She can only stay there for 2 years. But now the county council cannot find her somewhere to live. She is 24. Every week the council has sent out their bulletin, but no organisation has come forward offering a supported living place. All her activities are in Stroud, she needs supported living.

I found a place - Barn Lodge in Stroud - which I liked. But the council have overruled this, saying "*most people living there are near retirement age, so we wouldn't support it*". So my daughter hasn't had a chance to visit it herself, to see what she thinks. There is a girl of 27 who lives there; and anyway, our daughter is out at her activities every day anyway. We know that there will have to be some compromises to make wherever she goes, and the age of the other people there seemed to us to be a reasonable compromise. I thought that individuals and their families were supposed to have a voice?

And the process is just so slow... the support worker works part time, and it is just dragging on and on. There are clearly not enough places in Stroud District for those with a learning disability. The disabled are meant to be able to lead normal lives, like everyone else. But if there are no places for them to live then clearly that policy is failing. This should be a matter of major concern in a civilised country in my opinion. If we cannot care for the least able in our society then we are not a civilised and caring state.

5.12 November 2016

My son has LD and goes to a day centre 3 days a week. This is really great as his funding was cut from 16 hours of 1:1 care to nothing.

5.13 July 2016-March 2017

July 2016

My adult son has a learning disability. He lives in a supported living house with three other adults. All are eligible for 24-hour care via GCC Adult Services. His Support Plan allows him no one-to-one hours; his hours are all either one-to-four, or two-to-four, as the care is all shared between the housemates. Legal and charitable advice is that Care/Support Plans must show how eligible need will be met; e.g. Professor Luke Clements (Cardiff Law School) says that “*Care plans need to be detailed statements spelling out how the eligible needs will be met by the provision of the necessary support including the fine detail - the ‘how, who, what and when’*”. My question is - how should my son’s one-to-one needs (such as support for medical appointments, banking, personal activities) be expressed in his Support Plan clearly, when all his allocated Support hours are shared?

At the moment, because there are no one-to-one hours, each person’s support is dependent on the needs and choices of their housemates. This also has a ‘knock on’ effect on my son’s finances - e.g. because he and other housemates are taxi-ed to GCC day centre, if one person chooses not to attend, the remaining people have a greater share or sole responsibility for meeting the cost of the taxi. GCC’s explanation is that this is done to give the Support Provider the greatest possible flexibility; and that “*some providers don’t understand shared care*”. In practice, this can have the effect of, for example, support staff having to choose between taking other housemates to the surgery for one person’s appointment; or, transferring time, previously allocated for a second member of staff to support the housemates on a planned weekend activity, so that an ‘extra’ staff member can give one-to-one support at the GP surgery.

September 2016

I don’t think that Support Planners have any idea about what it is actually like to be a parent of someone with a learning disability. At the last meeting, the Support Planner said to me “*there is no need for you to get stressed about the support plan. That is what I am paid to do - to take on the stress*”. This is about my son.

(.../continued)

(.../continued) September 2016

I promised to keep you updated about my son's Support Planning process. I have just received an email from the Support Planner, sent to all four sets of parents. He has recently had a meeting with staff from the Support Provider and CLDT, to discuss our sons' household and how to solve its various problems, and now invites parents to a further meeting, on October 10th, with all concerned at the first meeting.

The meeting time and date was not discussed with us; it will be for two hours; and it will be chaired by the Support Planner, who has also set an Agenda of 'Past, Present and Future' with the focus on 'Future'. He explains that we have now all had the chance to comment on our sons' draft Support Plans, and he has "*considered and worked in your comments where I can. Please be aware that where comments made were related to the **Assessment**, these are pre-set and I am unable to change them. If you need me to I'll explain this when we meet.*" He also offers the chance to discuss individual concerns separately from the meeting, with himself or with the Support Provider.

