What are Parents told about Autism on the Internet?*

Melina Yaraghchi, a volunteer at the Center, was interested in learning more about autism. In discussing the matter, we all wondered what general information about the topic was being provided parents on internet websites, especially with respect to treatment recommendations. So as a special project, she did a websearch; the following is what she found.

How is Autism Described?

With respect to autism, the abundance of information available on websites is likely to be overwhelming and at times confusing for most parents. Desperate parents are confronted with a variety of "facts" and treatment recommendations, many of which are not supported by sound research. At the same time, considerable agreement is found about the following:

According to the organization Autism Speaks, *Autism Spectrum Disorder (ASD)* is a neurodevelopment condition characterized by difficulties in social interactions, communication, and engaging in restricted and stereotyped behaviors. In the U.S.A., autism is diagnosed 4-5 times more frequently among males (i.e., 1 in every 42 boys; 1 in every 189 girls are diagnosed).

Autism appears to have its roots in early brain development. Noticeable symptoms tend to emerge around two years of age. The Center for Disease Control and Prevention (CDC) indicates that 1 in every 68 American children are diagnosed with ASD. This represents a significant increase in diagnoses over the last 40 years. Part of this increase is attributed to increased awareness and improved diagnosis. However, controversies are widespread about both the cause of autism and the nature of the diagnoses themselves (e.g., whether autism is primarily genetically or developmentally caused; the degree of coincidence between autism and intellectual disability). Despite years of etiological research, the specific primary instigating causes remain undetermined.

What are Parents Told to Look for?

Autism Speaks lists the following as "red flags" that could indicate risk of ASD:

- No big smiles or other warm, joyful expressions by six months of after.
- No back and forth sharing of sounds, smiles or other facial expressions by nine months
- No babbling by 12 months
- No back and forth gestures such as pointing, showing, waving, or reaching by twelve month
- No words by 16 months
- No meaningful, two- word phrases (not including imitating or repeating) by 24 months
- Any loss of speech, babbling, or social skills at any age.

The material in this document was culled from various websites and links to literature mentioned (see the attached reference list) by Melina Yaraghchi as part of her work with the national Center for Mental Health in Schools at UCLA.

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Children with Autism Spectrum Disorder may exhibit a wide variety of difficulties with communication, social skills, flexible behaviors, and language. Two people diagnosed as autistic may have different abilities and perform differently on similar tasks.

What Does the Diagnostic and Statistical Manual (DSM) Indicate as Criteria for Autism Spectrum Disorder?

According to the DSM 5, individuals must meet the criteria A, B, C, and D below to qualify for diagnosis of ASD.

A. Persistent deficit in social communication and social interaction across contexts, not accounted for by general developmental delays and manifests by all 3 of the following:

1) Deficits in social, emotion reciprocity

2) Deficits in non-verbal communicative behaviors for social interactions

3) Deficits in developing and maintaining relationships

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the followings:

1) Stereotyped or repetitive speech, motor movements, or use of objects.

2) Excessive adherence to routines, ritualized patterns of verbal or non-verbal, or excessive resistance to change

3) Highly restricted, fixated interests, that are abnormal in intensity and focus

4) Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects on environment

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capabilities.

D. Symptoms together limit and impair everyday functioning.

What is Said about Cultural Differences?

In responding to disabilities, cultural background and beliefs regarding cause play a significant role. For instance, in Puerto Rico, it apparently is still common to believe a child's disabilities are the result of the mothers' sins. Similarly, in some parts of India, there is a belief that disability is a punishment due to sins committed in the past life by the child or his/her parents. When a child's disability is perceived to be caused by negative forces, there might be less willingness in the society to seek treatment and expend resources on the problem. Similarly, when an individual's disability is perceived to be God's will, parents are more likely to see the condition as unchangeable and not seek out treatment.

Children diagnosed as having ASD in the United States are likely to be diagnosed in South Korea, as having reactive attachment disorder (RAD). This disorder is commonly referred to as lack of secure attachment and love, which embodies the idea of a refrigerator mother. Despite the fact that RAD directly blames the mother for the condition, many prefer this diagnosis to autism, because RAD, unlike autism is seen as having a "cure" (i.e., providing love). Also, the diagnoses of RAD stigmatizes only the mother, while autism stigmatizes the whole family and influences the marriage prospects of an autistic person and their relatives.

Even in cultures that have a positive outlook and attitude toward disabilities, families may opt not to pursue treatment. For example, Navajo tribes perceive a person with disability as a teacher bringing special lessons and gifts. Treatment is seen as potentially preventing the child from delivering special messages to the community. Researchers also report that, compared to whites, African Americans and Asian/Pacific Islander were found to less likely view many unusual behaviors as symptoms of an underlying disorder. In general, some folks are more likely to perceive delays in communication and language as a temporary developmental phenomenon that will be outgrown and/or to differences in motivation.

Cultural factors also influence help-seeking in collectivistic societies. Among such groups, rather than going to professionals, many seek help from relatives, friends, religious leaders, faith and natural healers.

What's Offered to those Seeking Treatment?

The variety of symptoms and variations in responses make it impossible for professionals to create an agreed upon standard care for autism. Thus, there are numerous treatments touted. Some have a degree of empirical evidence; some are controversial. The process of selecting a treatment usually is described as overwhelming by parents.

