

Meeting 20 October 2022

#### Attendance

Name	Organisation
Cllr Rachel Bentley	Councillor, North Bermondsey Ward
Alan Burnham	Relative
Amee-Lee Abraham	Mencap National Office
James Robinson	Mencap
Janette Dyer	Carer
Jean Jacobs	Carer
Joyce Toland	Carer of Seana and Ciaran at Bede
Sheila Faucher	Carer
Henry Kehoe	Carer
Maxine Smith	Parent/carer
Esmé Dobson	Councillor
Teresa Raven	Carer
Eileen Wall	Carer
Wendy Cookson	Bede Chair
Elizabeth Smith	Community Southwark
Marina Ahmad AM	London Assembly Member Lambeth and Southwark
Mary Kumara	Carer
Cassandra Brown	Councillor
Nimali Kumara	Bede attendee
Davion Jacobs	Bede attendee
Sarah Roff	Bede attendee
Josie Roff	Bede attendee

On 20 October, Bede hosted an afternoon for clients with learning disabilities and their carers to meet local councillors.

11 relatives or carers and 5 Bede clients met with 3 local councillors and the London Assembly member for Lambeth and Southwark. We were joined by staff from Mencap and Community Southwark.

People shared examples of their experiences.

- Many carers outlined the disjointed treatment between different departments and agencies
- Many outlined how they had to repeatedly prove the same information causing stress and anxiety. One had to pay £60 for a GP letter to renew proof that they had Down's syndrome.
- All carers were providing unpaid care that was not recognised.
- Some families were receiving warning letters for unpaid debts, but had not been notified that charges were being levied. They had no idea that they were building up a debt.
- People with learning disabilities, and their carers, did not understand how the care charges had been worked out. Charging letters did not provide a clear breakdown.
- Care charges were coming out of benefits, which are not going up at the same rate as the overall costs. One had had charges rise from £14/week to £72/week overnight.

A and C, siblings of L, who attends Bede and Surrey Docks Farm in the week. L lives on his own with support from the wider family.

- L received notice when he reached state pension age that he was required to pay £170 per week towards support.
- We pay out of their own budget to support L in his home. They are unpaid carers.
- The Reviews and Charging Team department started contacting L directly, when I have repeatedly told them not to as it puts so much stress on him. The letters are now coming to my house and my wife is worried about the debt. L is worried that he will lose his flat.
- L says now that he would rather not go to Bede, although he loves it. If it going to cost this much, he will stay at home and watch TV all day.
- We receive letters every single year saying L has to prove his handicap [sic] even though it is a lifelong disability. He worries that he will lose his flat if he doesn't meet the criteria.

Mother of K, 26, who attends Bede

- We have not been charged yet but we were getting 40 hours support and coming to Bede House. Now after a review we are getting 16hrs support and 3 days at Bede. [We are paying for an extra day ourselves]
- They [the council] wanted her to go to work, but she would need so much more support to get there and back. The Access to Work budget would cost so much more
- There is so much change to deal with, and always a different social worker
- Social workers suggest inappropriate things. One suggested that K join a dating website instead of coming to Bede.

Mother of N, 41:

- The government are picking on most vulnerable in society
- There is no rhyme or reason to the charges
- Why do we go from no cost to now exorbitant fees
- Why can we not get an answer as to the breakdown of fees
- And why charge now with the cost of living crisis?
- Why when you ask for help or explanation is there no answers?
- What about the future? What happens when I and my husband are no longer around? Some independent living places are too independent – some places are a dump.

Brother and main carer of M, 47;

- The cost is a concern and could determine if I go back to work, because we'll be worse off.
- Would M's benefit be cut, and also have to pay costs for service.

Grandmother and main carer for D, 42

- Why should independent people have their days cut just because they are independent? This was in response to the discussion around her grandson's day service being reduced.

The group asked Councillors, London Assembly members and local MPs for their help:

- To consider abolishing care charges entirely in Southwark. LB Hammersmith and Fulham has done this <https://livingindependently.lbhf.gov.uk/care-and-support/financial-support/care-and-support-costs/>
- Raising awareness of the impact on Southwark's disabled residents and their carers through the video 'A Tax on Disability' <https://www.youtube.com/watch?v=3l2MqxwHui8>
- Inviting families to speak at Council meetings so that they can hear the voices of the group
- Making information on councillor meetings and surgeries more accessible for people with learning disabilities