

From: Dee
Sent: Tuesday, November 01, 2016 4:45 PM
To: Phillips, Jeanie
Subject: Fwd: Sharing our concerns/difficulties

Hello,

I would like to correct my typo in the email attached below. In 2nd to last paragraph, I meant to say please create guideline that are "not voluntary" but "are mandatory".

Thank you,
Concerned mom of CT public school student

Sent from my iPhone

Begin forwarded message:

From: Dee _____
Date: November 1, 2016 at 1:57:32 PM EDT
To: jeanie.phillips@cga.ct.gov
Subject: Sharing our concerns/difficulties

Dear members of CT food allergy task force,

I would like to remain anonymous for the fear of retaliation from some of my child's 504 team members/my school/district. My son is in middle school and has 504 for food (peanuts/tree nuts/coconut) allergy and asthma. He had IHCP for this from k-1st month of 5 th grade. Then we got 504 due to non cooperative and refusing to understand class teacher and other multiple new school staff/administrator. After putting lot of effort into educating various levels of school staff and educating myself in my child's right of safety and equal inclusion (concept not clearly understood by school staff) compared to non disabled peers, we finally had a 504 plan with acceptable clear wording without leaving much room for loopholes. This year new 504 coordinator removed key safety and "equal inclusion" wording even after agreeing to retain all wording of last school year's 504 plan at audio recorded 504 meeting. 504 meeting was on 9/19/16; we got the draft to review after 3 weeks from the meeting after I followed up. Apparently they are not responsible for typing up the plan with agreed wording at the meeting or within 2-3 days after meeting. We reviewed the plan and send detail email with our questions/concern and asked them to provide us in writing why they dropped certain key wording. Apparently 504 coordinator is too busy with her other work and she said she will work on it when she is free next...no concrete 2-3days. This is clear stalling and harassment practice by 504 coordinator because apparently there is no law or state requirements governing these kind of things. We asked twice by email that while we are waiting for them to get back to us with answers to our questions and concern on new 504 draft, is our old good 504 plan still in effect. No one from the team has bothered to answer it. 504 coordinator said she left office early on Thursday 10/27 due to sickness and will get back to us upon her return. Why couldn't she answer simple question with "yes, old plan is in effect till new plan is finalised" or "no"! Apparently

there is no back up for this 504 coordinator or other 504 team members copied on the email who can answer our emailed questions or concerns or resolve anything.

We are treated so poorly by our 504 coordinator and she seems to have support of all her higher ups. They included us parents in the 504 meeting but lied to us on audio recorded meeting and deceived us by removing very important wordings/language on last year's 504 plan even without discussion and agreement at our 504 meeting. They don't want to provide "equal" inclusion. They won't even define inclusion for us. Last year my child's 7th grade had end of the year team celebration with Dublin donuts doughnuts. I told them they are not safe for nut allergic child like my child to eat, and to consider either replacing it with safe Oreo or chocolate chip cookies or cupcakes or consider non food activity for team wide celebration as there is nothing life essential about DD doughnuts. They said they will not change their plan and I should send some safe food for my child to eat...that's their concept of equal inclusion compared to non disabled peers! They they said fine we will buy safe pretzel and he can eat pretzel. I said, that's not same as sweet treat. They said every child in 7th grade team will have a choice of DD doughnuts or pretzel. I explained them that they are truly not providing my food allergy disabled son equal choice, infant he does not have choice. But I don't think team leader or school nurse understand equal inclusion to even enforce it.

I can go on and on about difficulties and resistance we face about safety and equal inclusion at our public school located in Connecticut in Fairfield county. Every year it's new 504 team and we start at ground zero. It's exhausting and takes great toll of our mental and physical health.

Please create guidelines that are not mandatory but every public school not only elementary but also middle and high school 504 team must follow.

Thank you for all your time and effort you are putting in this task force.

Thanks,
Concerned mom of CT public school student