

Report of Healthwatch Bradford and District to the meeting of the Health and Social Care Overview & Scrutiny Committee to be held on 8th September 2016

Subject:**G****Consultation on changes to Adult Social Care Contributions Policy, City of Bradford Metropolitan District Council****Summary statement:**

The proposed changes will have significant impact on many vulnerable people across the District, affecting over 3,500 service users. The biggest impact will be on young people and working age adults with disabilities.

Healthwatch Bradford and District have heard concerns from a number of organisations and individuals about the proposed changes.

This report is based on case studies which highlight the potential impact on people's lives if the Council adopts the proposed contributions policy.

Portfolio:**Health and Wellbeing**

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1. Summary

Healthwatch Bradford and District spoke to people affected by the proposed changes to the contributions policy, to gain an understanding of the potential impact on individual service-users and carers, and to add depth to the Council's own consultation.

The appendix to this report contains five individual case studies, which highlight the potential impact on people's lives if the Council adopts the proposed contributions policy.

2. Background

In May, Healthwatch went along to the first public meeting for this consultation. We heard significant concerns from people who attended; they were frightened and worried about the impact of the changes, and they were also concerned that the information which had been sent out to service-users was not accessible or easy to understand.

Healthwatch raised concerns with the Council about the consultation; we asked them to extend the closing date to enable more people to participate, to work with partner organisations to help spread the information, and to create Easy Read information about the proposed changes. The Council told us they would extend the consultation and would send out improved information which would include examples and be more accessible.

Healthwatch put information about the extended consultation on our website, on social media, and in our newsletter. We encouraged people to share their views in the Council's consultation.

Healthwatch worked with partner organisations to understand their perspectives on the changes, including People First organisations in Bradford and Keighley, Choice Advocacy, the Parents Forum, and some supported living services.

We carried out a small number of one to one and group interviews with service-users and carers, to enable people to share the direct impact that the proposed changes would have on their lives.

3. Report issues

The proposed changes will have significant impact on many vulnerable people across the District, affecting over 3,500 service users. The biggest impact will be on young people and working age adults with disabilities.

People we heard from have found the consultation difficult to understand, and have struggled to work out how the changes will affect them. For example, the questions about 'double-ups' confused people as it was not made clear that this would only affect service-users who fund their own care. As a result of the difficulties with the consultation, many people have not understood the proposals and therefore the full impact of the changes has not been realised.

Many people will face significant increases (in some cases almost 100%) in the amount of contribution they will be expected to pay. This will mean some service users will be unable to continue with activities that benefit their health and wellbeing; it may also increase

social isolation among vulnerable groups, push people into poverty, and lead to some people disengaging from services.

Although Disability Related Expenditure can be taken into account in a financial assessment, it is unclear how this will be applied and the Council's guidance does not include a full range of costs, particularly for people with learning disabilities or communication needs. Many care plans do not currently include such Disability Related Expenditure.

The Council carried out an Equality Impact Assessment (EIA) on the proposed changes to the contributions policy. The EIA signed off on 12 February 2016 judged that there were high impacts relating to age and disability, but only a 'medium' negative impact on people on low income / low wage. The feedback Healthwatch has had from service users makes clear that there will be a disproportionate impact on low income groups. It is not clear how this impact will be mitigated.

4. **Options**

The committee may wish to consider the following issues:

- Whether the proposed changes may adversely impact on the health and wellbeing of service-users, and cause unintended consequences for service-users, carers, and the health and social care system
- The need for greater clarity on Disability Related Expenditure and how this will be applied.

5. **Contribution to corporate priorities**

- Supporting and safeguarding the most vulnerable adults, children and families
- Reducing health inequalities

6. **Recommendations**

6.1 That the concerns highlighted in the report and case studies be noted.

7. **Background documents**

N/A

8. **Not for publication documents**

N/A

9. **Appendices**

9.1 Case studies



Proposed changes to Adult Social Care Contributions Policy: Case studies

The following case studies are based on individual conversations with service users and/or their carers. We have changed people's names in order to protect their anonymity. Figures given are based on service users reported income/expenditure and calculations have been made using the Council's published examples of the new contributions policy.

Case study 1 - Abbas

We spoke to Mrs A, who is the main carer for her son Abbas. Abbas is 22 years old; he is autistic. He lives at home with her and his younger brother. The family have adapted their home to accommodate his needs and allow him to have some independence while remaining in the supportive family environment, where he doesn't rely too heavily on social care services.

Abbas attends college. He has been through travel training which was successful and he is now able to travel on the bus independently to get there. Sometimes his autism and his obsessions take over; without appropriate activities to keep him engaged he can become very aggressive and difficult to manage. He receives 5 hours support each week from Supported Lives. They take him out in the community; help him participate in activities like playing snooker or football. In addition to paying his contribution to the council for this service, Abbas takes money to pay for the activities, food/drink while they are out and has to pay for the support workers too.

Mrs A has received the information from the council about the consultation:

"I got the letter and the questionnaire from the Council but to be honest I didn't have a clue how to respond and it didn't make sense to me. I did fill it in but I just ticked 'I don't know' for everything."

