

ASIF Family Brief

Towson University/MSDE/NIDRR

Winter 2015

Topic: Advocacy

Many families of children with autism advocate for their children so that they can receive the appropriate services and treatments. This advocacy role can be challenging if parents are not equipped with information and resources. Below you will find some of the challenges and recommendations our families reported about advocating for their child.

Challenges Faced by Families

- ❖ Preparing research to get your child additional services
- ❖ Time and monetary costs of advocating for child
- ❖ Fewer support and advocacy groups for fathers
- ❖ Finding appropriate information on advocacy and services
- ❖ Friction with education and treatment providers
- ❖ Resistance from school and health systems to get children services
- ❖ Children having few opportunities to speak and advocate for themselves
- ❖ Finding credible advice from advocacy and resource services that do not have first-hand experience with autism

"We are their voice so I think parents should get involved and never give up on their kids, 'oh he's autistic or she's autistic and there's not much you can do so whatever happens it's okay.' No. Give them the chance to push and it's going to work out." - Parent

Recommendations from Families

- ❖ Conduct yourself in a business-like manner and have questions prepared before IEP meetings
- ❖ Network with other families through blogs, parent-teacher meetings, and support groups for advice and instructions on advocating for your child
- ❖ Research and study autism and available services
- ❖ Be involved with the school and communicate with your child's teacher
- ❖ Hire an educational or family lawyer when important issues arise
- ❖ Consider arbitration or appeal if your request is denied

Resources Reported from Families

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- ❖ [Department of Disabilities E-mail listserv](#)
- ❖ [Guy Talk – Support Group for Fathers](#)
- ❖ [Parent Blogs](#)
- ❖ [PTA Meetings](#)
- ❖ [Developmental Disabilities Administration \(DDA\)](#)
- ❖ [National Alliance on Mental Illness \(NAMI\)](#)
- ❖ [Kennedy Krieger Institute](#)
- ❖ [Autism Speaks](#)
- ❖ [Autism Society of America](#)
- ❖ [Maryland Coalition for Inclusive Education](#)
- ❖ [Maryland Coalition of Families for Children's Mental Health](#)
- ❖ [Pathfinders for Autism](#)

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Published Research Related to Topic

Summary

Parents of children with autism transition into an advocacy role in order to obtain services for their children. Mothers report that their motivation for advocating comes from a desire to change things for their children and to help other families avoid the same challenges they face. Such parent empowerment is associated with fewer mental health problems and greater acceptance related to their child's autism

References

- Ryan, S., & Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*, 43 – 53. doi: 10.1111/j.1468-3148.2008.00438.x
- Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Vecili, M., & Lunksy, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism, 0(0)* 1 – 14. doi: 10.1177/1362361311422708

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Topic: Case Management

Families of children with autism often benefit from someone who helps them find, obtain, and monitor their child's services. Sometimes this person is a hired professional called a case manager. Other times, the family members themselves fulfill this role. Below are some of the challenges and solutions to accessing case management services.

Challenges Faced by Families

- ❖ Finding and getting services
- ❖ Handling disagreements with service providers
- ❖ Understanding the IEP process and other entitlements
- ❖ Managing the child's transition into adulthood

"You have to show that you're involved... You have to make sure you know the teacher. I personally know [their] e-mail, phone number, cell phone number, and then some. I'm not the type of parent that will be at every field trip, but I'm the type of parent that will call her once a week and say we need to meet." - Parent

Recommendations from Families

- ❖ Seek out service providers that have a case management program
- ❖ Establish and maintain open, honest communication with your child's teachers and service providers
- ❖ Use the internet to look up information about
 - Available services in your area
 - The IEP process
 - Other entitlements
- ❖ Start the transition process early

Resources Reported from Families

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- ❖ Autism waiver coordinator
- ❖ School transition coordinator
- ❖ Child's primary teacher
- ❖ The agency providing direct services to your child
- ❖ Maryland Coalition of Families for Children's Mental Health
- ❖ Social service agencies
- ❖ Disability service agencies
- ❖ The Arc
- ❖ Autism Society
- ❖ Pathfinders for Autism
- ❖ Autism Speaks
- ❖ Division of Rehabilitation Services (DORS)

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Published Research Related to Topic

Summary

Children who have someone to help coordinate their special health care needs, including autism related services, receive more specialty care services than children who do not. Also, parents who coordinate with their child's providers report that the services more positively impact their family's functioning. They also report lower stress related to parenting their child with autism.

