

FAMILY MODULE TWO: FAMILY RESOURCES AND SUPPORT

*Developed by the Indiana Resource Center for Autism
Indiana Institute on Disability and Community
Indiana's University Center for Excellence on Disabilities
Indiana University*

Having a child on the autism spectrum can be challenging and stressful for families. Most likely you did not plan on having a child on the autism spectrum. The entire family is on an unexpected journey. There is much uncertainty. Anxiety, fear, grief, anger and sadness may take over when your child is first diagnosed. It is important to take time to work through these initial emotions. It is also important to start to look for resources, and to learn to ask for and accept help. Each child with an autism spectrum disorder is different. Each family will have unique experiences. However there are many issues and concerns that are similar among families who are raising children on the autism spectrum.

For example, your child on the autism spectrum may have difficulty communicating basic needs which can lead to frustration and challenging behaviors. Your child may react to sounds, smells, sights and other sensory information in the environment which may overwhelm him/her. Sensory overload can result in more challenging behaviors. The social skill deficits and lack of play skills can make it hard to take your child out into the community and to structure his/her time at home. Unusual sleeping and eating patterns may be a daily issue that impacts the entire family. Raising a child with a variety of intense needs and behaviors can require an array of resources. Reaching out to other families, community members and professionals, and using available resources can make an important difference for all family members. The life of your child and your family can improve!

I. SERVICES AND RESOURCES

In Indiana, there are various agencies and services that may be helpful for you to understand. The Indiana Resource Center for Autism maintains an updated list of articles that describe services in Indiana, and resources both in and outside Indiana. Visit the website regularly since this list of services continues to change and evolve. On the Indiana Resource Center for Autism (IRCA) website at www.iidc.indiana.edu/irca/ServArticles/resourcesta.html is a listing and description for selected state resources. On the website at <http://www.iidc.indiana.edu/irca/family/famnatresources.html> is a listing and description for selected national resources.

Articles on specific services, such as Medicaid Waivers, Social Security Income and others can be found on the IRCA website under Services in Indiana. Let's walk through some of these. First, let's review seven programs or agencies that can provide financial assistance to individuals with an autism spectrum disorder and/or their families.

Medicaid Waivers

The process of applying for Medicaid Waivers is described on the IRCA web site at <http://www.iidc.indiana.edu/irca/ServArticles/waivers.html>. Medicaid Waivers are a program where Medicaid funds are made available for individualized supports in the home or community as an alternative to institutional care as long as the cost for this care is no more than the cost of supporting the individual in an institutional setting. There are three Medicaid Waivers in Indiana for which persons of any age with an autism spectrum disorder might be eligible: the Autism Waiver, the Support Services Waiver and the Developmental Disabilities Waiver.

There are many different services that can be provided on a Medicaid Waiver. When a person has been found eligible for a Waiver, they are now put on a waiting list. It is still suggested that you apply for all three Medicaid Waivers mentioned above for your child even though the waiting lists are lengthy. Please see the specific web site listed above for more information about services available and where to apply for these waivers. Also see www.in.gov/gpcpd/2359.htm to access an extensive, reader friendly booklet on Medicaid Waivers in Indiana from the Governor's Council for People with Disabilities.

Insurance Mandate

In 2001, Indiana passed an insurance bill mandating insurance coverage for individuals with Autism Spectrum Disorders for certain accident or health insurance policies that are issued on a group basis (large or small). Also, insurers selling individual policies must offer the option to include coverage for Autism Spectrum Disorders (ASD). For more specific details concerning this bill, visit the IRCA website at <http://www.iidc.indiana.edu/irca/ServArticles/INhealthInsurance.html>.

Supplemental Security Income

The process of obtaining Supplemental Security Income is explained on the IRCA web site at <http://www.iidc.indiana.edu/irca/ServArticles/supsecincome.html>. Supplemental Security Income (SSI) is financial assistance in the form of a monthly check provided by the federal government. Persons of any age who are disabled and seniors ages 65 and over who have a limited income, few resources and meet the eligibility guidelines may qualify to receive SSI benefits. For a child less than

18 years old, the parent's income and resources are assessed according to the income eligibility criteria. Application for SSI is made at the local Social Security Administration office. You can get more information at the Social Security website at www.socialsecurity.gov.

Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE)

The CHOICE program is described on the web at <http://www.iidc.indiana.edu/irca/ServArticles/choiceART.html>. This program serves both persons who are 60 years old and older, and persons of all ages who have disabilities and are eligible due to long term or life long limitations in certain skills. Limitations in communication, self care, and the inability to make decisions and recognize the consequences of one's actions are some of the 14 areas of functioning that are assessed to determine eligibility. If eligible, services that may be provided include case management, therapies in the home and respite care. To apply for the CHOICE program, contact the local Area Agency on Aging office for the county where you live. To locate your Area Agency on Aging, check their web site at www.in.gov/fssa/da/2551.htm .

Children's Special Health Care Services Program

This program is described more thoroughly on our website at <http://www.iidc.indiana.edu/irca/ServArticles/CSHCSprogram.html>. Children's Special Health Care Services Program of Indiana provides financial assistance for needed medical treatment to children with serious and chronic medical conditions from birth through 21 years of age, who qualify both medically and financially. Autism (but not Asperger syndrome or PDD-NOS) is an eligible medical condition that may qualify a child for this program. To apply for the program there are three access points: Riley Hospital, the local First Steps Office if the child is between 0-3 years old, and the local Indiana Family and Social Service Administration Office of Family Resources. You can obtain more information by visiting the website for the Indiana State Department of Health at www.in.gov/isdh/19613.htm.

Indiana Governor's Council for People with Disabilities

The IRCA website at <http://www.iidc.indiana.edu/irca/ServArticles/funds.html> describes training funds available through the Governor's Council for People with Disabilities. The Indiana Governor's Council is an independent state agency that receives and disseminates federal funds to support programs that promote planning, collaboration, research and advocacy to empower individuals with disabilities and their families. One ongoing program is the Consumer Investment Fund. This program is designed to provide funds for individuals and their families to attend educational and advocacy events. Applications for this program must be received at least 30 days before the event. Applying up to 60 days before the event is highly encouraged. If there are many families applying for funding for the

same event, there may be a limit to how many families get funding. For more information, check the Indiana Governor's Council for People with Disabilities web site at www.in.gov/gpcpd and click on "Consumer Investment Fund".

Indiana's Family Involvement Fund

This program is currently administered by the Indiana Institute on Disability and Community (IIDC). There is an article on the IRCA web site with further information on this program at <http://www.indiana.edu/irca/ServArticles/FamilyFund.html>. Indiana's Family Involvement Fund (FIF) provides financial assistance for families of children with disabilities ages birth-21 to increase their knowledge and understanding of their child's disability, and/or the programs and services that support their child. This financial assistance may be given to attend conferences, workshops, public forums or hearings, task force meetings or other similar events. The FIF may also provide financial assistance to participate in online training and teleconferences as well as for the purchase of print and electronic materials.

There are yearly monetary limits per person and family that are subject to change. More information and an application are available at the Indiana Family to Family web site at <http://www.inf2f.org/F2F-FIF.htm>. The toll free number to ask questions and get further information about the FIF is 1-800-825-4733.

OTHER PROGRAMS AND AGENCIES FOR INDIVIDUAL AND FAMILY SUPPORT

It is helpful, as time permits, to explore information on other agencies and programs that can provide support to families of children with disabilities. Though autism spectrum disorders offer unique challenges from other disabilities, organizations and programs that provide resources and support to families regardless of a child's specific disability can be important resources for your family. Below are a few other resources; most which provide support for families of children and adults with any developmental disability.

Respite Care

Respite care is short term, temporary care provided for individuals of all ages with disabilities. Respite services are intended to provide assistance to the family. Care is generally in the family home for a few hours at a time on a periodic basis. However, services may be provided in other ways depending on the provider and your family's needs. You may be uncertain about your need or interest in respite services. Just as each family is different, so too will be the importance and need for respite care.

All parents need time away from their children. This is certainly as important when you have a child with a disability, though appropriate care for a child with an autism spectrum disorder may be much more difficult to arrange. You should

learn more about respite care and the providers in your area. Explore ways to use respite care to benefit the entire family including your child(ren) with an autism spectrum disorder. For more general information on respite care and a listing of respite care providers in Indiana, visit the web at www.iidc.indiana.edu/irca/ServArticles/respite.html and www.iidc.indiana.edu/irca/ServArticles/RespiteDir.html.

The Arc of Indiana

The Arc advocates for the rights and full participation of children and adults with disabilities. This includes autism spectrum disorders. There is a large network of Arc's in most states and many local chapters within these states. The Arc's mission is to improve systems and supports, connect families, inspire communities, and advocate and influence public policy. In Indiana, some Arc's at the local level provide residential and employment services to people with developmental disabilities.