I asked for my son's amended Support Plan so that I could read it before the meeting. His reply was "*There are some important aspects to the Support Planning process which I will be explaining to you all before we revisit the plans.*"

Bearing in mind that most of the Support hours in the house are shared and that many of the problems stem from that in relation also to the tenant mix and support needs; and that I know that the Support Provider has requested more Care hours; it seems to me that, in giving us a joint meeting, while not giving us whatever knowledge about Support Planning in general which he obviously feels we lack, and also failing to give us sight of our sons' Support Plans and Individual/personal budgets; our sons are very much being 'fitted into' the system, rather than identifying need and discussing how best to meet it.

This feels to me very much like 'co-production on GCC's terms, and strictly under its control.' I feel we have almost to beg for information.

(.../continued)

(.../continued) October 2016

Families have now had the joint meeting with GCC Support Planning, CLDT, and staff from the Support Provider.

Unfortunately I found it most unsatisfactory, and deeply unhelpful, for several reasons. One of these is, having been asked before the meeting to address any issues personal to our individual families to the Support Planner or Provider outside of the meeting, I was pressed, out of nowhere, for a reply on changing the day/hours of my son's voluntary work, even after I asked to discuss it outside of the meeting. Since I have discovered that at least one party who should be involved knows nothing about this proposal, and I suspect my son doesn't either, I have to consider why this is being pushed.

I and another parent feel we need to complain, specifically about the conduct of the meeting. I would prefer to have the updated draft Support Plan before complaining and have requested it, but I'm not sure it will be forthcoming before it goes to Panel. Some of the issues affecting our families, and one in particular, are very sensitive and we feel we have been left with absolutely no guidance as to how to handle it. We were criticised for emailing CLDT without copying in GCC and the Support Provider, on the grounds that we are thereby excluding them. However, in withholding information from parents, this is exactly what GCC is doing.

November 2016

Another parent and I have both made a formal complaint on the grounds that our sons' Support Plans appear to be led by financial restraints on GCC rather than by need; and that the Support Planner said there was virtually no chance of getting any extra support hours and he did not intend making a case to Panel for any. We feel this is a failure in duty to our sons. Also, in my son's case, two assessed needs are not addressed in his Support Plan (for support with weekly banking, and for support out in the community including on public transport). We await confirmation of a meeting date in December.

I have also contacted my own and my son's Borough Councillors re taxi-ing vulnerable adults rather than supporting them to use the bus. Cheltenham Borough Council appears to take a very different view from GCC. I hope to be able to take this further eventually.

(.../continued)

(.../continued) January 2017

I now have what I assume is a decision on my complaint - which is that there will be no change in the allocation of care hours, and it will now go to Panel.

The email from GCC contains the following

“Whilst I can see the statement made in [name of individual]’s Assessment re weekly banking - the suggestions made at the Support Planning stage are equally valid - i.e. that this can be carried out weekly but will mean altering support elsewhere or less frequently which could mean there is a lesser impact upon other activities” and further, that the Support Provider had *“not found it impossible to facilitate weekly banking - again, this simply means that support would need to be drawn from elsewhere in the week”*.

There is no comment on support in community (I was trying to get an answer on whether a person alone in a taxi is actually being supported at all; and, if so, by whom?) although it was touched on during the complaints meeting.

There were no suggestions made during the Support Planning stage, until things got to the complaint stage. Since my son is not supported by the Support Provider to get to his weekday activities, and does not have any one-to-one support out of the house (except presumably for medical appointments, which would be only with his GP since I do Dentist and Optician), I can’t see how the Support Provider can ‘draw from elsewhere’ without it impacting also on the other tenants. During the complaint meeting GCC informed me that places at local authority Day Centres - where my son currently spends two days a week - are to be prioritised for people living with parents. The implication was very strong that his two days would soon cease. Therefore the only interpretation I can put on the above statement from GCC is that he would be expected to give up a Day Centre day in order to visit the bank.

