



Center for Speech and Language Disorders

Donald's Story

Donald was a beautiful baby. His parents, both young, talented professionals, were ecstatic. They could not help but feel that this baby was destined for greatness.

Everything went well the first year. Donald reached the right milestones at the right times. But before he was two, his parents became worried. He did not seem to understand as well as other children his age, and his early language began to disappear. When Donald was 2 ½, his parents sought help. Five months later, they emerged from this tunnel with the diagnosis of autism, with all the heartbreak that the word brings.

Donald's parents labored indefatigably to find the best help they could. "Surely, in this day and age," they told each other, "there is a treatment and a cure for this problem." Instead, they found many experts with no real answers. They found miracle cures that could not be replicated. They found zealous advocates of self-promoting treatment plans. Fortunately, they also found caring and experienced teachers and therapists. Donald's parents gradually realized that although there were many experts on autism, they themselves were the real experts on Donald.

From office to office

Convinced of the critical value of early intervention, Donald's parents immediately enrolled him in occupational therapy, speech and language therapy and in-home tutoring with a special education teacher. They enrolled him in preschool and play groups and spent hours working with him on their own. They searched out professionals who could combine the best of the treatments they had read about. Donald's mother was exhausted from driving him to therapies and preschool, trying to make sense of conflicting information and worrying about each decision they made. Donald made progress in some areas, but seemed to regress in others.

Because Donald was soon to be three years old and eligible for public school programs, his parents hoped that the public school could now take over and provide all that Donald needed and that they could pass the major part of educating him over to the school. What they found was that, while school could give valuable help, Donald needed much more. The hectic schedule of multiple therapies continued.

Soon after his third birthday, Donald's parents brought him for an evaluation to me, at the Center for Speech and Language Disorders in Elmhurst, Illinois. He had begun showing signs of hyperlexia. He spelled the word "chipmunk" with his wooden alphabet letters and soon was spelling the names of many animals. While I felt that the family had done a wonderful job of finding talented teachers and

Main Office: 606 N. Michigan St., Elmhurst, IL 60126
Phone: 630-530-8551 • Fax: 630-530-5909 • E-Mail: info@csld.org • www.csld.org
Chicago Site: 430 W. Erie St., Suite 206 Phone: (312) 335-0453 • Naperville Site: 552 S. Washington St., Suite 109

Therapy that makes a difference.

clinicians to work with Donald, I was concerned about the number of interventions going on simultaneously. The family and I developed a plan for case management that drew successful ideas from existing programs, but was also individualized for Donald's particular situation.

From Office to Home

Donald's parents invited everyone working with him to a meeting at their home. Many of the professionals had seen Donald only in their clinical and school settings, and it was important that everyone get a sense of Donald's world. The meeting ran from 6:30 to 8:30 one evening, and food was served. The purposes were to encourage everyone who works with Donald to share information about what they were doing with him, to develop some common goals, to solve problems, and to support each other.

At that first meeting, the group decided to develop a communication notebook as a starting point. Everyone could refer to the minutes to review the priorities they identified and the concerns expressed. The group also decided to meet every six weeks to update progress and set new priorities. These meetings continued for nearly four years. Teachers and clinicians changed, and not everyone could come to every meeting, but it became a valuable part of Donald's overall program. At first I facilitated the meetings. As Donald's parents became more confident, they became equal partners and then leaders in the meetings. As the pros and cons were discussed, new therapies and interventions were thoughtfully introduced into Donald's life. The group helped to develop strategies for school placement. New teachers joined the group and successes, failures and problems were shared. Through these meetings, Donald's parents were empowered to become case managers and advocates for their son.

From Home to Home

Donald's journey is still before us. He completed his first year in a typical Montessori classroom and is working on his academic and social skills. His team, though quite changed from the beginning, continues to meet. The people with the most consistency and drive are his case managers, his advocates, his cheerleaders, his seekers, his researchers, and his strength – Donald's parents. This is not just Donald's success story. We have replicated this case management model with other families to help other children. Some have needed continued mentoring in order to present ideas and concerns in a way that could be received and acted on by a group. Parents develop relationships with schools and other professionals and learn to communicate in ways that avoid adversarial stances. Both parents and teachers develop a greater understanding of constraints and philosophies that others work with. The result is what everyone wants-thoughtful, appropriate intervention for the children, who then respond with progress and growth.

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