

Devon: The benefits of enabling a young person's voice to be heard

The context

B is currently 15 and is now in Year 11. He has dyslexia and processing difficulties and has had ongoing support from Child and Adolescent Mental Health Services (CAMHS) for anxiety and depression. We have provided information, advice and support from March 2017 when he was in Year 9.

B's parents initially contacted Devon Information, Advice and Support (DIAS) for advice around a Specific Learning Difficulty (SpLD) and accessing support and referral for assessment. Over the following months B's school attendance became more of an issue. He was anxious about attending school as he felt that his difficulties weren't always believed by teachers. He was also having severe headaches.

The school referred for an educational psychologist (EP) assessment and the parents took B to the GP who made a referral to CAMHS. However, the CAMHS referral was refused at this stage on the grounds that any recommendations arising from the EP assessment would need to be in place prior to any CAMHS involvement being considered. The school also contacted the Education Welfare Officer who attended some school meetings. A part-time timetable was introduced in an attempt to reintegrate B into school, with the aim of increasing attendance to full time. During this time, there was some disagreement between the parents and the school about what level of support was in place. B felt that some teachers still did not understand his needs and were telling him he just needed to 'try harder' despite the Special Educational Needs Coordinator (SENCO) telling parents that the EP and other recommendations had been shared with all staff. Teaching assistant (TA) support in classes was limited to lessons with the highest literacy content due to capacity. B was concerned that this was not always consistent and felt he could not access the lessons without it.

The school agreed to complete an Education, Health and Care Needs Assessment (EHCNA) request. The local authority officer attended Special Educational Needs (SEN) Support meeting at school and subsequently agreed to assess. Advisory teachers had visited B in school and made recommendations around ICT support. The school said that they were unable to put all of this in place due to limitations in their budget and in accessing the school system from an iPad. Attendance at school continued to be an issue.

The local authority (LA) decided that an Education, Health and Care Plan (EHCP) would not be issued, on the grounds that they believed B's needs could be met by the school, and the parents decided that they would appeal. DIAS supported at mediation where B also attended and gave his

views. The LA representative explained the decision was made on the basis that they felt B's needs should be met from the resources available within the school. The LA representative agreed to meet with school SENCO and the Deputy Head to discuss this and what the school's responsibilities and next steps should be for SEN support and reintegration.

The parents appealed the LA's decision not to issue. Both the parents and B attended the hearing. The judge ordered that an EHCP should be issued. The EHCP was then issued with another mainstream school named. The parents had some reservations but felt that the school appeared more willing to support B. They also felt that travelling further afield to a more specialist school would not be the right thing for B due to his anxiety and ongoing headaches. The LA initially agreed to additional funding to for ICT and TA support. B attended on a reduced timetable but continued to struggle with headaches and accessing text in lessons where TA support was not in place. It was at this point that CAMHS became involved.

At a recent EHCP review, the LA have agreed to fund bespoke provision. B will remain on roll at school but will have teaching for 5 GCSE subjects from specialist tutors from an Alternative Provision (AP) provider. B attended the review and shared his views. It was agreed that B would be able to follow a reduced timetable and focus on core subjects as these would enable him to attend his desired course at college. It was also agreed that this was necessary in order for him to manage his anxiety.

Some of the key barriers in this case were that, despite the fact that the parents tried to work constructively with school staff, some staff, including senior leadership, clearly felt that too much was being expected of the school and that parents should trust them to 'do their job'. The fact that B appeared confident and positive at school meant that some staff found it hard to understand that he had difficulties with accessing work. On one occasion, B's CAMHS worker told the parents and B that it might be better if he was to have a break down at school as they would then have a better understanding of what was going on below the surface.

Due to the nature of the B's SEN, i.e. complex visual and SpLD needs, not all the underlying causes had been fully understood or diagnosed. B has had ongoing health appointments with specialists, but these professionals were never in attendance at meetings, so the parents were left to explain complex medical needs that did not yet have a diagnosis. Both the parents and B sometimes felt that they were not believed, and it was clear at times that there was frustration from school staff that there was not a clear diagnosis.

The process

DIAS supported with advice around preparing for meetings, what SEN support should mean in practice, and suggestions for possible strategies to move things forward, e.g. requesting a referral for advisory teacher support. We assisted the parents to prepare for meetings and made suggestions around how to raise concerns, work constructively with school staff, and improve lines of communication. DIAS volunteers and staff supported at a number of school meetings as well as assisting parents with gathering B's views and sharing them in meetings. When the school submitted the EHCNA request, we supported parents with advice around writing their views and collecting B's views.

