



VOICES FROM THE FIELD - A Parental View on Autism

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Parental perspective

As the parent of an 11-year-old child with severe autism, I try to review as much of the current literature on autism as I can, especially the papers outlining specific practical interventions and strategies that can help me deal with the many daily struggles surrounding autism. It is also important to be familiar with any information around new services, sources of funding and/or support that may become available. As both a parent and a teacher, I am always interested in the latest etiological articles; however, they are less useful to me in surviving my daily work and home life.

Charman¹ discusses *Autism and Its Impact on Child Development*, clearly presenting the problems associated with raising a child with autism, the physical, social and societal issues a child will face, and the cost to the family and to society. He reviews the most popular interventions and points out that improvement is now being observed with early intervention. For a parent, this was a good review, short and to the point. The language was not too technical, and it ended on a positive note.

As a resource teacher, I find the information presented by the CEECD succinctly put and feel it would be excellent to distribute to school boards' Autism Intervention teams (such as the team at the Durham Catholic District School Board) and to other school resource teams. Two key things stand out for me:

1. Charman gives professionals a look into the lives of families living with autism, reminding those on “the outside” that these families experience the high stress of finding financial resources to support their child, and that in many ways, the future looks bleak and hopeless for these children and of course, for their families.
2. The author closes by essentially saying that greater societal acceptance of differences in social engagement and behaviour is required. To me, this serves as a reminder to professionals that these children, mostly boys, are still children. It is incumbent upon us as teachers and resource teams to help these autistic children communicate (for example, by finding voice output devices that speak for them), and to recognize that each child can be reached and we cannot give up looking for an appropriate educational plan for any child.

Stone and Turner's article *Autism and Its Impact on Child Development: Early Effects on Social Development*² discusses the early symptoms of autism, those present before the

usual age of two years plus at which the diagnosis is made. The authors indicate that early diagnoses can present implications for services of “at-risk” children.

I agree that more services are needed for “at-risk” children, and in fact, families who receive the shocking diagnosis of autism need greater access to information.

I have experienced with my son all the symptoms mentioned in the articles. Having to deal with the lack of sleep (for child and parents alike) and fear of the future hinders the average family’s ability to seek out information on the best way to help their child. When I was beginning this journey with my son, not one professional suggested specific services that I could access to receive assistance and guidance. A lot of praise for being pro-active and best wishes were sent my way as I faced the huge challenge of my son’s behaviour problems. I went about finding services and getting placed on waiting lists that often took many months (two years for Sensory Integration Therapy). If a child is “at risk,” waiting for many months is not the best scenario and falls short of the early intervention ideal to treat or decrease the negative effects of the symptoms of autism.

In the early 1990s, the Internet was not as prevalent as it is now. Today, you can find virtually anything on any topic related, however remotely, to autism. Back then, information about wonderful programs travelled more slowly, from family to family in support groups, sometimes from physicians or community agencies to families. The Autism Symposiums were very helpful in providing some direction. However, they were a little overwhelming: you had to be able to take in all the information, assimilate it, and develop your own plan of action to help your child. The book displays at these events also provided information about treatment options.

Even if you can develop a plan or are lucky enough to engage professionals to assist in implementing early interventions, a new problem arises. Suppose a family were to go ahead with the Applied Behavioural Analysis strategy, they would (in the early 1990s) have had to fund it themselves to the best of their ability. Couple this with a nutritional approach, perhaps eliminating gluten or casein from the diet, providing recreational activities involving memberships, joining clubs or leagues, and so on. It is financially ruinous to provide all these services to one child in a family, while going through all the emotional turmoil, fear and exhaustion, as well as maintaining the household on a minimum budget.

So, yes, early intervention is wonderful – the earlier, the better. But as parents, our first step toward intervention must include answers to some questions: Who can provide information to families on how to find out if your child is at risk? Who can help fund the implementation of whatever program is deemed most effective for a child? Who helps the family decide which is the best plan or direction to take? And are there financial strategies in place to help the parents emotionally?

I feel thankful to have survived these last 11 years, doing my best to wade through available information and try to find the right programs to help my son. I also feel thankful that an alert family member recently recognized the signs of exhaustion and burn-out and took the initiative to seek out supports for me and respite opportunities for

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my son. The waiting lists for these services are also very long, and some programs are not even taking names because their waiting list is endless. I eventually got my son signed up for bi-monthly weekends. This has been a positive experience, and I would hope all families dealing with such overwhelming issues, especially families with lower functioning autistic children, will have easier access to the same information.

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