Presumably he is also expected to choose between supported bus travel to the Day Centre, or leaving the house in the evening or at a weekend. If he chooses the bus, it would not impact on just him alone, but on all the tenants, since a lone Support worker can’t take out any three of the four tenants together due to their differing support needs. Matters were certainly not discussed in these terms at the Support Plan meeting.

I don’t think this choice is what the writers of the Care Act intended - but the point I’m trying to make is the lack of clarity and lack of information in all this.

(.../continued)

(.../continued)

What worries me even more is the implication that, whatever was in the Assessment, the “*suggestions at Support Planning are equally valid*”. In the original draft of the Support Plan, there was a sentence to the effect that my son could make a bus journey alone as long as it was direct and he was met at the other end. This was in direct contradiction of his assessment - and read as a statement of fact, rather than as something to be worked towards. When I queried it I was told this was “*an aspiration - better to start positively*”. I did get it removed, but if GCC is going to make these moves out of the blue and from no basis then I find it extremely worrying.

I believe that if people have to accept these trade-offs between meeting assessed need versus social activity, the Support Plan should contain information. If it is at the discretion of the Support Provider, then that should be made clear, with provision made for proper explanation and support for the individual and his or her family/advocate. I still don't see how individual tenants can be expected to make choices concerning the meeting of assessed need if their choices impact on their housemates.

I would also have appreciated entering the complaints meeting at the same time as the Support Provider's staff. In both complaints meetings I have had, several years apart, although arriving 10 minutes early for each, I was kept waiting beyond the start time and eventually shown into a room full of everyone except me. It seems deliberately set up to discomfort the complainant.

March 2017

GCC meetings

As someone whose son has a congenital condition and thus has been a 'client' of the local authority since childhood, I'm aware of the assessment/support planning process, but someone new to it possibly doesn't realise the importance of it and I don't think all support workers do. Therefore I think something in writing would be helpful, together with specimen forms, or at least an idea of the questions which will be asked. It isn't always easy to answer these 'cold'.

(.../continued)

(.../continued)

An outline of Direct Payment and managed budget options etc in Easy Read would help those able to use this independently, and also Support Workers/families/charities could use these as a basis for preparing someone without that capacity for the meetings. If it is possible for people to produce their own Support Plans, some idea of how to go about this is needed. This all needs to be provided with sufficient time for the person/family to digest.

I also feel other GCC meetings should be properly minuted. In my case:

- a joint meeting, chaired by a Support Planner, between families of the tenants of my son's Supported Living house, Support Planning, the Support Provider, and CLDT. This was to discuss issues concerning the household as a whole rather than individuals; but was considered part of the Support Planning process for all the tenants
- This was followed, for my family and that of another tenant, by a complaints meeting
- Both meetings were minuted by another Support Planner, and families felt neither of these reflected parents' views fully, and were somewhat 'skewed'. Families' additions/amendments were allowed to be included only as an addendum. The complaint decision did not advise the possibility of going on to the Ombudsman. The meeting itself, for both formal complaints I have made, appeared to have been immediately preceded by a meeting between GCC and the Support Provider; which doesn't make the complainant feel very listened to
- To go back a bit further, I was asked to attend a meeting with GCC and the then Support Provider as part of a Safeguarding process. I took my elder son with me as I felt he, being of my disabled son's generation, might be listened to rather than myself as his mother. My son was listed as an attendee, but nothing he said was minuted. I asked for his comments to be added to minutes, plus other points which I felt had not been recorded. I've never received any amended minutes for any meeting, so don't know if any of my family's views have been recorded.

As far as frequency of Reviews goes, my son's most recent took place three years after the previous assessment; in spite of his change of address, support provider and day provision 18 months previously. I have no faith that annual review will happen on time.

