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Family Leader Orientation:
Enrichment Session 1

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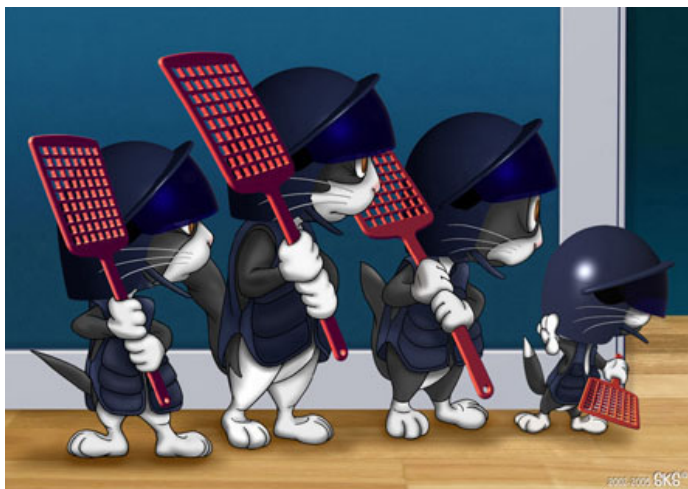
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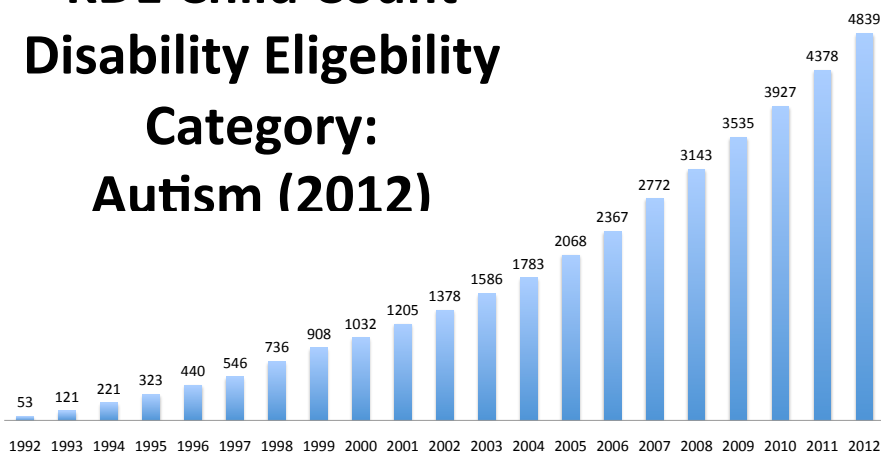
History of the KATC

- 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

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KDE Child Count Disability Eligibility Category: Autism (2012)



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

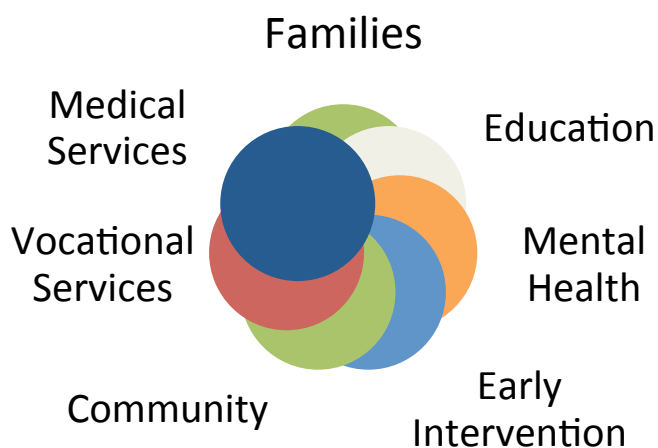
Estimated Number of Individuals with ASD in Kentucky

...Birth to 3-yrs old	2,563
...4 to 21 yrs old	11,823
...18 yrs old +	35,923
...Across the Life-Span	49,311

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)

Systems of Support for Individuals with ASD



The KATC Evolution



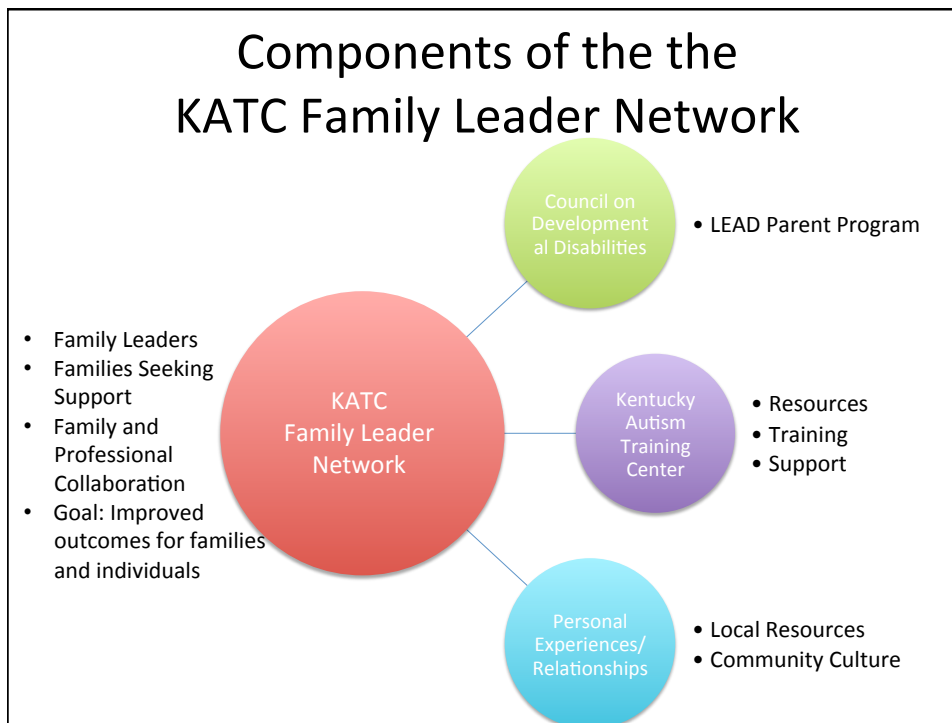
Vision: Systemic Support and Local Capacity

