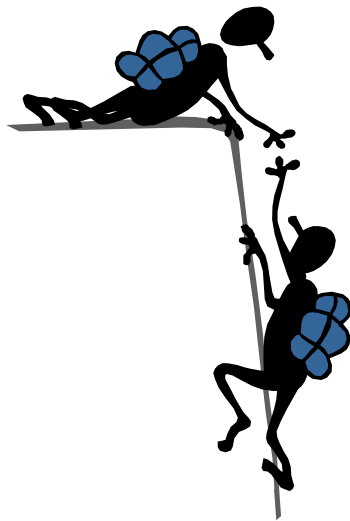


Step Three: Information on Available Support

This section lists many places to find support after the diagnosis. It includes information about reaching out to friends and family as well as support groups and other support sources.





Clarifying the Services of the Indiana Resource Center for Autism: What We Do and What We Don't Do

Contributed By: Dr. Cathy Pratt

In the past, I have been asked several times to clarify the activities of the Indiana Resource Center for Autism. I finally decided it might be best to explain what we do and don't do to hopefully unravel the confusion. The overall goal of the Indiana Resource Center for Autism is to conduct outreach training and consultations, engage in research, and develop and disseminate information on behalf of individuals across the autism spectrum, including those with autism, Asperger's syndrome, and other Pervasive Developmental Disorders. Our efforts are focused on providing communities, organizations, agencies, and families with the knowledge and skills to support children and adults in typical early intervention, school, community, work, and home settings. We are a university-based program and part of Indiana's University Center on Excellence in Disabilities. These associations require that we emphasize systems change and local capacity building.

So, quite simply, why would you call us? The part and full-time staff members of the Indiana Resource Center for Autism engage in a range of activities that address issues that impact individuals across the lifespan and across the spectrum of autism. Here is what we do:

- Develop and disseminate written and video materials. Some of these materials are available for purchase; others are available for free or on the web.
- Develop and distribute a newsletter three times a year. The newsletter is free to Indiana residents, and available to those outside Indiana for a minimal cost. In the last 8 years, the number of individuals receiving this newsletter has jumped from 4500 to over 9000.
- Organize and conduct regional and statewide training events. Each year, regional workshops are organized throughout Indiana on topics such as early intervention, education, adult services, and positive behavior

Reprinted with permission; Obtained online from Indiana Resource Center for Autism at: www.iidc.indiana.edu/irca/ClarifyServices.html

- supports. In addition, IRCA staff present at parent support groups across the state.
- Organize and conduct training events involving nationally recognized speakers. IRCA hosts speakers from around the country to provide one to three days of intensive training. In previous years, IRCA has hosted Carol Gray, Bennett Leventhal, Gary Mesibov, Ron Leaf, Cathy Lord, Kathleen Quill, Brenda Smith Myles, Vincent Carbone, Diane Twachtmann-Cullen, Sally Rogers, and many others.
 - Engage in applied research. As a university-based program, a primary responsibility of the Indiana Resource Center for Autism staff is to conduct research. Strategies and policies that enhance the quality of life for individuals within the autism spectrum are a primary focus of research. Every three years, the IRCA conducts a Needs Assessment survey to gather data from families and/or professionals about the status of programs and supports related to individuals across the autism spectrum. In addition, doctoral students are supported in their individual research efforts.
 - Disseminate information. IRCA serves as a state clearinghouse for information about Autism Spectrum Disorders by responding to individual requests for information, maintaining a library collection of relevant books and videos for public distribution, producing written and video materials, and monitoring current information on external resources, trends, policies, services, treatments, workshops and so forth using a variety of formats.
 - Maintain an active website. Increasingly, families and professionals are accessing the web to gather information. Our website includes information about resources in Indiana, articles written by staff members, a list of training events, and much more valuable information. The website is updated on a regular basis.
 - Train teams. Every year, local special education planning districts are invited to organize a team to receive more intensive training in educating and supporting students across the autism spectrum. Once trained, IRCA staff are available to provide ongoing support to assist individual teams in achieving the goals within their district.
 - Engage in individual consultations. IRCA staff are available to address individual needs within broader systems change activities by observing the individual in natural settings, and collaborating with the person's team and family members to suggest appropriate services and supports. These consultations require a time commitment from all involved and include follow-up support.

Step 3: Information on Available Support

- Conduct university coursework. Because of our association with Indiana University, IRCA staff teach both course lectures, and offer entire courses focused on Autism Spectrum Disorders, positive behavior supports, and other topics.
- Maintain a listserv forum. This listserv is for anyone interested in proactively collaborating on topics related to Autism Spectrum Disorders.
- Participate in national/state/local organizations. IRCA staff members are also involved in various local, state and national organizations in a volunteer capacity and serve on various boards of directors.

While we engage in many activities, there are a number of activities that are outside our work scope. These are highlighted below:

- We are not a direct service provider. Children and adults with autism do not reside at the IRCA, nor do they attend any programming provided through our agency.
- IRCA staff do not attend case conferences, conduct formal assessments, evaluations or testing, or provide diagnostic services. We are not a crisis management program, but instead focus on proactive programming. IRCA does maintain a list of professionals who can diagnose and assess, and may be able to identify professionals who can provide other forms of assistance.
- We are not a lobbying organization. As a university-based program, we are clearly instructed not to lobby. Instead, our job is to inform the state of the current status of services, available options, and model programs in other states. As part of this information providing process, we conduct a Needs Assessment Survey every three years and participate every fall in meetings of Indiana's Legislative Commission on Autism.
- We are not a funding agency. The Indiana Resource Center for Autism works with limited funds, and is not funded to provide financial assistance to families, professionals, or individuals across the autism spectrum.
- The Indiana Resource Center for Autism does not promote one intervention method or a single approach. Instead, IRCA staff strive to address the specific needs of the individual by providing information and training on a variety of strategies and methods.

Hopefully, this will clarify our work. If you have additional questions or concerns, do not hesitate to contact the IRCA via email at prattc@indiana.edu or by phone at 1-812-855-6508. Visit our website at www.iidc.indiana.edu/irca for additional information.



