

## Medicaid Waiver Bill 7280

The month of May will bring an important milestone for our family. Aaron, our autistic son will reach age 18. The age of majority. The beginning of adulthood – for some. Unfortunately, not for our son. No matter how hard we wish, dream and plan, he is a long way from being an adult. Chronologically 18 for sure. Physically as well. But not in the ways that really matter for his future, or ours. His numerous challenges mean that he will never drive and, as significantly, may never be able to hold, and keep, a full time job. Certainly his school years have been difficult at times with a hefty dose of heartache thrown in for good measure. But the reality is that they have been a walk in the park compared to what lies ahead as our son reaches “adulthood.”

It took until the end of his junior year for the school system (**one of the very best we are told**) to recognize the need for a vocational vs. academic program for our son. It took until his senior year to get him started with a daily job in the Town Hall mailroom. From the start, the feedback was fabulous, “He caught on immediately.” “The best worker we’ve ever had.” “He is so smart and works so hard.” He was proud, enthusiastic and motivated. Home free I thought, perhaps I should say, dreamed. He can do this. He can succeed at a real job. Then it was December. A tough month for our son for as long as we can remember. The reality of autism has set him apart from his peers, accentuated his being “different.” In December, the fact that he is Jewish sets him apart all the more. It is the month where he cannot contain his anger at the world for being so isolated. His fuse is short, his social skills at an annual low. It is us vs. them, a sports cliché that becomes his reality.

They can see the change at school. They are used to it. Always a little bit better than the year before, but not good enough. He begins to bark at his coworkers. He asks, “Is everyone here Christian?” The halls are brightly decorated for the season. Folks are taking too long with the mail. They are wasting time, chatting and spreading holiday cheer. And all those greeting cards are slowing him down, making his job harder. It is getting tougher to be “The best worker they’ve ever had.” He hates going to work now

and his untrained supervisor tells him he must be nice to his co-workers. Sure, he says but without a greater, more learned and trained assist, he continues to boil inside.

This first chapter in the saga of his work experience ends when he refuses to take someone's mail because she took too long. He throws the envelope back at her with the suggestion, "Take it to the mailroom yourself!" They call the school to say that they must let him go. How could that happen? He was so good at sorting the mail, so error free in divvying up the packages. The mailroom activities were not difficult for my son. The intelligence is there. What is the problem? How could he possibly need help? At an IQ above 70 he just does not meet the criteria for services. No Medicaid waiver. His IQ is just too high to qualify him for help with his issues. It almost makes us wish that his scores were lower. How many parents have ever wished that their children were less smart? Probably not many. But sometimes secretly we do. He can sort the mail you say. He can divvy up the packages you declare. He just cannot interact with his coworkers and for that reason, if no other, he may never succeed in the workplace.

You feel it is not your problem. You cannot help EVERYONE. But, at what cost will you pass him by? What cost to our son, our family, and his community? To save the cost of extending the Medicaid waiver to people like him today you ensure the greater cost in the future due to his lack of options, connectivity to the outside world and that all important sense of belonging somewhere. Please help us help all of the folks like our son in our community. The reports are in, their number is increasing at an incredible rate.

Help stop the cycle of isolation for our autistic children. Please support the Medicaid Waiver Bill 7280.

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