

# “I am different, not less”

- *Dr Temple Grandin*

*Experiences of CAMHS and Mental Health support for children and young people with Special Educational Needs and Disabilities (SEND) in Milton Keynes*



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# Acknowledgements

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Healthwatch Milton Keynes would like to acknowledge and thank the parents and carers who have shared their stories, thoughts and experiences with Healthwatch Milton Keynes and the Parents and Carers Alliance Milton Keynes (PACA MK), in order to improve the experiences of others.

A selection of the comments and observations made by people about their experiences have been included, verbatim, to provide insight into the thoughts and views of parent carers who are trying to navigate the system to ensure they, and their children, are included and heard.

We hope that the thoughtful responses and insight will encourage more involvement of parent carers, and the young people they care for, in the design and delivery of services provided for them.

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The ASC (Autism Spectrum Condition) community is huge in MK and there is nowhere to go to help our children. No one is listening, no one is prepared to make the changes our children need, and our children are suffering. - *Parent carer*

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# 1 Introduction

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PACA MK is a parent forum which aims to give parent carers a voice in the development and improvement of local services.

The group is open to parents and carers of children and young people aged 0–25 years old with disabilities or additional needs who live in the borough of Milton Keynes. It is an independent and voluntary group run by parent carers.

PACA MK run a variety of events to offer parent carers an opportunity to have their say and to share experiences with like-minded people.

PACA MK also run an annual information event in partnership with the MK SEND Information and Advice Service (MK SENDIAS) which includes speakers, information stands, crèche and workshops for parents, children and young people.

PACA have advised that Milton Keynes have adopted the acronym ASC (Autism Spectrum Conditions) rather than refer to ASD (Autism Spectrum Disorders). Healthwatch Milton Keynes have used this term to acknowledge that people with an Autism Spectrum Condition range from being highly skilled at learning, thinking, and problem-solving to be severely challenged in these areas. Some people with autism require a high level of daily support, while others need far less support and live independently.

Treatment for autism spectrum conditions needs to be as individualised as the person who has been diagnosed.



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## 2 Methodology

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In June 2021, PACA MK invited Healthwatch to a focus group they were holding to gather the thoughts and views of parent carers on the Child and Adolescent Mental Health Service (CAMHS). Notes taken during this virtual meeting have been used in this report.

The PACA MK team gathered parent carer accounts as well as conducting a survey amongst parent carers of their experiences of accessing mental health support for their children and young people with Special Educational Needs and Disabilities (SEND) in Milton Keynes.

Healthwatch Milton Keynes have also gathered the views of parents, carers, and young people around their experiences of seeking Mental Health and Social Care support.

One family have provided a detailed case study of their journey and experiences across a number of statutory organisations who are charged with providing education, health and social support for children in Milton Keynes. Three other families have provided in depth accounts of their experiences trying to access support for their child. These have been included in full, as to do otherwise would minimise the evidence of the impact the current system has had on these children and their families.

These personal accounts, and the survey findings, have been collated and presented in this report. The recommendations for improvements have been drawn from the stories and suggestions of those who come up against the barriers and gaps in the system.



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## 3 Summary of Findings

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The conversations highlighted the gaps for young people with Autism Spectrum Conditions (ASC) trying to access services in Milton Keynes. As with the adults ASC offer, much of the support is provided by voluntary and charity organisations (VCSE). The statutory organisations, such as NHS and the Local Authority, have a much more stringent criteria for admission into services and often, these criteria create barriers for families struggling to get support.

That there appears to be very little in the way of respite care, short breaks, support, or treatment available in Milton Keynes for people with ASC has a profound effect on the families needing these services. This also has ramifications for those professionals who are charged with fulfilling the provisions set out in the Care Plans written after Care Assessments have been completed. The 28 July 2021 Local Government and Social Care Ombudsman's decision<sup>1</sup> reflects the injustice caused to families, and the further cost to the Local Authority, in not having these services commissioned and available.

The NHS recognise that people with Autism are affected by anxiety. The NHS webpage also acknowledge that the anxiety may be caused by a change in routine or as a reaction to a noisy or brightly coloured place. They also suggest that “[i]f your child is often anxious, ask your autism assessment team or child mental health team for a referral to a counsellor or therapist with experience of autism”.<sup>2</sup> The experience of parents trying to get their child referred to CAMHS indicates that these referrals are being rejected due to an ASC diagnosis.

The integration of services, and the commissioning of services that recognise that a person with ASC should be treated according to their presenting need rather than their diagnosis, or lack thereof, is vital to improve the lives and the experiences of the many families affected.

