



MO-FEAT

Missouri Families for Effective Autism Treatment



Get ready to **MOVE YOUR FEET**
for MO-FEAT—May 1, 2010

NEWS AND NOTES

Siblings and Autism

Funny, painful, and frustrating are just some of the words that 14 year old Renee Lohan of Washington, Missouri thinks of when talking about her brother Jeremy. She, like many siblings of people on the autism spectrum, talks about the added responsibilities autism brings to her life, such as making sure she doesn't leave her makeup out for fear of graffiti on the walls or finding her brother eating her lipstick. *See feature articles pages 3-6.*

Insurance Legislation Frequently Asked Questions

Many families find that insurance companies in Missouri do not cover basic treatment for children with autism spectrum disorders. If families lose their insurance coverage, it is difficult for them to find new insurance to cover medical care for their child with autism, let alone treatment. These issues have driven families to seek fair and equitable legislation for insurance coverage. Find answers to common questions about legislation for autism insurance coverage below based on the legislation that was considered in 2009, which will be filed again for 2010.

Why is the bill important?

Research tells us that early and effective treatment is vital for helping children with autism to make maximal progress. Through this bill, Missouri will join 15 other states in requiring insurance coverage for autism-related services.

What types of treatment does the bill address?

This bill focuses on medically-necessary diagnostic and treatment services for autism that are prescribed by a physician or licensed psychologist, including but not limited to speech, occupational (OT), and physical therapy (PT); psychological services; and applied behavior analysis, which research tells us is one of the most effective intervention for autism. *-continued on page 6*

Missouri Autism Commission Subcommittees Discuss Ideas for Goals— Nov. 18

Education: This committee must: 1) Assess special education capacity by region, 2) Develop recommendations regarding certification and degree programs. They are currently conducting a survey of chief academic officers. They are continuing to look at additional goal focuses.

Workforce Development: Initial ideas for goals include: 1) Practical training for employers on employment of people with autism, 2) Develop a task force consisting of state agencies and providers to further examine issues, 3) Emphasis during Transition on job choices, and 4) Address rural transportation needs so that people can get to their job. Discussion of the commission concerned whether an additional task force was necessary.

Health: 1) Develop standards for screening, diagnosis, and assessment of autism spectrum disorders. This goal has been addressed through the Missouri Autism Guidelines Initiative, 2) Review and recommend whether (see page 5)

What is MO-FEAT?

Missouri Families for Effective Autism Treatment (MO-FEAT) is a non-profit 501(c)3 whose mission is to provide education, advocacy, and support for families and the autism community, and to promote early diagnosis and effective treatment.

In This Issue

- Insurance Legislation—1
- Autism Commission Report—2
- Autism at Home Series:
 - Focus on Siblings and Autism—2
 - What is a SibShop—3
 - SE Missouri Autism Center —3
 - Recommended Books—2, 3
 - Siblings: Sharing Our Stories—5
 - Recommended Websites—5
 - 2008 Annual Report—7
 - Don't Pitch It—Pitch In!—8

Happy Thanksgiving!

Autism at Home Series



Focus on Siblings & Autism

Renee Lohan, a 14 year old from Washington, Missouri, is an exceptional young woman. This March, she was recognized as a role model for other youth when she received the *Do the Right Thing* award given by KMOV Channel 4 in partnership with the St. Louis Metropolitan and County Police Departments, St. Louis Suburban Journals, and Cooperating School Districts. Renee received the award for her work with young children who have autism, just as her brother Jeremy (age 4) does. "She is making a difference in our community and no doubt will be an extraordinary adult," her mother, Beth Lohan, said.

Renee says that despite the difficulties autism can create at home, the moments shared *because* of autism are what we should try to remember above all. "Sometimes I wish he didn't have autism. I would like to know what it's like to have a neurotypical younger sibling but then I realize that some of the best moments with him wouldn't have happened if he were neurotypical. He wouldn't care where I was all the time and stuff like that."

Renee's mother, Beth Lohan, finds that it is often difficult to balance parenting a child with autism with attentiveness to siblings. "I feel Renee's childhood is so different from that of her older siblings in both good and bad ways." Yet Beth also sees many positives too. "She is more mature and so much kinder than her siblings were at this age. Renee is such a strong and kind young lady." Renee interviews her friends and their parents before she deems them worthy to spend the night. "She is very clear that there is nothing 'wrong' with her brother that they are coming into HIS environment and that's just that. I am humbled by this quiet act of kind-



Renee's younger brother Jeremy, age 4, has autism.

