Partnering for Autism

Alison Singer, Ann Palmer and Dr. Patricia Manning
Today’s speakers

Alison Singer  Ann Palmer  Dr. Patricia Manning
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
Cincinnati Children’s Hospital Medical Center
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