Reviewing Approaches for Children with Autism:

Perspectives of Parents of Children with Autism

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Introduction

Parents of children with disabilities have made it clear that one of the things they value most from professionals is receiving information that helps them make informed and valuable decisions (Trute, 2007). Parents look to professionals to inform them about the nature of their child’s disability and what can be done to assist the family and child. In Manitoba the first place parents of children with autism receive information is the Child Development Centre (CDC). Information at CDC comes in the form of consultation and print materials. Information from the professionals who work at CDC typically covers material on the causes of autism, prognosis, and the variety of treatments (approaches) available to support children and families. In the last ten years parents have also been able to access information on the internet. The internet is a source of both general and specific information for parents. For instance, parents can find various National and Provincial organizations such as (provide a couple of examples) that provide information and advocacy services related to autism. Another major source of information for parents is the school system. In the school system parents can access information from special education teachers, occupational therapists, and speech therapists. A final source of information is the Department of Family Services and Housing – Children’s Special Services. This is where parents can access information and funding (if eligible) for Applied Behavioural Analysis (ABA).

The issue examined in this paper is the extent to which the information provided by these sources has assisted parents in making decisions and supporting their children. The paper will examine parent’s perspectives on the quality and quantity of approaches for supporting individuals with autism. Three parents of children with autism were interviewed for this study.
Parents were asked a set of questions designed to get their perspectives on the efficacy of various approaches to support children with autism. The paper will report on parent’s experiences, preferences, concerns, and recommendations relating to various approaches. The paper will also include an overview of conceptual frameworks that influence both the understanding of autism and responses to it. Throughout the paper the terms ‘autism’ and ‘autism spectrum disorder (ASD)’ will be used synonymously.

Approaches for Supporting Children with Autism

Many approaches have been developed to both explain autism and suggest how to support individuals who experience it. The following are examples of various approaches: applied behavioural analysis (ABA) that is conceptualized with a behavioural approach, occupational therapy and physiotherapy conceptualized within a rehabilitation approach, treatment and education of autistic and related communication handicapped children (TEACCH) that utilizes an educational conceptualization, speech therapy and Floortime that is underpinned by a communication conceptual framework, and relationship development intervention (RDI) conceptualized as a social approach. Research in many cases has supported the positive effects of various approaches.

Research in many cases has supported the positive effects of various approaches used to support children with autism. Heflin and Simpson (1998), for example, discuss interventions based on relationship formation, skill-based treatments, physiologically oriented interventions, and comprehensive educational and treatment programs. In the area of autism new concepts about the cause and treatment occur on a regular basis. However, not all the new concepts are tested by research before parents learn about them or try them with their children. Frank, Margaret, and Donald (1999) reviewed the following programs for effectiveness: UCLA Young
Autism Project (YAP), TEACCH, Learning Experiences Alternative program (LEAP), ABA, and the Denver Health Science Centre Program (DHSCP). Their research concluded that all these approaches were effective in the following areas: producing developmental gains, helping parents access less restrictive school placements, and documenting increases in measured IQ.

Maurice, Mannion, Letso, and Perry (2001) discussed that present parents or caregivers still face serious challenges in identifying scientifically validated treatment models, and in securing competent and well-trained therapists. Green (2007) discussed the need for parents to have access to unbiased, scientifically validated information about approaches to autism. The introduction of the Internet as a source of information for parents exposes them to a wide range of ideas about effective treatment and autism. A potential problem with the typical internet postings is that they are all reported as if they are effective, are often found on sites biased towards particular treatments, and are generally not research-based. (Green, 2007)

There also appears to still be limited research related to how the parents of children with autism feel about the quality of the services they can access and the approaches advocated for their child. Examining parents’ perspectives on approaches on the quality of the services may shed light on how these organizations can support parents and families more effectively. An issue that this study attempts to learn more about is whether having a focus on academic/scientific research is part of parents’ process in choosing approaches for their child. Questions of interest include: 1) Do parents consider the research related to autism when choosing an approach to use with their child?, 2) What do parents report about the process of choosing an approach?, 3) How do they feel about the current approaches being promoted and offered?, and, 4) What approaches for supporting their children have worked for them? The
study attempts to hear the voice of the parent that is so often lacking in the scientific research on autism.