***“There isn't a blanket rule that an autistic child is anxious only due to autism. Autistic children need and deserve specialism from those who fully understand how Autistics process and what they need to heal and recover” - Parent Carer***

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<sup>1</sup> <https://www.lgo.org.uk/decisions/education/special-educational-needs/20-009-914>

<sup>2</sup> <https://www.nhs.uk/conditions/autism/autism-and-everyday-life/help-for-day-to-day-life/>

## 4 Mental Health support survey

### Mental Health Support for Children/Young People with SEND in Milton Keynes

PACA conducted a survey of Parent Carers to explore their experience of accessing mental health support for children who have Special Educational Needs or Disabilities (SEND). The survey asked Parent Carers to provide comments. The 63 responses received showed that while 69% of respondents had accessed CAMHS for support, parents also used a number of other services:

Deaf CAMHS -

GP

Child and Family Support

MASH (Multi Agency Safeguarding Hub)

EMDR (Eye Movement Desensitisation and Reprocessing - a form of psychotherapy)

Relate

Family Support Worker

Counselling (individual and family)

Mental Health Support Team

### What was good about these services and what worked well?

- Can easily get prescribed anti-anxiety medication and medication to aid sleep. CAMHS also supported us (parents) when trying to convince school our child was too unwell, mentally, to attend and their needs must be met to enable them to attend school.
- Deaf CAHMS supported us at a meeting with college staff.
- Referral was quick- multiple referrals by Paediatrician, school and GP- discharge was also very quick.
- Finally being assigned a 'permanent' consultant instead of a locum. Good to build a relationship with a trusted consultant.
- "Art therapy" over Zoom was a surprising hit!
- Personally found it very helpful. What worked well was getting the support and diagnosis for my son.

However, not every parent was able to provide a positive comment:

- Couldn't get counselling until ASD diagnosis so they had appropriate counsellor excuse. The first counsellor had my child in tears telling him off for not speaking! He has social communication difficulties and anxiety disorder. He hardly talks due to stress and freeze response. I changed to a male counsellor. It was not helping as it is a talking therapy and not equipped for selective mutism children. Services should be chosen by non neuro typical mother. Rather than a man in a suit.
- Nothing, it took 5 referrals to be accepted because of an ASC diagnosis. Was told it's normal for children with ASC to have anxiety, it may be but it shouldn't mean it goes untreated. 5th referral accepted in August and still on the waiting list.
- Advised by CAMHS that 'services' non-existent. Delay in accessing took over 4 years.
- No it was not a good service. They ignored my son's mental health for years and I said he had traits of ASC...he got so bad that he ended up getting sectioned and sent him to a hospital to be assessed. He was diagnosed with ASC, anxiety and depression...6 months on we have still not received any support.

While this question covered all of the services, most of the comments refer to CAMHS as this is the service that most people had. Parent Carers suggested the following improvements:

- Shorter waiting times
- More streamline referral process Reduce the barriers to access the system
- More choice of therapies instead of medication
- Support for those with ASC- not just blaming everything on this condition
- More staff available to provide advice and signposting to self-help areas until can be seen, lack of support for ASC and anxiety.

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*“The good and bad in a person, their potential for success or failure, their aptitudes and deficits - they are mutually conditional, arising from the same source. Our therapeutic goal must be to teach the person how to bear their difficulties. Not to eliminate them for him, but to train the person to cope with special challenges with special strategies; to make the person aware not that they are ill, but that they are responsible for their lives.” - Hans Asperger*

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### Thinking about CAMHS, what worked well?

- Finally being designated a 'permanent' consultant instead of a locum.
- When the actions for the best interest of the child from the parent was taken into consideration.
- The support from [unit outside Milton Keynes] was amazing and the diagnosis of autism that lead to getting treatment needed
- Being able to talk to someone about my son's difficulty's and having regular six-monthly checkups.
- Once in our appointments with our clinician was great, she really helped our daughter. Picked up on eating disorder. Diagnosed Tourette's

There were considerably more negative experiences related by parents with eleven respondents simply writing 'Nothing' while others provided examples of the issues they had experienced:

- Nothing. More stress as they wanted to report my sons to social services as one hit the other.
- Nothing they still haven't contacted me
- Was referred by paediatrician but CAMHS got in touch to say my child didn't qualify as he is in a special school.
- Nothing!! Too busy blaming parents than actually wanting to help child.
- Absolutely nothing. One phone call. Had to fight not to be discharged. No one contacts us. Been on their books two years.
- We are on a waiting list and have been for 18 months, we are now on another pathway with CAMHS and another waiting list. Cannot comment further as we have not yet had any treatment

### What could be improved?

- Waiting times too long, more face-to-face therapy and support.
- Carry out a whole service review - fit-for-purpose tailored to individual needs. Learn from surrounding counties that do it well. Retaining staff to ensure continuity would help a lot.
- Make the ADHD pathway clearer.
- More training for all in ADHD/ASD and masking in girls. Improve accessibility for ASD.
- Have a handover from children's to adult's mental health teams

- Lower the criteria so children with low level mental health get the support when the need it before they reach crisis point.
- Support for anxiety.

