

Open Forum Notes
New Britain High School
May 28, 2014

Below are notes distilling the comments made by participants during the Open Forum. Generally, the comments are listed in the order in which they occurred. Redundancy with respect to comments has not been eliminated. This information will be combined with input from other sources and will inform development of Connecticut's Children's Behavioral Health Plan. If you have comments about these notes, please email project staff at: info@plan4children.org.

Summary of Comments

- Speaker 1
 - One of our mandates is to work with families and enroll them while the mom is pregnant and screen them for mental health issues especially for post traumatic depression. There are 20 programs funded to do this work. It's interesting that it's called the children's health plan because children don't have mental health problems in isolations. Recommendations include:
 - Universal depression of screening of parents by OBGYN Offices.
 - Connect dots that already exist—don't require additional funding. Strengthen connections like early child hood visiting programs, early head start, etc. We need to connect with OBGYN and pediatrician offices and normalize home visiting support for all families.
 - Training for facilitators to provide support for families. Including DCF funding for the circle of securities trainings. For parents, going to support groups can be as effective as therapy.
 - Create reports to provide information on issues families are facing.
 - To work on increasing and improving maternity and paternity leave.

- Speaker 2: Prevention coordinator with DCF
 - Too many children and parents are not thriving in life. Need communities to use a tool called "circle of security parenting". A key aspect in kids thriving in life is for them to have security, curiosity, etc. These skills need quality parent child relationships to build secure attachment. Many families have a poor/insecure or disorganized attachment with their children. Children need a strong attachment. Circle of security parenting gives the families the tools. (1) as you develop a plan, include a strong focus on building and supporting secure attachment (2) seize the opportunity to bring circle of security parenting to every community in CT.

- Speaker 3: Parent of now adult child that was diagnosed with Tourette's, ADHD, OCD (with intrusive thoughts) at age 16
 - Child went through entire school system undiagnosed. He received many disciplinary actions throughout school. Child is now going to be 19 years old trying to get him support and diagnosed. He graduated from high school with honors through home schooling that the school supported (Many families don't know about this option).
 - A pediatrician should do a behavioral assessment. Our pediatrician didn't conduct a behavioral assessment. Our child had early symptoms but I didn't know what it was. I would have preferred a pediatrician versus school doing the diagnosis. A diagnosis does

not change the impression staff and administrators have of kids with the disorder my son has. He was “bullied” by the adults. This hurt him more.

- Require school districts of their right to special education for their children.
- There is a law in place that entitles your child to these services regardless of whether your district has funds.
- There are special education advocates that are available to represent families. Special education laws are very complicated.
- Creation of parenting classes for parents with children of special needs. Once we started doing the right things, we noticed improvement in child.
- Child’s family should secure a therapist who is knowledgeable in behavioral problems. Everyone should be equally involved—school, kids, psychotherapist.
- Attempt others ways to treat children without psychotropic medications.
- We need to explore who as a parent I was never approached the possibility of testing my child. Some parents are approached and others are not. Is there a way to standardize the process of approaching parents.
- CT parent advocacy center in Niantic. They were my starting point.
- Speaker 4- Human services director for a local municipality
 - My son was on the verge of getting a bipolar diagnosis at age 4. Pediatrician wasn’t sure what to tell me.
 - We are on the special diet—clean diet eating has allowed him to be free of medication, doing well in school. His impulse control was greatly improved. When off diet—he is a whole different person. I would love to see State of CT as a leader here in the importance of clean diets.
 - We asked our pediatrician and she recommended I look at my insurance list. We need a resource guide for parents.
 - Lastly- a friend’s daughter has schizophrenia- she has been in the ER stuck waiting for a psych bed. Can we have a better place for these kids to wait for services?
- Speaker 5-- Woman in long term recovery.
 - Recovery starts in treatment.
 - Proven supports—peer to peer support in schools, and community centers, ER access to recovery support specialists, programs that bring into consideration families and their needs.
 - Focus on family system—one that promotes recovery.
 - Need long enough treatment program time and specific to gender and age.
 - CTYF—has the statistics and programs and people to help with the solution.
- Speaker 6---Vice President of planning and performance improvement at CMHA—Child Guidance Clinics
 - We serve about 1200 families/year. It’s becoming increasingly difficult to run our clinics. Our Medicaid reimbursement is only 50% of the cost to cover care
 - Recommendation: Look at Medicaid rates and raise them to an adequate level so we can continue to provide services. Also- commercially insured have high deductible rates. They can’t see a clinician because they can’t meet the deductible.
- Speaker 7--Parent of a child who was diagnosed with ADHD and Autism spectrum.
 - We went to pediatrician and there is a problem. They said he was too young to diagnose him with a problem. I said to the school—I know he has issues but doctors said they can’t diagnosis him because he’s too young. Then schools said they can’t help because he doesn’t have a diagnosis. Went to a new doctor and the new doctor said we don’t want to label him. Then finally at 4th grade—a pediatrician referred me to a