Mission Statement & Project Descriptions

*The mission of IN*SOURCE is to provide parents, families and service providers in Indiana the information and training necessary to assure effective educational programs and appropriate services for children and young adults with disabilities.*

COLLABORATIVE PARENT INVOLVEMENT PROJECT

Since the 1970s, IN*SOURCE and the Indiana Department of Education, Division of Special Education, have worked together to address shared educational concerns and issues facing Indiana's students with disabilities and their families. IN*SOURCE and the Division have initiated the *Collaborative Parent Involvement Project (CPIP)*. CPIP focuses on helping parents, educators and local communities work together to address a variety of challenges including transition, assistive technology and surrogate parent programs and preparing for transitions.

The project also supports ways to facilitate communication among families and various groups to promote sharing of ideas and resources and to foster the development of regional and state networks.

INDIANA PARENT TRAINING PROGRAM

The *Indiana Parent Training Program (IPTP)* is a federally funded parent-to-parent training and information project that began in 1980. By disseminating information and materials and conducting training workshops throughout Indiana, IPTP instructs parents about their rights and responsibilities in the early intervention and special education processes under state and federal laws.

IPTP provides:

- Individual assistance to parents and professionals.
- Workshops for parents on their rights and responsibilities in the early intervention and special education processes; coping skills and

understanding disabilities; state and local services for infants, toddlers, youth and young adults with disabilities.

- Regional Parent Resources (RPRs) to serve as sources of support and information to parents in their local communities.

REGIONAL REHABILITATION TRAINING AND INFORMATION PROJECT

The *Regional Rehabilitation Training and Information Project* operates in conjunction with three other Midwest parent training and information centers through a federal grant. This program provides information and training to parents, family members, advocates and persons with disabilities about the provisions of the Rehabilitation Act and Amendments; understanding the process of making a successful transition from school to adult life; and effectively providing information, individual assistance and training to others.

UNIFIED TRAINING SYSTEM

IN*SOURCE is part of Indiana's Unified Training System (UTS) group. The **UTS** has developed and is implementing a coordinated training and technical assistance system for families and providers serving children with special needs, birth to age six. Financial assistance in the form of reimbursement for UTS activities is available from the Family Involvement Fund through IN*SOURCE.

Parents Helping Parents, A Regional Approach

IN*SOURCE believes in the value of the parent-to-parent model. There is need for parents to acquire knowledge and develop skills in order to be effective participants on decision-making teams. Training and information coming from someone who is able to identify with and relate to their needs is likely to have a more positive impact on parents' confidence in their own expertise as parents with vital knowledge of their own children. IN*SOURCE currently has staff located in nine different communities in the state and over 300 Regional Parent Resources statewide. IN*SOURCE believes that parents working with other parents in the community where they live is a very effective means to reach and serve families.

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PHONE: 574-234-7101 or 800-332-4433
FAX: 574-234-7279
EMAIL: insource@insource.org

Inside About Special Kids

What We Do

About Special Kids is a “Parent to Parent” organization that works throughout the state of Indiana to answer questions and provide support, information and resources. We are parents and family members of children with special needs and we help other families and professionals understand the various systems that are encountered related to special needs. Our central office is located in Indianapolis, Indiana where parents from the entire state can access information, resources and support. Regional Parent Liaisons are located in southeastern IN serving Clark, Scott, Floyd and Harrison counties as well as northwest IN serving Lake and Porter counties.

The mission of About Special Kids is: Supporting children with special needs and their families by providing information, peer support, and education, and building partnerships with professionals and communities.

We define children with special needs as children with:

- Physical, mental, emotional disabilities
- Developmental delays
- Chronic illnesses
- Mental health concerns
- Behavioral disorders
- Learning disabilities and educational delays
- Children who have risk factors or who are showing signs of a suspected disability

As a parent, once you make contact with About Special Kids, you will likely be connected with a staff Parent Liaison who is a trained and experienced parent of a child with special needs. Parent Liaisons focus on teaching families how to anticipate child and family needs, identify family and community resources, and access community systems to help them meet the needs of their children. Additionally, About Special Kids Parent Liaisons follow up with each family that contacts us using a system of HAT (How Are Things?) calls. After a family makes the initial contact, About Special Kids staff follow-up with families for at least one year. So....even if there is something that you forget to ASK during that first call that you make, you will have plenty of contact with our parent staff to anticipate and to help answer your questions.

About Special Kids - Central Office

7275 Shadeland Ave. Suite 1 Indianapolis, IN 46250

PH: 317-257-8683; Toll Free: 1-800-964-4746; Fax: 317-251-7488

Business Hours: M-F 8am-4:30pm

<http://www.aboutspecialkids.org/>

Policy Change: Case Conferences

About Special Kids (ASK) has made the decision that it can no longer attend Individualized Educational Program meetings (case conferences) for families in Indiana. While this was not an easy decision for us to make, because we do not receive funding related to this very important yet time consuming and costly task, we can no longer afford to dedicate the enormous amount of staff time and resources that it takes to attend these meetings with families. You may have questions about why we are making the change and what it will mean to families. We hope we can answer some of your questions here.

Why can you no longer attend case conferences?

ASK is a statewide nonprofit organization that relies on grants and fundraising for its activities so that it does not have to charge a fee for services provided. Unfortunately, ASK does not receive specific funds related to attending case conferences to advocate and support families. While we think there is a vital need in our state for more one on one advocacy for families so they know how to work with schools to achieve the best outcomes for their children, we cannot continue to do this without funding to support these activities. Preparation, travel time and attendance at case conferences has stretched our staff and funds so much that we struggle to provide the comprehensive parent to parent support and information that is the foundation of our mission.

What type of educational support can ASK provide?

A majority of calls that ASK receives from families are about special education issues. We plan to continue answering questions and guiding families through the appropriate steps to take. Our parent liaisons will be available across the state to provide parent to parent support and assistance as it relates not only to special education but also to community resources, health insurance, respite, child care and many other topics. We are a "first stop" for many families and have answers to their questions. If a parent calling ASK is specifically seeking an advocate to attend a case conference, they will be assigned to a parent liaison to discuss possible actions with the school. This parent liaison will not, however be able to attend the case conference with the family. If the family has a strong desire for this type of support, ASK will provide a list of organizations and/or individuals who provide this service. Upon agreement from the family, ASK can provide notes and information to these other entities to ensure that families are not repeating their issues to multiple parties prior to a case conference. Your parent liaison will then continue to serve the family in many other ways throughout the course of at least a year. Additionally, ASK offers comprehensive trainings to families so that they can better understand the special education laws and the IEP process.