Mrs A says that Abbas wouldn't be able to understand the information in the consultation, it was too complicated, and he hasn't got a real concept of money.

- **Currently Abbas contributes £18.18 per week for services.**
- **Under the proposed policy, his contribution would potentially increase to £42.84.**

Mrs A is very worried that the increased contribution will make their lives very difficult. If Abbas is not able to continue with the activities he enjoys, she feels his behaviour will deteriorate and he will become more withdrawn and his mental health will suffer.

“I don’t think people understand what the impact will be; they don’t know how hard it is. If we’re not able to manage to keep him at home like we do now, it’ll be much more expensive in the long run.”

“If he was unable to go out and do his activities like he does at the moment, he might start having more outbursts and aggression. Then we’d need to have involvement from social workers, and the behaviour team. That costs more money.”

Mrs A felt that the council’s list of Disability Related Expenditure was very limited, and she was worried that it said only items in the care plan would be included. Abbas sometimes wets or soils himself, so he incurs additional laundry and replacement bedding/clothing costs. However this is not documented in his care plan, because at that time they didn’t realise it would need to be. She says she will request a new care assessment in order to make sure all his needs and expenses are recorded.

Case study 2 - Kate

Kate is in her fifties; she has learning disabilities and health problems, she lives independently in a sheltered housing scheme. Four days a week, she receives care at home - they support her with personal care and prompt her medication.

Kate doesn’t remember getting a letter about the consultation. She says she finds it difficult to understand lots of things that she receives, so ignores them.

“It’s a bit awkward because I don’t know the value of money.”

Kate says she doesn’t have much money. A few months ago she was taken advantage of by someone who pretended to be her friend but took her money, the police were involved and it was a very distressing experience. Since that happened, she has received an additional service where someone comes to help her with her bills and paperwork once a week.

She currently pays a contribution towards her services, but doesn’t know how much it is. She says sometimes she thinks it’s too much and it’s not worth it.

When we explained the Council’s proposals for the contributions policy, she was quite worried. If she had to contribute more than she pays now she would find it very hard. She thinks it would be hard for a lot of disabled people.

“A lot of people might not even have a couple of quid to spare. It’d take me whole income off me, every week.”

Kate’s main social activity is to go to the pub with her friend, apart from this she doesn’t go out much or do any activities. If she wasn’t able to afford to go out and meet her friend as often, she would get lonely and depressed.

“I wouldn’t talk to anybody. I suffer with depression. It makes me feel angry to think about it.”

Kate talked about what she might have to give up if she had less money to spend. She thought that maybe she could stop paying for the support she receives to manage her money and bills, because she'd rather give that up than to stop seeing her friend. Kate's learning difficulties meant that she is unable to recognise that this might leave her open to someone taking advantage of her again, or of getting into further financial difficulty. This highlights the choices that vulnerable people might make as a result of increased contributions for services, and which could have significant impacts on their safety and wellbeing.

Case study 3 - Tahid

Tahid is 21, he is autistic. He lives at home in the BD3 area of Bradford with his mother Mrs H, who is his full time carer, she takes him to and from college and support services, helps him with personal care, cooks for him and looks after his health needs.

Tahid goes to college four days a week in Shipley - Mrs H drives him there every morning and picks him up every afternoon. They have been through travel training, but it was not successful and he is not yet able to travel independently.

Tahid enjoys creative activities, such as art, knitting. These things give him a focus and keep him calm. He spends about £20 per week on materials for these activities. Without this outlet he gets easily bored and this leads to outbursts and aggression. His communication and social interaction is limited but he uses the internet to follow his interests.

Once a week, he goes to the Learning Zone where he takes part in a range of activities. Since he has been attending, his social interaction and confidence have slowly increased.

He does not currently receive any other social care services.

Tahid gets Employment and Support Allowance (ESA) and Disability Living Allowance (DLA) with both the care and mobility competent awarded at the higher rate.

- Tahid contributes £22.73 per week to the cost of the Learning Zone service.
- Under the new proposals, his potential charge could increase to £42.84

“If he didn't have the money to follow his interests, it would really be bad for his health and wellbeing. We need to keep him busy otherwise he will get angry and violent - he's hard to handle. I wouldn't be able to handle him if his behaviour was worse. This is the fear I have, that he'll have to end up going into a care centre somewhere.”

“I am struggling on a low income already, and they are saying we need to pay more for services. I don't think it's fair. It's really upsetting for the family, because you don't know what is going to be happening tomorrow. The lifestyle that he is living at the moment is ok, but if the contribution goes higher it's going to be very difficult to manage.”

“I have suffered depression in the past; it’s sometimes hard to deal with everything. I worry a lot about money, and when I am worried and depressed it’s harder to care for Tahid. If I got ill, I don’t know what would happen.”

Mrs H has not responded to the consultation.

“I don’t understand the questions they are asking. I was really confused. The second letter had some examples, and that was a little bit better. It asks if Bradford should be the same as the rest of the country - but I don’t know what it is in the rest of the country, so how can I answer?”