(.../continued)

(.../continued)

Travel between Cheltenham and Gloucester

My son has 24-hour support and needs to be supported at all times outside the house. He lives in Cheltenham. When his five days per week at GCC Day Centre (Oakley) was cut to 2 days, the Support Provider maintains it was unaware of this change in Day Centre provision when it accepted the contract, and then became responsible for supporting him to 'access community provision' instead. However it was not funded to give him choice, thus he could only go out if other tenants also wanted to go to the same place. In addition, Support Workers didn't always get him to where he wanted to be, for various reasons.

There was very little suitable for him to do; and during school holidays virtually nothing, since many activities are run termly. After a year of this he was very unhappy, and the situation was saved only by a suggestion by a housemate's mother that he could access PACE (a private facility in Gloucester). This was arranged.

He now has a voluntary job for two hours in the middle of Saturdays, also in Gloucester. There was a move to add to these hours a full day's voluntary work, which would be on an 'Oakley day'. This would mean five weekdays in Gloucester; which would make banking, medical and other appointments very hard to arrange without having to miss at least half a day's, and probably a whole day's, activity. This is what often happens in shared Supported Living houses; as there are insufficient care hours to enable a Support Worker to be available to get a person to and from an appointment outside 'normal' rota-ed hours. GCC has made it clear that it considers all these issues to be a matter of 'individual's choice' (implication is - wrong choice!) rather than an insufficiency of care hours.

At the same time, GCC will not enable the individual to plan reasonably: e.g

- I was told at my Complaint meeting that it is probable that my son's days at Oakley will cease. Oakley has given no inkling of this either to my son or myself. If this is going to happen, there are some things such as Horseriding, which he currently does via Oakley, which are probably possible as an individual, but probably involve a waiting list, a certain day of the week etc, not to mention possible one-to-one support to enable him to do so. He may like to continue these activities; but unless we have some warning, we can't discuss this, or organise it. I've emailed the Support Provider but had no response and doubt anything will be done.

(.../continued)

(.../continued)

- Some Supported Living tenants travel from Cheltenham to Gloucester to attend PACE; then travel back to Cheltenham with PACE to attend The Butterfly Garden; then travel back to Gloucester with PACE; then travel back home to Cheltenham. This does seem ridiculous.

Taxis

Under pre-2014 legislation, local authorities had a duty to provide transport (at cost charge to the client) to local authority day facilities. This has never been provided for people in Supported Living. My son used to walk to Berkeley Court with other tenants and a Support Worker, and when he moved to Oakley was at first accompanied on the bus. This soon became travel by taxis, unsupported. The current Support Provider started with a Support Worker's car and mileage charges, but again soon changed to taxis.

Over the years there have been various issues; such as dropping him in the wrong place thus missing his Support Worker, taxi drivers demanding petrol money, etc. The post-Care Act position doesn't seem clear. Local Councillors take the view that Cheltenham Borough Council does not expect its licensed taxi drivers to be 'delivering social care' and that, should anything untoward happen, GCC might be at least partly responsible.

I don't see how a vulnerable adult can be assessed as requiring support outside the house at all times, but this support is withdrawn while he is in a taxi; and I really do want an answer on this one. It is such a common thing in Supported Living.

(.../continued)

(.../continued) Summing up

I believe that GCC needs to be a lot more transparent and informative in its dealings with disabled people and their families; and there needs to be a lot more honesty and information-sharing between GCC, Support Providers and individuals and their families.

GCC needs to ensure its Support Providers are up-to-date with all relevant subjects such as Housing Benefit, Council Tax, TV licensing and, above all, banking arrangements for those lacking financial capacity - all of which have caused many headaches to myself and other families.

GCC can't expect individuals to take responsible decisions if it doesn't ensure they have the information, support and time available to do so. It isn't acceptable to attribute every failing/difficulty to 'individual choice' without this being in place.

I say this while recognising the individual employees of GCC who do their best to engage with individuals/families.

As you will have gathered, I feel very strongly that, at least for those individuals assessed as suited to shared supported living, 'choice and control' is absolutely not happening and GCC continues to fail to provide/encourage information-sharing and co-production, and fails to enable a reasonable overview/planning of an individual's life, current or future.

