

**Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013
Notes and Discussion**

I. In attendance:

	City	Role
Pat Benningfield	Bowling Green	KATC Family Network
Ashley Bradford	Lexington	KATC Family Network
Billie Chain	Banner	Support Group Leader
Heidi Cooley-Cook	Statewide	KATC
Diane Cowne	Statewide	KATC Board Member
Julie Denton	Louisville	State Senator
Whitney Durham	Corbin	KATC Family Network Support Group Leader
Melissa Flickinger	Richmond	Support Group Leader
Donovan Fornwalt	Louisville	Council on Developmental Disabilities
Karla Gibbs	Louisville	Support Group Leader
Diandre Glover-Thomas	Statewide	KATC
Rebecca Grau	Statewide	KATC
Debbie Gilbert	Statewide	KATC Family Network
Sandra Hammers	Owensboro	Support Group Leader
Patricia Hicks	Lawrence	KATC Family Network
Donna Littrell	Somerset	KATC Family Network Support Group Leader
Whitney Logsdon	Owensboro	Support Group Leader
Alicia Owens	Bowling Green	KATC Family Network
Pameal McDaniel	Louisville	Council on Developmental Disabilities
Shannon Priddy-Marin	Webster	Support Group Leader
Amy Cooper-Puckett	Statewide	Kentucky Cabinet for Health and Family Services
Karen Ricci	Louisville	Council on Developmental Disabilities
Shelley Shepherd	Warren	KATC Family Network Support Group Leader
Terri Srinivasan	Mason	KATC Family Network Support Group Leader
Elizabeth Sternberg	Warren	Support Group Leader
Larry Taylor	Statewide	KATC
Rebecca Thompson	Louisville	Support Group Leader
Diane Wrocklage	Louisville	Liaison Teacher

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013
Notes and Discussion

Morning

II. Overview of KATC Services, Resources and Supports (Cooley-Cook)

- Background of KATC and how this relates to past/current activities
- House Bill 156 with oversight given/based at UoL
<http://www.lrc.state.ky.us/kar/013/002/080.htm>
- Now part of the U of L Autism Center: Clinical Services, Research & Training
- First Steps- If autism suspected, child under 3 can be seen within a month for evaluation at Weisskopf, compared to be put on their waiting list to be seen in as long as 8-10 months
- This lead to discussion on where parents are going for evaluations-Cincinnati and Nashville not taking Kentucky kids,
- New diagnostic options:
 - EPS Pediatric Services, LLC, c/o Elizabeth Sternberg, D.O.
1540 Aquarius Way - Bowling Green, KY 42104
Phone: 270-266-4212 - Fax: 270-266-0157
Email: eliz.sternberg@gmail.com
- University of Kentucky Referral Process
- Talked about differences between medical and educational autism diagnosis- eligibility and criteria are different for each. Specifics outlined in Family Guide
<http://louisville.edu/education/kyautismtraining/resources/family-guide/katc-familyguide-chapter1.pdf>
- Activities of KATC discussed:
 - Early Childhood Training Initiative
 - Autism Internet Modules- 43 modules, can get college credit or CEU's for completing at a cost or can watch for free without receiving credit
 - Roll out of training sites
 - 40+ Support Groups- discussed some are online only, offer specialized training free, information packet
- Discussed Kentucky Department of Kentucky December 1 Child Count and changes over time. In 1992, 53 students with identified autism and in 2013 4,839 students met the criteria for the disability category of autism.
- KATC Evolution from SWAT to Systems Level
Now: Resources, Training, Support, Coaching, Information Dissemination, working both at trickle up/down levels with services

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013
Notes and Discussion

Before: Put out fires on individual./school level, discussed what this meant/limited impact

Now: Focused more on capacity building, discussed different projects, including CASE, KY TOTs, and now KY Family Network.