Method

This report contains the findings of an interview-based study on the perspectives of three parents (mothers) of children with autism in Manitoba. The pseudonyms of Eve, April, and Grace are used to indicate the names of the three parents in the study. Eve was the mother of a 17-year-old son with autism, April was the mother of a 4-year-old son with autism, and Grace was the mother of a 5-year-old son with autism. All parents who consented to participate were aware that their perspectives on the approaches they have used to support their child with autism were the topic of a study. The study took place between September 2008 and December 2008.

Interview protocol

The interview protocol included one introductory question and six questions related to parental perspectives on approaches for children with autism. The questions were designed to examine: what approaches have been used for children with autism; the extent to which the approaches have worked with the children, and suggestions or concerns the parents had related to their use of different approaches. The interview questions can be found in Appendix A.

Procedure

In order to access participants for the study, a letter was sent to the Autism Society Manitoba to ask for its support to help recruit parents. The letter indicated the purpose of this research and asked that the society forward an advertisement of the study to parents of children with Autism. After the posting, interested parents contacted me and I picked the first three parents, Eve, April, and Grace. The parents and I made appointments for face-to-face interviews by email and telephone. Each interview lasted one hour on average. Prior to each interview, each parent
received an interview guide and a consent form by email. All the three interviews were recorded by digital voice recorder. The data from the interviews were transcribed and analyzed according to qualitative research guidelines (Bogdan & Biklen, 2006). Reductive analysis (the identifying, coding and categorizing of data into meaningful units) was used to identify themes and patterns in the data. Commonalities and/or anomalies were determined through careful comparisons of the informants’ discourse (Wallin & Crippen, 2007).

Findings

The following sections contain the findings from the parent interviews based on the study questions. The areas covered in the study questions were: child characteristics, common approaches, learning about approaches to support individuals with autism, criteria for choosing an approach, effectiveness of various approaches, suggestions and concerns, and additional issues.

Child Characteristics

Three families were involved in the study. All three children with autism discussed in the report were male. Eve is the parent of a 17 year old young man attending a regular high school, April is the parent of a 4 year old child with ASD who has not begun school, and Grace is the parent of a 5 year old who attends two different kindergartens, one a regular setting and the other a Montessori setting.

Common Approaches

Parents reported on the various approaches they chose to use in supporting the growth and development of their child. All three parents reported using the traditional development approaches of speech and language therapy and occupational therapy. They all reported that they had all, at one time or another, acted in the role of ‘teacher’ with their child supporting some type
of development. Eve used speech language therapy, occupational therapy, physiotherapy, Greenspan’s Floortime, physical activities (e.g., Special Olympics and swimming), music therapy and inclusion in regular settings (e.g., daycare and school). When she mentioned the Floortime, she described that "Greenspan's Floortime was basically getting into his world and trying to make connections" and singing was a sort of a representation of it. She added that "we tried different things to teach him, such as sign language." April used applied behavioral analysis (ABA) and reported that "it was my feeling that the ABA program was the best possible option for him. The principle of ABA is behaviour modification. It is a method that can be used to change negative behaviour to whatever behaviour is desirable." Grace used a variety of approach, including occupational therapy, physiotherapy, speech therapy, the Floortime, the Hanen approach, ABA, the casein-free and gluten-free diet (i.e., taking off dairy and breads), inclusion in a regular classroom, music therapy, physical activities (e.g., walking and jumping on a trampoline), social stories, a visual calendar, picture cards, newspaper, and computer games. The Hanen approach was recommended for Grace's son as a speech therapy that had been published by Hanen organization which is an organization that operates in Toronto. She described the inclusion that "the focus at his public school is primarily on socialization and getting him to function in a class setting, listening to a teacher so as not to need an aid later on." She added that she "learned enough to do the programs to know how to structure something" and created her own strategies for her son (e.g., her own picture cards, physical activities, songs and social stories).

