GRANDPARENT RESOURCE SHEET

An Autism Spectrum Disorder, or ASD, diagnosis can rock a family straight to its core. Many family members, including grandparents, are often left wondering what they can do and what the outcome for their entire family will be. This resource sheet is intended to provide grandparents with an overview of ASD, including what to expect, as well as some helpful suggestions on how to support both your adult child and your grandchild.

WHAT IS AUTISM SPECTRUM DISORDER?

According to the National Institute of Mental Health (NIMH), Autism Spectrum Disorder (ASD) is a development disability characterized by the following:

- Persistent deficits in social communication and social interaction across multiple contexts;
- Restricted, repetitive patterns of behavior, interests, or activities;
- Symptoms must be present in the early developmental period (typically recognized in the first two years of life); and,
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

It is important to keep in mind that the term "spectrum" is used in reference to the wide range of symptoms, skills, and deficits that individuals with ASD may have. This means that every person with ASD is different and has unique needs.



WHAT TO EXPECT...

Social communication and Social Interaction deficits:

- Difficulty participating in back and forth conversation
- Conversations may feel very one sided
- May become fixated on one conversational topic of high interest
- Misinterpretation of conversational cues (idioms, humor, and sarcasm)
- Difficulty making and keeping friends
- Difficulty identifying when they are being bullied or rejected
- Difficulty interacting with same age peers
- Difficulty joining and participating in games
- Difficulties may present differently as the individual ages

Restricted and repetitive patterns of behavior, interests or activities:

- May be routine-driven to the point of being rigid, insisting that things be done in the same way at all times, and find it challenging when their routine is changed
- May engage in non-functional routines, such as repeatedly turning lights on and off
- May display strong interest in specific topics that may seem odd or inappropriate for their age
- May engage in repetitive play or leisure activities, such as watching the same video over and over, lining up toys as opposed to playing with them, or only wanting to play with very specific toys
- May be sensitive to change in their environment and insist that things remain the same
- Difficulties may present differently as the individual ages

STRATEGIES...

Strategies to support your grandchild with Autism Spectrum Disorder:

- Take note of your grandchild's very unique interests. Schedule activities that align with them. As a grandparent, you are in a unique position to help foster your grandchild's growth using their unique interests.
- Maintain realistic expectations. Your interactions with your grandchild may differ in quality and quantity to what you expect.
- Establish a predictable routine with your grandchild. Whether it's a weekly phone call at a designated time or an online chat, become an expected part of your grandchild's routine.
- Use clear and concise language. Avoid using language that your grandchild may find confusing.

Strategies to support your adult child:

- Work through your son or daughter, not around them. They are the experts on their child. Go to them first with questions or concerns you may have.
- Listen without judgment. To become a grandparent, you had to first be a parent. You dealt with hardships and celebrated successes. You have valuable knowledge to share. All that being said, keep in mind that there will be times when your child does not want advice on what to do nor do they want you to solve their problem. When those times come listen, provide support, and hold off on sharing your suggestions for another time.
- Provide respite as you are able. It is very difficult for many families to locate adequate respite providers in their area. As you are able, offer to watch your grandchild. Be sure to provide them with a safe environment free of access to harmful substances (medications, cleaning products, etc.) and experiences (limit access to pools, busy streets, etc.).
- Ask questions! If your son or daughter is comfortable sharing any recent reports with with you, take some time to familiarize yourself with the information. If one has not been completed with your grandchild in recent years (3 or less) consider encouraging your son or daughter to seek out a thorough evaluation.

- As children grow, they change and evolve. You might be surprised to learn about your grandchild's development!
- Learn about the services and therapies your grandchild receives both in school and at home. Many individuals with ASD receive a variety of different services and supports across the life span. Become familiar with what services are in place and what role they play in your grandchild's life. Provide financial assistance, as you are able. It is tempting to want to invest a great deal of money in therapy for a young child. When providing financial assistance, keep in mind that the financial burden of an ASD diagnosis does not end after early childhood. You may want to consider pacing yourself.
- Become informed about Special Needs Trusts
 and how funds you may be leaving your
 grandchild in death can impact their ability to
 access benefits down the road.
- Provide hope and encouragement!

HELPFUL LINKS AND RESOURCES:

FAU Center For Autism and Related Disabilities: http://www.autism.fau.edu

Special Needs Trusts Tip Sheet: http://www.americanbar.org/content/dam/aba/publishing/ rpte_ereport/te_lewis.authcheckdam.pdf

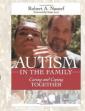
A Grandparent's Guide to Autism:

https://www.autismspeaks.org/family-services/community-connections/celebrating-grandparent



Grandparents Guide to Autism Spectrum Disorders: Making the Most of the Time at Nana's House (available at Amazon.com for \$19.33)

Autism in the Family: Caring and Coping Together (available on Amazon.com price ranging from \$19.68 used to \$25.55 new)



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