6 Feedback from support providers involved in support planning, collected May - September 2016

6.1 May 2016

It is really hard for organisations that provide services to plan provision, when the decisions about funding from GCC come so late in the day. Parents contact us about decisions about support for their (adult) children as they think we will have been informed before they are, but we have to say “*We haven’t heard anything yet either!*”

6.2 September 2016

Eight people live at this home, and none of them ‘fit’ the boxes on the support plan. There is no room for variation - we all have good days, and bad days.

6.3 September 2016

One gentleman we support is from a farming family. He loves to be outdoors as much as possible, and he likes to go for a walk every day.

He would like to walk for 3 hours, every day. But he only has one hour one-to-one per day in his plan. So, when we go out, when we’ve been out for half an hour, we have to say “*we need to turn round now*” which he finds really distressing, because he’s only just getting going.

But when he has a support planning meeting, the support planner asks “*do you go for a walk every day?*” “*yes*”. “*Do you like that?*” “*yes*” . And that is the end of the questions about it.

So, he’s not living the life he would choose to lead.

7 A note on quantitative and qualitative evidence

Quantitative evidence provides an overall picture based on large numbers; but one of its limitations is that instances that do not match overall trends can risk being overlooked. Qualitative evidence is more subjective and provides rich, detailed information; but inevitably, it focuses on the experiences of a small number of people.

HWG acknowledges that the feedback contained in this report is largely qualitative evidence. Nevertheless, taken together it highlights important issues which need to be considered by GCC as it pursues its objective stated in Section 1:

“to produce a support plan and personal budget for each person which delivers on meeting their needs and outcomes and is co-produced with the person, family and carer”

As HWG has noted in other reports it has produced, someone’s experience of engaging with the health and care system is very personal to them, and can be very subjective. Service user experience data is perhaps more challenging to use than other types of “evidence” in the health and care system.

8 Key findings

8.1 Feedback from people with learning disabilities

HWG met with 22 people who shared their experiences. As we said in section 3, the interviews were carried out in a conversational style, rather than mechanically working through a sequence of questions.

The transcripts of the feedback reproduced in section 4 provide rich, detailed information.

There are some key themes which appeared in a number of these people's experiences, and which are shown in the table below:

experience	Yes	No	I don't know
I was given enough information to understand what support planning means for me	2 people	7 people	
The support planner was someone I had met before	1 person	5 people	
I was in control of my support planning meeting		5 people	1 person
I could speak up in the meeting	5 people	1 person	
I was offered an advocate	1 person	1 person	
There was enough time in the meeting	1 person	1 person	
I was in control of my plan	4 people	5 people	2 people
I can live my life the way I want	10 people	6 people	

People shared their suggestions for improvements. These included

- 10 suggestions about information and preparation:
 - 2 people suggested information beforehand
 - 2 people suggested questions to think about beforehand
 - 2 people suggested Easy-Read information
 - 2 people suggested getting to know the support planner
 - 1 person suggested someone to sit down and explain it to them
 - 1 person suggested more time to make the plan
- 2 suggestions that the plan is split into sections, dealt with on different days
- 2 suggestions about access to more support
- 2 suggestions about speeding up the overall assessment and planning process, so it is not so drawn-out
- 1 suggestion about fewer meetings
- 1 suggestion about having pictures or symbols to use to help in answering questions

8.2 Feedback from the families of people with learning disabilities

HWG heard from 13 people. The feedback, which is reproduced in section 5, provides rich, detailed information.