Learning about Approaches for Autism

All three of the parents reported that the Child Development Clinic (CDC) was the major resource for learning about approaches to utilize with their child with autism. All
three also reported that they learnt about autism through non-profit parent support organizations like the Autism Society. Other sources of learning included the internet and various types of parent networks. For example, Eve reported that she accessed the Parents’ Guide for Autism from a Public Health Nurse. She also accessed information from the CDC who helped her family set up contacts with BC. In addition, the family was referred to Children Special Services where they had access to a Family Services worker. Finally, she received information from both the local school through music therapy, and from the Autism Society. April got a package that explained all available sources of programming for her son from CDC and added that "prior to the diagnosis, I discussed the situation with people who were familiar with the ABA program, many people told me about their experience with it." Grace reported that she was received information from CDC, speech therapist, her own research and Autism Society Manitoba. She described how she accessed more information through the Autism Society Manitoba, "I found the casein-free and gluten-free diet from online and I sent an email to Autism Society Manitoba and asked if any parent who were doing the gluten and casein free diet and willing to provide the information. And they sent my email address to this woman who then corresponded with me and told me where to shop and where to get recipes all that kind of stuff." She added that "parents’ support is huge because we all find out about it and try different things, and then we talk to each other."

*Criteria for Choice of Approach*

All parents reported that when it came to selection of an approach for their child with autism that intuition played a major role in decisions. A major criteria in making choices was their opinion about what their child needed. In other words parents based their choices on what they
felt and believed would benefit their child based on what they knew about their child’s individual personalities, characteristics, and interests. It was clear in the reports that parents chose approaches based on a holistic and caring understanding of the whole child, and not just about autism per se. For example, Eve suggested:

I do not know we actually had any. I know our criteria why we did not choose ABA was we definitely do fit in a neuron-diversity perspective and I think our family philosophy was we never wanted our son to think we would love him more if he was not autistic. And so we would never do something that would try to make him not who he is. It is valuing him as a person, helping him be the best with his autism. … My friend and I say our kids are low functioning and we are proud of it. … What I can say is we decided to not use ABA. I took the behaviour modification course at the University when I was an undergrad, and I understand the principles behind it. We just did not like the approach that it aims to make him not autistic and to cure him. We do not think our son is sick. He does not need to be cured. It is part of who he is.

She was clear that she considered autism with a neuron-diversity perspective and that her family decided approaches based on the belief.

April reiterated the instinctual element of choosing approaches based on a mother’s understanding of her child’s needs:

Intuition. Just knowing my child well enough. An instinctual feeling as to what would be best for my son. He needs more intense programming. He needs somebody to be here to work with him daily because he will not learn as readily unless he has ongoing contact with the person. … You will just know what is best for them. That is a God given gift. … I would be reluctant to try other approaches with him because it may interfere with his programming.

Her motherhood influenced her to know her son's needs and what to do for him.

Grace concurred with the finding that “criteria” typically included instinct but also added in an understanding of research, prior parental experiences, internet information and the context of the family:
I sort of went with my gut. I did not really have criteria. It was more what I felt would be best for him at the time. But for certain things, I was influenced by research. So ABA, for example, was highly regarded in the research that I looked at. So I was pretty confident with ABA but I also used my intuition and my common sense in choosing ABA because I was presented with a sort of two different options: going through sort of a mishmash of community services on one hand; or ABA where you would not get all these other community services. … I would also go with what other parents said so I would visit parents’ logs and parents’ sites and take a look at what the parents are saying about various things.

She collected information through various ways such as research and other parents' opinion, however, the chosen approaches were basically depended on her belief to support her son.

Effectiveness of Approaches

All three parents had perspectives on the efficacy of the approaches used with their child. Eve reported the following:

Floortime was mostly because he liked it. It did not really help the autism. ... Sign language was not really anything, not specifically for the autism. People can use those for other kids who have language delays. … I would say the best approach that worked has been inclusion – having him in the regular classroom with other kids because I think he learned a lot from the other kids. … He has changed a lot over the years and he is so much more outgoing than he used to be and wanting to interact with people – of course in terms of what he wants to do, but still that’s leaps and bounds from him just wanting to be by himself. … He has learned some signs, … some words, and he can say bathroom quite clearly, … can count.

