

APPENDIX C

Please note that this small number of case studies can only be anecdotal and illustrative of some of the challenges being faced by some families and carers and is not necessarily representative of all those who use and receive SEN services.

Insight Into Contacts From Individuals About Special Educational Needs To Healthwatch Essex Between January 2019 and January 2020

Issues relating to special educational needs have featured regularly in contacts made with Healthwatch Essex by members of the Essex community, fairly evenly spread across the five Clinical Commissioning Groups which the charity covers. The following case studies summarises data collected from the lived experiences of people in Essex of special educational needs, under the age of 25, who have chosen to contact Healthwatch Essex for information and signposting in the past twelve months. The matters and opinions reflected are those stated by the individual and are not a reflection of, nor representative of, those held by Healthwatch Essex and its staff.

Case 1

Caller has a little boy aged seven who she describes as "*not being wired right*." She has been pursuing a diagnosis unsuccessfully. He was referred to a specialist centre for assessment, but the results were inconclusive. She says that he still can't speak properly. He regularly soils himself and will sit in these soiled garments all day at school. He is badly bullied at school and is currently reluctant to attend. He is physically and socially withdrawn and does not like to interact with other children. He also does not sleep at night. Caller said she had no SENCO support at school but had spoken with the headmistress who suggested that she should go back to her GP for a further referral for assessment. She is now looking for local support herself.

Case 2

Caller has just moved in to the xx area. Her 21-year-old son has a mild learning disability and is waiting for an assessment for autism. He is feeling very lonely and isolated and she wondered if there were any groups where he could find friends and socialise. He needs extra support and has been volunteering at a hospital. Due to what the caller believes was a problem with miscommunication, his work there was suspended and since then, her son has been really struggling and is very unhappy. He feels that he is being judged by people at the hospital and that he has failed in some way.

Case 3

Caller rang about support for her brother who has learning disabilities and autism. Caller says her brother, 24, lives with her 84-year-old father. Her father is his carer and the caller feels he is starting to struggle with this role due to his old age. Caller is concerned about her brother and feels he is becoming withdrawn and just sits at

home playing computer games. Her brother did have a social worker a few years ago and they were supposed to be looking into getting support for him to go to college, but this never happened. Caller feels that her brother is not eating properly as he needs treatment for his teeth but refuses to go to the dentist. She has booked an appointment for her brother to see the GP as she is concerned that he may be depressed. Caller is worried about what would happen to her brother if her father became unwell and wants to know what support he can get.

Case 4

Calling to discuss her concerns about an incident that happened with her disabled daughter and another incident with a neighbour. In March, her disabled daughter was allegedly attacked by her escort on the way to school in the school bus. An investigation was held but her daughter is non-verbal and wasn't able to confirm what had happened. The case was dismissed due to lack of evidence. Caller was not completely happy with this outcome and is wondering if there is anywhere else that would be able to give her some legal advice about this. She is also dealing with an incident that happened two years ago when a safeguarding concern was raised via the NSPCC from a neighbour. Caller believes this was a malicious call as there have never been any concerns about the care of her children and the police didn't take it any further as they could not find any concerns. However, this police call keeps showing up on the system. The caller is a healthcare worker and she finds it very upsetting when she has to keep explaining that nothing came of the call and she wants to know how it can be removed from the system.

Case 5

The caller is a school support worker requesting access to services for a pupil at her school. He is a six-year-old boy with Autism. His mother is a single parent and only gets support from her ex-partner's mother who just transports him to school and back. This was taken on as he desperately needed a school place but lived out of the catchment area for free transport. He is very keen on sports and leisure activities and his Mum is in need of some respite. He has just had a family support worker allocated via the school. School worker wants to know what is available for him to attend locally.

Case 6

Caller is looking to find information about support for her daughter with global delay and suspected autism. Caller is trying to access an assessment to confirm her daughter's autism with the local paediatric unit. Caller was given a sheet to fill out in preparation for the assessment to see what autistic traits her daughter had. Caller filled in the form and sent it back to the assessment team. Caller was then told a little while after that her daughter didn't meet the requirements to be assessed for autism and so the CCG will not pay for the assessment to be done. Her daughter is managing to hide her symptoms well at school but when she comes home, she is acting out and slapping herself in the face out of frustration. Caller would like to know where to go for support.

Case 7

"I was given your address by NAS concerning making a complaint to social care. My son xx has autism; he is paying for his own care and also for a day at college transport and art therapy out of his benefits. He lost his care package 2 years ago and was recently assessed by social care a month ago and nothing came out of this; we waited a month to hear from this social worker we haven't received her report she just recommended I rang them if xx needed more support but the problem is we can't make ends meet. He has no real care package, I'm a mum on her own struggling to cope with making his money last to pay for him to attend college and art cafe here in xx and pay his carer and pay his taxi fares. I was given a template to complain to social care but is it possible you could help with this?"

Case 8

Dad calling to find out what autism support groups are available in the xx area. His son is nine-years-old and has recently been diagnosed with autism. He is looking to find local groups to support him and his wife and any groups for his son.

Case 9

Caller has a son with ADHD and special needs, and she is looking for some clubs and activities for him to join who are patient and understand his difficulties. He is seven and finds it difficult to wait his turn. The caller is looking for gymnastics, football or similar clubs.

Case 10

"I wonder if you could help me. I have a 20-year-old son who is autistic and currently living at home after leaving residential school in July of this year. We were going to do assisted supportive living for XXX and he was to move to a property in YYY in September of this year. This has fallen through and my son is now in limbo and we are at a situation what to do next. We have gone through the correct channels (Social Services) and it is becoming increasingly frustrating. XXX's mood swings are getting unpredictable by the day and can be frightening. Any pointers what to do next would be much appreciated".

