

**NEEDS AND PREFERENCES FOR
INFORMATION AND SUPPORT FOR FAMILIES
OF CHILDREN AND YOUNG ADULTS WITH AUTISM:
RESULTS OF FOCUS GROUPS**

**Final Report
August 2008 ***

Executive Summary

As part of its preparation for developing a series of training opportunities for Kansas families with autism, The University of Kansas Life Span Institute Center on Autism conducted a series of four focus groups to learn about information needs for parents of young as well as older children with autism. We conducted the four groups in Wyandotte and Johnson County; total participation was about 60 parents. Highlights of findings include:

1. Parents want better training for professionals in educational and community settings (e.g., child care) to enable them to meet the unique needs of individual children.
2. Parents want more social and community opportunities for their children.
3. Parents want a wide range of information topics covering all aspects of information needs, including financial planning, participation with educational decision-making, learning more about resources, managing daily life, helping children with their learning, behavior management, and daily hygiene.
4. Parents prefer to receive information from other parents.
5. Parents want a central clearinghouse for information that included an immediately available “hotline” for responding to urgent questions or needs for support.
6. Parents find attending face-to-face symposia difficult with all their other obligations and emphasized the need that such training opportunities would need to include child care.
7. Parents want information available in alternative formats in addition to face-to-face symposia or workshops, e.g., print materials, on-line materials.

* Please see Appendix A for the Summary Report October 2008 of the Parent on-line Survey. These findings from 43 participants in Kansas and Missouri support the recommendations found from the focus group participants.

Introduction

In 2007, the University of Kansas Life Span Institute (LSI) received support and a mandate to launch a Center on Autism. Its purposes are to conduct research on causes and treatments of autism and to provide training to meet needs of families and professionals who are serving children and adults with autism. The Kansas Department of Social and Rehabilitation Services awarded a contract to the LSI Autism Center to provide training to parents in the form of workshops or seminars. As part of that work, we decided to conduct a series of focus groups with parents to learn more about their training and information needs and preferences.

Dr. Debra Kamps, Director of the Kansas Center for Autism Research and Training “K-CART”, convened a small Task Force to organize and conduct the focus groups. The Task Force consisted of two parents of young adults who are involved in providing family support services through the University of Kansas Medical Center, and one LSI professional with experience in designing, conducting, and analyzing focus group data. The primary questions to be addressed through the focus groups were:

What type of supports do you currently have or need to manage daily activities for your child/young adult with Autism Spectrum Disorders and your family?

What topics for seminars are of interest to you and your family?

What supports, training, service needs do you foresee for the future for your child and family?

Method

The Task Force met to discuss the development of specific questions, sampling plans, and recruitment of the focus group participants.

Sampling and Recruitment

The primary goal in focus groups is to create a purposive sampling plan to recruit participants to a series of focus groups, each designed to accommodate a homogeneous group, but across the series to reach diverse groups. We decided that two key factors might lead participants to have different responses to our questions: (a) location in middle- to lower-income areas, and (b) parents of younger versus older children. This led to a 2 x 2 design for the focus groups: two groups held in Wyandotte County (one for parents of younger and one for older children), and two groups held in Johnson County. We made an attempt to organize a focus group in western Kansas, but logistics and schedules could not be accommodated. The concentration of the sample in Eastern Kansas is a limitation of the study that should be addressed in the future.

We recruited participants for the four groups through parent organizations in both counties, including the Autism Society of the Heartland in Johnson County and Families Together in Wyandotte County. Coordinators of these organizations sent an invitation letter to their members with the purposes, dates, times, and locations of the groups.

Overall attendance at the focus groups totaled about 60, ranging from 5 to over 40 participants in individual groups. Participants were predominantly mothers, but about 15 fathers in total attended the groups with their wives.

Procedure

To accommodate participant schedules, we scheduled two groups for an evening and two for a Saturday morning. We offered light snacks and an appreciation gift bag (teas, lotions) to the participants. Participants were seated around a large conference table.

