

Autism: A Parent's Guide to Services

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A Profile of My Son John and Intervention Services

- * John is now 47 years old. He has autism. He is bright, funny, lovable and has been our teacher throughout his life.
- * He is also perseverative, obsessive, has high anxiety at times, dwells on the past and has a short attention span, unless he initiates or is highly interested in the task.

History

- * Since John's birth in 1965, my husband and I immediately took charge of John's life. We learned everything we could about autism. We joined the Mass Association of Autism, the National Association of Autism and did outreach to leading researchers in the field. Our search for any and all answers still continues today.
- * The most powerful influence in our lives has been the parents of children with autism. Our friendships and unfailing support for each other, through both the good and the bad times, have endured for close to 50 years, when we started on this journey.
- * Note: I have developed two chronicles on John's life, which are on PowerPoint if anyone is interested in viewing.

Health Issues

- * We researched hospitals and clinics in the area and chose Children's Hospital and the Kennedy Memorial. We received the diagnosis and different opinions about our decisions about John's and our future.
- * We chose to follow our own instincts by doing everything possible to give John a good life. He was our only child at that time and we were determined to help him to learn and thrive.
- * He had many ups and downs, health-wise, very sickly as a baby, did not require much sleep and was extremely hyperactive.

Health Issues (Cont.)

- * He developed grand mal seizures at adolescence, but has only had 4 in 47 years. They seem to be under control with medication.
- * As an adult, he has had a fractured shoulder, due to a fall from a swing; some ear problems (swimmers' ear and infections, as well as wax buildups) and recently a case of conjunctivitis.
- * Note: Generally speaking, he has been in fairly good health over the years.

Employment/Community Service

- * Throughout the years, John has had some jobs, which have included working with plants at a Nursery; stocking carts at Stop and Shop; delivering packages (he can read and write) and working at a Candy Factory.
- * He is now mainly doing volunteer work in Senior Centers, the Library, and assisting wheelchair residents.
- * The Day Program is always seeking new opportunities for the clients in several communities and John seems very happy.

Housing

- * Home (1)

After turning 22, John lived in a home in our town of Bedford for several years. The Provider went out of business, and we then searched for a new residence.

- * Home (2)

A parent was building a new, lovely home in Billerica for her son and three other young men. We had been friends over the years and this seemed like a wonderful arrangement. It was for several years. However, due to some differences, the owner of the home decided to go with another type of arrangement for her son. The other parents stayed with the same Provider and moved to a new residence owned by the Provider.

Homes (Cont.)

- * Home (3)

There are now four young men in a new home in Littleton. Three have been together for many years, and there is now a fourth resident. It is a beautiful home; each young man has his own bedroom and bathroom; it has a living room, a dining room, a kitchen, a lovely porch and a large back yard.

- * Issues to consider: (1) the compatibility of roommates; (2) the relationship with the Provider (Parents as important members of the Team); (3) many activities provided; good nutrition and physical activities; (4) continued opportunities for growth, both cognitively as well as physically; (5) relationships with people, both with and without disabilities; and a good rapport with House Manager and staff.

Family Support

- * Along with the support of many families of children with disabilities there was also support from doctors, support staff, family members, schools (mainly private schools), hospitals and clinics and organizations like the ARC, the Federation for Children with Special Needs, MAC, and Universities, like Lesley, Brandeis, Syracuse and others.
- * My husband and I were most fortunate to become actively involved, and John was the benefactor of all these services and relationships.

PALS (Personal Advocacy and Lifetime Support)

- * This is an organization that a few parents started several years ago which was to help with Networking and Future Planning for our children with disabilities.
- * We developed a “Future Planning Book” to help parents record all their wishes, plans, and any and all important information to help siblings and others plan for their child’s future.
- * PALS, Inc. is now part of the ARC.

Social Networking

- * Real Friends Project: Advisory Committee
- * This is a grant to assist families in developing friendships for their children with disabilities.
- * The purpose of the grant is to locate all the programs across the state that have programs that are working; to share resources; to do trainings with staff in all regions of the state; to become involved with the New England Index to share information about the Project and to do outreach efforts.

Activities Provided for John

1. Horseback riding (Ironstone Farms)
2. Assistive Technology (I pads)
3. Neuro-feedback (Ladders Program)
4. Bowling League
5. Special Olympics
6. Museums
7. Group Home Parties
8. Awards Ceremonies
9. Holiday Parties

Classes

- * Special three year grant at Lesley funded by the NL Marks Foundation: The ARTS Café... Involved adults with autism who received classes in photography, the visual arts, movement, dancing and singing. They attended classes at Lesley every other Saturday for three years, and felt they were college students. They developed many skills and independence in choosing their activities. Faculty from the Special Education Department, Expressive Therapies and Creative Arts and the Art Institute of Boston were the instructors.
- * Students from Lesley volunteered each session and developed lasting relationships with the students with autism.
- * It was an amazing experience for all of these young people.

Suggestions

* Public Policy

1. Get involved with key agencies that help to influence public policy and protect the funding for our children.
2. Get to know all your public officials: reps, senators, congressmen and governor.
3. Know your rights as a parent in both schools and in the adult world.

Additional Suggestions

1. Be sure to start the Transition Process at age 14, and be sure the schools are informing you at every level for the plans for a smooth transition.
2. Research the Providers in the state: Meet with them, and be sure they encourage Parental Involvement.
3. Start the Future Planning Process now!

Life is a roller coaster ride ~ ups and
downs... but it is worth it