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**



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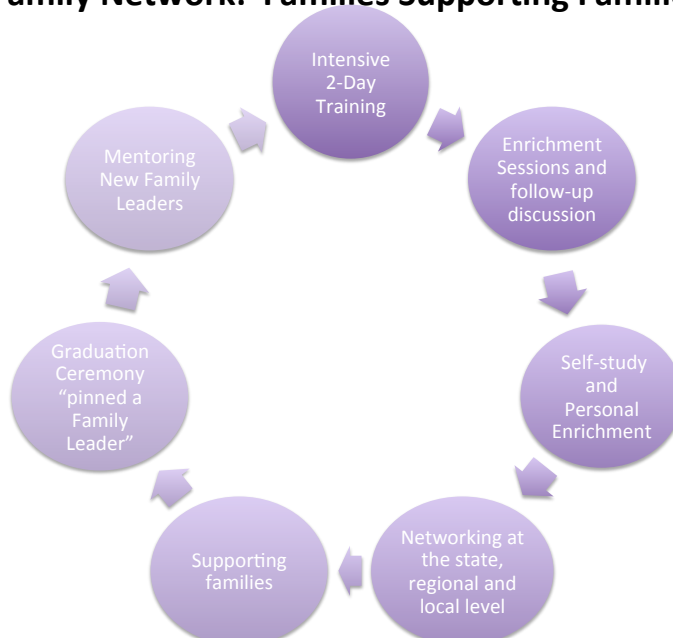
Family Leaders

- 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



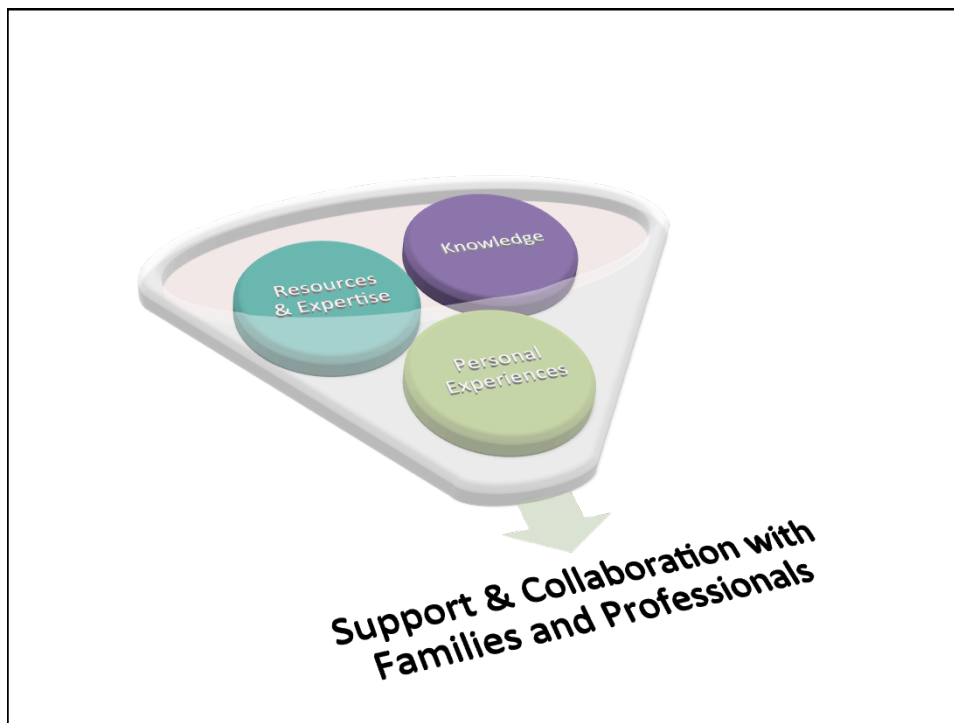
Evolution of a Family Leader with the KATC's Family Network: Families Supporting Families