References

- Boudreau, A. A., Goodman, E., Kurowski, D., Perrin, J. M., Cooley, C., & Kuhlthau, K. (2014). Care coordination and unmet specialty care among children with special health care needs. *Pediatrics*, *133*(6), 1046-1053. doi: 10.1542/peds.2013-2174
- Warfield, M. E., Chiri, G., Leutz, W. N., & Timberlake, M. (2013). Family well-being in a participant-directed autism waiver program: the role of relational coordination. *Journal of Intellectual Disability Research*. Advance online publication. doi: 10.1111/jir.12102

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Topic: Finances

Many families report financial issues related to their child with autism. Financial issues can put a strain on the children, parents, and the overall quality of life of the family. However, there are many resources, pieces of information and helpful tips that can help families overcome financial burdens.

Challenges Faced

- ❖ Paying for resources out of pocket
- ❖ General financial challenges
- ❖ Health insurance coverage/deductibles
- ❖ Autism-related financial burdens
- ❖ Non autism-related financial burdens
- ❖ Finding financial assistance resources
- ❖ Qualifying for financial assistance resources
- ❖ Guardianship/future financial worries
- ❖ Impact on social activities
- ❖ Lack of family financial support
- ❖ Changing employment/schooling to manage responsibilities

“The finance part I’m dealing with right now, but the main thing is taking care of kids with special needs when they get older. That’s the main thing. Something has to happen for them. And another part of that is finding somebody that if anything were to happen to me or my husband, finding somebody that’s gonna take care of my son’s finances properly” - Parent

Family Recommendations

- ❖ Hire an educational consultant
- ❖ When completing applications, fill in the remarks and comments columns with all of the behaviors and reasons you can think of why you qualify for assistance.
- ❖ Shop consistently at a store that will give you discounts and rebates for loyalty purchasing
- ❖ Speak with transition coordinators about future financial planning
- ❖ Use listservs and other ways to communicate with other parents for advice

Resources Reported from Families

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- ❖ Local community centers/places of worship
- ❖ Friends/family
- ❖ Local school district
- ❖ Developmental Disabilities Administration (DDA)
- ❖ Low Intensity Support Services (LISS)
- ❖ Social Security Disability Income (SSDI)
- ❖ Division of Rehabilitation Services (DORS)
- ❖ Autism Society
- ❖ Pathfinders for Autism
- ❖ Autism Speaks
- ❖ Medical Assistance
- ❖ Pell Grant
- ❖ Social service agencies
- ❖ Disability Service agencies
- ❖ The Arc
- ❖ Local agency grants
- ❖ Listservs
- ❖ Free/discounted passes for national parks, amusement parks
- ❖ Maryland Coalition of Families for Children’s Mental Health
- ❖ Benefits/services from employers

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Published Research Related to Topic

Summary

In general, parents of children with autism earn less income than most other families, including those with typically developing children and children with other disabilities. These parents also report that their child's autism has a larger financial impact on their family than parents of children with other disabilities. Annual financial planning can help prepare families for the long-term costs associated with caring for a child and young adult with autism.

References

- Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics, 129*(4), 617 – 623.
- Sharpe, D. L., & Baker, D. L. (2011). The financial side of autism: Private and public costs. In Mohammadi, M. (Ed.), *A Comprehensive Book on Autism Spectrum Disorders*, 275-296.
- Zablotsky, B., Kalb, L. G., Freedman, B., Vasa, Roma, & Stuart, E. A. (2014). Health care experiences and perceived financial impact among families of children with an autism spectrum disorder. *Psychiatric Services, 65*(3), 395 – 398).

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Topic: Health Services

Children with autism have the same range of medical needs as children without autism, if not more. However, accessing health services for children with autism can be challenging for parents and families. These challenges will be discussed in the following brief and recommendations from families of children with autism will be provided.

