

AUTISM SOCIETY OF COLORADO (ASC)
GUIDELINES FOR
ASSISTING FAMILIES IN EVALUATING SERVICES

I. ASC Mission Statement:

The mission of the Autism Society of Colorado is to promote quality of life for people with autism spectrum disorders (ASD) and their families.

As part of its mission and to expand options for families in need of treatment for their loved one who has been diagnosed with an ASD, ASC has put together some general guidelines to help you with the decisions you may face when determining what types of services are best for your family. ASC does not endorse one specific therapy over another, but rather wants to give you information about therapies, research and questions to ask when you are evaluating services. We hope that this information is helpful to you.

II. Current Treatment Standards for Autism Early Intervention

Though we have learned much about autism over the years, the breadth of treatment options is as broad as the spectrum of this diagnosis, and the field is still trying to understand and improve the interventions that best help individuals with autism. We know that *early intervention*, and using *empirically-based strategies* (strategies derived from experiment and observation rather than just theory) both behavioral and developmental are effective means of addressing the many aspects of autism. We also know that each child with autism is an individual, and one that changes over time. Awareness of the different strategies available will give families the information they need to begin choosing a strategy or a combination of strategies that may work best for their unique child at different times in his/her life. Combining interventions that incorporate both **behavioral** and **developmental** learning theories may be one way to target many issues at once. In any case, *early intervention* and *ongoing observation of how strategies are affecting the child* are strongly recommended (Gabriels and Hill, 2002).

III. Evaluating Nontraditional (not empirically-validated) ASD Treatments

Despite the current understanding that ASDs are neurodevelopmental in nature with a strong genetic component, the field is still struggling to understand causes and ‘cures’ for ASDs. Along with this, there is a wealth of information regarding various medical and behavior-oriented interventions, including many that have not yet been empirically-supported (i.e., supported by research). All these factors can be overwhelming to practitioners and families.

The increase in the rate of children diagnosed with autism spectrum disorder (ASD) has sparked a parallel interest in services and treatments for children with ASD. Current

consensus suggests that the best approach for ameliorating the core symptoms of ASD includes a program of coordinated intensive behavioral and educational interventions. However, there is lack of agreement concerning the best combination of treatment approaches and expected outcomes. This combined with the fact that many children with autism have poor access to effective treatment; it is not surprising that families turn to complementary and alternative medicine strategies. In addition, many children with ASD have associated medical difficulties that standard treatments do not address, such as sleep disorders and gastrointestinal problems.

There are other problems that contribute to the confusion regarding being able to seek out new (not researched) forms of treatment. For example, the current lag between the discovery of more effective forms of treatment in health care and their incorporation into routine patient care is on average, 17 years (Levant, In Press). Clinical practice often has to precede science, yet the caution is that this should not be an invitation to charlatanism (Fox, 2003). In other words, many good people are out there trying new and possibly helpful things before science can support them. *However*, there are also many people out there doing things that are *not* helpful, and may be harmful to individuals with an ASD and their families. Research allows us to reproduce results over and over again until we can comfortably say, “This seems to be helping.” Parents will do well to trust their instincts, *but also* to check in with research and science about strategies that are well-researched and effective. For practitioners, it is recommended that providers must start with the needs of the people who come to them and then apply all the knowledge, information and skill they have to help resolve these problems (Fox 2003).

Along with this, families considering nontraditional treatments can carefully assess the program by asking important questions. The following information is also available in more detail on the TEACCH website:

Questions to ask regarding the program description:

1. What is the treatment program?
2. Is there written information available about this program?
3. Exactly what is involved for my child and family?
4. What is the length and cost of treatment?
5. Does the treatment focus on a particular skill area or is it a comprehensive approach?
6. Do parents, care providers, others need to be trained in the treatment technique?
7. Is there coordination between the treatment program and other providers working with my child and family?
8. Are the treatment goals individualized for my child and family?
9. How is my child’s progress measured and reported?
10. Is there follow-up support after treatment is over?

Questions to ask regarding the rationale/purpose of the program:

1. What is the rationale, philosophy/theory, or purpose underlying this treatment program?
2. How is the philosophy/theory tied to the specific treatment techniques?

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3. How were the philosophy and treatment methods developed (e.g., scientific research, clinical experience, application or extension from a related field, such as learning disabilities or mental retardation)?

Questions to ask regarding the credentials of the program director and staff:

1. What is the level of education and experience of the program staff?
2. What is the staffs' training and experience with autism?
3. What is the staffs' understanding of the nature of autism?
4. Are the program staff open to questions and input from my family or other professional who work with my child?

Questions to ask regarding the program's effectiveness:

1. What is the supporting evidence for the effectiveness of this program?
2. Is there any independent confirmation (e.g., studies done about this program from personnel not related to this program) confirming the effectiveness of this treatment program?
3. What are the possible negative effects or side effects of this treatment?
4. What impact might this program have on my family's life style?

Questions to ask yourself and other family members:

1. Are you, as a parent, comfortable or do you agree with the philosophy of the program?
2. Does this treatment program reflect our family values regarding discipline, teaching and learning?
3. What changes would have to occur in our family routine to incorporate this program into our lives?
4. Can I really afford to implement this program? Do we have the financial resources to support this program without compromising the stability of the whole family?
5. If this program doesn't "work" how will our family support the individual with ASD over the long term – financially, emotionally and physically?
6. Is this a publicly funded program? If not, why not?

Be a good consumer:

1. Ask for references — and contact those references.
2. Check with the Better Business Bureau online at www.bbb.org to see if there are unresolved complaints and statistics about other complaints that may have been filed.
3. Check with the Secretary of State (or whatever agency keeps records on business names) to see if the company or organization does business under any other names.
4. Ask around. Contact local support groups and email discussion groups to see if anyone has past experience with an organization or a particular form of treatment.

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IV. References

Websites:

TEACCH

<http://www.teacch.com/guidelin.htm>

Better Business Bureau (Consumer Tips)

<http://www.bbb.org/alerts/article.asp?ID=496>

Literature:

Fox, R.E. (2003, August). Toward creating a real profession of psychology, Paper presented at the Annual Meeting of the American Psychological Association, Toronto, Ontario, Canada.

Gabriels, R.L. & Hill. D.E. (2002). Autism From Research To Individualized Practice. Jessica Kingsley Publishers, London.

Levant, R. (In Press). The empirically-validated treatment movement: A practitioner/educator perspective. *Clinical Psychology: Science and Practice*.