### Is there anything else you would like to tell us about your experience of mental health services in Milton Keynes?

- They need to be more accessible. The feeling around the area is that CAMHS is not well staffed which leads to a high threshold to access help. This leaves a lot of families without help.
- Please reform CAMH Milton Keynes. Bring in fresh minds who genuinely care about the people of Milton Keynes. Set up a 'Task Force' or 'Focus Group' and learn from neighbouring counties what excellent medical practice in mental health looks like.
- There is no help for children in Milton Keynes!! Daughter referred to CAMHS no help! She's now self-harming, referred back to CAHMS in December and we are still waiting to hear from them!
- There's no deaf awareness at Milton Keynes CAMHS.
- The whole thing has been a shambles!! 18 months on a waiting list with no contact or support during this time. Violence escalating. It would just be nice to have some communication to know that you weren't forgotten, some tips and advice to help in the meantime whilst you are on the waiting list, maybe to know how potentially long you may still be on the list for, to help manage expectations.
- Waiting lists are far too long. Staff retention is an issue and this has knock on effects on patient care. CAMHS needs to accept children with an ASD diagnosis in more cases. Whether an issue is ASD related or not, the child needs the support from the specialist service.
- Support felt like a parenting course which in some ways was appropriate but the practitioner never met or even spoke to our child. I think this should be different.
- Needs major improvement for the welfare of children / young people. Making mental wellbeing a part of the curriculum and having easier access to support for those that need it.

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## 5 Parent experience 1

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I have been taking my child to A&E for assessments with the CAMHS Liaison and Intensive Support Team (LIST) since they were 9 years old. During lockdown I had to take them 8 times within a couple of months. My child got frustrated as every time we went, they had to repeat themselves despite LIST having notes on them already.

On one occasion the woman in the LIST team did not listen to anything I said. She put the behaviour down to hormones and because they could not see their friends as we were in lockdown. I explained that my child was unstable and needed some antidepressants and she laughed at me. She said they were too young and that they were fine now.

Children should be listened to.... just because they may have calmed down by the time they get to A&E does not mean that there is not a problem.

We saw the same woman saw one evening when my child was extremely bad and she bought a security guard with her. She was not helpful at all and kept asking 'what did we want her to do'. I told her my child needed sectioning, and she laughed. I told her to contact children's social care as I wanted their support. My father who was with me at the time became annoyed with her as she was not listening.

Two days later my child was sectioned. Nothing was done for my child and it ended up with them being sent away. It was also particularly bad that they had to go into the Campbell Centre for four days when we were told it would be 72 hours. My child cut themselves whilst they were in there.

My child had some sessions with someone called Hazel when they were about 10.....she disappeared after having a couple of sessions with no other support being offered. By the time she came back there was no point continuing.

I have to continually chase CAMHS up for information

We've had two family therapy sessions, not really family therapy, since April... I turned up for an appointment in April to be told that all the practitioners have left. We have another booked this Thursday.

The whole process of CAMHS is too slow.... More children need help than ever, and they are not fit for purpose. This is not a service that should be supporting children... they cannot provide the support children need and perhaps a more multi-[agency] organisation is needed where everything is provided so they can support children with diverse needs rather than ignoring those with ASC

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## 6 Parent experience 2

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My child was suffering in primary school and your team (CAMHS) came to a school meeting and without them we would have struggled to get the Local Authority to understand there was an issue. But services that work together as a team around a child should not be able to simply side with education when they can see there is an issue. My child was discharged when they needed you most.

Education at the time (and they were diagnosed) felt there was no issue (despite them not being in school and vomiting and clearly not ok.... school felt it was all my fault). Your services had an opportunity to be the voice of the child and really stand up for them and say no this child is not ok and we need to look at education. It was a missed opportunity in my mind. (My child had no EHCP at the time we had got one afterwards.)

I have no issue with what happened now but if we are really truly going to learn we must ensure we advocate for the CHILD and ensure the child is heard and listened to especially if they are telling us through behaviours. Even if that means Standing up to schools and staff who have no training or understanding of the condition (irrespective of title and training). Your team had the power to put an end to the distress that education caused my child, yet they didn't. My child suffered in education and no one came to help.

My child is now supported thankfully and is ok but trauma doesn't go away without help and we have nowhere to take them in the current system as they are autistic.

Your team writes excellent documents yet when schools don't - or fail -or won't (as in our case they simply wouldn't do as your team suggested) - There is nothing we as parents can do to enforce it. Which means again the child suffers.