In summary, ASK will continue to provide the following services to families related to education:

- Phone support to answer questions and provide information for preparing for the case conference
- Resources to help families prepare for case conferences
- Trainings throughout the state about Article 7 (Indiana's Special Education Law) and preparing IEP's

If ASK won't be attending case conferences who can I turn to for this type of support?

ASK offers comprehensive trainings in Indiana's Special Education law as well as how to develop a good IEP and how to work with the school during this process. ASK encourages families to attend these trainings as they will greatly assist in preparing families for their child's case conference. Additionally, ASK will share a list of providers of case conference advocacy (actually attending a meeting with the family) including nonprofit organizations and individuals and groups who can provide this service for a fee to families. If you are aware of other individuals or groups who provide case conference advocacy service who aren't on our list, please contact ASK so that they can be added to our list. ASK will be working in the coming months to establish a fund to assist families with expenses associated with case conference advocacy.

What do you hope to accomplish with this new policy?

Internally, we hope to improve our organizational efficiencies which will benefit the families and professionals we serve. Externally, we hope to raise awareness at the national, state and local levels that more funding is needed for this type of service to families. Advocates at case conferences play an important role in helping families understand special education laws and how to partner with their school to help students achieve success.

Finding the Right Support Group

At the bottom of this page you will find information about the various support groups in Indiana. It is important to keep in mind that this list is not an exhaustive list of all support groups, others exist and more are probably forming all the time. Additionally, it is important to remember that each chapter or group is different. Some focus almost exclusively on a formal learning model, with lectures and talks. In other groups, however, parents get together outside of those formal meetings to provide additional sources of support to one another. Some chapters might include play groups, while others might have regular support meetings. Every family has different needs; make sure you find the group that best meets the needs of your family. Try one group, and if it isn't what you need right now, try another one until you find the best fit.

Autism Society of America (ASA)
7910 Woodmont Avenue, Suite 300; Bethesda, MD 20814-3067
800-3-AUTISM or 301-657-0881; www.autism-society.org

Autism Society of Indiana (a state-wide chapter of the ASA):
Autism Society of Indiana University; Teachers College, Room 722
Ball State University; Muncie, IN 47306; www.inautism.org

The Arc of Indiana
107 N. Pennsylvania St., Suite 300, Indianapolis, IN 46204
317-977-2375 800-382-9100; <http://www.arcind.org/>

The Indiana Family to Family Initiative (INF2F)
1-800-964-4746; 317-257-8683

Indiana Resource Center for Autism (IRCA)
Find an online link to support group information
www.iidc.indiana.edu/irca/servarticles/chapters.html; or call: 812-855-6508.

Indiana Resource Center for Families with Special Needs (IN*Source)
1703 South Ironwood Drive; South Bend, IN 46613
574-234-7101; 800-332-4433; <http://www.insource.org/>

There are many options for support available; you simply must be willing to seek it out!



Respite Services

Contributed by Marci Wheeler

All parents need time away from their children. This may be especially true for the family of an individual with a disability. Living with a family member who needs almost constant supervision and care can create continual stress. Respite services provide families with temporary relief from the sometimes 24 hour a day job of supervising and supporting a person with a disability. Respite is an option for any child, adolescent, or adult with disabilities. Depending upon programs in your area, respite may be available for several hours a week, overnight, or for several days or weeks at a time. Respite services provide temporary relief and peace of mind by placing the family member with a disability in capable hands.

Respite services may provide the following:

- Individual care in the family home or in the provider's home on an as needed or on a regular hourly basis.
- A training companion to accompany the individual to community recreational activities.
- A short-term placement in a group home, family home, or other residential setting.
- Assistance to attend a camp or day program in the summer.

Agencies that provide respite services operate under state guidelines and regulations, but individual agencies have flexibility in the design and implementation of programs. Respite workers can sometimes be paid between \$8.00-\$18.00 an hour depending on the level of assistance required for the individual, and the skill level required of the respite worker. Agencies providing respite services set fees according to a sliding fee scale based on a family's income. Agencies also can direct families to funding sources to defray costs. Many agencies can offer subsidized respite that is very affordable. Respite providers should be contacted directly to clarify options, arrange services, and discuss cost.

To locate respite provider agencies in your area, call the local Arc, Integrated Field Services Office (sometimes referred to as the Bureau of Developmental Disabilities Case Management Field Offices), Autism Society of America local chapters, local parent support groups, the local special education planning district, or other local groups who work with persons with disabilities and their families. Many area respite contact staff work only part time. Therefore, it may be hard to reach certain respite contact staff on the first phone call. However, once you leave a message, contact staff are usually good about returning phone calls.

Many times, respite services are not used because parents are not aware of programs or because they feel guilty or anxious about using services. At times, respite provider agencies lack personnel trained to deal with individuals with significant disabilities or with challenging behaviors. These are valid concerns, but hopefully will not prevent a family from seeking or receiving respite services. Agencies are required to train respite staff. Most agencies try to provide advanced training to respite workers who are interested in and capable of working with persons with the most severe disabilities and/or challenging behaviors.

When using respite services, it is important for families to provide specific information about their family member with a disability to agency staff. Maintaining a notebook with information about the individual's method of communication, areas of concern, preferred activities, systems of reinforcement, medications, behavior support plans, suggestions for interactions, and a daily schedule can be helpful. Information about dressing, eating, bathroom use, and bedtime routines should be documented and readily available. Emergency numbers and emergency procedures should be clearly posted. Visual systems of support such as picture sequences, calendars, and checklists should be easy for the respite worker to access. Keeping updated information in one location will help the respite worker be successful, ease your peace of mind, and assist your son/daughter in adjusting to a new person.

