Next Steps Manual

family guide into autism spectrum disorders
The HANDS (Helping Answer Needs by Developing Specialists) in Autism® Interdisciplinary Training & Resource Center is located within the Department of Psychiatry at the Indiana University School of Medicine. Support for the foundational development of the HANDS in Autism® Center has been provided through a combination of federal and state funding as well as private philanthropies. To learn more, please contact Naomi Swiezy, Ph.D. HSPP, Director, at nswiezy@iupui.edu or find us at www.HANDSinAutism.org.

Help us in our continued efforts to serve medical, school, family, and community members in supporting families, caregivers, and individuals affected by ASD! We greatly appreciate any and all donations that allow us to provide information, training, and resources to individuals, families, and caregivers in your community. All donations are tax deductible to the extent allowed by law and you will be provided with the necessary documentation of 501(c) tax exemption status (www.HANDSinAutism.org/donatehands.html ). For further information, contact us at hands@iupui.edu.

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This manual contains a wealth of information for caregivers of individuals with Autism Spectrum Disorder. The manual is divided into 7 major sections with each section arranged in a similar format in an attempt to provide caregivers with a functional, easy to use manual that may serve not only as a resource but also as a reference guide to share with others. Each section begins with a cover page that provides a brief overview of the materials included within that individual section. Following the overview, each section contains a combination of articles written specifically for caregivers as well as other materials that are appropriate and beneficial to share with family members, professionals, and others you feel would appreciate additional information. The materials contained within each section were selected in an attempt to guide your “Next Steps.”

Section 1: Information on Autism Spectrum Disorder

Section 2: Family Life

Section 3: Available Supports

Section 4: Rights and Regulations

Section 5: Treatment and Intervention

Section 6: Practical Strategies across Settings

Section 7: Resources and Action Planning
Dear Caregiver—

The HANDS in Autism® Interdisciplinary Training and Resource Center offers this manual and the accompanying workshop as a service to parents, grandparents, other caregivers and professionals to address the very challenging time of learning that your child has Autism Spectrum Disorder (ASD). Many years ago and in my role as a clinical psychologist providing medical diagnoses to families, it became readily apparent that it is immensely challenging for caregivers to hear the diagnosis and then immediately be provided with information and direction about resources and interventions. At the time of the diagnosis, the family often just needs time to grieve and process this information. After doing so, they then are often ready to learn more and to determine their “Next Steps”.

The HANDS in Autism® Next Steps manual and workshop may be used in combination or separately. The information is not meant to be fully comprehensive. Rather, it is meant to provide the input, direction, and information that may be most needed in considering the essential next steps when first programming for an individual with ASD. Of course, autism spectrum can present with varying social, communication and behavioral issues to consider across individuals and the lifespan. In addition, it can co-present with a number of other comorbid or coexisting disorders as well. This all increases the complexity and information and resources necessary for success. Although not all potential questions and challenges will be addressed in this manual, we have incorporated the input and feedback provided to us over the years from participating parents, grandparents, professionals and other caregivers in an effort to address the information most commonly requested in the most up to date and empirically supported fashion.

We hope that you will take time to participate in a workshop near you (see www.HANDSinAutism.org/nextsteps.html) or contact us at hands@iupui.edu to request a training. Please also provide your individual comments and questions about either the manual or the workshop. This will allow us to continually improve our product for present and future iterations.

Most respectfully,

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Raising a child with Autism Spectrum Disorder is not the same today as it was 10 or 20 years ago. Today, there are many more interventions and treatments available, there are more professionals who are informed about working with children on the autism spectrum, and there are many options for helping your child reach his or her potential. Specialized professionals and services are available to help your child and it is sometimes easier to identify appropriate services once a diagnosis is received. Services are available through a variety of mechanisms including First Steps (if your child is under 3), your local school system (if your child is over 3), and the Medicaid Waivers. Before receiving a diagnosis for your child, your time was likely focused on getting answers about why your child behaved, progressed, or interacted differently than you expected. Now that you’ve received a diagnosis, you can focus your energies on the process of helping your child reach his or her potential and accessing resources and services.

Initially, you may feel that you need more information about your child’s diagnosis. There is a wealth of information available about Autism Spectrum Disorder and related disabilities, the more you know about the diagnosis the more you can advocate for all that your child will need both now and in the future. By learning the facts about your child’s diagnosis, you will have a greater capacity to understand how this diagnosis may impact your child’s education, behavior and everyday life.

Another area you may consider relates to how the diagnosis will affect others in your family. Within your family, each caregiver and family member may react differently to the diagnosis. Differences in reactions are not uncommon. It is important to rely upon one another and allow each other to adjust to the diagnosis in the manner and progression that works best for each person individually and as a whole family unit. The diagnosis will have an impact on all of the children within the family. If you have other children, talk to them about the diagnosis and answer their questions as honestly as you can. Even if only for a few minutes each day, take time to do things as a family that you would typically enjoy together while also ensuring each child has a few special minutes devoted to them. Extended family will also need to adjust to the diagnosis. You can help by providing information at a pace and in a format (e.g., internet, handouts, books) that make sense for them.

A third area of consideration occurs with the realization that you cannot or do not have to do it alone. There are many sources of support that are available. Family and friends can help you but want and need to know what would help most (e.g., preparing meals, participating in carpool, listening when you need to talk). Other parents who have children with the same diagnosis can be an invaluable resource. Among various statewide and regional supports, representatives from Autism Society of Indiana (ASI), About Special Kids (ASK), and INSOURCE are available to provide assistance to families and within communities across the state. You are not the first one to walk this road. Learn from the experiences of others and remember to ask for guidance and help when you need it.

Further, and reflected in the fourth section, is material to inform you about the rights and laws that are in place and designed to protect both you and your child. You will want to learn what support is available for your child through insurance, Medicaid, and other government funding. In addition, you will want to begin networking and collaborating with professionals in your community, especially those at your child’s school.

Of course, caregivers are always eager to learn about available interventions and treatments. It is essential to carefully determine your child's needs, consider the various treatment options available, and systematically evaluate which treatment or intervention will work best in the context of your child and your family. Remember, you are the expert when it comes to your child and you are an essential part of the team. The knowledge and understanding you have of your child will be critical when working with your child’s school and medical professionals as programming decisions are made.

Finally, the last section will provide you with information regarding practical strategies that can be applied across the variety of environments and settings that your child will be engaged in on a regular basis or will encounter throughout their life. It will be helpful to become aware of these strategies to advocate and support their use for your child so he or she can seamlessly navigate the various settings and demands that may occur. At this point, you should feel equipped and ready to gather your resources and build collaborative partnerships with the many possible professionals that may play a role in your child’s life. Therefore, it will be important to organize yourself so you can best help your child. You will benefit from creating a binder with all of your child’s evaluations and information to share amongst those involved in caring for your child. The binder will also allow you to share the strategies and information that will assist all of those involved in your child’s programming within their everyday interactions and participation in your child’s life.

Receiving a diagnosis for your child can be overwhelming. It can be challenging to know precisely what to do next given that there is so much to consider and so many potential professionals to be involved. We offer this manual as a way to consider your “Next Steps” and the various areas to consider in making this process a bit easier to navigate. Though the emphasis is on the early years, those caring for older individuals will certainly find the information and resources to be of assistance as well.