Lack of accountability is my biggest issue with the whole system (education mostly) yours was a small part in what went wrong for us so not all to blame. Yet there could have been a different outcome had these changes been in place by your team.



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## 7 Parent experience 3

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I had managed to get my child, who is 8 and currently going through the process of being assessed for potential autism (and applying for an EHCP), referred to CAMHS, the first time we were rejected and then an additional request was also rejected.

My child has been saying some concerning things in regards to their self-esteem (no one likes them, they're a let-down, no one understands them, it would be better if they wasn't here) as well as extremely difficult behaviour at home (saying no to everything, refusal to sleep sensibly often staying up too late and eating during the night, invades personal space, refusal to do what they're asked at school or any out of school activities, being destructive at home, aggressive, faecal smearing, poor hygiene, being unsafe by jumping on furniture or throwing things at me, spitting and being physically intimidating) They are young but already wearing clothes for 13-14 year-olds and is very strong. They have refused school for an extended time and when they can make it in, it is very random and sporadic. They have a reduced time table; SENDIAS, CFP, local Children's centre and GP are involved.

With the two refusals to CAMHS, my GP says there is nothing that he can now do although he wishes he could. On the surface it could appear that my child is a badly behaved child and whilst I am deeply concerned I can see that what is at the heart of it all - unmanageable anxiety and emotional overwhelm. I can't imagine anyone behaving like this for no reason. I want my child to get help so that their behaviour doesn't deteriorate to the point that it blights their life. I want my child to avoid hurting themselves.

CAMHS have stated she doesn't meet the threshold to activate their services and have also recommend that I utilise the services I'm already involved in. I have also contacted Service Six and they are too oversubscribed to be able to help.

It worries me greatly that my child would either have to be self-harming or suicidal to trigger CAMHS involvement when there is a need right now, today. I do not want my beautiful, much loved, and bright child to reach that point when it could be avoided by getting help now. I do appreciate that CAMHS are oversubscribed too, underfunded and probably with a high turnover of staff, I'm also acutely aware that nationally CAMHS is not regarded highly by many but if there is an even a small chance that they could help I'd take it. Other families, if they can afford it, go privately to get help but I am not able to self-finance private care.

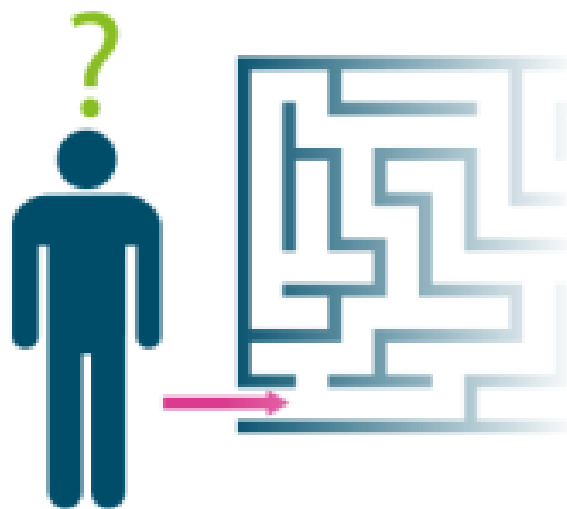
At the moment I am lost at sea with no buoy in sight, watching my child descend into increasingly concerning behaviour with the aggressive side turning physical and aimed at me, whilst I have nowhere left to turn to get either counselling or some other mental health service that can help them get a handle on how to cope with

how the world is, or even to diagnose them if that is something that becomes necessary.

I believe my child has a demand avoidance trait and I'm doing all I can to learn about it so that I can implement better language use and demeanour to help my child manage the day to day. PDA children and adults, at their core, have intense anxiety, which is a mental health issue.

I'm now in a position where I am viewing, and being on the receiving end of, a child whose behaviour is crying out for help and there isn't a single thing I can now do other than wait for things to get even worse. Families like mine shouldn't be put in that position. Home life is not the calm haven I want it to be for my child. I hear, see, and feel their distress and anxiety and I weep inside because I can't do anything meaningful to help.

I'm not expecting a magic wand to be waved but voicing my frustration is needed at this point because I don't doubt for a moment that I am the only person feeling like they can't access what they feel they need for their child



## 8 Case study

### CAMHS support for autistic children

My son's paediatrician requested a referral for him in 2016 for a potential diagnosis of ADHD and for a functional assessment of behaviour. They accepted him for the diagnosis but declined to make any assessment of his behaviour. We had an interesting conversation, more or less as follows. The nurse asked what my expectations were of the service, and I responded by saying that I thought they might offer CBT because this therapy had an evidence base and was recommended in the NICE guidance on managing autism in children and young people. They seemed surprised that I should give an informed answer and the nurse hadn't heard of the NICE guidance.