At the beginning of the focus group meeting, the Director explained the mission and plans for the new KU Autism Center and the specific purposes of the focus groups. She distributed consent forms and explained the participants' rights to refuse to answer questions, assurances of confidentiality, and what the plans were for using the information. She then answered questions from the participants.

The focus group moderator then began by explaining the general purposes of a focus group and reminded the group of the "rules of the road" of focus groups: respecting others' comments and keeping discussions confidential. She then posed an "ice breaker" question asking parents to give an example of their child's strengths. Following this, she posed the three primary questions noted in the introduction. Throughout the discussions, the moderator added probe questions and follow-up questions to get clarification and expansion of the discussions. She monitored participants to make sure everyone had a chance to contribute.

At the first focus group, we learned that some parents tended to follow another parent's comments about a need with suggestions or resources. To keep the focus on assessing needs, we asked participants to hold discussions of suggestions for solutions after the focus groups. Parents did stay after the groups to share resources and information with each other.

Analysis

All the focus groups were tape-recorded and transcribed. The focus group moderator analyzed the transcripts by first reading all transcripts and identifying three major themes: (a) needs for further training and support services for the son or daughter with autism; (b) needs for training topics and types of supports for family members; and (c) preferences for formats for delivery of information.

Within these three overarching categories, the analyst used a constant-comparison method to identify sub-themes and topics. A constant-comparison method requires the analyst to begin with the first transcript and develop codes representing themes emerging from that transcript. These codes are then used to analyze the second transcript, resulting in a revision of the codes, and so on, through all four transcripts. The basic process results in sorting similar themes into categories and sub-categories to address the primary research questions.

Results

Table 1 provides a detailed listing, for each of the three major themes, of the needs/issues, sub-categories of those needs, and one or more example quotations from participants illustrating those needs. Following are some highlights for each of the three themes.

Needs for Better Services and Supports for Children with Autism

Themes related to additional supports needed to help families manage daily activities resulted primarily in comments about needs for additional professional/provider training and services for the son or daughter with autism. Basically, the message from these participants is that improved educational and community services for children and adults with autism IS a family support, since it would significantly reduce stressors on the family. For example, one parent shared that she had recently completed professional training in a field that would enable her to significantly improve her job prospects. However, she said she could not accept a more demanding job because the school frequently called her and asked her to take her child home when they could not cope with her son's behavior. She believed she needed to stay in her lower-paying job with more flexibility that enabled her to leave when she needed to attend to her son's needs. She believed that better trained personnel, with better resources to support them in the schools, would improve her overall family quality of life and her employment prospects.

Another area of need for services for children and adults with autism, expressed by all four groups but with greater emphasis from parents of older children, was a need for social and community opportunities for their children. Parents wanted more opportunities for peer and social interactions, and more opportunities for children and adults to be integrated in the community.

Information Topics and Needs for Families

No clear priorities for information topics emerged from the comments of these parents. The result was a lengthy list of types of information that would be equally useful to some or all parents. For parents of younger children, the focus was on learning more about the "disability world," including basic information about autism, about partnerships in the education and other decision-making planning processes, and about learning more about "what's out there" and "what to expect." For parents of older children, the requests for information ranged from a need for help in how to accomplish daily hygiene tasks (e.g., how to shave a young man who doesn't like the sound of a shaver and "we can't even think about a razor") to long range financial planning and guardianship.

With regard to support needs, many participants expressed a desire to have more interchanges with other parents, both in face-to-face support group meetings, and in knowing someone to call. Specialized supports for different family members (fathers, siblings, grandparents) were also mentioned.

Preferences for Training and Information Formats

Several patterns emerged regarding preferred formats. First, parents expressed a need for a “hotline,” i.e., a resource to call at any time day or night. A hotline would include urgent evening or weekend issues such as behavior “meltdowns,” as well as immediate answers to relatively simple questions (“I shouldn’t have to make an appointment for a quick question”). Second, and related to a hotline concept, parents emphasized a need for a centralized source of information, a “one stop shop.” Some parents expressed unease about the sensation of “stumbling upon” resources and wondered what else they were missing for their child. This seemed to be an important criterion for a successful centralized clearinghouse – that it would reliably provide up-to-date information on a whole range of information topics, services, and upcoming events.