Family Network: families supporting families, KATC works to accomplish this through a partnership with Council on Developmental Disabilities

16 participants, 10 counties, 9 graduates

III. Brief discussion of changes to the DSM-V

DSM -V Changes: Info from Autism Speaks, have a good explanation of the 5 major changes find at: <http://www.autismspeaks.org/dsm-5/faq#criteria>

Discussed the 5 major changes (from AS):

1. The new classification system eliminates the previously separate subcategories on the autism spectrum, including Asperger syndrome, PDD-NOS, childhood disintegrative disorder and autistic disorder. These subcategories will be folded into the broad term autism spectrum disorder (ASD).
2. Instead of three domains of autism symptoms (social impairment, language/communication impairment and repetitive/restricted behaviors), two categories will be used: social communication impairment and restricted interests/repetitive behaviors. Under the DSM-IV, a person qualified for an ASD diagnosis by exhibiting at least six of twelve deficits in social interaction, communication or repetitive behaviors. Under the DSM-5, diagnosis will require a person to exhibit all three deficits in social communication and at least two symptoms in the category of restricted range of activities/repetitive behaviors. Within the second category, a new symptom will be included: hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment.
3. Symptoms can currently be present, or reported in past history.
4. In addition to the diagnosis, each person evaluated will also be described in terms of any known genetic cause (e.g. fragile X syndrome, Rett syndrome), level of language and intellectual disability and presence of medical conditions such as seizures, anxiety, depression, and/or gastrointestinal (GI) problems.
5. The work group added a new category called Social Communication Disorder (SCD). This will allow for a diagnosis of disabilities in social communication without the presence of repetitive behavior.

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013
Notes and Discussion

Discussed more in depth the dimensional ratings for DSM-5: Very substantial support, substantial support & support, given for both social communication impairment & for restricted interests/repetitive behaviors

- **How will these changes affect diagnosis, treatment and support services?**

No one should be reevaluated or “lose” their diagnosis because of administrative reasons of the DSM-5. Many individuals may wish to retain their previous diagnosis as the label is considered part of their identity or may reflect a peer group with whom they identify. This is perfectly acceptable. A clinician can indicate both the DSM-5 diagnosis as well as the previous diagnosis, such as Asperger syndrome, in an individual’s clinical record. There will not be any new Aspies diagnosed under DSM-5.

The DSM-5 text states “ Individuals with a well-established DSM-IV diagnoses of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder”.

Revisions are intended to more reliably capture *all* those who would have legitimately received a diagnosis of ASD under DSM-IV.

IV. Overview of State Level Initiatives

Amy Cooper-Puckett, LCSW, Autism Specialist & Policy Liaison
Outcomes, Transformation, & Education Branch
Dept. of Behavioral Health Developmental Intellectual Disabilities
(502) 564-4860 ext. 4479 - amy.cooper-puckett@ky.gov

- Gave background on House Bill 144 & basics of what is a Medicaid State Plan- says to the federal government who, what, why, what will do, a State Plan is a contract between a state and the Federal Government describing how that state administers its Medicaid program.
- Michelle P. & SCL Waiver basically says in state plan, going to ignore all people to focus on these groups of people
- Level of Care to get into waiver- for adults, easy to calculate, estimate budget neutrality (can't spend more than this amount), cost to be in Oakwood facility
- Kids don't get SCL services because basically need to be homeless to get services and kids aren't considered homeless by state
- Individuals on SCL waiver waiting list- first to get Michelle P. services, still put on SCL waiting list, given services based on need. Michelle P. written primarily for adults- reason behind MAP 351 language
- State did not anticipate number of children who would end up on Michelle P. Eligibility Issues have come up recently because Medicaid says developmental disabilities or IQ below 70 but residential waiver- determination based on IQ below 70

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013

Notes and Discussion

- Eligibility for Michelle P.- first conversation, determination if meet criteria with diagnosis of ID or DD
 - Adaptive functioning deficits- likely to continue indefinitely, results in substantial functional limitations in 3 or more areas
 - Before a school evaluation, a First Steps evaluation can provide evidence of these limitations
- Before signing anything- read what is being prepared
- Also discussed: Pamela McDaniel- From CDD, legislators want to hear from parents, don't see her in that role, Can sign up for E-Blasts from them (Council) Disabilities Awareness Day in Frankfort has been moved from February to January.