She then told me (in front of my son) that autistic people are unable to empathise and therefore can't be offered CBT. This is ridiculous, my son can empathise perfectly well - he says it is a learned skill. He was distressed by these actions and started throwing the furniture around the room. There had been no consideration given to a private space for the nurse and my to have a conversation about him. I concluded that the service had a very limited and uninformed understanding of autism and that it was probably best for my son if he didn't go there.

Later I discussed this experience with the local Healthwatch and was told that in MK, it was understood that CAMHS did not provide a service to autistic children. The argument [CAMHS] make is that symptoms of mental distress are likely to be a result of the child's disability and therefore not a mental health condition. Healthwatch agreed with me that excluding children with a particular disability could be discriminatory. It is like saying to a wheelchair user that you won't give them physiotherapy, even though this might help them, because their problem is the result of a disability and not a health problem. The criterion should be whether the child would benefit from the service, and consideration could be given to whether parents are already doing their best to make autism-friendly changes, have attended training, etc.

More recently I sought a referral to CAMHS (again via my son's paediatrician) for possible anxiety / OCD-like behaviours. Again, this was initially rejected in a letter of 26 Feb 2021. I then emailed them as follows:

"In this letter, you state that my son does not meet the criteria for MK Sp CAMHS because 'MK Sp CAMHS are not commissioned to provide support for young person with ASC that do not have a comorbid disorder or evidence of a co-morbid disorder'. You also state that 'the reported anxiety appears to be in keeping with ASC'. I note that you have not



made a formal assessment of my son for anxiety, not have you met him as part of this referral.

I am writing to ask you to reconsider this decision. At first glance there appear to be a number of problems with your statement.

1. You state that my son's anxiety is in keeping with his ASC. However, my understanding is that clinical anxiety is a separate disorder under the diagnostic guidance, with its own criteria. The criteria for ASC and anxiety may overlap, but one is not a subset of the other. Not all people with ASC have clinically significant anxiety, and not all people with clinically significant anxiety have ASC.

2. Either my son's anxiety (if confirmed) is co-morbid or it is a separate condition. Your statement 'in keeping with his ASC' suggests that you think it is co-morbid.

If co-morbid, you cannot decline the referral. You say you are 'not commissioned to provide support for young persons with ASC that do not have a co-morbid disorder'. I therefore assume that if the disorder is co-morbid, you would be commissioned to accept the referral.

If separate, and you declined the referral because of my son's ASC, this would be a case of straightforward disability discrimination on the part of the NHS. I cannot possibly believe that this would be the case.

3. Without a proper clinical assessment of my son, I don't see how you can make these judgements anyway."

I then went on to provide more clinical information about my son's difficulties. This did the trick, and they accepted the referral. He has now had a triage appointment and is on a waiting list for treatment (1 year).

Bridge Academy see a number of autistic children and their understanding is that, in MK, CAMHS do not treat autistic children. They were surprised at our success in having the referral accepted. Autistic people are much more likely than the general population to experience mental health difficulties, yet (in MK at least) cannot access services. This is really not acceptable. They should be treated according to the same criteria as everybody else. It would be better for them if they did not have a diagnosis of autism, since this only seems to act to limit their access to services.

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“The criteria for ASC and anxiety may overlap, but one is not a subset of the other. Not all people with ASC have clinically significant anxiety, and not all people with clinically significant anxiety have ASC”

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## Occupational Therapy Support (OT)

While attending Middle School, my son was referred to the paediatric OT service for help with fine motor control (writing and doing up buttons). They decided to visit him in school and made a complete assessment, not just of fine motor skills but also gross motor skills, organisational ability, attention to task and sensory issues (which until that point had not been prioritised). The school implemented the OT's recommendations, and this had the most profoundly positive effect on his progress in school. I honestly think that without the OT's intervention, he would have had to leave mainstream school at that point because he was more or less unable to attend class and was being babysat in a meeting room for much of the day, for about 3 months (doing upside-down jigsaws). With the OT's input and a fantastic teacher and SENDCO in Year 6, he became able to access a mainstream class and made the fastest progress of any child that the SENDCO had previously seen in her career. The OT provided a number of aids, including a specialist chair to help with motor support.

I now believe that the OT service should be used much more in the management of autistic children. There were many areas where we were not aware that he needed their help, nor was his paediatrician.

On transition to secondary, I requested input from the OT service again. The service assesses the interaction between a child and their setting, thus with a change of setting we needed a reassessment.