Third, parents expressed a preference for getting their information from other parents. In all four groups, many participants said they believed other parents who “have been there and done that” were their most trusted source of information. A typical comment on this point was, “it would be neat to have a program to empower a group of parents to run something like an information clearinghouse, since everyone has such good information . . . I mean parents can be so many things that agencies don’t know how to do.”

Fourth, parents were not universally keen on receiving information or training in a more traditional workshop/symposium format. Many noted that their work schedules and family obligations would prevent them from being able to attend, and suggested the same workshop should be repeated several times to accommodate family schedules. Others emphasized that workshops would need to include child care or respite. Several parents noted that some kinds of information might be more useful as printed information (e.g., financial planning information) or available on-line.

Almost all the parents in these four groups had used internet resources to one degree or another. Some said that the internet was their only option because the only time they had to search for information was after their children were in bed. Others, however, expressed ambivalence about this resource because there was an overwhelming amount of information on the web, and because they did not know how to determine what was reliable. However, they believed a web-based resource coupled with a reliable information clearinghouse would be useful.

Basically, the overall conclusion about formats was that parents want a variety of choices about how to get information: in face-to-face meetings, in print format, by phone or “hotline,” and via the internet.

Table 1.
Parent Identified Needs from Four Focus Groups

<i>I. Needs for supports for child or young adult, improved services, and training for providers</i>		
Need/Issue	Sub-category Need	Example Quote
Teacher training issues	General – teachers need to know more	The push now is for inclusion – all teachers need to know more Need trained professionals who understand every child is unique, what works in one situation doesn't necessarily work in the other
	Better training on behavior issues	At the drop of a dime they may call and say, hey you know what, your son is having a behavior issue, come get him . . . They don't want to handle behavior, they do not know how to handle it. . . they find it a lot easier to go ahead and call mom
	Training beyond behavior	Teachers stop short with behavior, don't know what to do next – they need communication and social/sensory strategies, school wide, not just special education
School-based Services	More extensive summer schools	Just a few weeks in summer isn't going to cut it.
	Transportation	I don't have transportation for my child to go to therapy.
School-based coordination	Home school coordination	Schools will say “we know how to handle it” and “we will deal with it” and ignore what the parent is doing. We as parents have learned how to deal with our kids' habits and behaviors. They can not blow you off.
	Regional coordination to share resources	Need regional coordination among school districts to share resources and information about who is doing a good job on what. Some simple organization that might pull these resources together.

Need/Issue	Sub-category Need	Example Quote
Training and services, non-school	Need more providers – need to pay more and provide benefits	<p>Money is available, but not the service providers. We have the funding and the hours, but don't have the people who are trained.</p> <p>You wait five years to get Medicaid and nobody takes it.</p> <p>Need respite care, but also need people you can hire when you do have it.</p>
	Training for day care providers	I work full time 9-5, so he goes to school from 8:30 to 2:30 every day and from 2:30 to 5:30, what is he supposed to do? Last year he went to 8 day cares, he was at one for 2 weeks and she was like I can't handle him.
Social supports and training for kids	Teach social skills	He needs somebody to teach social skills
	Camps and other options	I don't want Special Olympics. I'm afraid he will model inappropriate behavior. I want typical peers
	Typical peer relationships	I would like to see a mentor who can take him to a . . . basketball game with the regular kids. A lot of peer support, a lot of peer interaction
Community support needs, young adults	General lack of resources	We need to have services for older kids geared to those who missed out on early intervention.
	Residential	Living situations for kids after high school who are too advanced for group homes, but not ready to be on their own.
	Job support and development	<p>We need to train transition specialists to look outside the box</p> <p>Need to learn about supported employment</p>
	Community access	<p>Need a young adult program for independent living skills, budgeting</p> <p>More about how to access the community</p>
	Social opportunities	We need a place for kids in their 20s, where they can get together and at least experience some of the things that our other children get to do.