Insurance Discussion

- Medicaid is only suppose to be payor of last resort, this is why changes to Michelle P. to EPST
- Changes Affordable Care Act will bring with no limits on amounts
- FEAT- Frankfort recently, had Autism Speaks lobbyist and attorney from Washington, speaking on not getting payment from insurance companies

2005 Autism Commission,

- Intent of committee- to unify & promote initiatives, improving KY's system of care for individuals with ASD and their families (22 members)

Community Forums

- Community needs assessment forums across state, every mental health region
- Relationship Building- what have/don't have
- Document for whole state to begin working from- end of December, Presentation in January
- Discussed issues parents may be facing - (denials, hearings, background checks)

V. Show & Tell- All Support Group Leaders

General theme of focusing on positive, speaker every other month, can have large number of members on Facebook but limited attendance at meetings, lack of funding, childcare

Allen/Warren- favorite was psychologist with family panel, topic was talking on your child about their diagnosis & when to start that discussion

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013
Notes and Discussion

Lake Cumberland- favorite was Autism Walk, 1st lap honored those with autism, given medal for bravery and courage

East KY Autism Group- go to businesses once a month, asking for support for walk

Diane Rockledge from Binet School, Jefferson County- works with parents on getting Michelle P./SCL waivers, same issues as rural counties

Parent to Parent Information- wants to build strong network of families across state to work with newly diagnosed 12 Commission Offices- wants parents to work with their offices

Knox County- hosts free art days, got nonprofit status in May

Maysville-Monthly tumbling for autism, Sunday afternoons, has childcare element built in, usually 30 there. Also hosted camp- 20 kids for 2 days, ambassador for each child, included fishing, art, music, horses, milking station

Council on Developmental Disabilities working on virtual classroom, do outreach to families, sibling support

Ideas for support group leaders from Show and Tell

- If have medical card, can purchase membership to museums/zoos at lesser cost
- Funeral homes will often supply tents at no cost
- UK Extension Office- has classes for support groups
- Developing Board of Directors: be aware of corporate connections of members, grants, donations, support of issues

VI. KATC Website- overview of site, changes coming to make it easier to find information

Service Directory- Map of KY, Autism Services and Providers- do your own research, not 'credentialed' by KATC, they have to come to KATC to be listed, if agency says does not provide a service that's listed, please let KATC know

Free Sources: interactive link- click on to page on each one (Website, Newsletter etc.)

Information for Families on site: to do list, Family Guide, Family Support Groups list by Special Ed Cooperatives, Family Leader Network, Transition to Adulthood (starting to build), Workshop Request Forms, Resource Library of materials, Additional Directories (Autism Speaks, Behavior Analyst Certificate, etc.)

KATC Online Community: Early Childhood Professional Development, Foundation of Autism Spectrum Disorders, Autism Internet Modules

Family Group Training: request family support training from site, no cost, usually 1-1 ½ hours

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013
Notes and Discussion

Individual Training- register to attend training event from site, 1. first set up account 2. Live webinars- limit 100 people 3. YouTube Channel- webinars without handouts 4. archive- handout downloads

Act Early on site: click on boxes, gives drop down box, materials free on CDC site sent to you
Promote- commercial available, could air locally, send file to include your support group logo in CASE training- link to materials

Family Leader Network: Dates to Remember, Documents, December 1, 2013 - Deadline to submit application for 2nd cohort of Family Leaders Spring 2014 Intensive 2-day Training for 2nd cohort of Family Leaders

Brochures: can download on family or professional page, space on back of it for Avery 5160 label with your group's info

Newsletters: archived online, article on DSM-5 in recent newsletter link to article:
<http://archive.constantcontact.com/fs168/1103629101734/archive/1114498625100.html>

Workshops: can download information from sessions from site

Electronic Mailing List: request to be added online

KATC cannot link to legislative updates, but can link to CDD <http://councilondd.org> and forward their legislative blasts

Support Groups- yes, please link to Family Guide from your site,

“Like” each other on Facebook, follow on Twitter, way to build own following and connect to with other parent, disability, education and advocacy groups

VII. Resources Shared with Attendees Towards the Goal of Linking Families with other Disability, Education, and family Leadership Initiatives in the Commonwealth

Special Education Cooperatives

<http://education.ky.gov/specialed/excep/pages/kentucky-special-education-cooperative-network.aspx>

The Special Education Cooperative Network is intended to assist local school districts in meeting the needs of its member districts. Services range from technical assistance, trainings,

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013

Notes and Discussion

professional development, specialized services, research, and other needs identified by member districts and the Kentucky Department of Education.

