



Mental Health Support for Children and Young People with Additional Needs in Milton Keynes.

PACA Listening Events February 2024

INTRODUCTION

PACA held two listening events in February 2024: 5 parents attended the online session on 6th February, 16 parents attended in person on 15th February.

Other attendees included representatives from [CAHMS](#) and [Healthwatch](#).

Our aim was to revisit our [joint report with Healthwatch, and](#) to find out if support for Children and Young People with Additional Needs in Milton Keynes had changed since 2022.

WHAT IS NOT GOING WELL

- There were concerns about what happens in a crisis. Parents wanted a clear understanding of the process and support in this situation. If not A&E, parents did not know where would be approachable. Parents have had to resort to calling the police because A&E is not appropriate.
- Parents described how concerns about their child's mental health often started in school when needs have not been met. This can lead to trauma and greater health needs when the young person is older or lead to hospital admissions later on.
- Navigating the system is still difficult.
- It's hard to get an Autism diagnosis. Parents are still needing to resort to private providers for many things such as therapies, OT and assessments.
- Trying to get a face-to-face doctor appointment and with the same GP since COVID is hard.
- Some children won't talk to adults.

- Parents have resorted to go for a private diagnosis and for counselling because of waiting times. However, they are being told that if they are on the CAMHS waiting list, private companies won't accept these new families.
- Social care had not been supportive for some. Not all parent/carers have access or aware of social workers and the support that is available.
- Parents asked how they can get respite if they are not eligible for the assessment from the children with disabilities team. Parents described feeling desperate and wanted to know what the criteria is for getting help.
- In the longer term without support the child becomes depressed, misses education, social interaction and can have suicidal thoughts. If left untreated can and does result later crime and possibility a custodial sentence. The prisons are full, and lot of the young offenders are from this cycle with their mental health needs not met during childhood.
- Access for speech and language at schools has not always been available
- It's sometimes only medication when they are eventually seen, not behaviour and emotional support which is escalated from the additional waiting time. Could medication be prescribed before this?

LIVED EXPERIENCES

- Two parents told us they had moved schools because of the SENCO teams and needs not being met. They have experienced an improvement but a big stress to go through that route.
- Parents also mentioned their own mental health crises are due to needs not being met during their childhoods and late diagnosis.
- Parents reported that their children's schools are not supportive and therefore children are missing school more often. The lower attendance rate affects academic and social progress, along with mental health.
- Rejections from GP and Schools for a first CAMHS referral. They have been told the waiting list is too high and is therefore currently closed for anyone to be added on too.
- If a child is 'gifted' there is no access to any help such as EHCP, FACT Plus, as they can mask at school. Parents described not being heard and just labelled as being difficult.

- One parent said their child had experienced a 7th suspension when the school could not cope with their child, or had threats of being expelled. "Parents know more and should be listened too."
- A lot of people are being diagnosed late in life, one parent told us she was diagnosed at the age of 43.
- Financial worries when child is not in school. Parents worry that they could lose their jobs and their careers. The stress affects everyone's sleep and leads to parent depression.

WHAT COULD BE IMPROVED

Parents told us what had worked well for their children and young people and gave some suggestions for improvement:

- Animal therapy with a trained therapist works well, but is not widely available unless you have funding, or it is stated in the EHCP.
- Right to Choose is helpful but GP's don't seem to be aware of this
- Parents would like to have information about what mental health services are available in schools, especially primary schools. New resources all seem to be set up for over 11's.
- Secondary Schools have onsite support but not always have knowledge of how to support SEND mental health needs.
- Text Reflect is for 11+. There is a huge need for support for under 11's – "the right support at the right time."
- To know what the Pathway is would be useful.
- MIDoS (NHS online directory) – parents were unsure about when this would be available and if services for children and young people be included.
- CAMHS to keep in touch with schools to get the full picture with attendance part time timetables etc. and to keep on top with what schools are and not doing and the gaps.
- ADHD Wise courses are very helpful. PACA will be running another course in June/July.
- A new group called Autism MK do online courses and are very supportive and keen to support and help where they can and signpost.

RECOMMENDATIONS

- To have clear information about Right to Choose. A written pathway and information should be available so that parents are fully informed and can give this to GP's.
- GPs now won't sign a child off school which results in parent battles with the school, and unauthorised attendance figure. This adds to parent stress and extra pressure to the child. Can this be addressed with GP's?
- Therapists should be trauma informed.
- Provide a safe space and an alternative to A&E for those with Autism, accessible at crisis point, for all ages. A sensory room design would feel less pressured than a clinical room at a centre.
- A separate Health Assessment Unit is needed not at MK Hospital A&E department.
- A local directory of mental health support which states at what ages CYP can access support.
- Early prevention in primary school for under 8years of age, a time when hormones and personal issues start.
- More support for parents so they don't feel alone and not listened to.
- Support is needed while on long waiting lists.
- Training for schools and sencos is needed, to have more emotional understanding, how to listen to and believe parents.
- Clarity about what the pupil premium covers and understand how funding is spent. What is and isn't ring-fenced and if early help funding is available.
- Post diagnosis support
- FACT Plus paperwork not designed for girls or older children, needs updating.
- More support for Home Educated children.
- Wrap around care.

SUMMARY

Parents talked about a merry-go-round of referrals to different professionals and being passed from "pillar to post". They felt that nothing was joined up and with no real support and little has changed since our report in 2022.

Parents feel that there is a need for a dedicated SEND mental health support service in Milton Keynes.

Since the listening events took place in February, an MK Wellbeing Service for 11-18year olds has been launched. However these services are aimed at over 11's and does not meet all the recommendations referred to above.

USEFUL LINKS AND SOURCES OF SUPPORT

<https://www.mksendlocaloffer.co.uk/health-conditions-and-disabilities/mental-health-and-wellbeing-hub>

<https://www.mind-blmk.org.uk/how-we-can-help/milton-keynes/young-persons-sanctuary-milton-keynes/>

<https://www.cnwl.nhs.uk/camhs/your-resources/borough-resources/milton-keynes-resources>

<https://pacamk.org/help-and-advice-about-send/>

<https://www.youngminds.org.uk/>