

The benefits of continued support in adverse circumstances

The context

We first became involved with the family when K was in Year 6. She had diagnoses of Obsessive-compulsive disorder (OCD) and anxiety and had been unable to attend her primary school for approximately 10 weeks. She had managed to do a number of transition visits to her allocated secondary school but it was unexpectedly closed and she was subsequently allocated a new secondary school. K was not receiving any education at this point.

The process

We looked at the paperwork from school and identified a pattern of learning difficulties and unmet needs that had been documented but not necessarily supported since Year 2. We supported K's parent to submit a request for an Education, Health and Care Needs Assessment (EHCNA). When this was refused, we supported K's parent in a meeting with the local authority (LA) to discuss the decision. At this point, K's parent was not ready to appeal the decision but we continued to support and attended meetings at the new school. K was unable to attend but we assisted her parent in discussions with the school in regards to an alternative package of support and in gathering information for a new EHCNA. This application was successful and we continued to provide support through the process via one of our volunteer supporters alongside case officer support. K was receiving input from CAMHS (Child and Adolescent Mental Health Services) so we also supported the family in ensuring that she received education at home via the Hospital Education and Reintegration Service (HERS). There were continued meetings with the school to look at additional educational opportunities beyond K's home and current school, including therapeutic interventions and educational visits to the city farm.

From early on, K's parent expressed the view to us that K presented as a high-functioning autistic young person but had not followed up on this as one of K's obsessions was a fear of 'catching' autism. The parent was very concerned about the amount of education K was missing but more so about her deteriorating mental health. In Year 7, CAMHS diagnosed K as being on the autistic spectrum. This was relayed to her in a counselling session and, as feared by her parent, impacted negatively on K. This occurred during the statutory assessment process and K was unable to engage effectively with any of the professionals, such as the educational psychologist. She was also unable to cope with the amount of teachers and hours allocated to her by HERS and it was deemed by CAMHS that she was only medically fit to access one hour of tuition a week. At this point, she was unable to leave the house, even to go into the garden. CAMHS were struggling to engage her and wanted to withdraw their support. This would have led to the HERS tuition ceasing as in this authority it requires ongoing medical involvement. We supported K's parent to

successfully challenge the decision and the support continued. We also had discussions with the parent about avenues of support for them and the rest of their family, including the Carers' Centre, Young Carers, and the Disabled Children's Social Care Team. They were given support at the draft Education, Health and Care Plan (EHCP) stage, including information about the types of school they could request. At this time, they decided that K would be unable to attend any setting and that they wanted to concentrate their energy on supporting her mental health recovery and chose to name the existing mainstream school on the finalised EHCP.

Throughout the support we gave K's parent, they expressed a view that mainstream education may not be something that K would ever be able to access again and that she may require some kind of therapeutic setting. We supported K's parent to express this view to the LA and the named school at an Annual Review meeting. Various options were discussed, including online learning via a virtual school. K was beginning to be able to leave the house and over the course of Year 8 became able to attend a drama group once a week which was able to deliver some of the provision in the EHCP.

At the end of Year 8, CAMHS again decided that they would close the case as K was not making the expected progress. We supported the parent at a meeting where the school and parent asked that the case remain open whilst an alternative education package was put in place by the LA. The outcome of this meeting was successful and an additional period of CAMHS support was secured whilst an urgent review was convened.

We continued to provide face to face and telephone support to K's parent and attended an urgent review meeting with senior LA staff. Online learning with additional therapeutic support was agreed, but the online provider decided that they were unable to meet K's needs. We continued to support the parent to explore all the options available to them, both conventional and creative. Eventually the LA suggested a bespoke package of support via a local autism specialist school. The parent had huge misgivings due to K's ongoing refusal to accept her diagnosis. We supported the parent in a visit to the school and meeting with the head teacher and were able to help them put across all their concerns. We also provided a sounding board for the parent to bounce their views off.

The outcome

After serious consideration, and with further discussion with the specialist school and LA, the parent decided to accept the place. It was clearly understood by all that a great deal of sensitivity would be needed and that K may never be able to physically attend the school. A package of therapeutic and academic education was put in place for K, initially in the home with the goal that it would progress into a community space and involve a small group of other young people with similar needs. This will be done at K's pace though and there is to be ongoing discussion and involvement with the parent at all points, especially on any occasions of proposed change.

Reflections on the outcome

Although a promising outcome was eventually reached, it took from the middle of Year 6 until the end of Year 9 for this to happen. The lack of highly specialised CAMHS support, especially around a young person who was distraught at being given an unwanted diagnosis and struggled to engage with once a week counselling, was a huge barrier to securing an education for K. Lack of

alternative provision and knowledge within the mainstream school, combined with a 'wait and see' approach by the LA due to the complexity of K's mental health difficulties, made it hard for the parent to unpick what was best for K. Although the parent was able to articulate their views to SENDIASS workers, and was supported in putting these across both verbally and in writing to the school and LA, they did not want to 'rock the boat' and often agreed to maintain the status quo.

We continued to support the parent to find their voice and, by the middle of Year 9, they were able to successfully articulate what they wanted and refuse to consider further inaction. We were able to empower them to stand firmly at the centre of the process in representing their young person's voice and as an expert in that young person. There were many opportunities where the parent could have made different choices, including a number of times when there was a right of appeal to the Special Educational Needs and Disabilities Tribunal, and these may have led to different or speedier resolutions and outcomes. However, K's education and mental health difficulties cannot be viewed in isolation and, as with many of the families IAS support, the parent was in the difficult position of balancing K's needs, the sibling's needs, and preserving their own mental health whilst looking after a very unwell child. They had to make informed decisions at each point that took into account a wider picture than just their legal rights.

Contact details

The service requested their details were kept anonymous.