

# Tracing the Paths of Autism Education

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## **Introduction**

Everyday we learn to navigate our worlds - to make decisions for ourselves and our loved ones that will support us, keep us safe, and ensure our success and happiness along the way. What happens though, when we are challenged with a new issue that we have never faced before? What happens when we realize that our child is not making the developmental progress that his/her peers are making? What happens when we begin to fear that their may be something “different”, “complicated”, even “wrong” with our child? What happens when a doctor says, “Your child has an Autism Spectrum Disorder”?

At this moment we embark on a new experience, one that will introduce us to individuals we never thought we’d meet, teach us to use toys, strategies, techniques, and tricks we’ve never heard of, and give us moments of struggle, frustration, joy, sadness, and confusion, we’ve never conceived of. This experience is sure to be an educational one, but what exactly does it entail? Who are the people we’ll meet? What are the tricks we’ll learn to employ? How will we manage the frustrations and the elations?

## **Purpose of Research**

This is a proposal to study a particular kind of Autism education. The study will trace the multiple processes that families must learn to navigate when a child is diagnosed with an Autism Spectrum Disorder. It will follow families who meet at parent support groups as they discuss choosing medical professionals, attending school meetings, searching for therapists and treatments, and planning for their child’s future. Additionally, this study will focus on the impact of these processes on various members of the family. Before, during, and after an Autism diagnosis is made, parents are bombarded with information about treatments and therapies potentially available

for their child, and must navigate legal structures that both constrain and support them. They are pressured by the weight of financial responsibilities and burdens, and must steer through a sea of support groups filled with other families navigating a similar path. What is currently missing from educational policy literature is a documented, systematic understanding of how families filter all of this information and choose what to do for their child. How do parents choose one play group over another? How do parents learn their legal rights and prepare themselves for educational meetings with school personnel? What factors help a parent decide to attend one therapy session rather than another? How do families interface with community members who may not be tolerant of children with disabilities? Equally important to documenting the people they meet, the places they go, and the decisions they make, is the creation of an experience narrative: as families of children with Autism live their daily lives, how do they manage the struggles and challenges; how do they celebrate the joys and successes?

## **Participants**

The participants in this study will include any family members, teachers, service providers, friends of the family, etc., of a child diagnosed with an Autism Spectrum Disorder (ASD) living in New York City. While the study proposes to explore the paths that families take in educating themselves after an Autism diagnosis is made, the researcher will no doubt interact with many other people in various roles, positions, and institutions that impact the experience of having a child with Autism. Children diagnosed with ASD may have any of five pervasive developmental disorders (PDD), which reside on a spectrum characterized by widespread abnormalities of social interactions and communication, severely restricted interests, and highly repetitive behavior.

The five PDDs are: Autistic Disorder, Asperger's Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS). Individuals labeled with Autistic Disorder are considered the most impacted by the disorder,

often have major language deficits, and sometimes are also labeled as mentally retarded (See Appendix C for the DSM-IV criteria for Autism). Individuals labeled with Asperger's Syndrome generally do not have the same language deficits, have average to above average IQ scores, and may present savant skills. Rett's Disorder differs from the others PDDs as its clinical features include a deceleration of the rate of head growth (including microcephaly in some) and small hands and feet. Childhood Disintegrative Disorder differs in that an apparent period of fairly normal development is often noted before a regression in skills or a series of regressions in skills. This feature occurs in some children diagnosed with Autistic Disorder also, and so a clear distinction between the two disorders is often difficult to pinpoint. PDD-NOS is diagnosed when the criteria are not met for a more specific disorder, yet many of the social skills difficulties, repetitive behaviors, etc., that characterize ASDs are present.

### **Background Information**

Today, it is estimated that one in every 110 children is diagnosed with Autism. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by Autism and government statistics suggest the prevalence rate of Autism is increasing 10-17 percent annually. While nearly one percent of the population is currently diagnosed with an Autism Spectrum Disorder, each of these autistic individuals presents varied symptoms, characteristics, behaviors, and levels of progress and need. As there are different levels of severity and combinations of symptoms in autism, there are probably multiple causes. While there is no definite cause of Autism, the best scientific evidence available today points toward a potential for various combinations of factors – multiple genetic components that may cause Autism on their own or possibly when combined with exposure to as yet undetermined environmental factors. Given the staggering prevalence statistics, coupled with no definite cause of Autism, families struggle to make

sense of the diagnosis and to understand what this label may mean for their child's development and future.

### **Methodology**

By gaining access to families who attend support groups to discuss their children who have been diagnosed with Autism, I hope to document intimately and through great detail, the everyday educational processes that families go through. I will use participant observation, including fieldnotes, photographs, and (possibly) video to navigate this process with families, and to document their educational journeys. Initially, I will make contacts with parents and caregivers at the support groups they attend, and listen to the discussions that they have with one another and with professionals in the field of Autism. If I establish greater rapport with some families, and given their permission, I hope to attend consultations with specialists and therapists, observe Individual Education Plan (IEP) meetings in the child's school, spend time in the family's home, and accompany the family on outings such as the park or the grocery store - all while documenting the interactions that occur. Additionally, I will conduct interviews to document personal thoughts and feelings. I will speak with the child's parents about their fears, concerns, questions, and hopes for the future. If the child with autism has any siblings, I hope to observe them as well, to learn about how they are affected by their loved one's disability. Interviews may also be conducted with teachers, or day care providers that know the children and families intimately. Finally, I will document the information that comes to families (or that families seek out) about various aspects of Autism (Internet sites, pamphlets, programs, parents newsletters, brochures, etc.,) to better understand the flow of information to and from parents about Autism.

### **Policy Implication**

Schools are not fully aware of the processes that families must learn to navigate, and the educational obstacles they face when their child is diagnosed with Autism. In short, many schools

are not aware of the educational journey that families embark upon when a child is diagnosed with Autism, and this educational experience is particularly fascinating because much of it occurs outside of formal schooling. Many teachers and administrators only see the family's experience as it appears at a parent-teacher conference or during a special education meeting. This study will systematically trace the experiences of families struggling through these processes, to contribute to policy focusing on the intersection of families, disabilities, and the school experience.

I propose that if education policymakers have a better understanding of the many obstacles that parents and caregivers face when trying to find and understand the resources available to meet their child's needs, educators will begin to bridge the gap between family and school experiences. A documented account of the various specialists that a family may meet with, the amount of literature (from schools, specialists, the Internet, other parents, etc.) that parents must sift through, and the ways that they struggle to support the additional costs of having a child with Autism, will encourage a much needed increase in compassion and understanding for families in this situation. This study aims to focus on one family in hopes to shatter the emphasis on statistics and faceless numbers that currently drives education policy.

## **Conclusion**

Through discussions that arise during documented interactions and interviews, I hope to learn more about the everyday education of individuals who are faced with a new challenge. This challenge is particularly noteworthy as Autism is an especially salient topic in American health, psychiatry, genetics, and most recently, legislation. I hope to uncover what kinds of supports and resources families will need and employ as they engage in this process of Autism education. I believe that documenting these journeys will further exhibit the ways that individuals actively engage in everyday education as they obtain, filter, seek, and question information in order to make choices about the success, safety, and development of their loved ones.