Family Leader Orientation: Enrichment Session 1

Rebecca Grau, MPA
Heidi Cooley-Cook
Pamela McDaniel, PhD

History of the KATC

• Initiated by families seeking training for educators, service providers and families
• House Bill 159 passed 1996 General Assembly (**State** Autism Training Center KRS 164.981 to 164.9819 )
• University of Louisville awarded administrative oversight – housed at the College of Education and Human Development
Children with disabilities ages 3-5 and 6-21 are reported according to their: (a) disability category and discrete age year based upon the child's age as of the data collection date; (b) race/ethnicity and disability category; (c) discrete age year and educational environment; and (d) race/ethnicity and educational environment. Data are analyzed and a December 1 Child Count.
About 1 in 88 children has been identified with an autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. (2013)
The KATC Evolution

Vision:
Systemic Support and Local Capacity

State Planning Team:
KATC, KDE, Special Ed Coops, Mental Health, First Steps, IHE ...

Family Leaders

Regional and District Specialists

School Building Level Staff and Direct Service Providers
Components of the the KATC Family Leader Network

- Family Leaders
- Families Seeking Support
- Family and Professional Collaboration
- Goal: Improved outcomes for families and individuals

KATC Family Leader Network

Council on Developmental Disabilities
- LEAD Parent Program

Kentucky Autism Training Center
- Resources
- Training
- Support
- Local Resources
- Community Culture

Personal Experiences/Relationships

Kentucky Autism Training Center

Family Leaders

- Someone who has personal experience in using resources/services to strengthen his or her family and speaks and acts from their perspective as a family member.

Parents Anonymous Inc., 2003
Evolution of a Family Leader with the KATC’s Family Network: Families Supporting Families

- Intensive 2-Day Training
- Enrichment Sessions and follow-up discussion
- Self-study and Personal Enrichment
- Networking at the state, regional and local level
- Supporting families
- Graduation Ceremony “pinned a Family Leader”
- Mentoring New Family Leaders

Kentucky Autism Training Center

Family Leaders

- Roles & Responsibilities
  - Represent the KATC at parent & professional activities & meetings
  - Deliver presentations
  - Networking
  - Collaborate with other groups & families
Why Collaborate

• Fostering collaborative partnerships leads to early dispute resolution and the prevention of more costly actions such as mediation, due process hearings, and litigation.

• REAL currency for families and students is TIME

Conflict Resolution

Due Process/Formal Complaint
Mediation
Superintendent
Director of Special Education
Principal
Teacher

Process Focused
Student and Instruction Focused
Time

Cooley-Cook & Grau (2013) KATC

Major Barriers

- Perceived disparity of power and authority in the relationship between parents and professionals:
  - Impedes ability to form consensus
  - Develop meaningful accountability
  - Impedes development of personnel preparation programs

Kentucky Autism Training Center

Blue-Banning, Summers, Frankland, Nelson, Beegle, 2004
Effective Collaborators

- Communication
- Commitment
- Equality
- Skills
- Trust
- Respect

Adapted from Blue-Banning, Summers, Frankland, Nelson, & Beegle (2004)

Quality of interpersonal relationships between those involved is vital to a successful collaboration

McWilliam, Tocci, & Harbin, 1998
Professional’s Expectations of Parents  
(Examples)

• Sending child to school ready to learn
• Participation in events at school
• Helping with homework
• Advocate for their child’s special needs
• Participate in decision making process through the IEP

Parents Expectations of Professionals

Respect
Treating children with dignity
Being positive towards children

Skills
Skills to support positive behaviors
Skills to facilitate inclusion
Willingness to learn continuously

Commitment
Going the extra mile
Bring committed to the whole family

Case Study

Levi is a 9 year old receiving IEP services under Autism Eligibility. He is crying at school on average 2 hours each day. In the mornings, he is crying that he doesn’t want to go to school and in the afternoon, he is crying that he doesn’t want to go home. He is not getting his school work done due to crying and is falling further and further behind.

Perceptions

Mom & Dad: Levi doesn’t like school and that is why he doesn’t want to come to school. School is not teaching him the right way and now he’s frustrated with schoolwork because he is so far behind. School just needs to take more time to work with Levi one on one. Worried that Levi is being teased and bullied at school – thinking about taking him out and home-schooling him.
Perceptions

Teacher: Crying must work for Levi at home. He cries everyday during math and science and is so disruptive that I have to ask him to leave the area and compose himself before returning. Sometimes he’ll sit in the cool down zone for the whole lesson. If I ask him to come back to his seat, he gets upset again and takes even longer to cool down. Mom and dad don’t work with Levi at home to complete his missed work. If something doesn’t change, he may not be ready for 3rd grade.

Professionals need to share:

• Their perspectives about how and why certain actions were taken
• What the limitations of their own lives might be

Parents need to share:

• How various actions or inactions have impacted their family
• How well intentioned actions or comments did or did not have their intended effect

NOW What?

• Questions for Parents and Teachers
  • What data is being collected
  • What Evidence Based Practices (EBPs) have been used
    • At home
    • At school
  • What has been successful
    • At home
    • At school
  • What is the desired outcome
    • What are the steps to get there


Evidence Based Practices Resources

• National Professional Development Center on Autism Spectrum Disorders (NPDC on ASD)
• Autism Internet Modules (AIMs)
• KATC Family Guide
References


http://www.moddrc.org/user_storage/File/12/Core%20Competencies%20for%20Family%20Leaders.pdf
References


The National Center on Dispute Resolution in Special Education "Encouraging the use of mediation and other collaborative strategies to resolve disagreements about special education and early intervention programs." - For Family members http://www.directionservice.org/cadre/forfamilymembers.cfm