Read letters from Renee and others about their experiences as siblings on pages 4-5.

ness from her in consideration for her brother," says Renee's mom.

Renee volunteers by helping her brother and other children on the spectrum. She works with a 3 year old boy who is non-verbal at Gateway Center for the Arts in Washington during sensory and social skills classes. Renee stands or sits with him, holds him and offers comfort. A natural at providing supports, she does 'hand-over-hand' teaching with him week

after week, and he now he holds out his arms for her when he sees her. She provides child care during parent group meetings, and assists children with autism at Exceptional Equestrians and at a tennis class. "If she had a nickel for every time she's been hit with a tennis racket or ball, she would have enough to purchase her first car." says her mom.

Beth is quick to point out that Renee is still a typical teen who feels it is abusive that soda isn't allowed in the house because of her brother and has a cell phone attached to her hands, texting day and night. Then she recalls, "When my husband and I went through parent training, she was right there at our side learning everything as well. She understands when her brother needs to be "squished" or needs to "roll". She lays on the floor with him, they hug and she rolls them over and over."

Recommended books for siblings:

[Autism and Me: Sibling Stories](#) by Ouisie Shapiro and Steven Vote (2009)

[The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs](#) by Don Meyer and David Gallagher (2005)

[Everybody is Different: A Book for Young People Who have Brothers and Sister with Autism](#) by Fiona Bleach (2002)

Find more books on sibling relationships, as well as children's books about autism, on the booklist at our website, www.mofeat.org. Click on the Resource tab.

What about the siblings?



Adult Siblings Share Their Stories

Many adults siblings of individuals on the autism spectrum find themselves reminded of a childhood very different from their friends. Sheli Reynolds, Director of Individual Advocacy and Family Supports at the Missouri Developmental Disability Resource Center at UMKC, writes "Having a sibling takes you down a different path in life. . . For some siblings this path is just something they experience and move on from. For me this path has helped me to become the professional I am today. Eric is my mentor, my teacher, my friend and most importantly my brother."

Inga Mockapetris is also an adult sibling of a brother who has autism. She writes of her brother, Tony, and captures her feelings of both longing and contentment. "I wish I knew what makes him smile, lightens his heart. I know he will never be able to tell me in a card or a phone call. But, when we sit at the park with our ice cream & he looks at me with that smile I know that we're going to be just fine the way we are."

Don't miss Sheli and Inga's stories on the next page.

What is a SibShop?

What are they: Sibshops are best described as opportunities for brothers and sisters of children with special health care and developmental needs to obtain peer support and education within a recreational context.

Who attends: Originally developed for eight-to thirteen-year-old siblings of children with developmental disabilities, the Sibshop model is easily adapted for slightly younger and older children.

What they do: The Sibshop model intersperses information and discussion activities with new games (designed to be unique, off-beat, and appealing to a wide ability range), and fun, recreational activities to enjoy together. SibShops are not designed to focus on any particular disability. They focus more on creating developmentally appropriate opportunities for discussion instead of teaching about disabilities.

How to find them: <http://www.siblingsupport.org/sibshops/find-a-sibshop>

Southeast Missouri Autism Center Officially Opens in Cape Girardeau

The Southeast Missouri Autism Center is officially taking appointments for autism evaluation. They are currently housed in the Southeast Innovation Center, located at 920 Broadway Suite 104, Cape Girardeau MO 63701 until their new center is completed. Connie Hebert, Director of the clinic says the new facility will house the University Diagnostic team, The Tailor Institute, and Touch-Point Autism Services (formerly Judevine Center for Autism) where each will continue to provide quality services and therapy.

When the new center opens, they will provide additional services for treatment and therapy in coordination with the in-house collaborators as well as other University and community programs and providers. Services may include social groups and clubs, support groups, parent education programs, professional development workshops, summer experiences and other specialty and event programming, she said. For more information or to make an appointment, call (573) 986-4985.

Recommended books for Parents:

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

Edited by Stanley D. Klein, Ph.D., and Kim Schive. Over sixty short essays by "veteran" mothers and fathers of children with varying disabilities tell the stories they wish they could have heard when they learned their own child's diagnosis.

Reflections from a Different Journey: What Adults with Disabilities Want All Parents to Know

Edited by Stanley D. Klein, Ph.D. and John D. Kemp

Siblings of Children with Autism: A Guide for Families

by Sandra L. Harris, from the Topics in Autism series.