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Family Leaders

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



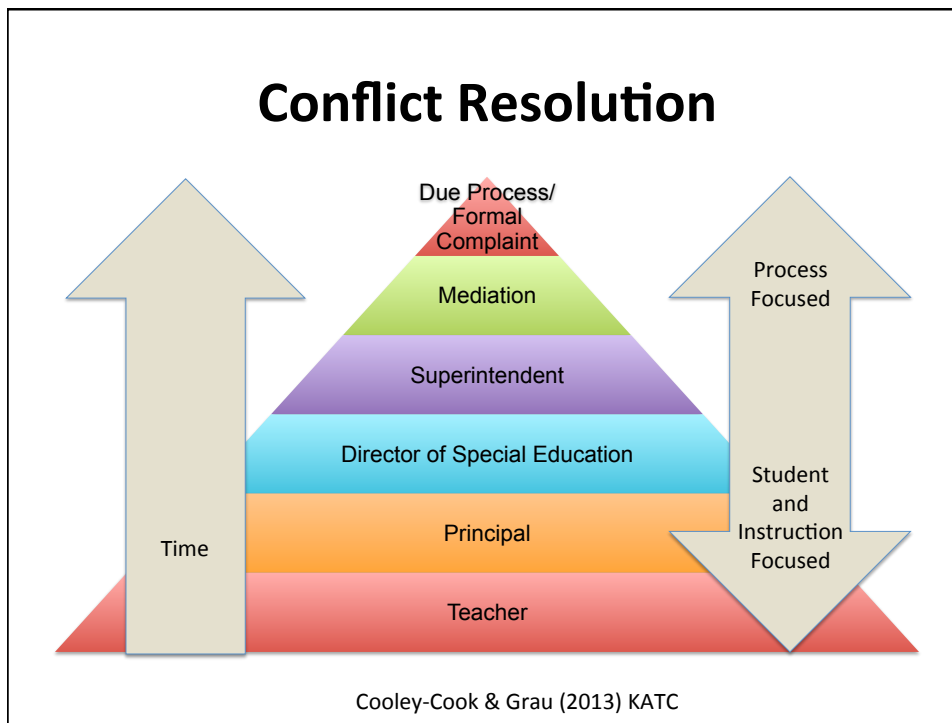
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Why Collaborate

- 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**

Feinberg, Beyer, & Moses (2002)





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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

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

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

Parents Expectations of Professionals



Park, J., & Turnbull, A. P. (2002).



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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.



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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.





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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.



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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

Blue-Banning, Summers, Frankland, Nelson, Beegle (2004)





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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

Blue-Banning, Summers, Frankland, Nelson, Beegle (2004)

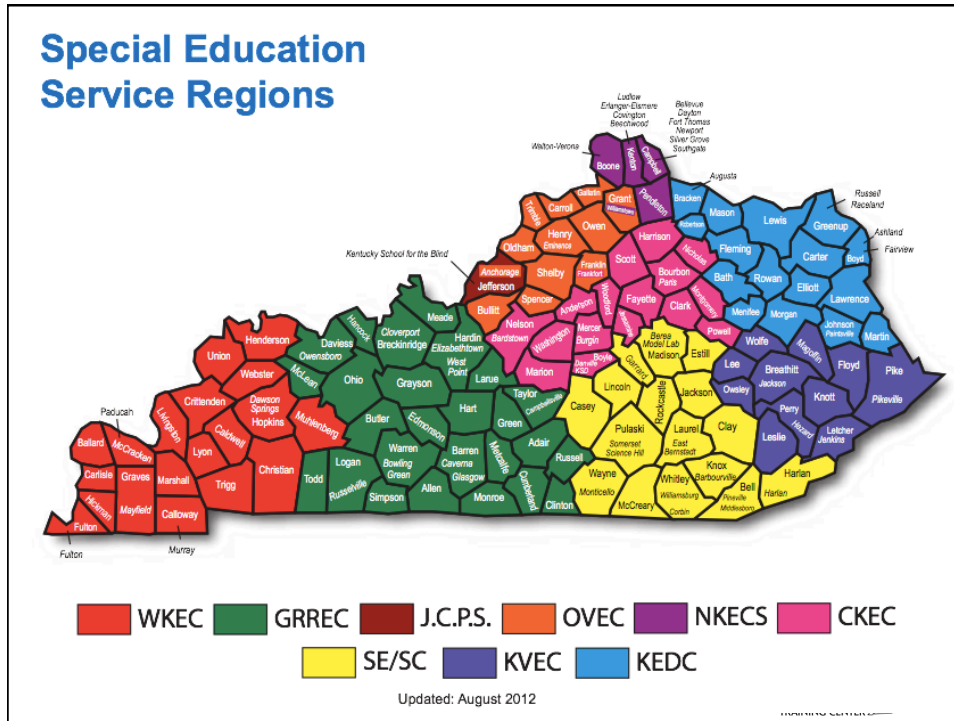


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Evidence Based Practices Resources

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





References

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PACER Center (2006). Working Together: A Parent's Guide to Parent and Professional Partnership and Communication within Special Education. Minneapolis, MN: Accessed on-line June 25, 2013 at: <http://www.parentcenternetwork.org/assets/files/national/Working%20Together.pdf>

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>