

December 15, 2008

DCF Public Hearing

My name is Phyllis Parmelee and I am the mother of two High Functioning Autistic Children with behavioral problems. I am here to testify about serious flaws and **discriminatory** practices within DCF's Voluntary Care Services Program and I would like to request that the Program Review Investigations Committee starts a formal investigation into this program and its practices. It is failing hundreds of children across the state.

My home is a constant battle field in which I fight every day to keep my family together and to keep my children in my home. Because of my children's needs the services we can access are limited. Our children are denied services through DDS because their IQ's are too high. They are denied services through the school because home based services are not the responsibility of the school. They are denied insurance coverage because Insurance Companies are not mandated to provide the specific autism related services that can help our children. Many families in CT, in the same situation, are left with only DCF as the last place to turn. Especially in cases like ours where behavior problems are serious enough to put a child at risk for being removed from the home.

We first applied for Voluntary Care Services in 2005 and had an open case until 2007. During that time we had a case worker that came to our home once every few months and needed constant reminders to set up services. He would promise to start something and a month later I would call him and he would say he forgot. We asked repeatedly for Parent training for our children and they sent us something called IICAPS. It is an intensive in home based mental health program that may work great for children who are merely behavior problems or who come from abused or drug addicted home, but for autistic children, who cannot utilize cognitive based therapies it was not effective.

In February of 2007 we were told our case was being closed because our children were too STABLE for services. This came a week AFTER my oldest son attempted suicide and was in the process of being placed into an extended day treatment program because our case worker decided he was too UNSTABLE to be in any other program. When I begged the case manager to keep our case open because we still desperately needed help he told me that my children are autistic and will ALWAYS be in crisis and that is NOT what DCF is there for. He hooked us up with Systems of Care telling us they would help us.

From May to August Systems of Care provided us with intensive babysitting for the children. They took the kids out for respite every day, accompanied my younger son to a summer program that they did pay for and sent us a parent educator, who unfortunately spent all of our time complaining about the people she was working for. We managed to get through one chapter in a book she was going to go through with us and eventually I asked that the rest of the funds for her be spent instead on more respite time with my older son.

We begged the Care Coordinator repeatedly for more, especially once school started and all the services we had over the summer ended. We were told that our family had reached the FAMILY LIFETIME CAP of flex funds (in just those 3 months) and the case would be closed. For the next 7 months we were

without any help at all. We watched as our children increasingly regressed. My younger son was restrained at school 35 times in that period and my older son was putting holes in our walls and biting himself to the point of leaving bruises up and down his arms. Our home has literally been a battlefield.

In March of 2008 I reapplied for Voluntary Care Services. Since then I have had the most unprofessional treatment I have ever experienced. ALL of my emails to both the case worker and her supervisor are read (I get notices on my computer when they are read) but ignored. Calls that either I or the staff working with us make are not returned. A personal email that I sent to our case worker was then forwarded to someone that had no connection to our case at all and that our case worker did not know. It was a woman looking for information on how to be DCF credentialed so that she could help families like ours and contacted our case worker introducing herself and our case worker forwarded her an email I sent her. This woman could have been anyone attempting to get information about our family and I was never asked permission nor was I ever apologized to when I repeatedly told both her and her supervisor how upset I was about it.

We applied for services in March but the only service we have had since we were approved in May is a mentor for my younger son. Just recently (3 weeks ago) an in home service started but it was a constant battle to get that and even that is not what is appropriate for my children. Repeated requests for other services that my children need are ignored. Those requests have come from me, my children's doctors, and the probate judge. Meanwhile, things have become so bad at home that we were forced to call 911 on Monday evening for my older son.

However, the most disturbing thing that I have come across with this program is the discrimination that is taking place in at least the New Britain Office. When I was first told that we qualified for services in May I was also told that we would NOT be able to receive any autism related services. We could either have the same IICAPS service we had last time or deny services. When I pointed out that the IICAPS service was ineffective and asked why we were being denied services that would help my children our case worker at the time, Angel Penn, told me that the New Britain Office had a meeting in April and it was decided that since there was such a huge increase in autism cases they were no longer going to provide services to those children and current cases needed to start being closed out.