Sharing Our Stories



Sisters Look Backwards and Forward at the Sibling Experience

Renee Lohan, Washington

My name is Renee. I am 14 years old. My little brother is Jeremy, he is 5 years old. Jeremy was diagnosed with autism when he was 2. I'd like to tell you what it's like to have a little brother with autism.

There are a lot of words to describe what it's like: sad, funny, painful, frustrating, jealous, etc. My life is better than some of my friends. I have more privileges. But, I do have to be more responsible than my friends have to be. I can't leave my makeup and stuff laying out in my bathroom or I'll have graffiti on the walls and he'll eat my makeup. It's stressful because it's hard to get homework done because he wants my attention and if I don't listen then he screams and slaps himself and spits and tries to hurt me and my mom. My friends don't get to come over very often and when I have certain friends over, the friends that understand when I explain about autism - they treat him like he is just a regular little kid, we have to wait until he is asleep before we can do anything that we want to do.



Renee and her brother, Jeremy, enjoy being silly together.

It is hard to go to anyplace public. He will be playing and someone will pick on him or bother him and he doesn't have the words to tell them to leave him alone and when he just gets overwhelmed and reacts then he is the one who gets into trouble and he can't tell us what they did to him. The other kids and their parents treat him like he is a freak and I hate that; it makes me really mad. I've learned that Playland at McDonalds is NOT a happy place. Also, I am not able to have any soda, sweets, or things I just LOVE to eat in the house because it either has dyes, high fructose corn syrup or dairy; all things my brother can not

have. And if I smuggle good food stuff in the house, he always finds it. Sometimes I feel jealous because my parents don't get to spend as much time with me.

There are some really good things about having a little brother with autism. I've learned so much about autism; something I didn't even know existed until he was diagnosed. He is a lot more caring than neurotypical siblings are. He does really funny things and he is very bendy and flexible. Even if he gets into trouble, he is still smiling and laughing at anything funny that I do. He wakes up happy and goes to bed happy and is usually happy all day long.

Sometimes I wish he didn't have autism, I would like to know what it's like to have a neurotypical younger sibling but then I realize that some of the best moments that him I have wouldn't have happened if he were neurotypical. He wouldn't care where I was all the time and stuff like that. I love the big squeeze hugs that he gives. And when I'm mad at everyone else, like my mom, I can go to him and he always makes me smile - he has the best laugh. If I had a choice between having a neurotypical little brother or a little brother with autism, I'd chose autism. Jeremy has taught me so many things and I am proud to have him as my brother.

Inga Mockepetris, Ballwin

As a teenager, I was self conscious when I would take my brother out in public. He would make hooting sounds or sit in the middle of a walkway and spin in a circle. I hated the way people stared and would whisper to each other. ("take a picture... it lasts longer" I would mutter).

I suppose I was resentful that I was always asked to babysit Tony when my parents would go out. I wanted to be with my friends. But no one else knew that he liked to be sung to. As we grew older, I became more protective of Tony and only recently learned how really cool of a guy he is. When we walk into a motorcycle shop and the owner knows him by name (he often visits in his day program) it makes me smile. His social life beats mine!

Recommended websites for siblings:

Kids' Health

www.cyh.com/HealthTopics/HealthTopicDetailsKids.aspx?p=335&np=282&id=2305



The Sibling Support Project
www.siblingsupport.org

Sibling Issues

www.nichcy.org/FamiliesAndCommunity/Pages/siblingissues.aspx

Autism at Home Series

I am brought to tears even today when we visit the Botanical Gardens, the grocery store or the Loop in U City and his eyes light up at something. I wish I knew what makes him smile, lightens his heart. I know he will never be able to tell me in a card or a phone call. But, when we sit at the park with our ice cream, and he looks at me with that smile, I know that we're going to be just fine the way we are.

Today, Tony is in a community-based program and still lives at home. Consistency of routine is essential for Tony. During weekends, I take him out in the community, now blind to any look we may get. I encourage him to communicate with others & explain that he uses modified language and some sign language. I will admit I am frightened about his future. We are investigating ways to keep him connected with us as we all get older. My parents are both elderly and are battling health issues, yet being at home with them is part of his routine. Turning his world upside down would devastate him, so we plan to ease him into the best situation we can arrange.

Sheli Reynolds, Kansas City

As I reflect on my life as a sibling, a smile comes to my face. This smile brings with it a full range of emotions; the happiness along with the struggles and lessons learned. This smile is a remembrance of a happy childhood which included a little brother with a developmental disability.