Inclusion in regular classrooms seemed the most supportive approach for her son's social interaction and some other skills. She represented that other approaches were enjoyable for her son, but not really for autism.

April reported the following:
One of the advantages of the ABA is that there are people in your home on a daily basis, giving you 30 plus hours programming. ... A child like my son needs daily and prolonged exposure to teaching methods. In the short time that he has been in the program, he is making a very good progress which is just confirmation to me that this is where he needs to be. … I have seen a lot of language development in the last month. He is getting much clearer.

She represented that she was satisfied with her son's improvement through the ABA in home setting.

Grace reported the following:

The Hanen approach goes through step by step how to engage your child in conversation and it is all about teaching your child. It is not mainly, necessarily developed for kids with autism. They are developed for kids with any sort of language delay. … Floortime is a similar approach but more scientific. … We did do the casein-free and gluten-free diet program and did actually find some improvement in eye contact with our son. ... The main benefit of the ABA that we saw after the first month was very much increased concentration. You were able to teach him things. What we found though was that as he developed and developed – once he learned them, then he started to rebel against ABA and so did we because we did not feel it was evolving to meet his needs. … We went to music therapy for two terms. It was very good experience for him because in the classroom that he was in [Montessori] he was the lowest-functioning because he was in a class with typical kids so he had not had opportunity to be a leader ever. In music therapy he got the opportunity to be a leader. … But again he outgrew that, too. … Occupational therapy was really good too. … The occupational therapist provided me with a manual on sensory integration therapy. She explained the different sensory systems and how when the sensory systems are out of whack you can get behavioural issues or blocked attention or whatever.

All the approaches that Grace used were effective in some ways. However, there seemed to be no approach for autism: 1) the Hanen and Floortime were effective for language delay, 2) the casein-free and gluten-free diet and ABA were effective for concentration, and 3) music therapy was enjoyable experience. She represented a good impression on occupational therapist because
the information from the therapist would be helpful to understand her son better and to improve her son's "function" in their environment.

**Suggestions and Concerns**

Parents had suggestions and concerns about the following: waiting lists for supports, opportunities to try different approaches, inclusion in school settings, communication, exit criteria, improved wages for therapists/tutors, behaviour of professionals, improvements in orientation to autism and approaches, and attention to needs of adults with autism.

*Waiting list.* Parents reported frustration with the waiting lists to access some approaches. Grace reported that “I have been on a speech therapy waiting list for my son since he was diagnosed! I have yet to receive the call. Occupational therapy, again. I asked for it. I have not even received the letter, nothing.” Speech therapy and occupational therapy are funded services from the Government of Manitoba. However, Grace could only access the waiting list. The parent decided to enroll her son in private speech therapy and occupational therapy and pay for it herself. April reported an opposite finding:

> After my son was diagnosed, we went to an introductory session that you have to go to at St. Amant before your child will be accepted. When I applied, I was told that there was no waiting list. I was not told that there was no waiting list but there is no spot available.

April had to wait several months until he could access the program.

*Opportunities to try different approaches.* Parents in the study reported the need for funding to try various approaches to support their child with autism. Parents reported that expense is a barrier to trying various approaches. Grace reported that there is some reimbursement for treatments/approaches through the Federal tax system but that it was complicated and slow. She spoke of her frustration with this process by suggesting, “You get sort of money back from your tax return like federal government has a disability credit or whatever but it does not cover it at all.
You do not get it until the following year so what happens to you. For years and years, you are trying to help your child. You end up nothing.” Grace reported a desire and need to have access to a variety of opportunities to support her child. She identified funding and expense as a major barrier to having opportunities.