Family Resource and Youth Service Centers

<http://chfs.ky.gov/dfrcvf/frysc/>

The primary goal of these centers is to remove nonacademic barriers to learning as a means to enhance student academic success. Each center offers a unique blend of programs and services determined by the needs of the population being served, available resources, location and other local characteristics.

Kentucky Family to Family Health Information Centers

<http://chfs.ky.gov/ccshcn/ccshcnf2f.htm>

The Commission for Children with Special Health Care Needs has received a grant from HRSA to create Family to Family Health Information Centers (F2F HICs) in Commission offices across the state. The Centers will be staffed by support parents who are parents of children with special needs. Support parents provide key support to families of individuals with special needs.

Commonwealth Council on Developmental Disabilities Reimbursement Grant

<http://chfs.ky.gov/nr/rdonlyres/6a23d941-1708-49a2-bcb6-ce865be7ef82/310457/ldf2013final.pdf>

The Commonwealth Council on Developmental Disabilities (CCDD) has a reimbursement grant available for financial assistance for Individuals with developmental disabilities and their close support network (parent, therapist, teacher, ect.) to participate in both in and out-of-state leadership development opportunities. The purpose of the fund is to empower individuals to achieve full citizenship and inclusion in their community through education, capacity building and advocacy.

Kentucky Partnership for Families and Children, Inc. (KPFC)

<http://kypartnership.org/>

KPFC's united voice works to:

- Effect policy changes at the state level,
- Educate legislators about the needs of children with severe emotional disabilities,
- Improve services so that all children and families will be able to receive appropriate services in their home communities, and
- Give a voice to the youth and families that live with this disability every day

Kentucky Special Parent Involvement Network (KY-SPIN)

<http://www.kyspin.com/>

KY-SPIN, Inc. provides statewide training, information and support to people with all types of disabilities, their parents and families, and professionals for all age groups.

Arc of Kentucky

<http://www.arcofky.org/>

Advocating for the rights and full participation of all children and adults with intellectual and developmental disabilities. Together with our network of members and affiliated chapters, we improve systems of supports and services; connect families; inspire communities

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013

Notes and Discussion

and influence community policy. The mission is accomplished primarily by its ability to enhance the lives of people with intellectual and developmental disabilities through

- Advocacy (the process of presenting their needs to local, state and national governmental and organizational bodies),
- Education (informing such persons and their families of the programs and processes that they can use, and by raising awareness of the general population of the needs and abilities of such persons so that they will be accepted as individuals by the general public).

Commonwealth of Kentucky Cabinet for Health & Family Services
Opportunities for Family Leadership (OFL)

Search on <http://chfs.ky.gov> "Opportunities for Family Leadership (OFL)"

Our goal is to ensure that the family voice is included in every stage of planning, implementation and evaluation of services for the special populations we serve.

The Division of Behavioral Health, within the Cabinet for Health & Family Services, values the participation of families throughout our system of care. OFL's goal is to ensure that the family voice is included in every stage of planning, implementation and evaluation of services for the special populations we serve. We strive to ensure that every family member has the opportunity to offer his or her leadership throughout the Commonwealth. A statewide network of Family Liaisons is employed to assist OFL with this program.

Resource Share from KATC Website

- KATC Free Sources for the Autism Community in Kentucky
- Autism Spectrum Disorders Related Support Groups in Kentucky Listings
- KATC Archived Webinars
- KATC Upcoming Webinars
- KATC Family Leader Application

Nationals Resources

- National Professional Development Center on ASD - Evidence Based Practices (EBPs)
<http://autismpdc.fpg.unc.edu/>
- Autism Internet Modules (AIMs)
<http://www.autisminternetmodules.org/>

Other Resources Shared and Available Upon Request

- PowerPoint Presentation - KATC Overview and Changes to DSM-5
- KATC Family Guide Chapters/Topics

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013
Notes and Discussion

- Family Support Group Leader Survey Results
- Data by County - KY Census Data merged with CDC's estimate of 1 in 88
- Behavioral Health Crisis Services

VIII. Feedback from Support Group Leaders regarding the strengths of their group

Small, tight knit group.

Lots of support offered

We are motivated as leaders to educate families & professionals about ASDs

We are free and open to anyone interested in attending.

We help families obtain points of contact for services they need

A few dedicated, loyal mothers

That we work together to support our kids and others.

Working well with the local school system.

Everyone gets along really well.

We network with one another and seem to help each other out even outside of the support group setting.