To access more information on the Arc of Indiana and/or to check for an Arc in your county, visit the website at www.arcind.org or call toll free at 1-800-382-9100. The Arc of Indiana has a Legislative Alert program that provides timely information and commentary on current legislative issues of major importance to person's with developmental disabilities and their families. Many family members find this to be extremely helpful information which assists them in advocating for programs that are important to their sons and daughters with an autism spectrum disorder. Information on the National Arc organization can be found at www.thearc.org.

About Special Kids (ASK)

About Special Kids is an organization supporting families of persons with special needs, and the professionals who work with them. ASK provides free information on disabilities, laws, education, social services, private insurance and Medicaid issues and resources throughout Indiana. They maintain a large network of Parent Liaisons in central, northern and southern regions of the state. They also maintain an extensive resource directory which covers each county in Indiana.

ASK writes and disseminates a free newsletter and periodically provides inexpensive trainings and workshops which focus on information that is important to families of children with special needs. For further information on ASK, check <http://www.aboutspecialkids.org> or call toll free at 1-800-964-4746.

IN*SOURCE (Indiana Resource Center for Families with Special Needs)

IN*SOURCE is a parent organization. This agencies mission is to provide Indiana families, parents and service providers with information and training to assure appropriate educational programs and services for children and young adults

with disabilities. IN*SOURCE helps to sponsor training events and parent networking. Educational advocates may also be accessed by contacting IN*SOURCE. On their web site at www.insource.org is a wealth of information and resources related to education issues and disability. Information is available about early intervention up through high school as well as college information for students with disabilities.

They have many materials they will mail you, including a free newsletter. There is also a parent to parent online discussion group which they sponsor at www.MyInsource.org. The toll free phone number for IN*SOURCE is 1-800-332-4433.

Parent Support Groups and Organizations

Raising a child with an autism spectrum disorder poses many challenges. Coping with the uncertainty about your child's development, meeting each family members needs, finding resources, and dealing with financial constraints are all potentially stressful. Many families feel less isolated and better connected when they find other families who have a child(ren) with an autism spectrum disorder. The Indiana Resource Center for Autism maintains a listing of parent support groups and organizations around Indiana. This list can be found on the IRCA website at www.iidc.indiana.edu/irca/ServArticles/Chapters.html.

Going to a support group meeting is one way to start connecting with parents in your area. Other parents can share information on resources, survival tips and things they have learned from their experience. Though not every parent you meet or talk with will have useful information and ideas, it helps to start networking with other parents. One way to do this is by attending parent group meetings and/or joining parent organizations.

II. CIRCLES OF SUPPORT

Autism is described by parents not as a death sentence, but as a life sentence. Because your child will ultimately become an adult, it becomes important to think about desired outcomes. Where will your child live? What type of job will they perform? What will they do for recreation? It is never too early or too late to start planning for the future. There are processes that can help with developing a long term plan, and in determining which resources and support to access. These processes are referred to as Person Centered Planning or Circles of Support.

The IRCA website at

<http://www.iidc.indiana.edu/irca/education/CircleSupport.html> and at

<http://www.iidc.indiana.edu/irca/education/MyDream.html> describes these processes. As a general rule, consider the skills and behaviors you teach in preparation for adulthood. While it may be easier to dress a child when they are young or to wipe them after toileting, this does not prepare them for adulthood. Bottom line....the earlier we intervene the better for all involved.

III. HINTS TO HELP LIFE AT HOME

Let's end with a few helpful hints. Most family members are not prepared for having a child(ren) on the autism spectrum. You may often ask yourself and your spouse where to go to from here as you begin this journey. No one can answer that question for you. Each family has to decide where they are going and how they are getting there. There are, however, some helpful strategies to keep in mind to help you along the way. Below are a few helpful tips for families.