I must point out, this wasn't anything I thought about growing up, it just was the way it was. Eric was a part of our family. He was a brother just like my other two brothers. Granted, he required a different type and level of attention, but in some ways, all four of us did.

If I have to think specifically about Eric, I think about all of the things that he has taught me and our family. He has

taught us the importance of relationships and interactions with others. Some of these interactions showed me the kindness and love that others have, and some taught me exactly how I didn't want to act or behave towards another human being. At times, I have had to learn to swallow both my tears and my pride because of the way someone was treating or talking about Eric. I learned at an early age how to "be the bigger person."

Having a sibling takes you down a different path in life—one where you interact and learn about therapies and medications and systems that you didn't even know existed. You interact with people you would have never have been in contact with. You talk to other families and siblings who are going through the same thing. You learn a whole new language filled with many, many acronyms.

When I was younger I was involved in Eric's IEP's and now that he is an adult, I have been involved in his person-centered plans along with the decisions about his life. Most recently I partnered with my parents to research and find a living arrangement that suited Eric's

Eric is my mentor, my teacher, my friend and most importantly, my brother.



Sheli poses with her twin brother and Eric.

needs and that enabled him to live a happier and more productive life. For some siblings this path is just something they experience and move on from. For me this path has helped me to become the professional I am today.

Eric has given me something I never would have had without having him in my life, and each day that I work in this field, I try to use this experience to create a better system. Eric is my mentor, my teacher, my friend, and importantly, my brother.

(Commission Goals, from page 1) additional autism centers are needed. The committee is learning towards moving to a network to connect providers as most diagnoses are made by community practitioners, and 3) Explore issues regarding prevalence data, 4) Access to specialists and mental health providers.

Family and Individual Supports: 1) Care coordination, 2) Identification of resource needs for families and individuals through a statewide needs assessment, 3) Improved Crisis Care and Prevention of Crises, 4) Improvements in training across agencies that touch the lives of people with autism through identification of councils, committees, and trainings already in place that could be targets for infusion of training, 5) Information for families regarding diagnosis and resources, and 6) services and supports for adults with autism and their families. Next commission meeting is Feb. 2010.

Insurance Legislation FAQ (cont)



Who does this bill cover?

The bill would apply to approximately one-fourth of Missourians whose employer offers a fully-insured health plan. The bill does not apply to individual policies, although it may also mandate that individual policyholders must be *offered* insurance coverage for autism-related services. The bill does not cover businesses with self-



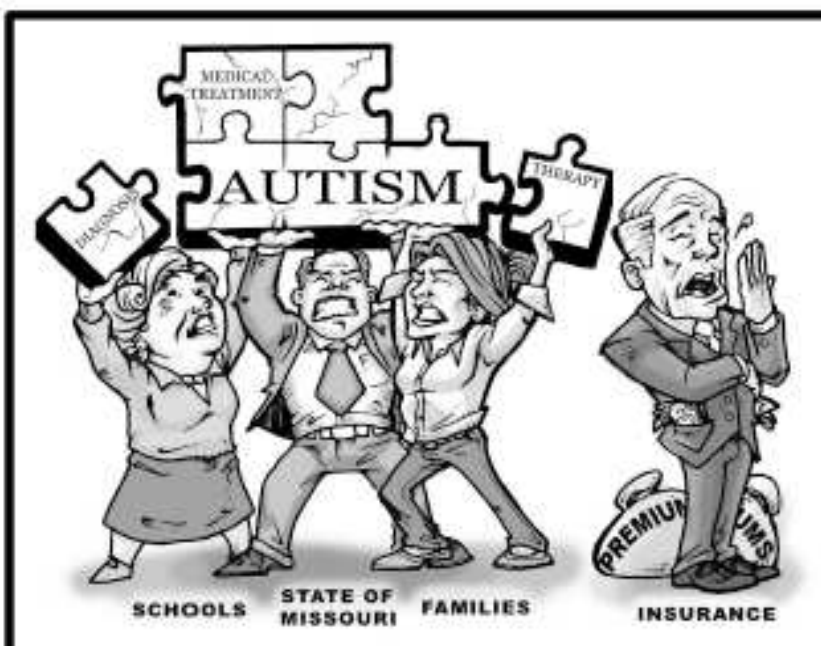
insured health plans, companies that fall under ERISA, or Medicaid plans. Your employer's human resources department would be able to tell you whether Missouri laws affect your insurance policy or not. Some large businesses in

other states, not covered by a law, have voluntarily offered coverage for autism-related services. In Missouri, Children's Mercy Hospital in Kansas City recently agreed to provide coverage for autism diagnosis and treatment for its employees beginning in 2010.