Time for running errands, relaxing, pursuing other interests, and strengthening relationships with family members and friends is essential for all parents. Respite services can provide relief and can help all family members feel energized, including the person with a disability who spends time with trained personnel. Consider the benefits to the whole family. Be persistent in finding and working with an agency in developing respite services that meet your family's needs. Respite services can truly enhance the lives of all family members.



Frank and Marian Snyder Family Resource Center

The Frank and Marian Snyder Resource Center, a 12,600 square foot Facility and one of the three largest of its kind in the United States, is a comfortable, convenient place designed specifically for the needs of families whose children are patients.

The Center brings together several premier services for families within a beautiful sanctuary within Riley Hospital for Children. The Four Components of the Frank and Marian Snyder Resource Center include: The Edward A Block Family Library, Riley Chapel, The Riley Family Education Center, and The Ronald Mc Donald House at Riley.

The Resource Center is located on the first floor of Riley Hospital, behind the Atrium. Each facility within the Center has their own referral criteria, hours of operation and contacts.

AUTISM SPECTRUM-RELATED RESOURCES
RILEY HOSPITAL FOR CHILDREN
EDWARD A. BLOCK FAMILY LIBRARY

HARDCOVER RESOURCES BY AUTHOR –
{NOTE regarding Call Numbers#: FAM SPT= FAMILY SUPPORT [Written for parents]; KC= Kid's Care [Bibliotherapy for patients]}

Call# - KC AME

Author – Amenta, Charles A., III, MD

Title – Russell is Extra-Special – A Book About Autism for Children

Publisher – American Psychological Association, 2001.

Summary – Describes the daily life, like and dislikes of Russell Amenta, who is a happy boy despite being severely autistic.

Call# - FAM SPT 616.8982 ATT

Author – Attwood, Tony

Title – Asperger's Syndrome. A Guide for Parents and Professionals

Publisher – Jessica Kingsley Publishers, 1998.

Summary – “Readers will appreciate the detailed discussions of the problems people with Asperger’s Syndrome will encounter and the practical suggestions for helping to overcome or compensate for them. This is a book to be read and consulted over and over again”.

Call# - FAM SPT 616.858832 ATT

Author – Attwood, Tony

Title – Asperger's and Girls

Publisher-

Summary – At long last, here is a book that provides up-to-date information about girls and women with Asperger’s Syndrome. Covering topics such as diagnoses, education, puberty, relationships, and careers, experts in the field share practical advice for both caregivers and the women and girls who are affected by Asperger’s. Other chapters are written by women who have been diagnosed with ASD. They candidly reveal their experiences and compassionately advise others. Finally, a book about autism that recognizes the unique problems of girls on the spectrum, instead of taking the “one size fits all” approach.

Call# KC EDW

Author - Edwards, Andreanna

Title – Taking Autism To School

Publisher – JayJo Books, L.L.C., 2001.

Summary - Angel explains to her friends about Sam and his autism. She explains that autistic kids are extremely sensitive, cope better if they have schedules, may "echo" what people say to them, learn easier with many repetitions, and often need medicines on a regular schedule.

Call# - FAM SPT 616.8982 GRA

Author - Grandin, Temple, Scariano, Margaret

Title – Emergence: Labeled Autistic

Publisher – Arena Press, 1986.

Summary – Temple Grandin tells the story of her emergence, of how she went from a fear-gripped, autistic childhood to become a successful professional, a world leader in her field. An astonishing true story, a chronicle of perseverance, courage, and the loving wisdom of a few adults who saw in Temple what others couldn’t. Emergence will give new hope and new insight into the tragedy of autism and the vast potential of the human spirit.

Call# - FAM SPT 616.89 GRA

Author – Grandin, Temple

Title – Thinking in Pictures: And Other Reports from My Life with Autism

Publisher - Doubleday, 1995.

Summary – In this unprecedented book, Temple Grandin, Ph.D., delivers a report from the country of autism. Writing from the dual perspectives of a scientist and an autistic person, she tells how that country is experienced by its inhabitants and how she managed to breach its boundaries to function in the outside world.

Call# - FAM SPT 618.928 NEW

Author – Gray, Carol (ed.)

Title – The New Social Story Book

Publisher – Future Horizons, 2000.

Summary – Selected by "Library Journal" as "Essential for All Collections," Gray's "The New Social Story Book" contains her groundbreaking concepts that are being used all over the world to teach vital social and functional skills to children with autism. Illustrations.

Call# - FAM SPT 618.92 HAR

Author – Harris, Sandra L.

Title – Right from the Start, Behavioral Intervention for Young People with Autism, A Guide for Parents and Professionals.

Publisher – Woodbine House, 1998.

Summary – 'Right from the Start', the trusted primer on Applied Behavior Analysis (ABA) treatment for children with autism, is back in a revised and expanded edition. It thoroughly examines the critical components of Early Intensive Behavioral Intervention programs for preschoolers with autism. These educational programs, based on ABA methods, use concentrated instruction to improve communication, social, and cognitive skills.

Call# FAM SPT 649.154 HAR

Author – Harris, Sandra L.

Title – Siblings of Children with Autism, A Guide for Families

Publisher – Woodbine House, 1994.

Summary - Siblings of Children with Autism is an invaluable guide to understanding sibling relationships, how autism affects these relationships, and what families can do to support their other children as they cope with the intensive needs of a child with autism.

Call# FAM SPT 618.9289 HAR

Author – Hart, Charles

Title – A Parent's Guide to Autism

Publisher – Pocket Books, 1993.

Summary - A comprehensive source book for meeting the challenges of parenting an autistic child--with love, care, and understanding.

Call# KC HEA

Author - Healy, Angie

Title - Sometimes My Brother : Helping Kids Understand Autism Through a Siblings Eyes

Publisher – Future Horizons, 2005.

Summary - Three-year old Foster explains his perspective of his older brother, Gavin, who has autism. Shows the challenges the boys face and the obstacles they overturn. Demonstrates what autism is all about, and lets other siblings of children with autism know that they are not alone.

Call# FAM SPT 371.943 VIS

Author – Hodgdon, Linda A. (ed.)

Title – Visual Strategies for Improving Communication

Publisher – Quirk Roberts Publishing, 1995.