II. Information and support needs for families/parents

Need/Issue	Sub-category Need	Example Quote
General information	General information – unique needs of different children	<p>Every child is different; we need to know how to understand those differences.</p> <p>We need someplace where we can have access to reliable local information that we can use</p> <p>Maybe topics on the spectrum (differences by functioning levels) because I think a nonverbal child faces different issues than a child that is low on the spectrum</p>
	Understanding changing needs	<p>As they get older things change, needs change, and how you communicate with them and the way they interpret the world changes, and it's very frustrating as a parent to try to figure that out. It would be nice if some of the people . . . who have years of experience in this would tell us, 'hey you might want to look at approaching it this way.'</p>
What to expect	Counseling and info for newly diagnosed	<p>You shouldn't have to be like digging for gold . . . kind of like having a map. You're worn out from the day to day and hour to hour. And then when you got time you hunt and dig, pull and tear. It would just be much easier to have a central counselor to tell you all that.</p>
	What to expect	<p>I would like to have a clearly laid out path.</p> <p>Have resources for newly diagnosed parents. You know, just resources on what to look for or to expect.</p> <p>What to expect the first year, what to expect at toddler years, and so on</p>

Need/Issue	Sub-category Need	Example Quote
Information on how parents can work with child	“Little tips”	I need information on all the little things – potty training, how did you get him over the fear of getting on the bus? Drink out of a straw . . . the more options and ideas that people have, the better.
	Helping child academically	I want a book or something with tips on what he can be learning – what parents can teach.
	Behavior	I need information on ABA How to deal with behavior incidents.
Information to improve home-school relationships	How to advocate	I have to dish thousands of dollars to the attorneys to make them do what is on the IEP . . . I need support, the school is so ill-informed, they have no information and they don’t want to know How to advocate. How to write a letter. I want more control of the services
	IEPs	Need help to advocate on the IEP. The IEP isn’t working Parents need people that know autism to come to the IEP meetings with them.
	Building trust with teachers	If you cannot find that trust, then there is a failure there . . . people need to know how to handle IEP meetings but also outside the meetings, with the day to day trust.
Transition to adulthood	Understanding the “relay system”	I want to know more about the future. For now I feel like he is going to have to live with me for the rest of his life and I worry about community homes and that is another big scary thing for me, where is a safe place? Give me the information, just let me know what’s out there.

Need/Issue	Sub-category Need	Example Quote
Financial and legal information	Financial planning	Setting up trusts, financial planning.
	Medicaid and other resources	A topic could be what resources are available through the state and federal Medicaid and then how do you access that? . . . It is almost like you have to belong to a secret society to know exactly how to do it.
	Guardianship	How and whether to get guardianship
Individual family member needs	Fathers	Training for fathers is very important. Dads don't want to talk about autism.
	Grandparents	We need to be able to provide information to grandparents and extended families to enhance acceptance
	Sibling support	My other son is six, what can I do for him? . . . they always say siblings of kids with autism need extra care too. I don't know what it looks like or anything or what it should be.
Medical alternatives	Diet and metabolic issues	Need information on bio-medical alternatives – diet, metabolic issues. Parents want to know about these things and the need to have reputable resources for doing that.
Information and resources for parents to help young adults	Hygiene	How do you teach a nonverbal teenage male to shave, when he doesn't like noise and you can't even think about giving him a razor?
	Sexuality	I am like so scared for when he goes through an adolescent phase—puberty—the “P” word. So maybe topics like that, stages of life.
Emotional supports	Relationships support for spouses	Better ways to communicate in stressful situations with your spouse. Or actually have time with your spouse . . . December was the first time in 10 years we had spent the night without the kids.
	Support groups	Stress relieving things for parents would be good. Is there something within the autism center where we could go . . . and not have to worry about your child . . . and maybe you don't even want to talk about autism.