When the parents were notified of the LA decision not to go ahead with issuing an EHCP, they contacted DIAS. We discussed options and the parents were clear that they were unhappy with the decision and wanted to appeal. We discussed the next steps, the pros and cons of mediation, and how the process would work. B was keen to attend the mediation so advised his parents to contact the mediator and the LA so that they were aware of this. We supported the parents and B at the mediation, where B clearly communicated his views.

When the parents made the decision to appeal, we supported with preparation for the hearing. B was very clear that he wanted to attend the full hearing so that he could give his voice and hear everything that was said by the LA and the school who were attending as witnesses. We sought advice on this and were told that it would be unusual for a child of his age to attend the whole hearing but it would be acceptable nonetheless. The SEN Judge initially suggested that B share his views at the start of the hearing and then be taken out. B clearly stated that he wanted to be in attendance throughout, and this was agreed. We supported the parents and B during the hearing and B participated fully throughout, giving his views clearly as well as raising some objections to points made by the LA and witnesses.

Once the EHCP was issued and another school was named, we supported the parents with transition meetings, and with sharing B's views at these meetings. We supported them to write a complaint regarding support at his previous school, and then subsequently with the EHCP review, which B attended. When B continued to struggle with anxiety and school attendance, we supported parents with complaints and meetings with the LA. We supported them to share B's views including his long-term aspirations.

The outcome

B now has an EHCP and is on roll at a mainstream school. He has a bespoke package in place which is focusing on outcomes which will enable him to reach his aspiration to attend a specific college course. Both B and his parents feel that his current one-to-one teachers understand his needs and have tailored the curriculum effectively for him. They feel that they have now been listened to and that B's needs have been fully acknowledged. B feels that his anxiety levels will be significantly reduced because he no longer worries about going into classes without support.

Reflections on the outcome

DIAS supported at key points on the journey and helped when things got 'stuck', for example, by liaising with other agencies and the school as well as supporting the parents to communicate constructively from an informed position. The parents have consistently sought to communicate constructively with all professionals and school staff. With our support and their effort, they gained an understanding of their rights as well as the responsibilities of the school and local authority and were able to engage fully with statutory processes. B has been keen to engage in the process of getting the right support and has been clear that he wants to access education. Through B's involvement in meetings, including mediation and the tribunal hearing, and more recently at school meetings, professionals have begun to involve him directly in order to understand his needs and develop the right support.

Both B and his parents have focused on his long-term aspirations while as prioritising the short term outcomes that will enable him to achieve these. For example, while the school's expectation was that a reduced timetable would be working towards reintegration to full time school attendance with B working towards 8 GCSEs, the parents proposed the alternative of B focusing on the core subjects needed to gain a place on his desired college course, and challenged the expectation that he would be required to attend full time when advice from medical professionals suggested that this would not be in his best interests. As a result, there is an increased understanding of the need to tailor B's education, rather than just tweaking what is happening in the classroom. There has also been shift in understanding the impact of anxiety and mental health on B's ability to engage consistently with the demands of a mainstream setting and the need to be flexible in order to accommodate this.

The parents of B provided the following feedback in terms of their experience of working with DIAS:

I cannot tell you how upsetting it is to have a child struggling with mental health difficulties. It has affected B to a great extent and had a knock-on effect on the whole family. As well as the emotional stress, there is a financial element as well, with the number of appointments and meetings involved. We have lost income. Z is self-employed and is not paid for time off work and I had five months off work due to stress and required NHS support.

These are some of the things we feel DIAS has helped us with and which have been very much appreciated:

1. DIAS always listened to B and supported him – this was really valuable when he was being blamed for his difficulties in school.
2. Consistency of support - we have had 2 and half years of struggling to get B the support he needs and DIAS has been there for us throughout all parts of the process when no one else has.
3. Involvement of DIAS has helped focus other parties' attention on B's needs, often bringing meetings back to the subject of B when schools have been more interested in their own requirements.
4. Help explaining the meaning of language and the law involved in SEN and the EHCP process.
5. Practical and emotional support for B and us, as parents, particularly around the court appeal – we are just normal people not used to going to court.

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