Summary – One of the major areas of difficulty for students with Autism Spectrum Disorders is the development of social and communication skills. Communication breakdowns can be a "root" cause of problems in social interaction, educational performance, and behavior. While it is common for educational programming to focus on developing communication skills, that focus in most settings tends to be directed toward developing the student's expressive communication. Comparatively little attention is directed toward increasing the student's ability to understand the communication in his life. This book demonstrates why an inability to effectively take in and understand information can be a significant factor in these student's performance. 'Visual Strategies for Improving Communication' contains numerous easy to use systems and strategies that have proven to help these students significantly improve their ability to understand, express themselves, participate in home and school routines and improve overall behavior.

Call# FAM SPT 616.89 HOL

Author – Holmes, David L.

Title – Autism Through the Lifespan: The Eden Model

Publisher – Woodbine House, 1998.

Summary - With numerous examples and case histories, "Autism Through the Lifespan" presents an in-depth model for helping children and adults with autism that will be of interest to professionals and parents alike.

Call# FAM SPT 628.928 HUN

Author – Hunter, Kathy

Title – The Rett Syndrome Handbook

Publisher – International Rett Syndrome Association (IRSA), 1999.

Summary - From a parent: "This is the most comprehensive book I have I have in my arsenal! IT is a must own for parents of a child with any form of developmental delay, neurological issues".

Call# FAM SPT 618.928 KAR

Author - Karasik, Paul

Title - The Ride Together, A Brother and Sister's Memoir of Autism in the Family

Publisher - Washington Square Press, 2003.

Summary - This groundbreaking work was excerpted in The New York Times for its ability to honestly, eloquently, and respectfully set forth what life is like with autism in the family.

Call# FAM SPT 641.151 You

Author - Klein, Stanley D., Ph.D. (ed.)

Title - You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities

Publisher - Kensington Books, 2001.

Summary - In "You Will Dream New Dreams", a compassionate, deeply felt collection of writings, you'll discover the common ground of emotions shared by parents of children with disabilities. Real life-fathers and mothers of kids with cerebral palsy, Down Syndrome, autism, mental retardation, and other life-changing illnesses speak from the heart on how they mourned for the child of their dreams...learned the importance of turning to friends instead of being "strong" all the time...experienced the wrenching disappointment of letting go of certain expectations for their child...and found the unexpected joy of discovering new dreams.

Call# FAM SPT 649.151 Ref

Author - Klein, Stanley D., Ph.D. (ed.)

Title - Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew

Publisher - McGraw-Hill, 2004.

Summary – Most parents of children with disabilities lack personal experience with adults with disabilities. Hearing from people who have lived the disability experience can provide all parents with essential information about the possibilities for their children.

Call# FAM SPT 371.94 TEA

Author – Koegel, Robert L. (ed.)

Title – Teaching Children with Autism: Strategies for Initiating Positive Interactions and Improving Learning Possibilities

Publisher – Paul H. Brookes Publishing Co., 1995.

Summary – This positive, research-based text dispels the stereotypes surrounding autism by providing accurate information on how much children with this disorder can learn. Extensively referenced and comprehensive, this resource discusses the behavioral characteristics of autism, available intervention methods, and key topics such as spontaneous language, overselectivity, social communication, and self-management. Detailed chapters also examine the goals of intervention, suggest concrete ways to support families, and offer a wealth of strategies that focus on long-term gains and short-term problem solving; contribute to developing a meaningful, functional curriculum; promote the independence of the child with autism; and include families as valued participants in planning and implementation.

Call# FAM SPT 618.92 KRA

Author – Kranowitz, Carol

Title – The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction

Publisher – Berkley Publishing Group, 2006.

Summary – The 'Out-of-Sync Child' broke new ground by identifying Sensory processing Disorder, a common but frequently misdiagnosed problem in which the central nervous system misinterprets messages from the senses. This newly revised edition features additional information from recent research on vision and hearing deficits, motor skill problems, nutrition and picky eaters, ADHD, autism, and other related disorders.

Call# FAM SPT 618.92 McC

Author - McClannahan, Lynn E., Ph.D.

Title - Activity Schedules for Children with Autism: Teaching Independent Behavior

Publisher - Woodbine House, 1999.

Summary - This book can be used successfully with young children, adolescents, and adults, rewarding them with more control over their lives.'

Call# FAM SPT 362.82 Per

Author - Perske, Robert

Title - Hope for the Families: New Directions for Parents of Persons with Retardation or Other Disabilities

Publisher - Abingdon Press, 1991.

Summary - This book is for families who are trying to turn a tough situation into a rich experience. If you are the parent of a person with mental retardation, cerebral palsy, autism, epilepsy, a learning disability, or other developmental disabilities...this book is for you.

Call# FAM SPT 618.92 Chi

Author - Powers, Michael D., Psy.D. (ed.)

Title - Children with Autism, A Parent's Guide

Publisher – Woodbine House, 2000.

Summary - Recommended as the first book on autism that parents and family should read, Children with Autism covers areas that are of special concern to parents. By providing up-to-date information about autism, this comprehensive book will ease the fears and concerns of many parents struggling to understand and cope with their child's disorder.

Call# FAM SPT 362.2 Eff

Author - Schopler, Eric (ed.)

Title - The Effects of Autism on the Family

Publisher - Plenum Press, 1984.

Summary - Based on a Division TEACCH annual conference, this volume discusses the four major ways professionals work with parents of children with Autism Spectrum Disorder (ASD): as advocates, trainers, trainees, and as an emotional support system. Chapters include: professional attitudes toward parents; research concerning families of children with ASD; helping children with ASD through their parents; developmental changes in families of children with ASD; the role of the National Society in working with families; the professional's role as advocate; parents as behavior therapists; training parent-child interactions; parents as trainers; explaining ASD to parents; family resources; coping with burnout; and sibling issues.

Call# FAM SPT 618.92 Sie

Author - Siegel, Bryna

Title - The World of the Autistic Child: Understanding and Treating Autism Spectrum Disorders

Publisher - Oxford University Press, Inc., 1995.

Summary - "The World of the Autistic Child" is a superb guide and resource that no one who cares about autistic or developmentally disabled young people will want to be without.