III. Preferred formats and ways to get information

Need/Issue	Sub-category Need	Example Quote
Urgent information	Hotline	<p>She had a major meltdown . . . and whenever my husband is not around I mean we have holes in the walls. It's scary and there is nobody to help.</p> <p>I need quick and easy information. I can't wait to set up an appointment to ask a simple question.</p> <p>I need information and I need it now.</p>
Information from other parents	Parents are best source	<p>Get involved with other parents and that's how you get your resources.</p> <p>It would be neat to have a program to empower a group of parents to run something like an information clearinghouse, since everyone has such good information . . . I mean parents can be so many things that agencies don't know how to do.</p> <p>Being able to talk to other parents who lived it, breathed it. Other families have been there and done that.</p>
Clearinghouse	One stop shop	<p>What we need is a clearinghouse, one for information and two for training of professionals and teachers, parents and others, coordination of information and coordination of services.</p> <p>One stop shop. It would be nice to have one place you can go to and feel like you are getting some good advice and information that branches you out to other things.</p>
Distill information	Too much information	<p>I am so exhausted from researching sometimes, I have to be intensively involved.</p> <p>Google has a million sites – how do you know what's right?</p>

Need/Issue	Sub-category Need	Example Quote
Alternate languages	Spanish	Need information in Spanish
Home visits	Trainer come to home	It would be worthwhile to have a trainer come to the home and help out with behavior problems, sleep issues, etc.
Printed material	Print material for some things	You need printed information about things like financial planning, knowing about government benefits, that type of thing. If it is printed, at least it puts the idea in your head and then tells you where to go from there.
Face to face versus other formats	Brief	Not all day. Let's not shoot for the moon. We can't do all day. Half a day, with respite care for all kids. And I think a combination of web.
	Combine with other formats	I work full time . . . I can't even make the meetings once a month. So the face to face on a week night or whatever, they are good but not always doable. And I think that is why it has become an option to email back and forth, phone calls and everything.
	Provide respite at trainings	<p>You would have to have respite care for a meeting.</p> <p>Need information and support groups with child care available. In order for it to work, there has to be some way to provide either activities for the kids, child care, something, cause that is the most difficult part of attending any of the events.</p>

**Appendix A:
NEEDS AND PREFERENCES FOR INFORMATION AND SUPPORT FOR FAMILIES
OF CHILDREN AND YOUNG ADULTS WITH AUTISM:
RESULTS OF ONLINE SURVEY
October 2008**

Summary

The Kansas Center for Autism Research and Training disseminated an online survey in addition to the four focus groups that were held in Wyandotte and Johnson County. The total response to the online survey was approximately 43 responses. Highlights of the findings include:

1. Parents want ongoing and accessible training on learning how to support their child at home and in the community.
2. Parents want better training for educators and other support staff (e.g. paraprofessionals, daycare providers, respite providers, mental health workers) who work with their children.
3. Parents want seminars on ABA; diets; therapies; social skill interventions; how to handle behaviors/meltdowns; developing supports/routines in the home; how to plan for and support individuals transitioning from school into the community; and co-existing mental health issues with ASD.
4. Parents want to be involved in the development and decision-making of KCART. Include them on committees.
5. Parents want a centralized system where they can access information on doctors, behavior specialists, and treatment centers. This would also include a lending library.
6. Parents want more rural and regional trainings that: 1. Allow for more interaction between presenter and attendee; 2. Workshops for the parent and child in order to learn how to work with their child; 3. Trainings on adult issues related to supported and/or independent living.
7. Parents would like to see research in the areas of biomedical interventions; medications and how they work; treatment and assessment of gastrointestinal/immune/allergy issues; causes and subtypes of autism; co-existing issues such as sleep issues; and sibling issues.
8. Parents would like to see parents of a newly diagnosed child be provided with case management in order to help them navigate the system.
9. Parents noted the need for better coordination between community groups to support programs, conferences, etc.
10. Parents shared that the high cost of treatment and therapies is a barrier and many families are not able to get those services for their child.

In regards to recommendations for the KCART planning committee it was noted that this committee should “think outside the box” in the planning and development of supports and services.

The online survey supported the results of the four focus groups. Parents of children from ages 2 years through young adults responded to the online survey. Approximately half of the responses were from Kansas parents and the other half were Missouri parents.