Shouldn't children get treatment through their schools?

Many children with autism receive special services at school that are related to their child's education. However, children with autism often have needs within the medical realm as well. Families need access to behavioral treatment, medical consultation, specialized equipment such as speech generating devices, and additional therapies that the school may not provide.

Who's bearing the costs? It is time to share the load!



All rights reserved. Brian Akles, artist. Contact info@stenoassist.org for reprint info.

Dear Missouri Legislators, What could you buy with 3 quarters, a nickel, and 3 pennies?



1. A bag of potato chips
2. Two stamps
3. 1/3 gallon of gas
4. A month's worth of insurance coverage for a child with autism.

What will you choose in 2010?

What Do Families Think Effective Autism Insurance Legislation Looks Like?

Basic Equitable Coverage of Treatment

- Prohibits the insurer from denying coverage or benefits to the insured person or their dependents based on a diagnosis of autism
- Prevents insurance companies from charging higher co-payments, deductibles, or coinsurance amounts to be applied
- Contains a reasonable definition of autism and of medical necessity
- Includes effective treatment such as applied behavior analysis and speech-language therapy

Reasonable Limits on Coverage & Costs

- Prohibits the insurer from denying coverage or benefits to the insured person or their dependents based on a diagnosis of autism

- Shall not be subject to any limits on the number of visits to a service provider

- Shall not be subject to a dollar amount cap

- Shall cover all prescribed treatment until age 21, equivalent to that provided under Federal and Missouri Medicaid

- Has a mechanism for protecting small businesses in the unlikely event that they incur significant health care cost increases

Reasonable Plans for Compliance and Follow-through

- Goes into effect as soon as possible

- Includes rule-making authority to implement the legislation, given to the Department of Insurance

- Requires tracking of compliance with the legislation or requires the Department of Insurance to report on compliance

Annual Report



2008 Board of Directors

Executive Director

Anne Roux, M.A., CCC-SLP

Officers

Steve Lorberg

President

Colin Peeler, Ph.D., BCBA

Vice President

Renee Van Horn

Secretary/Treasurer

Directors

Leonard Green, Ph.D.

Stephen Kanne, Ph.D., ABPP

Patti LaVesser, Ph.D., OTR/L

Michelle Levi-Perez

Kerry Youngerman

Scott Zajac

Community Advisory Board

Tanya Bergantz

Anna Leitch, R.N.

Dana Lorberg

Research and Effective

Practice Advisory Board

John Pruett, M.D.

Paul Shattuck, Ph.D.

Technical Advisory Board

Scott Hall

The largest, independent, family-centered autism organization in Missouri since 1997, providing you with resources and supports, information, and advocacy for improved state autism policy

2008 Accomplishments

- Served 2,214 families through phone supports, resource packets, family outings and parent-professional meetings, and presentations.
- Doubled our Autism Resource Directory, to include statewide resources.
- Appointment to the Missouri Commission on Autism Spectrum Disorders.
- Selected to participate in the project to establish screening and diagnostic standards for Missouri; Selected to serve as the family partner on Thompson Center's federal grant.

2008 Fast Facts

- MO-FEAT **served 2,124 families** in 2008, an increase of 80% from 2007.
- We distributed **over 4,000 resource directories** across the state to families and key diagnostic centers

What We Did

Education

- Reached over 600 people through ten Parent-Professional meetings and a social-skills conference
- Gave 5 presentations at professional meetings and multiple talks to grad students
- Literature on autism and intervention
- Lending library of autism-related books

Family Supports

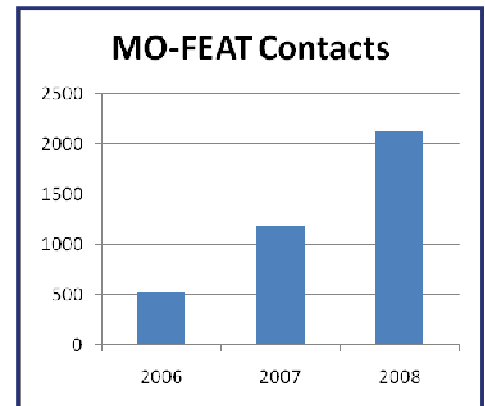
- Phone, email and website supports
- Quarterly family community outings
- Parent-to-parent mentorship program
- Online Missouri autism event calendar
- Participated in the St. Louis Regional Health Commission's committee on children's mental health

