

Darlington Parent Carer Forum

Life for Families of children with additional needs during lockdown, and thereafter.

Background

Darlington Parent Carer Forum are a group of parents, who work with education, health and social care as well as other providers to ensure that the services delivered meet the needs of families in our area. We are the Department for Education recognised forum for parent participation in Darlington. We work to represent the views of families in Darlington to influence both service development and strategic decision making.

Covid 19 Response

At the beginning of the pandemic as for everybody life was confusing for parents of children with additional needs, messages didn't come quickly enough and were often not clear. Within the first week we identified that parents were suddenly feeling very isolated so in response to this we set up twice weekly zoom meetings for parents to access peer support but also to tell us of their challenges.

Initially we were hearing about a lack of differentiation on work set and children struggling with routine changes, we hosted a zoom session with Tony Murphy from the LA to provide clarity on what could be expected for children with SEND and we know he spoke to head teachers to relay the message and parental concern.

"My daughter went back to school in June, she has an EHCP. She so needed this routine" -Feedback from a Darlington Parent



SENDIASS also assisted in a few meetings with specific schools who made sure work was accessible.

We heard that some families were told that children with EHCPs were not able to access school places, due to risk assessments, staffing levels and PPE. However guidance from the DFE was clear that a risk assessment was to be used to highlight the risk to the child and making sure school was the safest place for them to be and not about risk to staff. Local Authority further clarified this and we hosted an online session for parents with Darlington's Head of Education to explain the position of the local authority that any child with an EHCP should be able to attend school should they/their family choose. However from feedback received from families, we believe that this was still not always the case for all children with EHCPs in Darlington.

Parents told us that the change/lack of routine was extremely difficult for their children/ young people. A lot of services stepped back during this time too. It became clear that though risk assessments had been done for families it had not been done with them as per guidance, this meant that we heard of families struggling, yet nobody had contacted them. According to a survey completed in August of 51 respondents only 4 had been aware such an assessment was done. This was disappointing as the risk assessments were designed to be done with families.

"The government required that all children and young people who were known to services had a risk assessment carried out jointly across education, health and care services. Have you been made aware of this and been part of this process in assessing your child/young person?" In terms of the EHCP process and panels we had differing feedback from parents. It was clear that it had been a trickier time for those who had already started the EHCP process who had the hard decision as to wether to carry on or "pause". Parents told us that though they have been frustrated by the situation and implications of delays had been in agreement with the decision as had wanted the reports of professionals who couldn't currently visit schools to be included. We were however thrilled to hear from parents who had had decisions for school placements agreed at panel and the move managed despite lockdown restrictions.

What did parents need?

Unfortunately a lot of parents of children with SEND in Darlington did not feel supported during the pandemic. Parents told us that mental health support for themselves as parent carers would've been helpful and that practical support was greatly needed. Training opportunities for parents who suddenly found their children without support and intervention. Parents also told us better support around transitions would've been beneficial

And Now

With ever changing guidance parents are still looking for clarity. This is made all the more difficult by differing school policies, cross border placements and changes to restrictions. Parents are concerned about the impact isolating has on children, particularly those with additional needs in terms of social communication difficulties where advice is to limit screen time, now everything is on screen. There has been difficulties with this for parents throughout the pandemic however the original message of "do what you can" seems to no longer remain with children expected to be participating in online learning and interventions regardless. We also heard from many families who struggled to have accessible IT equipment, this is something that needs to be looked into moving forward. We've also had contact from many parents in early years who are looking for advice on socialisation and strategies to use within the family in identifying non verbal communication. The overwhelming message from parent carers if one of fatigue, trying to keep up and a general sense of overwhelm. Respite has been limited. It would be an impossibility for us to write a report giving recommendations for these families however it has been clear throughout this year that families of children with additional needs have in some instances been overlooked. Coproduction hasn't happened as it should have and decisions made about rather than with families. It would be our hope moving forward that there has been some learning from this.