

Changes to Drumbeat School after-hours services:

Parents' impact statements

June 2017

1) Parent 1

The prospect of Drumbeat's After School Club closing in September 2017 fills me with dread and makes me feel extremely anxious. My child attends the After School Club at Drumbeat's Brockley site four days a week, Monday to Thursday. My child would attend five days a week but the club doesn't run on Fridays.

My child is severely autistic and has severe learning disabilities. My child has severe communication difficulties and challenging behaviour. My child has no established friendships and no social life. Drumbeat's After School Club, therefore, is a very important part of my child's life as it gives my child the opportunity to spend time with peers in a relaxed environment which is different from the structure and routine of the school day. My child is given the chance to try out a variety of fun activities in a safe place with adults who are trained and know my child well.

In addition to Drumbeat's After School Club being very important for my child's well-being and social development, it is also extremely important for me. In recent months we have had a number of violent incidents at home involving my child physically attacking me. This has been absolutely terrifying and very distressing as my child is bigger and stronger than me. The police and ambulance services have been called to the house and on one occasion our neighbour had to come round and intervene when they heard me screaming for help.

I am scared to be on my own with my child now at home and extremely reluctant to go out anywhere with my child unaccompanied. My partner works full-time, so After School Club fills that crucial time in the day when I would otherwise be at home on my own with my child. All my child does at home is watch favourite DVDs again and again and it's very difficult to engage my child in anything else. After a while my child gets bored and frustrated and that is often a trigger for my child to become agitated and violent.

I have looked at what is on offer in Lewisham to see if there are any alternative places where my child could go when this After School Club closes but there simply isn't anywhere suitable where my child would be safe. We tried accessing a mainstream playscheme a few years ago but they were unable to cope with my child. My child escaped while out on a trip with them to the Broadway Theatre in Catford and was later found by a member of the public wandering around outside Lewisham Hospital.

In conclusion I would say that the After School Club at Drumbeat is holding us together as a family – a family which is already a pretty fragile set-up due to the immense strain we are all under. Without the After School Club, I can see our situation deteriorating very rapidly, potentially creating a much greater financial burden on public services when we find ourselves no longer able to care for our child at home.

To further illustrate my current situation, I would like to add some quotes from a letter written to me by my counsellor which is an account of a recent therapy session:

“At our last meeting you had described the stress and heartbreak of [your child’s] barely controlled outbreak, the police having to attend and how it had impacted both physically and emotionally on you and the family...We concluded that matters with [your child] had become almost unmanageable and that more professional help was not only indicated but urgent.”

“My concerns...are that the urgency of your situation seems not to be understood by the authorities that can help. I surmise that, given your years of experience of coping, the common sense, courage and intelligence you bring to your family’s circumstances, obscure the significance and severity to others of the way things are developing for you.”

“...you now describe being afraid of [your child]. As I said, this is not the same as ‘I can’t manage [my child]’. This is a considered fact given that [the child]...[is] taller and stronger than you and given to wild, violent and prolonged outbursts.”

“As we were able to acknowledge today, things are not as they were. While [your child’s] outbursts would appear to be random, [your child] is actually targeting you. Your description...‘Making sure I am not cornered’ was, in part, how you put it, fearful of another attack...being ready to lock yourself out of the house if need be...In your anxiety about not managing [your child] physically any more, you have said that you are reluctant to take [your child] to places without support for the very real fear that [your child] could and has been a danger to others. Your recent experience of having to seek help from the police again while attempting to take [your child] to the theatre shows us that, whatever safeguards are in place, you must have immediate support when [your child] melts down as you put it.”

“You have considerable and obvious strengths...I’m so pleased that you have shown one more today in admitting to yourself that this situation is no longer containable.”

2) Parent 2

For the past 3 plus years extended services have been critical to sustaining family life and helping to assure the physical and mental wellbeing of both my children, Child 1 who attends Drumbeat and Child 2 (sibling). The after school and holiday schemes and the Saturday club meant that we stayed together as a family and both children were able to continue to live at home.

It has provided safe, fun, high quality care alongside other children, for Child 1 who has significant challenges emanating from severe learning disabilities, autism spectrum disorder and ADHD.

At the time that the Drumbeat shortbreaks kicked in we were a family teetering on the edge and I was adamant that without effective support we would need to consider the option of Child 1 living away from home. That was a painful and tough conclusion, not one reached lightly. We had managed despite the challenges for a long time but had reached breaking point. Child 1 was regularly launching physical attacks on Child 2 and on me. I was taking a significant battering in my efforts to keep Child 2 safe.-sometimes standing guard for several hours after returning home from a stressful fulltime job. Child 2 was having to lock themselves in the toilet to study. Child 2 was also carrying a huge amount of concern for my safety. The incidents generally took place when my spouse, already only working part-time, was at work. After school Club bought Child 2 some protected time during which Child 2 was able to complete homework in peace and to achieve at the very high level commensurate with Child 2's abilities. The stress Child 2 was under was phenomenal and we have sometimes wondered if we should have cried out for help earlier.

There are no services in Lewisham to replace the After School Club and there is no way that the proposed diluted holiday scheme could compensate for the current high quality provision. The loss of the possibility of safe, quality leisure time spent with others and supported by staff who know and understand Child 1 would lead to an elevation of Child 1's already high levels of agitation and anxiety with the likely result of increased incidents and outbursts- throwing, hitting, smashing things -at home, putting Child 1 and the rest of us (especially me and Child 2) at risk. There would also be impacts at school as the loss of stimulation, interaction and opportunities to play and participate in a wide range of activities supported by staff with the knowledge and skills to do this effectively, would impact Child 1's mood and focus. Even with the current support we are already living a constant state of alert, unpredictability and sometimes fear of the likelihood of physical and mental injury.

3) Parent 3

My child is a regular user of the Drumbeat After School and Holiday Club. My child is of secondary school age and has severe autism, a significant cognitive impairment, and exhibits many behavioural issues. My child is still in nappies, only has a few words of speech and needs one to one or two to one care at all times. Drumbeat Club has been able to meet my child's needs more than satisfactorily. My child enjoys spending time there, and I know that my child is stimulated, entertained, safe and looked after while there.

I am a working parent. I have worked all my adult life, and am proud of that fact that I have been able to parent a severely disabled child while all the time being able to hold down a full time challenging job which has allowed me to not seek state handouts. Drumbeat club has allowed me to work. Without that wraparound care I now find myself in a situation where I will no longer be able to work, as there is no other place at all that my child can attend. There is no way on earth that my child can attend a mainstream club, my child wouldn't even last an hour at one (this has been tried and tested when my child was in reception year – things are exponentially more difficult now that my child is older). There is no other provision at all in the borough for disabled children. Sadly that leaves me with 3 options:

1. Seek a residential placement for my child. This is not likely to be possible given the state of the local authority's budget, and would involve lengthy, expensive and stressful tribunal hearings.
2. Put my child into full time care. This would be a heart wrenching decision for me, but one that I may seriously have to consider if I can no longer look after my child.
3. Give up work, lose my home and everything I've worked for, for all these years. Lewisham would need to rehouse me urgently as I have a vulnerable child.

I understand things are difficult for the local authority, but don't take that out on disabled children and their families. We as parents have it tough with these children. Autistic children are challenging, sometimes I go through periods of months where I can't even leave the house with my child as my child is displaying such challenging and violent behaviours. There is nowhere my child can go as people don't understand and taking away the only provision in the borough where my child is understood, is to me a total catastrophe.

Please reconsider funding this club which is a lifeline for many of the most vulnerable families in this borough.