There are some key themes which appeared in a number of these people's experiences, and which are shown in the table below:

experience	no. of people
The process was drawn-out	5
There was a general lack of information provided or available	4
Each time, it was a new member of staff to get to know	3
Lack of knowledge/understanding about the individual by a support planner	3
Lack of knowledge/understanding about families by a support planner	3
Lack of transparency in a support plan about how needs will be met	3
Not joined up with Community Learning Disability Team activity	3
Families' suggestions about possible support providers were dismissed	3
Lack of Easy-Read information	2
Lack of flexibility in weekly support allocation	2
Details of personal budget not shared/only shared after repeatedly asking	2
Current support not meeting needs	2
Constraints on process due to format of paperwork	2
The process was stressful for families	2

People shared their suggestions for improvements. These included

- More information; such as a list of the questions which will be asked in the support planning meeting (2 people)
- Access to independent help and advice for families (2 people)
- More training for support planners (2 people)

8.3 Feedback from support providers involved in support planning

HWG heard from 3 people. The feedback, which is reproduced in section 6, provides rich, detailed information.

The themes of this feedback include

- A lack of information provided
- Constraints on the process due to the format of the paperwork
- A lack of knowledge/understanding about an individual by the support planner, which meant the individual's plan did not enable them to live the life they would choose

9 Recommendations

9.1 That information about what support planning is, and about the questions posed in the process, is be provided as a matter of course to people with learning disabilities and their families, in a form that is accessible to them

People with learning disabilities, their families, and support providers involved in support planning, all said that there was a lack of information provided about support planning.

Almost a third of the people with learning disabilities who shared their experiences with HWG said that they were not given enough information to understand what support planning meant for them.

Some information of this nature is available from national disability organisations; for instance, In Control produce an easy-read booklet *Making your support plan: an easy-read booklet*

<http://www.in-control.org.uk/media/36867/making%20your%20support%20plan%20.pdf>

which is available to download; and it also publishes *Top Tips and In the Driving Seat: A Workbook to help me plan my support*

<http://www.in-control.org.uk/publications/toolkits/top-tips-and-in-the-driving-seat.aspx>

9.2 That people with learning disabilities are offered planning choices; and it is made clear throughout the process that the support plan ‘belongs’ to them

None of the people with learning disabilities who shared their experiences with HWG said that they felt they were in control of their planning meeting; 5 people said they did not feel in control of the meeting, and one person said they did not know whether they were in control or not.

One person said they did not feel able to speak out in the meeting; another said

“Sometimes, I feel that I put an opinion across and it is dismissed. That’s not just in support planning, that’s in other things in my life too. So sometimes I don’t have a voice”

5 people said they did not feel in control of their plan; 2 people were not sure whether they were in control of it; and 4 people felt that they were in control.

The Department of Health’s *Care and Support Statutory Guidance Issued under the Care Act 2014* published in October 2014 says that

“The person must be genuinely involved and influential throughout the planning process, and should be given every opportunity to take joint ownership of the development of the

plan... Indeed, it should be made clear that the plan 'belongs' to the person it is intended for...

The planning choices offered should range from support for the person, to jointly develop their plan with the local authority alone or with their family, friends or whoever they may wish to involve (this might include web-based resources, written information and peer support), through to one-to-one support from a paid professional, such as a social worker which may be the same person who undertook the assessment...

The plan should be person-centred, with an emphasis on the individual having every reasonable opportunity to be involved in the planning to the extent that they choose and are able. This requires the local authority to ensure that information is available in a way that is meaningful to the person, and that they have support and time to consider their options...

9.3 That the training programme for support planners is reviewed, particularly in relation to working with families

Two of the families of people with learning disabilities raised the issue of training for support planners; and a number of the experiences shared in this report by people with learning disabilities, their families, and support providers involved in support planning suggest that mandatory additional training, in developing a deeper understanding of what it is like to be the parent or sibling of a person with learning disabilities, might be beneficial.

9.4 That GCC use the personal stories in this report to gain greater insight into the experiences of people with learning disabilities and their families; acknowledge the value of the 'personal story' to enable system learning; and look to gather further stories from people with learning disabilities and their families

10 Acknowledgements

HWG would like to thank those people with learning disabilities and their families and support provider staff who shared their personal experiences, knowledge and reflections.