With no specific treatment identified as sufficient to address autism, many children receive multiple therapies at a given time. Often in desperation, parents try anything and everything in hopes of effecting desirable changes, especially early-age interventions since they don't want miss a critical developmental period.

Decisions usually are made on the basis of recommendations from others (e.g., other parents, medical doctors, psychologists, behavior analysts, educators). The recommendations often include treatments that are controversial.

While parents obviously prefer treatments with few or no negative effects, the more severe the symptoms, the greater the tendency to seek out controversial treatments, especially when media presentations portray the treatment positively (even as a potential cure). Moreover, parents are more likely to use such treatments when they become dissatisfied with a current one. Children with ASD often are involved in multiple treatments. This fact, and placebo effects, have made it difficult to determine treatment effects.

A Controversial Treatment

"Complementary and Alternative Medicine (CAM)" is used with many children diagnosed with ASD (estimates range from 33-92%). Parents report that such interventions were recommended by other parents, the internet, and medical doctors. As categorized by the National Center for Complementary and Alternative Medicine (NCCAM), CAM stresses techniques such as whole medical systems, mind-body medicine, biologically based practices, manipulative and body-based practices, and energy medicine. It is emphasized that the distinctions between therapies aren't always clear-cut, and some practitioners use techniques from more than one category. Studies indicate that families use unconventional approaches such as mind-body medicine (e.g. meditation or prayer), homeopathic remedies, probiotics, alternative diets or more invasive therapies such as vitamin B-12 injections, intravenous immunoglobulin or chelation therapy. Researchers suggest that some of these carry significant risks.

What Educational Interventions are Stressed?

Families seek information about educational interventions to address communication, social skills, daily-living skills, academic achievement and maladaptive behaviors. These interventions generally are described as developing knowledge and skills with the hope of enhancing independence and responsibility. As highlighted by Myers (2007), the major approaches are:

Applied Behavior Analysis (ABA) implements interventions based on learning principles derived from psychology research. ABA methods are used to increase desirable behaviors, reduce maladaptive patterns, and teach skills that would generalize across contexts. Functional behavior analysis is significant in ABA treatments. Behaviors tend to serve three functions: (1) attention, (2) access to specific object, activity, or sensation, and (3) escape from demands or situations. Functional assessments include detailed description of a behavior, identifying an antecedent of a behavior, consequence of actions, environmental factors that maintain a behavior, and developing hypothesis for function of a behavior.

Structured Teaching derives its name from its emphasis on structure. Important elements of this treatment include structured organization of physical environment, predictable sequences and activities, schedules, and routines. The emphasis is on teaching individuals necessary skills and modifying environments in order to accommodate for deficits.

Speech and Language Therapy – To develop functional communication, interventions may include teaching gestures, sign language, and the Picture Exchange Program (PECS). PECS is widely used and often incorporated with ABA therapy. Through this program, the child is taught to make requests with pictures and persist until receiving a response. Proper speech is viewed as more likely in a child who has first learned to communicate symbolically.

Social Skills curriculum aims at enhancing responses to social approaches from other children and adults, initiating interactions, and minimizing stereotyped behaviors. Social skills groups, social games, video modeling, scripts, peer-mediated learning are used.

Programs for Older Children and Adolescents – While the majority of services target young children, educational interventions for older ones are typically based on ABA principles. Such treatments are designed to reduce maladaptive behaviors, maintain desirable behaviors, teach skills, and generalize behaviors and skills across contexts and situations.

What Questions May Parents Expect Clinicians to Ask?

Internet sites offer recommendations for clinicians in working with parents. They stress being aware of parents' cultural background and beliefs. Here are examples of questions that have been suggested as guidance in interviewing families in order to better understand what might affect their treatment decisions:

1) What did you call your child's problem before it was diagnosed?

2) What do you think caused the problem?

3) Why do you think it started when it did?

4) What do you think autism does? How does it work?

5) How severe is it? Will it have a short or long course?

6) What are the chief problems your child's autism has caused?

7) What do you fear most about it?

8) What kind of treatment do you think your child should receive?

9) What do you expect from this treatment?

Concluding Comments

In a recent interview Dr. Robert Hendren who is on the Autism Speaks Treatment Advisory Board stated: "We know that many parents do research on their own, and this includes comparing notes with other parents or individuals. It's important to remember that another person's experience is not the same as evidence from a carefully designed and conducted study. Also, because autism encompasses a complex group of disorders, some treatments may work for one person but not another." Furthermore, he stresses that, given the relative lack of information on the effectiveness of alternative treatments, families should carefully consider time, effort and finances. He concludes: "A costly intervention that lacks clinical evidence of effectiveness is an expensive shot in the dark."

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A Few Websites:

Centers for Disease Control and Prevention (CDC) -- http://www.cdc.gov/ncbddd/autism/index.html

Autism Speaks -- https://www.autismspeaks.org/

Autism Society of America (ASA) -- http://www.autism-society.org/

Autism Treatment Network -- https://www.autismspeaks.org//science/resources-programs/autism-treatment-network

Center for Parent Information and Resources (CPIR) -- http://www.parentcenterhub.org/