

Parent and Carer Alliance



Care Action Protect Empower

Update on Issues raised with Director of Children's Services at meeting on 19th September 2018

DCYPS threshold for assessment and the provision of Direct Payments

The threshold is not understood by parent carers and appears to exclude children with Autism without carrying out an assessment to determine need

58 families responded to a direct payments poll as follows:

32 families whose children have SEND do not know about direct payment,

10 families were told they do not meet the eligibility criteria

2 families feel that assessments and setting up direct payments takes an excessive amount of time

"We desperately need help but I was turned down at the first hurdle via just a telephone interview and I'm now too scared to fight for help".

"When I called initially, it was assumed that I could access help by using my son's DLA. Yes, if we didn't have to spend the DLA on replacing and repairing and all the extra costs that incur with having a disabled child".

Responsibilities and support for managing Direct Payments

1 family say their direct payments have been properly funded

7 families say their direct payments do not cover the costs of being an employer

5 families have been given no training in the responsibilities of managing direct payments

4 families have had unfair treatment as a result of their direct payments

3 families have turned down having direct payments as they fear the responsibility

2 have made a complaint about their direct payments and have been excessively audited as a result

"More hassle (from fighting for it to the paperwork to it working well long term) than what they were worth"

"Regretting ever having Direct Payments, dread the next review and another new social worker"

Overpayments

5 families have been overpaid, have been stressed by the responsibility of holding large amounts of the local authority's money, and have had difficulty in finding out how to repay the money

Recruiting Personal Assistants.

5 families are unable to recruit PAs due to the travel time to rural areas, complexity of care needed (including intimate care) and the amount they are allowed to pay

Using Care Agencies

2 families have had to receive care from agencies that charge a much higher hourly rate, claim travel expenses and have a high turnover of staff - requiring young people to have to cope regularly with care from effective strangers

Unlawful practise

4 families say there is unlawful practise in how direct payments are provided

"The lead for direct payments has been due at the Learning Disability partnership board to answer people's concerns about unlawful practice - she hasn't turned up for 2 meetings"

Social Care Involvement in EHCP

Some families reported excellent support from social care

"Our social care worker was amazing and went above her remit and attended every meeting"

"Rewrote whole EHCP with social workers help for college as it said things like child hoisted and unable to stand then a line later child toilets independently and needs to be encouraged to walk around in his lunch break. She now attends every review to ensure it is right"

The majority reported no social care involvement in the EHCP process even when a child has a direct payment

"SC sent a short generic letter for my daughters EHCP. They use a my plan plus instead for her social care needs. EHCP is simply a statement -education only."

"Completely separate from EHCP. Meetings & assessment all duplicated for the parent & child. Invites sent by senco to SC rarely even get a reply or acknowledgement"

"Direct payments and social care assessment mentioned in ehcp linked to an outcome about helping son be more involved in local community but no representation at the review"

Off rolling of pupils.

Families have raised the issue of their children being excluded with the Inclusion Team and have been told that the Inclusion Team 'cannot challenge a maintained school'.

Families listed 1 nursery, 13 Primary schools and 2 secondary schools where their SEND children had been off-rolled or excluded

"It may have the word school in its title, but it was run as a business, and anyone who didn't conform was out (or frightened into towing the line)".

"That's exactly the experience we have had too although they won't admit it. I thought we were the only ones"

"If a school named in an ehcp then exclude your child they can keep the EHCP money until the EHCP has been updated with the new school"

"First they exclude my child for 3 days for having a meltdown even though they are not following the EHCP now they won't have my child back and organised a managed move. My child is inconsolable and starting a provision School tomorrow"

Culture of blaming the parents if they raise issues or challenge decisions and support for their children

The PCA are very concerned about the use and abuse of the Fabricated and Induced Illness procedures in Gloucestershire. Following the BBC Radio Gloucestershire items on the subject in November, we have been contacted by 12 Gloucestershire families who have been wrongly accused of FII and who wanted to share their experiences. Many more families told PAC that they too have been accused, but they are too frightened of the consequences to share their experiences

The purpose of gathering this information is to highlight the issue, explain the pain and distress the allegations cause, and to try and prevent families experiencing similar in the future. The PCA are compiling these stories into a report to try and understand what is happening.

Our intention is to share the report with the Local Authority, and other agencies if appropriate, once it is completed. We can say at this time that none of the FII concerns made against these 12 families were substantiated and the allegations had a massive and negative impact on the families.

Other issues raised:

Social workers have not been knowledgeable about other services that might support the family and offer advice

Other members of the family, such as siblings, are being designated as at risk but there is no intervention to support or protect them

CYPS are not effective with Autistic children who have challenging and violent behaviours

Ineffective post adoption support is putting families at risk

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