However, there had been a change in the OT service. The service told me that they had not been commissioned by the CCG to perform assessments in schools and recommended that I make a complaint to the CCG about this, which I did. The CCG came back and said that they believed they had commissioned the OT service to come out to schools, but that the contract was not overly specific. I became very frustrated - I knew that I had the right to make a complaint to the healthcare service for failing to provide services that my son needs, however I didn't know which part of the service to complain about. Somebody told me I needed to find a woman called [Name redacted] who works in the healthcare service and would be able to help, but I didn't know how to find her. Fortunately, she happened to be attending the MK SEN day that year, I was able to explain our predicament and she was very sympathetic. Two days later we were contacted to make an appointment. The service made it really clear that they were doing this as a one-off and that I couldn't expect to get the same treatment again. I expect they might have been concerned about the threat of an official complaint, which might have forced them to change the service more widely.

## Educational placement

We have been trying to find a school placement for my son for over 16 months, via the council which has the statutory duty to find him a place that will meet his needs. Initially we concentrated on reviewing his EHCP so that prospective schools would be able to make a proper assessment. During this period, my son had home tutoring of 2-3 hours per day, rapidly scrambled by the LA. Then lockdown came, and the tutors went online and it didn't work anymore.

Despite being considered vulnerable and entitled to attend school, my son remained at home with home schooling and BBC Bitesize. The lockdown impaired the LA's ability to find schools, but even so their progress has been poor as they didn't start any official consultation processes until late October / early November 2020. He was found a supposedly temporary and part-time placement at Bridge Academy West, which is a "medical Personal Education Centre". It has been successful in terms of meeting his SEND needs, but they cannot meet his academic needs fully (for example, their science provision is limited, and they cannot support Triple Science at GCSE).

Although individual members of Local Authority staff have been very supportive, overall they seem understaffed and therefore slow. They do not have an obvious school placement within MK for a student who is academically able yet who has sensory issues that can prevent access to a classroom. I believe there is a local gap in provision. What is available is set out below:

<u>SEN status</u> <u>Ability</u>	<u>Neurotypical</u>	<u>ASC - can access a class</u>	<u>ASC - can't always access a class</u>	<u>Social, emotional and mental health (SEMH) difficulties on EHCP</u>
<u>Academic</u>	Mainstream secondary	Mainstream ASC department (St Paul's, Radcliffe, Stantonbury)	Specialist unit needed - gap in provision	Ditto
<u>Preference for vocational subjects</u>	Mainstream secondary	Mainstream ASC department	Stephenson Academy (ASC classes)	Stephenson Academy (with limited academic options)
<u>Learning difficulty</u>	Mainstream secondary with support / special school	Special school (some specialise in ASC)	Special school (some specialise in ASC)	Special school (some specialise in SEMH)

As things stand, we can't get the SEND provision my son needs in a mainstream school, so we have to bring mainstream education into a special school, or substantial SEND provision into a mainstream school. The first of these options won't work, as my son needs to socialise with peers who have a similar ability to him. But we are struggling to get any mainstream school to accept him, even with

additional (funded) council support. The council has consulted with St Paul's Hazeley, Radcliffe and Sharnbrook. I have requested visits to Hazeley and Radcliffe. Even the ASC departments we have discussed this with so far (St Paul's and Radcliffe) have rejected the application because they cannot deliver the curriculum outside a classroom. We are trying to push back.

Over 1% of the population is autistic, so this is one of the largest groups of disabled people that can require significant support (especially at school). Some other local authorities have ASC units in a mainstream school, ie spaces that are run by qualified teachers who can deliver the curriculum, and that can be porous in the sense that students can access classrooms or not, depending on their capacity to do so. An example is Lincroft Academy in Bedford Borough, Kingswood Academy in Corby. We applied for a place at Lincroft, but this was rejected because they are full. Although we could challenge this decision legally, the reality is that there would be a delay of perhaps 18 months before a place became available. Bedford Borough make the decision about which students to place, at present there is a waiting list and places seem to be allocated to students who previously attended their ASC unit in primary school.

### **Bridge Academy**

After about 5 months of home schooling, the council found a place for my son in Bridge Academy West, a Pupil Referral Unit (PRU) based in Bletchley. They are a "Medical PEC" (Personal Education Centre) for young people who have been excluded from school or are at risk of exclusion, and who have medical needs (often mental health). Despite not being a school for autistic students, their experience in dealing with anxiety has made them a good place to give my son the help he needs and turn him around. When he was excluded, his behaviour regressed but they have halted this and also helped him to improve. They are meeting his sensory and social needs and have seen no incidents of challenging behaviour. He has benefitted enormously from their therapeutic approach. They now tell me that another 4 children like my son will be starting to attend - maybe the council has realised that they can be a suitable short-term placement for children with ASC.