Case 11

"The young man in question is 19 years old and has learning disabilities and chronic anxiety. He is very able but does benefit from clear and direct language. He is supported in the community by his LSA, also a young man of a similar age. He is making amazing progress now and has a clear pathway with us. I would like him to develop his independence around food and drink prep and think this might work best out of the home. The challenge will be to find an appropriate class for him as he would not necessarily relate to a group geared up towards those with complex needs, and he would need a class during the day. I think he would be happy at a mixed class, and yes, he is a complete beginner. I'd be grateful for any advice – I know this is a tricky request".

Case 12

Asked to gather some information for the grandparent of a child with ADHD and possible autism. Grandmother is the primary carer and has a special guardianship order. She is finding the parenting side difficult and would benefit from some support at home. She is still waiting for a diagnosis and is waiting for the paediatrician to send a report to school about the autism diagnosis.

Case 13

Caller's son (6) who has global developmental disorder has also recently been diagnosed with autism. Caller wanted to move to a new house to enable her to access specialist support services and schools, but housing services have assessed her family as low priority. Caller says the school, which her son currently attends, is not able to cope with his requirements. He is just beginning the process for an education, health and care assessment and the caller has sourced a specialist school which she would like her son to attend. She is on the waiting list for a move to her preferred location, but this could take two and a half years. Caller is looking for sources of practical advice and support.

Case 14

Caller son is 18 and has Asperger's. He lives with his grandparents as the caller (Mother) has long history of mental health issues. He recently had a meltdown at college and the college has now said it is too risky for him to be there. He is currently receiving ESA. Caller is concerned as he does not appear to be coming out of his room. She knows he is smoking and using Marijuana and taking anti-depressants. Caller says he is awaiting an assessment from the mental health team. Caller says her parents go out all day and leave him to it and her dad keeps saying he is going to take him to the Job Centre but this has still not happened. Caller says her parents are now in their 70's and she worries about them too. Her father has just been very unwell and was in hospital which is what has sparked her own deterioration in her mental health Condition. Caller would like to know what support there is for both her son and her parents.

Case 15

Caller has a 16-year-old son who has a diagnosis of autism and Intolerance of Uncertainty. The caller shared that she has struggled to get support for many years but is having particular difficulty with her son's transition period from childhood services to adulthood services. Caller says that on the ECC website Local offer, there is a service listed which offers a specific type of transition service by a qualified O.T who is trained by the National Autistic Society. Caller says that she is trying to get this service for her son as it seems to be exactly what he needs due to his specific condition. However, she is being sent round and round in circles by ECC. She was told that he could pay for this via a personal budget, so she started that pathway. She requested a social worker and an assessment but was then told that anyone under 16 could not have a personal budget although on the ECC website it states that you can. Caller says her son was getting good support from a mainstream secondary school but there is no school or college that can give him that independent support now. He has just started a school that will take individuals on

until they are 18 but caller says the children have such profound autism that her son is struggling to the point that he is in tears about going and the caller believes that he will start refusing to go. He is so highly intelligent that this school is not challenging him and not giving him the life skills to transition into adulthood. Caller believes that if he could access this particular OT service, he would get the skills to become independent and then he would be able to go to a mainstream college. The caller has raised a formal complaint to ECC and is awaiting a response. Caller has split up with her husband but they still live in the same house as they cannot financially afford to live apart due to the child care costs and support that her son needs.

Case 16

Caller has a son with autism who is 15 years old. She is trying to convert an outhouse as a sensory room for her son and is trying to find information about grants for this adaptation. She said her son received his diagnosis five years ago and she has been experiencing a great deal of difficulty accessing care and support. He attends a special school.

Case 17

"I found your service in Essex county website and would like to speak to an adviser in regard to housing and support services for my daughter who is 13 and has autism and ADHD.

I just wanted to know if there was some specific to contact in regard to this and for my area in xx.

Please could you let me know."

Caller had also telephoned into the service. She is currently living in a first floor flat in xx with her 13-year-old daughter who has autism and ADHD. Caller says that her daughter finds getting out of the flat difficult due to her special needs and mobility issues too. The caller also has fibromyalgia, asthma and anxiety. Caller believes that the landlord of her flat will not let her carry out any adaptations because it is privately rented. Caller has contacted the council, but they have told her that there is not anything they can do until she has been in the property for 3 years. Caller is currently appealing for her daughter to get into a specialist school. Caller has repeatedly asked for an audiology referral from her GP but this is being refused each time with no explanation. Caller is struggling to get support for her daughter and would like to know if there are any more services that she can ask. Caller has tried One Support, Turn2Us, InterAct, HealthyMinds and has made a referral to EWMHS today.

Case 18

Caller is looking to find support for her 26-year-old son with high functioning Asperger's. He has been sectioned a few times since finishing University. He is having difficulty coping with getting into work and socialising.

Case 19

Caller ringing to ask for support regarding her 22-year-old son who has autism. The son also has mental health issues, anxiety paranoia and can be very verbally aggressive. Caller recently moved into a flat in the xx area but has had transition problems due to getting beaten up outside the flat. Caller says her son would not

involve the police due to his paranoia, so the council are not helping him relocate. Caller has regularly been sectioned and is under the care of xx House. Her sons CPN and GP is in agreement that he needs to move as it is making his condition worse and has written letters to support this. Caller is currently having to stay with her son or have her son stay with her. This is having a huge impact on her as he is verbally aggressive at times. Caller was tearful as she believes if she can get him moved, he will settle again, although on discussion she admitted that his condition is getting worse.

*this document is produced for the purpose of conveying lived experiences to the People and Families Committee.