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My name is David Jaskowiak, and my wife and I are the parents of a 23 year old young man who suffers from autism. We are currently without any waiver services at all. My son is unable to work and relies on us for all of his needs. I am here today to try to give you some sense of the struggles and hardships which we experience from the lack of any services or programs.

Initially, we did not understand how the complicated waiver service program even worked until a couple of years ago when, by sheer happenstance, I explained our situation to a friend who said that we had better start looking into it because it could take some time. Unfortunately, we had received no information, guidance, or assistance from our local educators before our son graduated from high school in June 2012. When we started looking into the various waivers, we found it confusing, to say the least. What did become apparent, though, is that our son would likely not qualify for the "ID" waiver program because of the rigid IQ score criterion that was used to determine eligibility. He is a little, but not much, above that arbitrary IQ threshold. Does that mean that our son is somehow able to be employed, live apart from a supervised setting, or even survive out in the community by himself? Not at all. Functionally, our son will continue to need 24/7 assistance for his health and safety as he gets older. He simply lacks the ability to understand the everyday challenges and dangers of life. He is unaware of those who would seek to manipulate him and take advantage of him. Although he clearly needs and wants people in his life who can accept him for what he is, our son lacks the requisite social skills to develop friendships and relationships necessary for living his life on his own. He lacks the tools to comprehend and understand "how the world works," and will never be able to live on his own. We looked into whether OVR could help him get a start in the working world, but were dismayed when we were told that OVR was only for those who are able to engage in "competitive employment." Our son is not just ready for that and needs supports and services if he is ever to reach that point..

Our first attempt to apply for the autism waiver was never completed. We left our name and number on the designated telephone number for the Bureau of Autism Services, but did not hear back. Finally, in September 2014, we were able to complete an application for the autism waiver over the telephone. I spoke to a woman at the Bureau who took down our information and then informed me that the waiting list was about two years. I expected to get some kind of written confirmation of *something* after that phone call, explaining how the process would work, what we could expect, and how we might monitor our waiting period. To this day, I am still waiting. I have called a few times to see where we are on that list and how much longer we might have to wait, but was told that the Bureau does not give that information out. It is truly Kafka-esque. We are still waiting, but we are not really sure for what or for how long.

We were heartened by the news last summer, ironically when our son was suffering from some of his biggest challenges, that additional funding would be on the way when the budget passed. Unfortunately, as I later learned, those extra spots are minimal and, with the budget impasse, even that isn't happening.

How do you explain all of this to an autistic young man who just wants to be happy and to be able to do something with his life? I truly wish that our son could describe for you his daily frustrations, boredom, and loneliness, but, although he is verbal, his communication skills do not allow him to do that. All of this is far beyond what he can comprehend. Perhaps in that way, he is really similar to all of the other parents out there, even me, who do not understand why this process is so difficult when there are autistic men and women who are so deserving of our help.

I am told that there are about 2000 adults waiting for services from the autism waiver program. I have also been told that new adult applicants become eligible for services at the rate of about 100 per year. At that rate I could be well into my late seventies and my son could be in his forties before he gets any services. We simply cannot wait that long. The longer we wait for some services, the more difficult it will be for our son. He is already going through a difficult adjustment period his early 20's which, even for a "normal" adult, is perhaps the most

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challenging period of that person's life. And heaven forbid that something should happen to my wife or me. A drastic transition for my son into some other living arrangement would be truly traumatic under those circumstances. The fact is that our son needs more people and services in his life *now* to prepare him for the inevitable transition.

Here is the other part of the problem. Without waiver funding, there are *no* programs available to help us. Even if we could private pay, many, if not most, of the programs will not open their doors to someone without waiver funding. That leaves only my wife, me, and our other son (who is 3 1/4 hours away in college) to provide for our autistic son's needs. Friends and family only go so far, and the truth of the matter is that most people, even with the best of intentions, lack the necessary insight and understanding of the special issues that autism presents unless they live with it. A trademark of autism is quirky, unusual behaviors. With small autistic children, that may be looked upon as "cute." It stops being cute, though, when kids with autism are all grown up. Unless you are properly trained, or really know the autistic individual, there are some behaviors that might, at first blush, be very concerning. So it is left to us, his immediate family, to help him. And there are no breaks. My wife is no longer able to work outside the home. We cannot get away on vacation. And even if we could get away, respite is simply not available. It is a 24/7 job.

But the biggest effect on the lack of services is the effect on our son. He wants more from his life, but he is finding out that the world is not such a hospitable place. He would like activities, friends, maybe even a job some day if he could be properly trained and supervised in a working environment that can accept his idiosyncracies. That is what he was promised by his teachers while he was in school. He struggles with understanding why that has not yet happened.

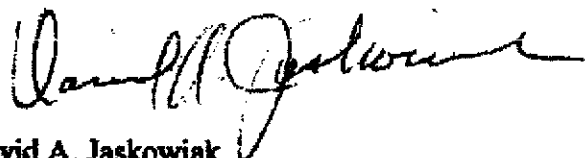
In deference to my son's right to privacy, I cannot explain all that has happened in the 3 1/2 years since he finished high school. However, I would like to try to dispel the notion that an autistic child who has received services while he was in school does not suddenly "get better" and become fully integrated into society upon graduation. In fact, without continuing supports

and services, exactly the opposite takes place. We have seen regression, including the loss of basic skills that our son had mastered in early childhood. That includes self care skills, eating and dressing habits, the ability to organize and follow through on tasks, and the ability to be motivated. All have been compromised. This time last year, we saw that our son unexplainedly began to lose weight despite a very good, balanced diet. We also started to see alarming, repetitive behaviors. We consulted with specialist after specialist and even had a brain MRI trying to rule out some organic process. Finally, with the help of a couple of exceptional, caring doctors, we were able to determine that his struggles were directly related to his discontentment at what his life had become. For a while, it seemed that he even blamed us despite everything that we have tried to do, and still do, for him.

What is important to understand is that our son finished school as a much more confident, optimistic young man. In fact, before he graduated, our son did his graduation project with the help of an aide which included giving a presentation on his food allergies complete with posters and other visuals which he had prepared to a number of teachers, administrators and us. He could not do that same project today.

Thankfully, we have seen some improvement recently, but we are scared that our son could backslide at any time. He needs more than what we can provide to him on a daily basis. He supports and services in real time to allow him to be out in the community. Without it, our son risks stagnating in his development as a person or, worse yet, further regression. We urge you to implement the necessary changes to allow those services to be delivered now without further delay.

Respectfully submitted,



David A. Jaskowiak

Dated: March 16, 2016