Call# FAM SPT 649.152 Tan

Author – Tanguay, Pamela B.

Title - Nonverbal Learning Disabilities at School: Educating Students with NLD, Asperger Syndrome, and Related Conditions.

Publisher - Jessica Kingsley Publishers. 2002.

Summary - "This book is a must have tool for the parent who wants the best for their NLD child and for the educators and professionals who will help them achieve it."

Call# KC THO

Author - Thompson, Mary

Title - Andy and His Yellow Frisbee

Publisher - Woodbine House. 1996.

Summary - The new girl at school tries to befriend Andy, an autistic boy who spends every recess by himself, spinning a yellow frisbee under the watchful eye of his older sister.

Call# FAM SPT 649.154 Vol

Author - Volkmar, Fred R., M.D.

Title - Healthcare for Children on the Autism Spectrum: A Guide to Medical, Nutritional, and Behavioral Issues

Summary - Parents of children with Autism Spectrum Disorders (ASDs) are in constant need of information about every aspect of their child's development. Now the task of understanding and managing their child's general health and medical care is made much easier with 'Healthcare for Children on the Autism Spectrum' - the first book for parents to focus on this important subject. While a child with autism can be as healthy as any other, autism creates challenges, such as sensory issues and communication difficulties, that become a factor when considering almost all healthcare decisions.

Call# FAM SPT 618.92 Wei

Author - Weiss, Mary Jane, Ph.D., BCBA

Title - Reaching Out, Joining In: Teaching Social Skills to Young Children with Autism

Summary - Practical and accessible, this guide offers invaluable expertise and easy-to-understand activities parents and teachers can practice at home or at school to help kids with autism in preschool through elementary school become more socially adept.

ELECTRONIC/CD-BASED PROGRAMS –

Call# FAM SPT REF BOA (Please note: CD is held in library office, manual/binder on library shelving)

Author – Mayer-Johnson, Inc.

Title – Boardmaker for Windows, v.5

Publisher – Mayer-Johnson, Inc.

Summary - Boardmaker is a graphics database containing over 3,500 Picture Communication Symbols (PCS) that can be used to create a variety of communication materials. The drawing window allows you to quickly create communication boards, device overlays, worksheets, schedules, calendars, etc. The symbols can be made any size, used in color or black and white, and displayed with text in a variety of languages. Over 250 blank template boards are provided to help you quickly build the boards you need.

PLEASE NOTE: The staff of the Christian Sarkine Autism Treatment Center have added templates to the four public access PC terminals in the Family Support side of the Edward A. Block Family Library, along with 'cheat sheets' that have been placed in the Boardmaker program manual that is kept on library shelving on the Family Support side.

VHS VIDEO –

Call# FAM SPT REF VHS BOA

Author – Mayer-Johnson Inc.

Title – The Boardmaker for Windows v5: For People Who Need Help Using Boardmaker

Publisher – Mayer-Johnson Inc.

Summary - This video presentation compliments the instructions found in the Boardmaker manual. It is held on the library shelving on the Family Support side of the library.

Safety Store

Child safety is our priority.

Keeping your child safe every day is important to his growth and development. At Riley Hospital for Children, we recognize that making your child's world safe is not always easy. In fact, it can be a full-time job.

Unintentional injuries are the leading cause of death for children ages 1 to 14.

According to the National SAFE KIDS Campaign, about 45 percent of childhood injuries happen in or around the home. And, most of these injuries can be easily prevented through education and the proper use and maintenance of child safety products.

That's why we opened the Safety Store, a place where you can buy low-cost child safety products and learn how to keep your youngest family members safe.



Welcome to the Safety Store.

Smoke detectors, bike helmets, cabinet locks, outlet covers, and bath water thermometers are some of the products you'll find at the Safety Store—just to name a few! The Safety Store also carries products designed specifically for children with disabilities or special health care needs, making it the first of its kind in the nation to serve all children.

The Safety Store provides an environment where parents, like yourself, feel comfortable to shop, learn, and ask questions about their child's safety, all under the roof of a children's hospital.

Trained Safety Store associates are on-hand to determine your family's needs and help identify and select products that you need. Your family will also learn how to use and maintain the products and how to practice child safety at home.

We can answer your questions.

Where is the Safety Store located?

The Safety Store is located in the Riley Outpatient Center, through the Over the Rainbow Gift Shop. Click here to see a map of the Riley Outpatient Center.

What are the Safety Store's hours?

The Safety Store is open Monday through Friday, from 9 a.m. to 4 p.m. and is closed on holidays.

Who operates the Safety Store?

The Safety Store is operated by Riley Hospital's Community Education and Child Advocacy Department, in partnership with The Cheer Guild.

How do I know which safety products are best for my child?

Safety Store associates are on-hand during store hours to help you identify and select products for your family's safety.

What if I don't know how a safety product is used?

Associates will show you how to use the safety products you select and will answer any questions you may have. They may also recommend other products for your family's needs.

Can someone answer my questions about child safety?

Child safety is our expertise. Associates will answer any questions your family has about general child safety and provide resources for you to take home.

How can I learn more about the Safety Store?

For more information about the Safety Store and available child safety products, call 317.274.6565 or toll-free 1.888.365.2022.

Religion and Autism

Below are two articles originally published in the ASA's member publication, the Advocate, on the topic of autism and religion. The articles provided here relate specifically to the Christian and Jewish faiths, but many of the tips can and should be applied to all religions.

The Christian Perspective

By Terri Connolly

The church experience is often one of generational tradition for many families. Other families recognize their need for a place of spiritual refuge and nurturing for the first time in their lives when they have children or at other trying times.

Christ's example of "agape," or unconditional love, is paramount to our understanding of the role of acceptance in the church. Too many parents and siblings, as well as the individual with autism, are asked to leave or feel so uncomfortable that they lose this most precious part of their lives, and at a time when they are most in need.

The behaviors associated with autism often present challenges for the family church experience, yet I often find myself wondering: "If not church, then where can an individual be accepted exactly as they are with unlimited love and inclusion?" Families of faith need to find a church where all of its members can be nurtured. By integrating the member with autism as a regular member of the church, with resource help and community-wide education, the church becomes accessible to the whole family, and the family, in turn, is strengthened through shared faith experiences.