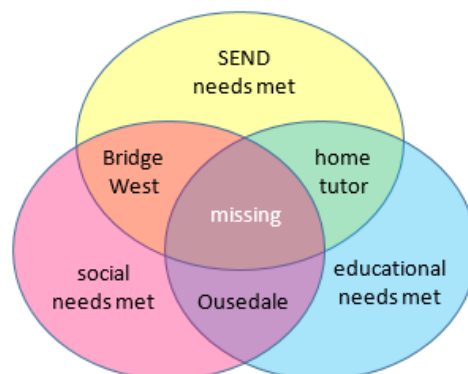
However, their Medical PEC status also means that they have no statutory duty to provide a full-time education and they do not have the capacity to do so. My son attends from 10:40-14:00 Mon-Thurs and 9:00 - 12:30 on Fridays. He now receives 2 hour of sciences per week (this is a core National Curriculum subject); this was arranged by the council finally after 4 months of asking and one hour is delivered online by a local tutoring agency. Another member of staff gives him a science lesson but we are uncertain about their expertise and Bridge currently say that they would be unable to teach Triple Science at GCSE, which is what my son needs (from Sept 2021).

Though part-time, Bridge has been excellent for my son’s social development and we are now seeking a dual placement with a mainstream secondary school where he would be able to transition and then start GCSEs in September in Triple Science. He would continue to study for GCSEs in maths and English at Bridge, and they would continue to support him and advocate for his needs with the mainstream school. Even this solution though will require him to be transported back and forth across MK, which might require us to do this if he cannot tolerate alternative transport options. We are struggling to get more than a bare minimum education, and one that will barely support a future transition to 6<sup>th</sup> form. Had he remained in mainstream, his prospects would have been so much greater.

Even so, we are struggling to find a suitable school for dual placement. Schools that have reacted positively to my son’s placement have had science labs or corridors with a smell (usually cleaning products) that he cannot tolerate. Two have refused visits on covid grounds, one saying that they were told to do so by the local Public Health team, one as we are “non-essential” apparently. So we are also now seeking a school that can provide teachers to go to Bridge Academy to teach him there. Given many schools’ staffing challenges, I am not hopeful.

Going forward, my son can expect to study a maximum of 7 subjects at GCSE: two English, Maths, three Science and RS if he wants that. This requires the science provision to be in place of course, which is not yet established (we only have 2 more weeks to organise it before the summer holidays). We can forget any prospect of gaining qualifications in a foreign language, humanities or ICT. This is irrespective of my son’s capacity. He is getting additional help for challenges associated with his disability, which is very positive, but we should really be led by my son’s capacity not the school’s, if we are to say that we are giving him the education to which he is entitled.

So it seems possible to meet My son’s SEND, social and / or educational needs - just pick any two. You can’t get all three in the same place.



## 9 ‘My needs aren’t “special”...

...How my needs are met may be different, and I have the same right to have them met as any other person’  
- Michelle Swan.<sup>3</sup>

A parent carer wrote the following, tongue in cheek, pathway. While we do not normally include humour in our reports, this highlights perfectly the inequality in access to support that people with ASC experience.

### What if wheelchair users were treated like autistic children?

#### Diagnostic referral

I can see that you can’t walk, but we need to make sure that this is sustained over a long period of time and not associated with your development.

We need to provide plenty of evidence of your mobility difficulties in different settings. Please could you just struggle along for a while so that we can collate the evidence.

Parents report that their child can’t get up the stairs at home, but we don’t see any access issues at school.

We find that children who wear a skirt don’t meet the criteria because we can’t see the disability.

#### Diagnosis (After about a year)

The panel agrees that you have impaired mobility. Here is a 2” stack of leaflets where you can find help and support. I suggest your parents go on the training into how to carry you about the house. Oh and by the way parents, remember to look after yourselves.

#### Referral for help (physiotherapy instead of CAMHS)

The GP didn’t tell us what criteria they used to assess why you needed an x-ray, they just said you needed an x-ray, so we rejected the referral.

Your mobility issues are associated with your disability; we have not been commissioned to provide physiotherapy services to the mobility impaired where the

<sup>3</sup> <https://hellomichelleswan.com/my-needs-are-not-special/>

issue is associated with the disability. We feel a better approach would be to train your parents to adapt your physical environment to enable you to manage.

### Occupational Therapy

We do not provide a service to schools. Initially, we would like you to pop into our drop-in clinic.

Oh, I can see that you are unable to get into the drop-in clinic as we haven't considered your access needs. Yes, I know we are an OT service and might have known how to facilitate your access.

We will come out and assess whether your wheelchair is suitably adapted for your house, but we don't go into schools to check that you can get into a classroom, or provide advice to the school to enable you to do so.