Challenges Faced by Families

- ❖ Finding the right health service provider to meet your specific needs
- ❖ Lack of collaboration with caregiver(s)
- ❖ Managing medications
- ❖ Managing multiple health service providers
- ❖ Quality of relationships with providers
- ❖ Managing your child's other mental health and physical needs
- ❖ Health providers not understanding autism (e.g. pediatricians and dentists)
- ❖ Out of pocket medical expenses
- ❖ Health insurance coverage

"We're lucky our general practitioner is here, our doctor himself has an autistic child...he's much more accepting of the idea that he does not know all the answers...that's the biggest thing in that respect, is whether or not the doctor, the trainer, whoever, is actually listening to you." - Parent

Recommendations from Families

- ❖ Seek referrals from professionals and family/friends you trust
- ❖ Have ongoing communication about your specific needs with your health service provider
- ❖ Shop around for providers
- ❖ Consider complementary or alternative health services and/or second opinions
- ❖ Seek public funding for health services

Resources Reported from Families

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- ❖ Friends/family
- ❖ Social worker/case manager
- ❖ Family pediatrician
- ❖ Educational service providers (e.g. teacher, nurses, psychologists)
- ❖ Division of Rehabilitation Services (DORS)
- ❖ Autism Society
- ❖ Pathfinders for Autism
- ❖ Autism Speaks
- ❖ Medical Assistance

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Published Research Related to Topic

Summary

Parents of children with autism are more likely to report unmet health care needs for their child. They are also more likely to point out the provider's lack of skills in treating their child as preventing them from obtaining needed services.

If the child with autism also has other medical conditions, parents are more likely to report problems with services when they experience:

- ❖ Problems in their relationship with their child's provider
- ❖ Inadequate insurance coverage
- ❖ Unreasonable healthcare costs

When doctors and parents have equal roles in the decision-making process, parents report:

- ❖ more satisfaction with their child's services
- ❖ more helpful guidance about treatment options

References

- Ahmedani, B., Hock, R. M. (2012). Health care access and treatment for children with co-morbid autism and psychiatric conditions. *Social Psychiatry & Psychiatric Epidemiology*. 47,1807-1814. doi: 10.1007/s00127-012-0482-0
- Brown, J., & Brown, J. (2014). Dental services for children with autism spectrum disorder. *Learning Disability Practice*. 17(3), 20-25.
- Chiri, G., Warfield, M. E. (2012). Unmet need and problems accessing core health care services. *Maternal and Child Health Journal*. 16,1081-1091. doi: 10.1007/s10995-011-0833-6
- Golnick, A., Maccabee-Ryaboy, N., Scal, P., Wey, A., Gaillard, P. (2012). Shared decision making: Improving care for children with autism. *Intellectual and Developmental Disabilities*. 50(4), 322-331. doi: 10.1352/1934-9556-50.4.322

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Topic: Informal Support

Informal support from family and friends can be very helpful for families of children with autism. Family and friends can help provide a range of support from emotional/moral support to financial assistance. There can be challenges, however, to relying on friends and family for support. Our families shared some of those challenges and offered some solutions.

Challenges Faced by Families

- ❖ Finding and keeping a babysitter
- ❖ Family and friends who don't understand autism
- ❖ Making time to spend with family and friends
- ❖ Family and friends who live far away

*“It took a village to raise [our child].
We thank God we had a village.” - Parent*

Recommendations from Families

- ❖ Offer to pay or trade favors for help from your family and friends
- ❖ Seek emotional support from other parents of children with autism
- ❖ Educate your family and friends about autism
- ❖ Consider moving closer to family/friends or other service providers

Resources Reported from Families

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- ❖ Local community centers and/or places of worship
- ❖ [Autism Society](#)
- ❖ [Pathfinders for Autism](#)
- ❖ [Autism Speaks](#)
- ❖ [Maryland Coalition of Families for Children's Mental Health](#)
- ❖ Neighborhood association listservs

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Summary

For parents of children with autism, informal support from family and friends is associated with

- ❖ higher well-being
- ❖ fewer mental health problems
- ❖ less chance that stress will lead to isolation

These supports help parents no matter how much autism impacts their child's behavior.

References

- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*, 39–52.
- Ekas, N. V., Lickenbrock, D. M., Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 40*, 1274-1284. doi: 10.1007/s10803-010-0986-y
- Lovell, B., Moss M., Wetherell, M. A. (2012). With a little help from my friends: Psychological, endocrine, and health corollaries of social support in parental caregivers of children with autism or ADHD. *Research in Developmental Disabilities, 33*(2), 682-687.
<http://dx.doi.org/10.1016/j.ridd.2011.11.014>
- White, N. & Hastings, R. P. (2004) Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 181–190