Our greatest strength is the bonding of our parents.

Everyone tries to help out anyone that is having a rough time.

If someone needs something we help and if we can't help we find someone who can.

We try to have someone come to all of our meetings to train, inform, or discuss things to help the parents.

We are more than a group of parents,

We are a group of friends and allies.

We have a welcoming atmosphere and 3 ground rules:

- 1) Maintain confidentiality*
- 2) Share talk time*

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013

Notes and Discussion

3) Needs surrounding conflicts with specific schools/teachers are best discussed privately with the facilitator at an appointment, so that monthly group time is not monopolized and a positive atmosphere is maintained.

Parents from adjoining counties and private school attend.

We have childcare and food. 2 essentials we were advised would help attract busy parents to the meetings.

The facilitator has had a lot of training in autism, evidence-based practices, positive behavior support, assistive technology and the parents appreciate that.

Variety of ages of the kids we support

The parent's participation.

We have amazing parents and children and we support one another.

My parents know that they can call me day or night with any issue and I will be there for them and if I don't know the answer I will do my best to find it.

We have some veterans who have been around, and don't come often, but will when we need them.

We have a lot of young parents who are eager to help their kids.

We have many professionals who are also parents. They really know their stuff.

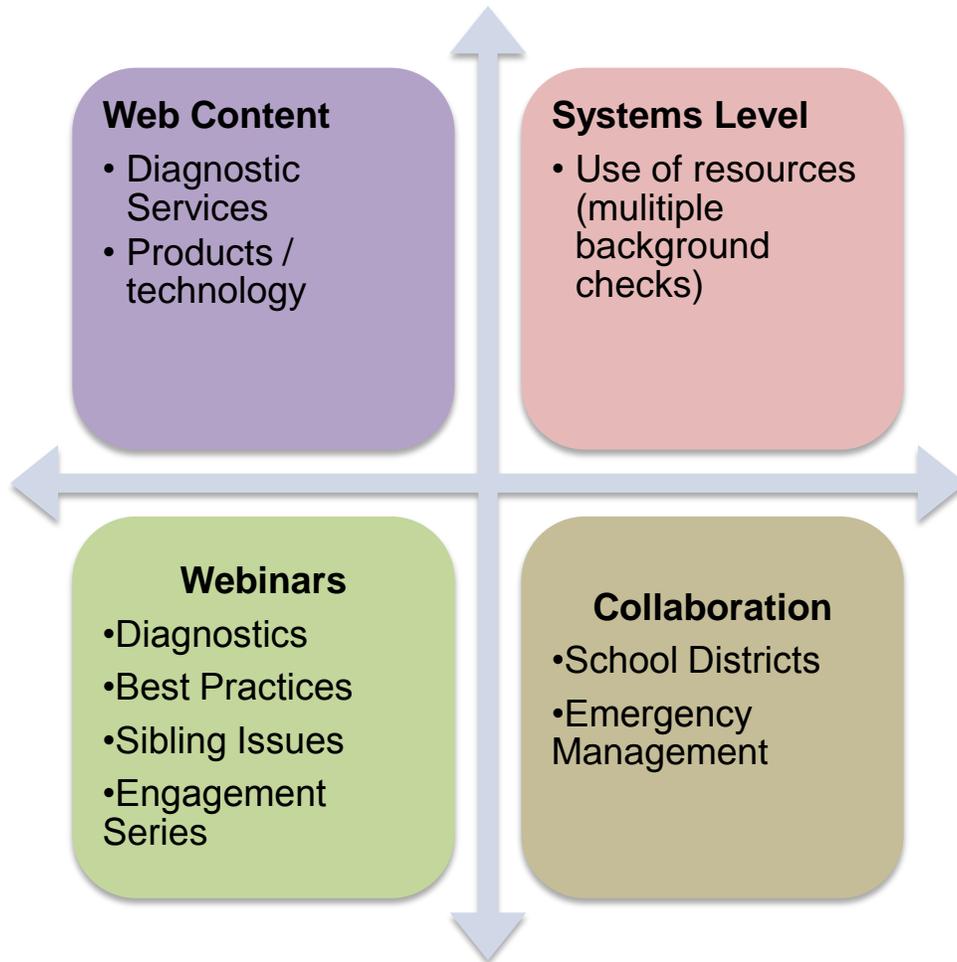
iX. Challenges of Support Groups – as reported by Support Group Leaders in Kentucky