- Set priorities and make a plan. Identify the top few concerns and needs for your child and your family. Start addressing these concerns and needs, and let everything else wait. While focusing on top concerns, you need to remember to leave time to focus on fun and “typical” activities, whatever those are for your family.
- Organize information about your child. Keeping all information on your child orderly and arranged in one place will help with problem solving when issues arise and when involving new people who need to have certain information. Many families find that using a notebook or a series of notebooks makes the information very portable for transporting to meetings with professionals and easier to organize for sharing with others. The IRCA produces a *Record Book for Individuals with Autism Spectrum Disorders* that may be a useful tool for organizing information.
- Learn ways to simplify your life and the lives of all family members. Though routines and structure may seem difficult in a home setting, your child will function much better with the predictability and consistency that this approach provides. Visual supports in the home are important to help your child understand expectations and routines. Most individuals with autism spectrum disorders process visual information much better than information that is spoken. Visual supports work regardless of your child's I.Q., or his or her ability to communicate. Check out these websites for more information on using picture cards at home as well as some free and inexpensive picture cards you can access: www.dotolearn.com; www.usevisualstrategies.com; and www.sandbox-learning.com.
- Learn to be consistent with praise and positive information. Minimize negative comments and punishment. Children with an ASD learn by being told what to do and what is expected in a positive fashion. Telling a child what not to do does not teach them what to do and frequently makes matters worse. It is easy to resort to negative comments and punishment because you are frustrated and convinced your child is not listening and/or is choosing to disobey because “they have been told many times and they should know better”. Realize your child is likely frustrated also and can not figure out “what to do” especially when emotions are high.

- Find leisure and recreational activities that all family members can enjoy together. It is important that you, your child, and their siblings find ways to enjoy time together. Schools can often assist by teaching skills that will help them participate successfully in family activities. Families need to make time for having fun with each other regardless of the challenges. See the web site at <http://www.coultervideo.com/powerfunessay.htm> to read a father's account of the importance of fun for his family.
- Find ways to take care of yourself. You can not do your best for your child and family if your physical and/or mental health is deteriorating. You need time for rest, exercise, laughter and time to enjoy things that interest you. You owe this to yourself and to your family. Practice staying calm and finding humor each day. Realize this is the best way to be there for your child and family over time. See the web site at <http://www.coultervideo.com/stressessay.htm> for an eye opening article, "Reducing Special Needs Parent Stress" by Dan Coulter.
- Work on establishing positive relationships with professionals. You need to work together to resolve difficult issues. Attack problems and not each other. A positive relationship is the most productive and the best way to make your child successful. See the IRCA website at www.iidc.indiana.edu/irca/education/whoFor.html for an article with information on how families and schools can work together to support children on the autism spectrum.
- Work with and build upon your child's interests. Learn to enjoy your child's unique perspective. Using your child's interests may be the best way to teach important skills. Be creative. These interests and strengths, when used to help your child learn, can lead to exciting accomplishments.
- Acknowledge and celebrate the accomplishments of yourself and all family members whether they are small or large. For some children with autism spectrum disorders small steps are a major accomplishment. Be proud of your child and yourself. All accomplishments are important! Also don't forget to acknowledge the accomplishments of your other children whether large or small. Last but not least, spouses need to acknowledge each others efforts. You are a team!
- Acknowledge that you can not do it alone. Learn to ask for help and accept it from others. This is an important approach that will help establish success for your child, you and your family.

One last thought, your sons and daughters on the autism spectrum have many wonderful skills and abilities in spite of the autism. We hope you can and will celebrate their wonderful qualities and the progress each makes; no matter how seemingly unique. If after you read this module, you continue to need

information or guidance, do not hesitate to contact the IRCA at mwheeler@indiana.edu.

Now let's think about your son/daughter and your family:

1. What are the service/resource needs for you and your family?

2. Now that you have completed this module, where can you begin to access these services and resources?

3. What are your long term goals for you and for your family?

4. Anything else?

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For more information about the Indiana Resource Center for Autism, visit our website at www.iidc.indiana.edu/irca or email Dr. Cathy Pratt at prattc@indiana.edu.

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The Indiana Resource Center for Autism (IRCA) is one of seven centers located at the Indiana Institute on Disability and Community at Indiana University, Bloomington. The work of the Indiana Institute encompasses the entire life span, from birth through older adulthood, and addresses topical areas that include:

- ◆ Early intervention and education;
- ◆ School improvement and inclusion;
- ◆ Transition, employment, and careers;
- ◆ Aging issues;
- ◆ Autism spectrum disorders;
- ◆ Disability information and referral;
- ◆ Planning and policy studies; and
- ◆ Individual and family perspectives.

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For more information, contact: The Indiana Resource Center for Autism, Indiana Institute on Disability and Community, Indiana University, 2853 East Tenth Street, Bloomington, IN 47408-2696, call (812) 855-6508, or visit our web site at www.iidc.indiana.edu/irca.

Indiana's University Center for Excellence on Disabilities

These materials are available in alternative formats upon request.