Advocacy

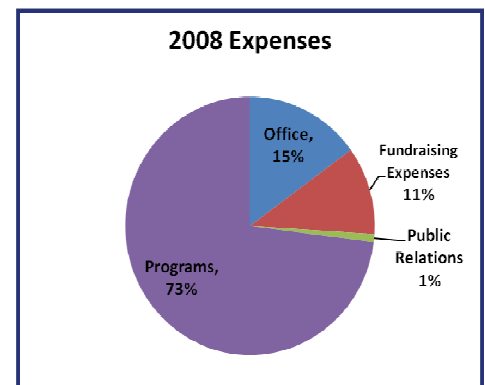
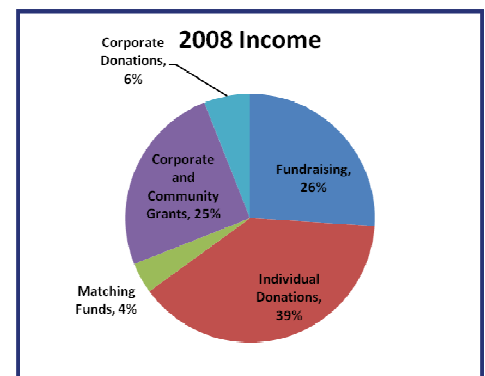
- Leadership within local & statewide advocacy efforts for autism
- Educated legislators about family need for autism insurance coverage

Families Say We Help Them Find...

- **Community**—a support network
- **Hope** that things can get better
- **Normalcy** in their lives by connecting with other families dealing with similar issues



MO-FEAT continues to nearly double the families we serve every year.





MO-FEAT

Visit our ever-expanding website at www.mofeat.org

Sign up for our **MO-FEAT List-Serve** bringing you information on events around the state, Missouri autism news, and important information updates.

Submit your questions on our **Ask the Expert** forum. Our current topic is Special Education and Autism. Read the answers to the ABA forum.

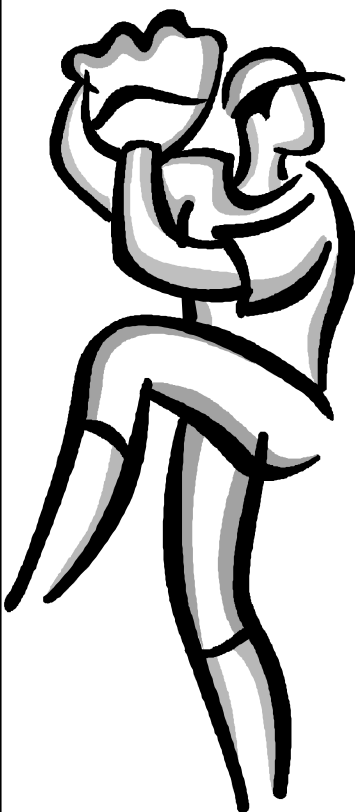
Fill out a form to become a **volunteer assistant** in our office for a variety of office tasks.

Check out our lists of recommended books and websites. Order from Amazon right from our website and MO-FEAT will receive Amazon gift-cards to help us stock our lending library!

Like what we're doing?

Make a secure, online donation today and help us expand our efforts. We're seeking donors to sponsor a collaborative Navigation Guide for Understanding Education for Missouri Students with Autism, and a Guide to Adult Services and Supports for Autism in Missouri. We are also seeking donations to fund our new tri-fold brochures for doctor's offices.

The MO-FEAT Resource Directory is now online! Search for the resources you need by topic and by region of state. Includes nearby Illinois and Kansas as well!



Don't Pitch It—Pitch In!

Don't know what to do with old books or therapy materials? We know families and schools who could use them!

Do you have ABA materials or other therapy items that you aren't using any longer? We have started an ABA lending library and are asking for your donations of gently used items. We are also accepting donations of books on subjects related to autism for our book lending library.

Last, we are in need of a storage cabinet for the ABA lending library.

Thank you for your donations!

NOW AVAILABLE

2009 MO-FEAT Autism Statewide Resource Directory

Navigating Autism Services: A Community Guide for Missouri

Produced through a family-professional partnership between Missouri's Office of Autism Services and MO-FEAT.

These resources can also be downloaded from our website at www.mofeat.org.

Families may request a print copy by calling 314 993-0806 or 1-877-275-8988, or e-mail us at info@mofeat.org. Please provide us with a mailing address.

Donations are appreciated to cover the cost of printing and mailing.