Tips to Supporting Inclusion

Initiate contact. Initially, parents may want to contact the pastor or Sunday School teacher to introduce themselves and prepare them to provide a successful experience for everyone. Include information about educational goals and discuss communication methods.

Discuss your expectations. When attending a worship service, it would be wise to discuss with the worship leader what they might expect. In return, the worship leader should offer supports to the family, such as someone to stay with siblings should the parents need to leave during the worship service or to accompany the individual with autism to another comfortable place should he or she become distressed.

Be prepared. Most experienced parents know that all children and many adults become fidgety during church. Being prepared with a quiet object of concentration, such as a rubber band, pictures, books, or an object of visual focus, can be very helpful, particularly if it has religious significance to enhance

the worship experience in a different way. Items that provide comfort and security at home might be made available at church.

Get acclimated. Since it is thought that many individuals with autism experience things holistically, attention should be given to the sights, sounds, and even smells within the sanctuary or classroom. A visit to the sanctuary and classroom in a church when they are empty might give the individual an opportunity to explore in ways that might be inappropriate when crowded. With special permission, one might also explore the organ or piano to prepare the individual for the sudden and sometimes loud sounds during worship.

Teach by example. The worship leader may comfortably acknowledge any distracting behavior with a simple, sincere acknowledgment. "So glad you could join our worship today, Tom," after which the worship leader continues as if Tom's participation is perfectly natural. The worship leader's acceptance is very important. Sensitivity and joint strategy planning are critical.

Develop peer partners. In order to help relationships and friendships blossom, peer partners who rotate responsibility for assistance can help to create a wide base of support for the individual while fostering a truer atmosphere of inclusion.

Help the individual feel welcome. Several adults or children should assume quiet lay leadership roles by greeting the individual with eye contact, a "Hi, Bryan," a high-five, a popular stylized handshake, or a pat on the shoulder. It is often this simple, yet critical initiation that communicates the gospel message. A kind of "underground" effort of greeting creates a wonderful atmosphere of acceptance.

Stand firm. Finally, the family should stand firm in their belief that we all have a place in the worship experience. When one member is missing, the experience of all is diminished.

Younger Children and Sunday School

In being part of the community of faith, all individuals need the opportunity for active participation. Doing what others do promotes a feeling of inclusion. For children in Sunday School, the following ideas have been successful:

Use the Bible. Encourage the child to hold the Bible open to the appropriate page. Use a bookmark or guide the child's hand to follow as others read aloud.

Ensure participation. Pass a ball or talking stick while sharing or learning parts of a memory verse. The child with autism is assured then a chance to participate with the help of another to communicate the message. A notebook from home could tell about experiences and add prayer requests, if necessary.

Rotate buddies. Remember to encourage multiple friendships and acquaintances by rotating peer escorts and buddies.

Use visual cues. Use extra visual cues, such as pictures, during a story at any age level. Quietly reword a story as needed so that it is understandable to the individual.

Encourage imitation. Encourage, but do not force, imitation of body postures, such as bowing one's head and clasping hands for prayer, standing to sing, and looking toward the person who is speaking. This will certainly vary with the individual, but it helps to create an attitude of prayer and participation.

Older Youth and Participation

Older youth and adults with autism can participate partially or fully in different ways, just as most youth and adults without autism do. Encouraging participation and service to others is important for the individual as well as the community.

The following suggestions are based on the approach that was used with a particular individual with autism:

- Greet people with a smile, and hand out service bulletins.
- Gather up the bulletins and papers left in the pews after the service, restoring order to the sanctuary.
- Carry the offering plates to the safe following service.
- Deliver crackers and juice to the little ones in the preschool classes.
- Collect and deliver Sunday School attendance records to the attendance clerk.
- Assist in the delivery of cards or food to homebound individuals.
- Participate with deacons in the packaging and delivery of food and toys to the needy during the holidays.

Christmas

Christians celebrate the birth of Christ with much pageantry, tradition, and cultural ritual. Augmenting the typical worship service adds to the richness of meaning, while making the celebration more personal.

-- Talk about the spiritual aspects of the Christmas time in normal daily conversations. Describe the upcoming ritual and pageantry through simpler methods, such as through pictures, role-playing, and storytelling.

-- Bring a special item that might represent some element of the holiday celebration that can be held during worship. It may be a piece of textured "swaddling cloth," a shiny star, nativity figures, or cinnamon sticks. One symbolic item brought forth at the right moment may become part of the holistic experience of celebration.

-- During the service, follow along in the bulletin and prepare the individual for the moment any loud, dramatic music is to occur. Covering the individual's ears and

gradually uncovering them may work. However, be prepared if does not; what is musical to one person may be cacophonous to another.

Giving Gifts -- A Unique Approach

One church that I know has a wonderful celebration in early December where they gather to recognize the natural talents and spiritual gifts of its members -a bit of a twist on the gift-giving theme. From young to old, with talents that range from the artistic and musical to gifts of compassion and hospitality, many are recognized and encouraged. It would be a wonderful tradition for any church to duplicate.

As for the individual with autism, I know of one individual who has amazing attention to visual detail, which could be displayed with examples of his or her favorite pictures. I know of another person who has the warmest smile I have ever seen. This friend also demonstrates amazing altruism, and would make a wonderful greeter.

Community Responsibility

Introduce the concept that the responsibility for every member of the congregation is a corporate, shared responsibility. This is a true fellowship. The participating and inclusion of the individuals with autism should not rest on the shoulders of one or even a few volunteers who are "trained" or "assigned." Children and youth will need guidance to facilitate inclusion, as will many adults. Gradually, the focus of special assistance should fade as everyone accepts shared responsibility.

It takes effort and intention to help a person with autism discover his or her gifts. But in doing this exercise, we all would be challenged to focus on what the individual can do. By providing for inclusion of one individual, we meet the needs of each individual in the family by allowing their full participation in a faith community.

Terry Connolly is the mother of five children and an active member of the Highland Baptist Church in Louisville, KY. She has a Master's degree in Special Education and provides consultation and training in early childhood development.