Meantime, I found out that all across the state other families were getting the services from DCF that we were looking for and I questioned Angel about that. She responded that she managed to get us approved for 40 hours of ABA therapy and wanted to come out to do the paper work. A week later she told me that her supervisor changed her mind and we would NOT be getting the service and had to have IICAPS. I asked to speak to her supervisor and I was put off until two weeks later when I received a letter telling me that we were assigned a new case worker, Alexandria Chisholm (Lexy) with no explanation.

I continued to ask Lexy and her supervisor (Kim Tait) why we were being denied services that families in other parts of the state (including Hartford and Manchester) were getting and I received a response from Kim that regional offices are no longer required to implement services on a statewide basis and each Area Director has the discretion to make decisions as they "SEE FIT". It was the Area Directors

decision, according to Kim, that since ABA, RDI and other autism therapies are not part of DCF's credentialing program they will not contract with anyone providing these therapies. When I asked her why the Manchester and Hartford offices were contracting for these services (specifically with an agency called Creative Interventions) I was told that if they choose to go with uncredentialed agencies that was their right but that New Britain would not. I asked if we could have our case moved to an office that did provide those services and were told NO. Our son's doctors and schools even wrote and called DCF to request that our family receives those needed services and they were ignored as well.

Meanwhile, other parents were continually telling me that they were getting approved for services, so I sent a letter to the DCF commissioner asking for help. Instead of responding to my letter, or having someone in her office respond to my letter, it was sent back to the New Britain Office to be handled and I was basically given the same response that Kim gave me. So basically, I was being told that because of what town I live in and what office I need to get my services from determines what services my children are going to receive.

I called a probate hearing and the judge agreed with us and requested that Kim find a way to provide our family with the services that we need. Kim mentioned an agency that does NOT provide autism related services but that had some experience working with autistic children and could try to help us. The judge directed them to FIRST attempt to get us into the Hartford office so we could go through Creative Interventions but if that didn't work we could try this other agency. The judge also made it clear that she was appalled at the way our family has been treated for the past 4 years by DCF and demanded that this change immediately. It has not. Yesterday (12/17) we had another Probate hearing and the Judge once again reiterated how disappointed she is in how our case has been handled for the past 4 years and does not understand why it is taking so long for us to get services. She addressed this as a statewide issue with Voluntary Care Services and she is the one that encouraged us to appear before you today.

I spent the next two months asking repeatedly for more information on this new agency because no one that I spoke to in the autism community were familiar with them, nor were any of my son's doctors or school personnel. I also repeatedly asked for updates on the Hartford office and my requests were constantly ignored. I also asked about other services that were mentioned in the hearing as well as by my son's doctors and those were also ignored. To date, since starting this process in March, we have had ONE mentor come out for my younger son and 3 HOURS TOTAL of this new agency coming out to try to work with our family. They come out once a week for about an hour and a half and meanwhile, I have had to call 911 on my 14 year old son for the first time because things have regressed to dangerous proportions.

Where else can my family go for help? How can one office deny services when all the other offices are providing those services and these children are getting better? Parents that go through the Voluntary Care program are desperate and in need of help and to have your calls and emails repeatedly ignored and programs constantly put on hold or taken away or to be treated like you are just one in a thousand other families seeking a hand out is frustrating to say the least. There is something seriously wrong with this program and it needs to be reviewed.

Yes, the number of cases of autistic children is rising and these families need help. If we can't go to DDS, insurance, the school, or now DCF, where are we supposed to go? This is discrimination at the absolute least. And it is a problem that in the long run will cost the taxpayers much more money than it would to provide the necessary services that they need now. Please start an official Program Review of DCF and their Voluntary Care Services program, and in particular, the New Britain Office. Thank you.

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