Inclusion in school settings. Parents were concerned that it was difficult to be fully included in regular classes. They reported on the quality and quantity of inclusion in school their children were experiencing. As Eve suggested, “School does not enough inclusion when you get to high school. So we had to push on that. … My son does attend regular classes, but I do not know that he is included. He is attending. That is the first step.” Grace reported the following:

I was very deliberate about inclusion. I wanted my son to be fully integrated in all that and he has been.

In the Montessori program he is in – because the Montessori program is more of an individualized learning concept – he is integrated in the classroom for group times of course because it is a part of it.

But for the most part he is working independently.

They represented that they were not satisfied with inclusion in classroom. Their children had been integrated but it did not seem that their children had been included.

Communication. Parents reported that they wanted and needed regular reporting on the progress of their child from professionals. Positive communication between professionals and parents was reported as important for approaches to be effective. A positive example on communication was with occupational therapists who wrote reports that parents could understand and know the direction to be taken next with their child.

Additional Issues Reported by Individual Parents

Exit Criteria. Eve reported concerns with exit criteria for various approaches used with her child. She reported the following:
Parents and children with autism stay with approaches for years and years even though they are not making progress. Consultants should have exit criteria to guide stopping using ineffective approaches and to recommend another approach when approaches seem not to work.

**Improved wages for therapists and tutors.** April reported that therapists/tutors were underpaid. She worried that low wages will lead to retention problems with therapists/tutors working in ABA programs. She described her concern relating to the tutor's wage:

> Tutors in ABA are not paid well. There is a difference in pay between a tutor, who is here on a daily basis and a senior tutor who is here once a week. … Tutors want to make more money. Why would not they? … The morning tutor was away almost a week at the end of October. ... I worried ‘What if she is leaving? What if she has decided to leave, then what happens to my son?’ That is always a fear.

**Behaviour of Professionals.** Grace reported about her experience with a physician. The physician was skeptical about alternative approaches to autism such as diet. She reported the following:

> When I spoke to my physician about putting my son on a gluten and casein free diet, basically he laughed at me. When I told my physician, “I am not going to be giving my son any more vaccines”, he was again quite negative about that. He thought that we were crazy I guess. But I have heard the same thing from other parents - that when they express reluctance to get their child vaccinated, they are met with a lot of negativity from their doctor.

The study in no way concludes that all physicians are negative about alternative approaches. It does however indicate that parents may experience negative responses the more they deviate from the traditional approaches to autism.

**Improvements in orientation to autism sessions.** April reported that orientation sessions presented information with little or no commentary on effectiveness. She felt that parents received little or no information on how effective various approaches were. She reported that there is little said about research on any of the approaches. She also had a concern about visual
material used in some orientations. She reported that more illustrations of the approaches in action would be helpful for parents.

*The needs of adults with autism.* Eve reported that as her child left the school system she would have to focus on learning about a new service system for adults. Issues like eligibility for funding and appropriate services create a new set of concerns for the parents. Issues that seem to be important for adults with autism are: training and employment, potential community living options, leisure/recreation opportunities, friendships, and participation in community.

**Discussion**

The purpose of this study was to examine parents’ perspectives on the quality and quantity of approaches for supporting individuals with autism through interviews. Research in the area of autism is based on different understandings of the condition. Conceptual frameworks for approaches on dealing with autism seem to be organized as behavioural, rehabilitation, educational, or social/communication in orientation.

A general report from parents was that they preferred approaches that increased both the competence and the amount of integration their child experienced. Parents looked for approaches that related to child development: language acquisition, vocabulary, and social skills. Parents also looked for approaches that supported inclusion in society: family, school, and community. Approaches mentioned in general as useful by parents included: applied behavioural analysis (ABA), diets (casein-free and gluten-free), relationship development intervention (RDI), Floortime and Hanen (conversation). In terms of integration parents reported that inclusion in the regular classroom and social skill development was also helpful. Parents reported that while all the above had some developmental value, none of them changed or “cured” their child of autism. One parent in the study reported that they disagreed with the behaviour modification approach
utilized by ABA. This parent supported the neuro-diversity perspective on autism because it focuses more on changes in society related to acceptance of difference.