The Jewish Perspective

By Joshua Weinstein

Before Passover, my other children enthusiastically presented me with the projects they had made in Yeshiva (Hebrew school). My heart sank when my son who has autism and attends a public school brought me his book bag, which I opened only to find the Easter egg he had painted in class. My son knows how to say the "Shema" prayer, but can also tell me stories about Santa and the Reindeer.

We have accepted that God has chosen for us to have a child with autism. When he became of school age and we sought to provide him with Jewish education, we were extremely disheartened to learn that not a single school program existed that would serve the needs of Jewish children with autism. Doesn't each and every Jewish child deserve the opportunity to receive a Jewish education to the best of their individual abilities?

-- Excerpt of a letter from a parent to the Shema Kolainu School

This was my first introduction to the pain and feelings of a Jewish parent on her inability to send her child to a school of her choice that would help keep the family identity. There were no Jewish schools using ABA (Applied Behavior Analysis, an intensive behavioral intervention technique) for children with autism anywhere in the United States.

Since I founded Shema Kolainu, the first Jewish school using ABA on a one-to-one basis for children with autism in the US in 1988, we have been flooded with phone calls from heartsick parents on a daily basis. Although not a religious school, Shema Kolainu fulfills the need to learn about Jewish culture and heritage as well as focus on the bilingual needs of its students. Our programs and services are designed to accommodate a broad range of functional levels and varying degrees of disabilities. Students are taught about Jewish holidays through music and arts and crafts, to give tzedakah (charity) at circle time, to say and read the Aleph Beth (alphabet), and are taken to a matzo bakery to bake matzo's before Passover, to name a few.

The official name of our school is Shema Kolainu, which means Hear Our Voices. Hearing the voice of the child and the family means assisting the child to reach his or her potential both in an academic setting as well as a community setting. It is not enough for a child to achieve in the classroom and then not have the skills needed to be successfully integrated into their community and partake of his or her own culture and heritage. This is extremely important and beneficial for the individual with autism, the family, and the community at large.

Rituals and Individuals with Autism

Children who have Autism Spectrum Disorders benefit greatly from consistency. The Jewish religion has practices such as daily prayer and weekly ceremonies in a synagogue. One mother told me of how her 16-year-old daughter who has autism attends synagogue each week, uses a prayer book, and even answers "AMEN" along with the congregation. A local synagogue gives a young person with autism the honor of collecting the prayer books after services.

Below are other examples of activities on which children with autism maybe encouraged to participate:

- Opening and closing the ark before the Torah (Jewish scripture) is read,
- Helping the reader turn page numbers

- Assisting in preparing and setting up the kiddush (Sabbath reception)
- Helping to put away the prayer shawls after services

Familiarity with these practices from an early age promotes greater inclusion into the community as adults and helps some children to better understand their cultural and religious practices.

Special Ceremonies

Ceremonies can be a wonderful and meaningful experience for both the Child and his or her family. When a Jewish child turns 12 or 13 years old, he or she under- goes a ceremony called a Bar Mitzvah (boys) or Bat Mitzvah (girls), which symbolizes entrance into the realm of adulthood and the observance of mitzvahs (positive deeds).

A child with autism, depending on his or her functioning level, can participate in a variety of ways:

- Some may be called to read from the Torah,
- Others may recite a passage from a prayer book
- Still others may recite a Bar Mitzvah speech

One family chose to make a Bar Mitzvah for their son with autism. They invited family and people who had made a difference in their son's life over the years. The mother says emphatically that this was the best decision she has ever made. Her son enjoyed the ceremony and reception, and the family felt comforted knowing that they were surrounded by people who love and support them. Their son's favorite activity is to look through his Bar Mitzvah album and watch himself on the video.

Holidays

The holidays can be a stressful time for a person with autism because it is a breach in their daily routine. If a child is educated about the holidays before they arrive, he or she will be more comfortable and feel at ease. This, in turn, will alleviate much stress from the family.

It is important, therefore, to remember to apply the techniques used to involve the individual with autism in daily activities to these special activities. The individual with autism may be asked to participate at some level in many rituals or ceremonies, such as:

- The weekly Sabbath festivities in the home,
- The Sabbath festivities at the synagogue,
- The Passover Seder,
- Chanukah candle lighting

All of these activities create a bonding between parent and child and the

community at large.

Judaism and Special Children

Judaism has strong traditions regarding special children. It is said that the Chazzan Ish, a great Rabbi, always stood up when a special child entered the room because he said that their souls are lofty and pure.

Even so, a local synagogue may need some guidance and sensitization to the needs of its special congregants. If there are issues that arise concerning a person with autism or other special needs, it is a good idea to set up a private appointment with the rabbi.

Issues that can arise may include a child's disruptiveness during services, inclusion into youth group activities, and fostering greater understanding and sensitivities from members of the congregation toward the population with autism.

Inclusion of people with autism and other disabilities into our community and places of worship is beneficial to us all. We can all learn a tremendous amount from them about patience, perseverance, dedication and sincerity.

When we introduce an individual with autism into a religious community and help them relate to the holidays, customs and celebrations become more meaningful to everyone. This, in turn, helps those in the community understand the child better as he or she performs certain rituals together. This brings parents and siblings closer to their child with autism and benefits both the family and everyone close to them.

It may sound cliché, but the following statement is both apt and true: "Families that pray together, stay together."

Joshua Weinstein, M.Ed., MBA, is the President and founder of Shema Kolainu - Hear Our Voices, the first Jewish school for children with autism in the US.

Step Three Summary

Although there will be days when you feel all alone, remember that there are supports available to you. Find the source of support that makes most sense for you, whether it is support from friends, from family, or from more official support services such as support groups or respite care. Realize that you are not alone and you are not the first person to raise a child with this disability. Seek out help when you need it. With some creative thinking, you can still have your child involved in religious activities (if those are important to you and your family). You can also call a local support group for suggestions when difficult situations arise or for support when you just feel overwhelmed. You can call for a respite provider when you need a break but are anxious to ask a friend to watch your child. Identify for each of the family members and friends how they feel they can best help so you will know who to go to for each need (respite, emergencies, consolation, education, etc). Support is available to you; you just need to be willing to ask for it.