### Education

Our policy is to support children to attend their mainstream school.

Oh, I can see that you need a ramp to get into the mainstream school. There is a special school that has a ramp, you can go there. Don't worry about your loss of learning, it's more important for now that we can help you with your mobility difficulties, then you will be able to access a full education later.

Oh, you don't think that school is suitable? Well you can appeal the EHCP, you have a right to choose a mainstream school. Yes, I know none of the mainstream schools have a ramp, but you have plenty of choice and we are certainly meeting the local need. We are trying to put a bespoke package together, it just takes a bit more time [after 18 months]. You have accepted the placement, after all.

Yes, there is a mainstream school with a ramp outside of this Local Authority. They are full and it will take you 18 months and a legal challenge to get there.



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## 10 Barriers and blocks

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- Waiting time to get support for a child diagnosed with Autism.
- Professionals don't seem to accept a child with Autism does and can still have mental health needs and therefore requires support just like any other child.
- Refusal to support an ASC child simply due to this diagnosis which isn't lawful and discriminates and disables the child further.
- If no service is going to be provided for an ASC child simply due to diagnosis, then where can parents go to ensure our children are not discriminated against when turned away simply due to diagnosis?
- The ASC community is huge in MK and there is nowhere to go to help our children. No one is listening, no one is prepared to make the changes our children need, and our children are suffering.
- Our options as parents are legal routes only and this takes time and money when they are entitled to this support anyway. This also then costs services when the law is upheld; it's a pointless system that wastes money and time and, again, our kids are the cost.
- School Refusal. School attendance barriers are vastly misunderstood, parents are blamed, schools often don't have a clue and children again suffer. The whole structure of this and how we best support our children and schools and families requires serious looking at and funding.
- The CAMHS service is set up and funded to deliver support to children, there is no ring-fenced criteria to limit who you support yet your services continue to let bad practice let our children down.
- This isn't ok. There needs to be accountability moving forward: all children without discrimination of diagnosis or suspected diagnosis should be entitled to the SAME service as another child?
- There isn't a blanket rule that an autistic child is anxious only due to autism. Autistic children need and deserve specialism from those who fully understand how Autistics process and what they need to heal and recover
- The circle of education often threatens fines.... that won't help reduce the stresses and pressures, our children don't need threats, they need support to alter the school environment to enable them to attend.





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## 11 What would help?

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- Have SEN Parents on panels which review practice and ensure robust, workable, fair policies for our kids. For all children without exclusion.
- We need to have the needs of children met locally within mainstream secondary schools. This will be too late for my son - we can't afford to wait for bricks to be laid and concrete to set - but it might not be too late for others. MK Council publishes a forward planning document for schools in MK and has a statutory duty to meet all reasonably foreseeable needs. There are new schools being built. Here lies an opportunity to provide an ASC unit (or units) in secondary education. The one at Lincroft could be used as a model.
- Any reduction in education hours for a young student should be limited by the student's capacity (any school may offer a part-time timetable to an individual) and not the school's capacity. All such schools should offer the core National Curriculum as a minimum. They should be funded well enough to make this a reality. I believe Bridge Academy is funded out of the local High Needs budget therefore funding this is a strategic decision on the part of MK Council.
- Until a local ASC unit can be established, Bridge Academy could be used as a pilot scheme and interim solution, by expanding its academic offer to all children (not just on a case by case basis, which as we have seen can take unacceptably long). In time it could become a feeder for excluded children with ASC into the unit.
- The CCG and CAMHS should provide a proper mental health service for autistic children and young people in MK, where their diagnosis is not an impediment to accessing services.
- If this policy changes and, given that "the word on the street" is that CAMHS do not provide a service to autistic children, there may be a reservoir of parents and professionals who don't see the point in making a referral. The service should review past rejections of referrals in the light of new criteria and make contact with affected families to see whether they still require a service. If so, their time on the waiting list should be calculated from the point of first referral. This would go a long way towards re-establishing trust with the local population and undoing the damage that has been done.





- The OT (Occupational Therapy) service have the largest positive effect on many children's access to mainstream school for the smallest amount of investment. It seems an oversight in commissioning that this service is not provided more widely, and / or that families may not be able to access it when circumstances change..
- The OT service must be an integral part of any offer. The diagnosis is a multi-disciplinary affair, with many professionals contributing, coordinated by the paediatrician. As far as ASC is concerned, sensory sensitivity issues are now a core part of the diagnostic criteria, and the OT service owns this within the NHS (with assessment procedures and strategies to use). If sensory sensitivities are indicated, there should be a seamless transfer to the service for detailed assessment and ongoing review (the sensitivities can change as a child develops).
- OT assessments must be made in schools where indicated.