Other challenges reported by support group leaders:

- Drawing and retaining membership
- Very few parents of middle/high school students
- Negativity
- Scheduling issues
- Logistics of the group [leadership structure, 501(c)(3)status]

X. Parking Lot Issues



Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013
Notes and Discussion

XI. Developing Plan to Strength Support Groups and Build Family Leadership

- *Conference Call - November 15, 2013 at 12:00 pm EST:*
 - *Continue discussion of challenges of support groups in Kentucky and brainstorm strategies to overcome these hurdles.*
 - **Call: 1-888-278-0254 Access Code: 9103753**
- *Conference Call & Webinar - December 11, 2013 at 10:00 am EST or December 12, 2013 at 3:00 pm EST:*
 - Opportunity for community to join conversation on how to revamp/update KATC's Family Guide
 - Open to anyone who uses Family Guide - Family Members, Individuals, Professionals
 - Participants of discussion encouraged to download/print the Family Guide Worksheet (Listing of chapters from Family Guide and the topics included under each chapter)
 - Participants can choose to 1) call in or 2) call in and log into webinar (to see PowerPoint slides related to Family Guide organization) *** Please note that there will not be audio associated with this webinar - to participate in the discussion, you will need to call in!
 - **Call: 1-888-278-0254 Access Code: 9103753**

Afternoon

Pamela McDaniel- Director of Family Outreach and Support at the DDC opened afternoon session with an overview of LEAD Project at the CDD and collaboration with KATC

- The purpose of the *KATC Family Network* is to develop a network of family members affected by ASD who will reach, collaborate, empower, and develop relationships with others throughout the state of Kentucky at both the local and state level.
- This spring the Family Leaders met in Louisville for an intense two-day leadership development program delivered by staff from the Council on Developmental Disabilities.
 - The training was adapted from CDD's LEAD program (Leadership, Education, & Advocacy Development).
 - The program was designed to train parents, advocates, and anyone who serves persons with disabilities in the areas of leadership and advocacy - by offering the support, resources, and various training in the law, collaborative communication, and more.

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013

Notes and Discussion

- Upon completion of the intense two-day training, Family Leaders will be asked to support families throughout the Commonwealth.
- Responsibilities of Family Leaders may include the following: provide direct support to families, mentor other families, deliver presentations and network with families as well as policy makers, and to collaborate with other disability groups throughout the state.

Larry Taylor, Executive Director. Kentucky Autism Training Center provided on update on Special Education Law – Major Points Include:

- Children Age 3 to 21- school-based services are an entitlement.
- Access to high quality instruction and positive outcomes are goals.
- Talked about changes in special education, first access to school, to main building, now general education
- Talked about What's Behind the Numbers: DSM-5 vs. public school regulations for services, must adversely affect educational performance.
 - Special education autism court cases have increased 10:1, from (Zirkel, 2012)
 - http://bestpracticeautism.blogspot.com/2012_01_01_archive.html
 - Most autism court cases are related to FAPE- can be lack of agreement among service providers on the definition of FAPE. Students with autism have same rights as other IDEA categories.
- IEP Development: present level of performance, based on data, IEP goals and objectives developed from this, also based on data
 - Can ask for independent evaluation- school is required to provide one at no cost
 - Goals and Objectives- how track, progress notes- report progress, method of measurement to determine change, specially designed instruction needed to reach
 - If can predict it, can prevent it- also help to reach goals
 - Behavior of the individual- how can we work with the teacher and students on preventing issues before they happen
 - Reporting progress- same interval as nondisabled students, unless need more frequently
- Placement- why will this be good for them, what need to be successful, how will it benefit the student
- Expectations- students with disabilities are no different than students without disabilities. Look at present level performance and push higher each time