Mrs H thinks a lot of people will not have understood the information that was sent out, and then when they suddenly get a big bill it will be a shock. She thinks many people might then just stop using services.

Case study 4 - Robert

Robert is 27, he has Down's Syndrome and related health issues including a heart condition. He lives in Supported Living accommodation, where he is thriving and has good social interactions.

Robert receives DLA at middle rate with low rate mobility and ESA. He has a tenancy agreement and receives housing benefit which pays his rent. He pays all the normal living costs such as utility bills, insurance and maintenance charges, furnishings and bedding etc, food shopping, clothes, etc. His mobility allowance does not fully cover the cost of a car pool at Supported Living, so he also pays additional travel costs.

- **He contributes £43.14 per week towards the cost of the support services he receives.**
- **If the new contribution policy is implemented, his contribution will rise to £85.69.**

Currently Robert is able to pay to attend his weekly rugby training, associated matches and trips to play other clubs. Taking part in sport has significant emotional and physical health benefits for Robert. Down’s syndrome puts him at increased risk of diabetes and he has a heart condition, so keeping active and maintaining a healthy weight are vital.

Robert’s other passion is music and he plays his drums every day. This is an electronic kit to minimise noise and it is starting to fail due to usage and age, and will need to be replaced. Robert goes out with his Personal Assistant one day per week, and he has to cover the PA's admission fees to activities, food and travel costs as well as his own.

Robert’s mother is very worried about the impact on her son.

“If the new charging policy is implemented it will have a life changing impact on him. It would take away all of his disposable income! The amount the government is saying can be allowed does not fully cover the normal living costs associated with

Supported Living accommodation, let alone any hobbies, sporting and social activities or anything else that requires any payment no matter how small.”

“I asked him how he would feel if he couldn't play in rugby matches. He was visibility upset about that and said ‘people shouldn't steal my money’. What could I say? How can I explain to someone who asks for very little and accepts society's poor standards and expectations of people with learning difficulties that he won't be able to buy his girlfriend a birthday card let alone have a holiday or leave the house at evenings or weekends because there won't be any money to do so. He will effectively be reduced to institutionalised living with all the risks that that carries.”

“I feel a tremendous sense of guilt and worry about Robert's future which in turn affects my own health and wellbeing.”

It is very difficult to quantify Disability Related Expenditure for Robert. He has a pace maker fitted and this means he needs additional heating to keep himself warm. He also has a tremor which means he tends to spill food so extra washing is required. He struggles with dexterity and is more likely to drop and break things, and also often loses things, e.g. his glasses, which need to be replaced. Not all of these additional expenses are reflected in his care plan.

Case study 5 - Jack & Steven

Two brothers, Jack 51 and Steven 39 have lived in Supported Living for the past 5 years with enormous success. They both have learning disabilities and a progressive physical disability.

Their mother, Mrs S, is very frightened about the impact on her sons of the proposed changes to how much they pay towards their care and support.

The manager of the Supported Living scheme where they live has looked at their current income and contributions, and calculated how much they spend at the moment on day to day living. Taking into account the bills they have to pay, spending on food and other groceries, personal care, clothing, and transport, she has estimated that their ‘bare minimum’ weekly expenditure is around £163.21 per week, more than the minimum income guarantee figure of £156.31. And this does not account for taking part in any activities, or what they spend when going out with their support workers.

At the moment, although things are tight the brothers are able to pay all their bills, live independently and take part in a range of activities.

- **They currently contribute £43.14 towards the cost of their services.**
- **Under the new proposals, contributions would almost double to £85.69.**

The Supported Living manager tells us that this could mean that they would not have money to afford any other ‘extras’ like holidays, Christmas or birthdays, or to keep anything aside for emergencies. And importantly that it would leave them with no money to spend on activities.

Due to their physical disabilities, it's vital for Jack and Steven to be as active - physiotherapists and doctors have recommended regular swimming. The brothers go swimming twice a week, at a cost of £10 each - they have to pay the costs for their support workers as well as themselves. To make this affordable, their mother provides transport at the moment, but due to her own health this may not continue to be possible for much longer. The costs would significantly increase if other transport was needed. Mrs S is worried that with the proposed changes, her sons would not be able to afford swimming and other activities, which are so important for their health and wellbeing.

“If they become wheelchair bound earlier in life with all the consequences of internal organ damage, surely this will cost the country even more? If their behaviour deteriorates they will need double the staffing they have now- more expense!”

“If they are left with insufficient disposable income their lives will be very much changed and possibly shortened.”

She is particularly worried about her younger son Steven, who is doing well at the moment but whose behaviour and health were very hard to manage in the past.

“If he is bored and frustrated he hits himself in the face, knocking out teeth, and bangs his head on anything available resulting in hospital visits and stitches etc. At the present time, since he has been in Supported Living his behaviour is perfect and he is very contented with all the social activities he can go out and enjoy.”

“It would break my heart as a mother and carer if he could no longer afford the activities that keep him and his brother well.”