

Partnering for Autism

Alison Singer, Ann Palmer and Dr. Patricia Manning

Today's speakers



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Building Supportive Relationships Within the ASD Community

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Importance of Parent to Parent Support

- Connects you with people who understand
- Lessens feelings of isolation
- Connects you with support when in crisis or dealing with challenges
- Promotes sharing of ideas, resources, and experiences
- Improves community advocacy efforts by connecting people

Why Develop a Parent to Parent Support Program?

- To help your staff meet the support needs of the families they serve
- To support families waiting for services
- To connect families with resources in their community

TEACCH Autism Program's Parent Mentor Program

- Started in 1996
- Has assigned mentors to over 1500 families
- Recruit volunteer mentors
- Train mentors
 - Guidelines, confidentiality, listening and providing support, resources in the community
- Match mentors to families

Mentors

- Over 100 volunteer mentors
 - Parents of children aged 3 to 45
 - Parents of multiple children with ASD
 - Parents of children with variety of needs
 - Father mentors
 - Grandmother mentors
 - Spanish-speaking mentors
 - Single parents
 - Parents who have used variety of interventions

Assessing Family's Need for Mentor

- How much support does the family have?
- Is family new to the geographical area?
- Are they asking questions about autism?
- Are they trying to locate resources?
- Has the family shown interest in meeting other parents?
- Is the family dealing with especially difficult issues around their family member with ASD?

Why Develop a Community Support Group?

- Provides support for both families and professionals
- Builds relationships between families and professionals
- Raises autism awareness in the community
- Creates a network for advocacy efforts
- Allows sharing of resources and experiences

Autism Society of NC Chapters

- Chapters established in 1973
- Currently over 50 Chapters across NC
- Chapters follow mission and vision of ASNC
- Chapter leaders are volunteers
- Chapters vary by size, location, needs of the families, how involved they are in the community

Starting a Community Support Group

- Identify need for a support group
- Schedule an Interest Meeting and advertise to reach families and professionals
- Have someone available to facilitate meeting
- During meeting, discuss goals for the group, needs of the community, resources available
- Recruit volunteers to help ongoing with group
- Find location for meetings (school, church, library)

It's easier when you're not going
through it alone.

Community Partnerships

Patty Manning-Courtney, MD

Associate Chief of Staff, Outpatient Services

Co-Director, Division of Developmental and Behavioral Pediatrics

Professor of Pediatrics

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Who am I?

- Developmental/Behavior Pediatrician
- Founded The Kelly O'Leary Center for ASD in 1999
- Current Co-Director of the Division of Developmental and Behavioral Pediatrics at Cincinnati Children's Hospital Medical Center
- Associate Chief of Staff for Outpatient services
- Still see patients
 - New and follow-up
 - Best part of my week

It all started with parents....

- Parents of children with ASD met with institutional leadership to request a more specific program for children with ASD at Cincinnati Children's Hospital Medical Center
- In 1999, The Kelly O'Leary Center (TKOC) for ASD was launched, to provide diagnostic services, treatment options and ongoing medical care to children with ASD
- Parents served as advisors during growth and development of TKOC

Partnering with community agencies

- Many TKOC members have served on the board of the local Autism Society of Greater Cincinnati (ASGC)
- TKOC directors served as ASGC co-Presidents at different times
- TKOC members participate in ASGC events- social and educational

Creating a forum for community connections

- The Regional Autism Advisory Council (RAAC) of Southwestern Ohio was developed to bring together all stakeholders serving children with ASD
 - County Agencies, Education Service Centers, TKOC, ASGC, and others
 - TKOC members present at annual RAAC sponsored teacher conference

Ongoing Parent Partnerships

- The Division of Developmental and Behavioral Pediatrics (DDBP) has a dedicated Family Advisory Council
 - Meets monthly
 - Multiple diagnoses represented
 - Assist with divisional initiatives, including providing input on research protocols
 - Participate as reviewers on internal research proposals

Partnering with Agencies, School Districts, etc.

- TKOC has an ongoing relationship with Cincinnati Public Schools (CPS), supporting a demonstration classroom on the first floor of our building, for the purpose of serving a small number of children, and training teachers
- The Hamilton County Department of Developmental Disability Services (HCDDS) provides us with a service contract to provide in school consultation within Hamilton County



Working to improve Community Experiences for individuals with ASD

- TKOC Staff developed a S.O.A.R. program to help children with ASD experience airline travel
- Expanding this model to other community experiences
 - Sensory friendly Nutcracker performance
 - Partnering with Cincinnati Zoo, and Cincinnati Parks



What I've learned

- I've learned as much, if not more, from stepping outside the walls of the hospital, and entering the community
- I've had more fun being in the community
- I didn't know everything I thought I knew

What works

- Being explicit and deliberate about community involvement (don't just expect it to "happen")
- Attending events, being present
- Joining boards
- Being a vehicle for others to come together