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013

Notes and Discussion

- Prevention of Conflict- important to establish system of communication upfront- how are we going to communicate, how often (could be email, call once a week), look at what works for you and people working with student.
 - Remain open minded- needs today look different than last year or one year from now
 - For meetings- make list of questions, maintain documentation from beginning
 - If issues getting what was discussed- email teacher/therapist- as we discussed, please send progress report, be progressive- don't start at top, go up the steps (document each)
 - Communication Problem Solving Options at School & District Level- start with classroom teacher, then building principal, Director of Special Education to Superintendent
 - Goal- how quickly can resolve issues, sense of urgency, children won't get the time back
 - School Statutes and Regulations- administrative procedures, you fill out forms, they take action (on things like bullying)
 - If can't be solved at school and district level- Mediation 707 KAR 1:340 section 9
 - <http://www.lrc.ky.gov/kar/707/001/340.htm>

- Procedural safeguards for students with IEP's, voluntary, impartial, non-confrontational, state pays for, mediator completely impartial to district and people involved
- Dispute Resolution Option- formal complaint, must be filed within one year of allegation by parent, organization, person who believes IDEA has been violated, adversarial, hearing officer presides. issues decision, expensive for school district
- Time to conduct investigation and issue decision is 60 days after filing, can object after appeal point
- Once 21- not entitled to public school, district makes decision how long can stay (day turn 21, complete year), once exit school, school may be covered under ADA or 504

Senator Denton gave an overview of Legislative Advocacy

Senator Denton was introduced by Donovan A Fornwalt, Chief Executive Officer at The Council on Developmental Disabilities

Senator gave an overview of here background:

- Mother
- Member of Kentucky Legislature for over 16 years
- Interested in disability issues
- More info about her at: <http://www.lrc.ky.gov/legislator/s036.htm>

When contacting a legislator:

**Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013**

Notes and Discussion

- She prefers emails – but phone calls are OK especially if issue is urgent
- Give information on issue and what you need from them
- Understand the bill if coming to them asking to vote for/against- why do/don't want a bill, know particulars, builds credibility
- Form letters- only start, use as outline, then use your own words
- Agree to disagree
- If you burn bridge with some legislators won't work with in the future

For her:

- Petitions are ineffective
- Personal stories do make a difference, sharing stories in context of public policy so legislators can internalize issue, what will be the outcome, negative or positive effect if do/don't do something

State Representatives and Senators:

- Are most responsive to their constituents – however; committees to represent a larger constituents
- Before legislative session, (prior to January) is time to build a relationship with your legislator
 - Approach them when you are not asking for anything: “I’m here as a resource on autism, introduce yourself to them.”
 - You can reach out later if have bill want support for in January talking about note sent in October, wanted to follow up on impact of particular bill/issue
 - Large turn out at committee meets does make an impression

Phone calls

- Legislators get green slips every day with every call, message on call helpful, intern divides them into bills with pro/con, seeing comments can make a difference

Tote sheet

- Pro/cons vote for issue, last snapshot before voting, might call a person to get insight on certain side of an issue

A good lobbyist tells everything good about a bill and what the other side is saying about it.

Hearings

- Band together, show support through t-shirts, pins with message about bill
- Be a force, be willing to testify
 - Testifying- put yourself on the line, supportive of parents, see the face and make it real for them

Kentucky Autism Related Support Group Leader Meeting [Morning]
KATC Family Network: Families Supporting Families. In partnership with The Council on
Developmental Disabilities (CDD) [Afternoon]
10/25/2013

Notes and Discussion

- If want to speak at a meeting- have to sign in, given to speaker of committee
- Do not have more than 2 speak from a group, let know in advance, can stand up as a group to show support
- How to prepare testimony: tells the truth and be prepared to say that you don't know-but will follow-up

Legislative Research Commission

<http://www.lrc.ky.gov/>

Write bills and do research on issues, what doing in other states, what works, what doesn't

Schedule of Bills- on LRC website, organized by subject area, jurisdiction, needs constant monitoring during session for updates/changes

Graduation Ceremony!

Heidi Cooley-Cook, KATC, and Pamela McDaniel, CDD, asked each graduating Family Leader to come up individually to receive their pin and speak to what being a Family Leader/ part of KATC's Family Network means to them.

Graduates included: Pat Benningfield (Bowling Green), Ashley Bradford (Lexington), Whitney Durham (Corbin), Debbie Gilbert (Varies - Commission for Children with Special Health Care Needs), Patricia Hicks (Webbville), Donna Littrell (Bronston), Alicia Owens (Bowling Green), Shelley Shepherd (Bowling Green), Terri Srinivasan (Maysville)

Also graduating but not present at the graduation: Ally Brooks (Oak Grove)