

Un-met Needs and Obstacles

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version 2

My name is Jim Karpe. I am a member of NYC FAIR, and the father of two teenagers with developmental disabilities. I am here today to talk about un-met needs. My focus is on the barriers which stand in the way of meeting those needs. My message to you: Getting services is very difficult.

The parents here tonight are lucky, or strong, or persistent. Most of us here have services for our loved ones. The parents who do not have services for their children don't show up at events like this, because they are fully occupied at home. For every parent who is here, there are one or two at home whose children should have qualified for services, but did not.

I'm going to share the story of my recent campaign for my son, Eli. The details are unique, but the overall shape of the story is completely typical, and will be all-too-familiar to the parents in the room, starting with the title: I call this story "101 days of 'No' ". My son Eli is approved for services with OPWDD. That puts him in the lucky half. And Eli is approved for Self-Direction, which puts me firmly into the persistent 3%. My story is not about either of those campaigns. They were not easy, but they are all done.

For this campaign, my goal was simple: Pay for a seven-week intensive program to teach Eli the skills needed to shop for and prepare his own meals. To accomplish that goal, we had to move approved funding from one bucket to another. That's it. Use of approved budget dollars for an approved goal. I thought I could get a quick yes.

So I partnered with a provider and we asked, and I got a 'No'. And I clarified, and I got a 'No.' And I persisted, and still had a 'No.' And I re-stated my arguments using OPW terminology and I brought in elected officials, and finally, after 101 days of 'No', I got a 'Yes'.

I was happy about the 'Yes', but I thought: This was way too hard. When I am dead, my son will never be able to do this for himself. A hired care-manager would never do this. But, I'm alive now, and I'm happy about that, too.

And I wish that were the happy ending to this story. But what happened next is I said, "Please write the check. You said 'Yes' after a 101 days of No, so please now pay for the program."

Their answer: "We can't help you, your request for payment falls outside of the 90-day window."

I hope this helps make it concrete for you, with one small example of the way it is not easy. I hope it helps you understand why you encounter so very many very angry parents, when you go out into the developmental disability community.

This was my unique story-- but the shape of it is absolutely typical, and all-too-familiar.

Thank you.

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