

Building Independence in the Totally Dependent Child

I use to get so annoyed and even a bit angry when someone would say to me “you’re too much with your child”; “stop hovering over him so much” or my all-time most annoying comment, “you got to let him go”. I use to think to myself why does everyone think they know my child better than I do.

Then it was like a light bulb went off in my head. I remember the day clearly. Kenny was 11 years old and got around driving a power wheelchair. To put this in context, Kenny, my son has cerebral palsy and he is a spastic quadriplegic. All that means is that the tightness is all through his body. He is non ambulatory, doesn’t sit by himself, his speech is affected – you get the idea. He needs to be fed, dressed, etc. He has some cognitive deficits but not bad. Anyway, back to the light bulb going off. We were coming for an appointment to see Dr. Diamond a Physiatrist at Children’s Specialized hospital. He is wonderful and now retired. He loved and supported his patients, his kids as he would say, and his families like me. Dr. Diamond had called me prior to Kenny’s upcoming appointment with him and told me when you get to the hospital, I want you to let Kenny drive to our ambulatory care center from the lobby by himself. You follow a little later. Dr. Diamond went on to say, my staff and I will be waiting to greet him. He can do this by himself.

I had never done this before and only did this because Dr. Diamond said to. When we arrived, we checked in with the registration staff and off Kenny went on his own. He knew exactly where to go as we had been coming since he was 10 months old. When he arrived in the ACC area Dr. Diamond was there and so was his staff. Kenny was so excited and happy to see them and he gotten there on his own without me.

This must sound so silly, but it was a true defining moment for Kenny and for me. Kenny felt so excited and found out he can do things for himself. I found out he could too. This was just the beginning.

We then began to give Kenny some chores at home. We had to think about what would be possible, safe, and meaningful. He would drive down our drive way by himself to our mailbox. I would run to the mailbox put the mail on Kenny’s wheelchair tray and run back. Kenny would drive it back to the house and say “Mail’s here”. We would say “Thanks Kenny”. For us to be able to thank Kenny for something he did for all of us was wonderful!

Another chore Kenny was now responsible for was to clear our dinner table dishes after we finished eating. He would tell us to pile the dirty dishes on his tray and he would drive them over to the sink. We would say “Thanks Kenny”. He would be so proud that he was helping us too!

As Kenny got a little older, we let Kenny go to the movies by himself with friends. Drop him off, get him situated in the theatre, leave, and come back when the movie was over. His friends would give him a drink and some popcorn, after we showed them how to do it in a safe way for Kenny. Afterwards, we were able to say to Kenny “Did you have fun? Was the movie good?” He got to share with us what he did and what he felt in his way in his own words. We would say “Kenny sounds like you had a great time!” or “Sorry Kenny maybe the next movie you see will be better.” He was so happy to add to our conversations about something only he knew and something he did on his own.

More and more we found opportunities for Kenny to be independent on his own or with friends.

There isn't one occasion he didn't rise too. Every one of these experiences helped him to grow up and to build his own confidence and identity.

Kenny is an adult now. He still needs to be fed, dressed, and toileted. He needs to be lifted out of bed and put into his wheelchair each morning. He will always have those needs. The lesson Kenny learned and taught us is that he is his own person and can participate and contribute to life in his own unique way. The other lesson we all learned is that although Kenny will always need support and help it doesn't mean it always has to be my husband and I. Kenny can ask us for help or choose others to assist. That's up to him.

Thank you, Dr. Diamond, for beginning Kenny's independence and thank you Kenny for asking us for more and more independence as you grew up.

Kenny is very independent, now, comfortable in his own skin, aware of his needs and is able to ask for support when he needs it. He is also a very happy, kind and nice man!!



Resources to Support Independence in Children with Special Needs

Let Go: <https://www.cerebralpalsy.org/inspiration/messages/let-go>

Independence And the Developmentally Challenged Child:

<https://www.nacd.org/independence-and-the-developmentally-challenged-child/>