

FEEDBACK ABOUT IMPROVEMENTS FOR YP SINCE THE PFA EVENT FEB 2020

Introduction: We hosted a feedback event at the Salvation Army in July 2021 for the parent carers who had attended the February 2020 session. Those parent carers who could not attend the session and wanted to contribute did so via Zoom and email. The key messages are below and followed by individual comments.

The personal PfA experiences and feedback of the members of our Steering Group have not been included in order to ensure this is an independently collated document of the feedback we were given.

KEY MESSAGES

- Parent carers asked us to remind you that they had already fed back on numerous occasions and they feel that you don't listen or act upon feedback given.
- They said that there are still no clear pathways for those with or without a learning disability (however you decide this!) for social care, health, mental health, living in the community and a place called home.
- Lack of opportunity and choice post 19, including subjects and placements
- Parent carers asked 'When are improved outcomes and lived experiences going to happen for young people? What is your timeline? (Covid blamed all the time and now fed up with hearing this!)
- Families do not understand what the offer is when the EHCP ceases and how and if their young people will be supported in to adulthood; the 18 cliff edge has moved to 25
- Accountability – there doesn't seem to be any! Who ensures that the provision in the EHCP is delivered particularly in college/FE
- When is the meeting of "you said, we did" going to take place? It was promised three months after the original meeting!
- Parent/carers said that the Local Offer is not fit for purpose and does not meet their young people's needs
- Lack of transparency re 'a place called home'; the placements available and how the costings/criteria are carried out and if the process is fit for pan disability needs
- Continuing Health Care

Individual Comments

- Since attending the Seminar, I can honestly say that we have not seen any positive changes, in terms of the transition into adulthood, resulting directly from that meeting.
- Our specialist education provision has done some work on this via Zoom but we have not had any support from the LA

- The whole issue of moving out from home and the options available is extremely frustrating. The Local Authority are not providing any person-centred planning and are insisting on Supported Living rather than the more appropriate option of residential care. "Please can SPCF do something on this subject as it is driving me MAD?"
- I am not aware of anything at all being put in place as a result of that meeting and am still waiting for the promised follow-up meeting.
- At that meeting, I asked for things to be put in place for people who do not meet the criteria of having a learning disability at aged 18. Nothing has changed! My son is 21 with multiple disabilities. We asked for an alternative pathway for those young people that don't meet the LD criteria at 18 (What is the criteria?)
- What has been done to put an alternative pathway in place for both social care and mental health? What is the referral process for this alternative pathway?
- What support is available for young people who don't have an LD but do have mental health issues and cannot access mainstream services
- The Local Offer website is not parent carer friendly; I cannot find anything for my young person and I don't know where to turn
- What is available, what options are there when you reach 18? Where do I find information; the Council website is not accessible
- What is the criteria to receive a service from the locality teams ; what is the pathway and where do I find it?
- In Annual Reviews for Y9 and Y10, there has been no reference or support up to and including June 2021 even though the EHCP Co-ordinator attended.
- A month before my young person's 18th birthday (Dec 2020) a parent made contact with CWDT four times and received no response. They had to get support from a Local Councillor to get any response at all. Finally, the parent received a response two months after their young person's 18th birthday. This has taken a further six months to reach The Locality Team.
- What are the criteria needed to fit into The Locality Team and what is the pathway?
- What is the pathway from CAMHS to specialist health mental services if you don't meet the criteria for the Learning Disability team or if you were not under CAMHS at the point of transition?
- What is the criteria for a Learning Disability
- There is still a complete lack of exclusive specialist leisure activities and appropriate peer group activities.
- The Financial assessment paperwork and process is neither parent carer friendly, young person/SEND friendly or helpful in any way and nothing has been done since that meeting to improve this
- Why are social workers still not able to give us a list of supported living and residential placements? How am I supposed to know what we can choose from?
- Nothing has improved, we still have to do everything ourselves and try and search the internet without any support from the Council

- There are still no additional Changing Places for families with disabled children so that they can stay out longer than one hour.
- At the meeting, which was supposed to tell parents pathways into next steps post EHCP for our children, we were instead asked to suggest what we would like to see for our children. I fear the meeting was an exercise designed to ask parents who do not know statutory requirements that should be in place, to comment, and then to be able to say afterwards, Sutton prioritised the requests of unwitting parents.
- It was very telling that when I asked the panel to spell out in detail all local offers and pathways into care and accommodations, I was met with silence and please see our website. The website details generic routes and an email to use for applications. Upon using that email to requests application for supported accommodations, I hit a brick wall of no-response and even making formal complaints all I uncovered is that Sutton has no provision for young people on EHCPs.
- I also took away from that meeting that Sutton has failed so many tribunals for EHCPs that there is a bulge of young people who are in out of Borough provision, about to return to Sutton. And Sutton LA has no provision in place locally for them for that transition, they have been so focused on opposing parents and having to make provisions out of the borough.
- After the meeting, my requests via social work teams about what supported accommodations were available in Sutton was met with obfuscation and a lack of response and being put into a look to approach Sutton Housing who pushed me back to social workers. It was only after formal complaints that we ascertained that Sutton has some supported accommodations for recovering drug and alcohol patients, and places for very high dependency autistic young people. None of which are suitable for our daughter.
- The route we found for ourselves was a housing association accommodations for special needs people, that is fully funded by housing benefits and universal credit. We located this option through advice from parents we know in other locations in the UK, as a route to follow. At no time in this process did Sutton LA teams know how to effect this provision. The process of how to get benefits was very tortuous and no one, at Sutton LA, in SEN, Health or Social Work/care knew how to effect this. We had to find it out all ourselves.
- There remains very little supported accommodations outside Sutton's own provision, for parents to access. I fear we accessed one of the few local facilities, and most parents will have to go out of the borough.
- What happens with an EHCP ceases? Where is the pathway for social care and other appropriate services?