Parents reported positive feedback in terms of the information available about what autism is and various ways to support individuals with autism. Parents reported that both the quantity and quality of information continues to improve. Improvements that could be made included: development of organizations at national and provincial levels dedicated to communication about autism (Autism Society) and that both general and specific information about autism is readily available on the internet. Information on the internet includes: academic research, information from autism organizations, and exchange of ideas and experience between parents.

Parents also reported that there is a problem with access to some approaches used to support individuals with autism. For instance, some approaches that are funded have long waiting lists. Parents reported that children need the approaches at the time they apply for them. Another issue related to access is the cost of some supportive approaches. If parents want to purchase the ABA approach, the costs are significant. Not all parents can afford to purchase expensive approaches. It was suggested by parents that the Government needs to improve service by decreasing waiting-time for service and ensuring that funding is available to families.

Another area of interest to parents was parent/professional communication. Parents reported that positive communication was important for the decision-making process around which approach to use. In the situation where parents want to use an ‘alternative’ approach (an approach without sanction/approval of dominant autism organizations) professionals tend to respond negatively. Some parents felt that professionals need to be more open-minded about ‘alternative’ approaches. Professionals need to learn more about the ‘alternative’ approaches and respect parent’s viewpoints.
The study revealed two distinct preferences of parents related to the age of their children. The parent of teenage children expressed an interest and willingness to use approaches that increased the presence and participation of their child in the community. The parents of younger children were interested and willing to use approaches that increased the skills of their children in specific areas of human development (speech, language, social).

Finally, parents expressed an interest in the effectiveness of various approaches. These parents’ understanding of effectiveness seems to be that it is achieved when their child develops and participates in society. Parents in the study did not measure how effective an approach was by its ability to cure autism. Parents were more interested in effective support than cure.

Conclusion

The analysis of the parent narratives produced some interesting information. In terms of access parents are clear that they want the Government to: (1) fund and organize supportive approaches to autism at a higher level; (2) train more therapists to work with children/families; (3) increase the wages of support workers; and (4) develop a flexible system that allows parents to try various approaches. Parents also expressed that they would like professional/parent partnerships that gave them more control over approaches selected and used with their child.

Parents do not believe there is any single approach to autism that works for all individuals or families. Parents felt that no one approach should be the single one option available regardless of how popular it was with professionals. A major theme in the study was that parents felt a need to be able to access multiple approaches.

In terms of satisfaction parents reported that in general the approaches available produced gains in development for their children. Parents felt in many cases these approaches were not
specific to autism and were more general human development in orientation. All parents reported they did not expect any approach to cure their child of autism.

Parents in the study were not clear about the amount of inclusion their child experienced in school. They reported that their children seemed to experience more physical than curricular integration. One parent reported that physical inclusion was the first step to more inclusion in school and society.

The limitations to generalize any conclusions from this study are obvious. The study examined the perspective of only three parents. This is too small a sample to claim that it represents a ‘parent perspective’ for parent’s of children with autism in Manitoba. What the study does do is point to the need for research that focuses on the experience of parents of children with autism. The study indicates that parents are very aware and very engaged in the quality of support their child receives. It also indicated that issues like access, communication, and quality are important to them. More extensive study of this area could learn more about these issues and improve the quality of support for individuals with autism.
References


Appendix A
Interview Guide

This interview guide will be used in actual interview. This includes one introductory question and six questions related to perspectives of parents of children with autism.

This study is to examine what approaches have been used for children with autism, how they have affected the children, and what suggestion can be presented. You will answer and describe with the following questions. You will take this interview in a face-to-face interview or via an email.

1. To start, tell me a little bit about your child.

2. What approaches have you decided and tried to support your child?

3. How did you hear about the information of the approaches?

4. What criteria did you use to determine which approaches you would use with your child?

5. How have these worked for you and your child? You might provide examples to illustrate what seemed to work best or what did not work well.

6. Do you have any issues, suggestions or concerns about the approaches?

7. Have I missed anything?

Thank you for your cooperation.