therapist. The therapist finally gave us some strategies. They didn't want to give him meds because he's too young. Now he is in 7th grade and he is finally on the right meds and can get services at school. He has all the proper paper work but there is not the man power to assist him. I had to stay home with my son, I worked part time with my son and I went online and went to other countries to get the information I needed. I don't think we should have to do that. People are not able to get the help they need. We need to start early. MH issues start early and they should get services early.

- Speaker 8-- Parent leader (First Connecticut Parent Power and other organizations and with Connect grant).
 - Parents need our help. A lot of parents are overwhelmed and don't have the time. Especially if you are a single mom. There is not time. When we lost parent liaisons in schools, we lost a lot of wonderful things. We need to give parents support.
 - Let's use social marketing- -think about where they are—pediatricians, DSS, WIC, Children's schools.
 - When she worked in AmericaCorp as a daycare worker—a lot of kids have a lot of behavioral issues. Maybe kids can get that in daycare...use the circle time as a time to talk about more sensitive emotions (not just happy or sad). Mental illness and abuse is happening to very young children. At 3 and 4 year old, these kids are facing things that you would not believe. The whole concept of support groups is critical. Need to have collaborations across State.
- Speaker 9-- Parent to 4 children and 2 are on the Autism spectrum.
 - Our 16 year old we adopted last year through DCF. He is on the Autism spectrum with PTSD and has been struggling a lot. In April he left school to go to ER due to suicidal ideation. We found out he is going to a local hospital that night—we go in and wait. They said we have him—good bye. We weren't asked to help with any paperwork. He remained there for about 1 week. They were ready to discharge him the following Tuesday. Husky said he is approved for another day. That night they started him on Depakote (the night before we bring him home). The following day they decide to release him. May 21st—3 weeks later, he loses it and comes at her with scissors. We called 911- he gets arrested and then comes home. He is suicidal and homicidal. He goes to St. Mary's ER and sits there for 6 days. He didn't get appropriate medication the whole time and then goes home because he said he's not going to kill himself anymore.
 - We need better communication between insurance/husky and hospital. Husky says there are beds available but hospital says there are not. He has been discharged and goes to Bridgeport Detention Center. There is nowhere to put him—there is no hospital available for him. He has to stay there until he can be evaluated. I was told he will get better mental health treatment in detention than in the hospital. Why do our children need to go this far before getting the services they need. We need more preventative services.
- Speaker 10-- father to a child who has Autism.
 - I am not against medication but we need to try to not go just to medication. We are creating more of a problem by jumping the gun and going straight to the medication.
 - Youth want to interact with others and want to get better. We need to spend more time with them. We need to modify the learning style for the kids instead of giving them meds. We need to let them burn off energy between learning and even while learning. Get innovative with how to teach kids who don't learn in traditional ways.
- Speaker 11--child with Autism Spectrum, ADD, OCD.

- My mother went through a lot with me. “I was very hyperactive, disobedient and went through a lot of medication that used to drug me up. They understand that I have the autism spectrum at age 12”.
- The medication slowed me down, they made me gain weight, which caused me to have bulimia. There are other ways to help people other than medication. Talk to kids about their problems and listen to us, and give us space to talk to you.
- Speaker 12--single father to 5 children.
 - Identifying support groups is key--24/7 support groups
 - I was referred to different resources. Now finally with my child at age 12—I’m getting support.
- Speaker 13--mother and aunt to special needs children (autism spectrum) and a parent leader.
 - When my son was younger and started school I went right away and said my son has issues and pediatricians said child is OK because he was hitting milestones. School wouldn’t test son without outside diagnosis. Once he received the diagnosis, still school didn’t do much.
 - Schools need more education and resources. They don’t seem to do much. No support for parents from hospitals as well. Parents want to get help but often don’t know how.
- Speaker 14—Was a preschool teacher for 20 years.
 - Need to diagnose children at age 2-4 have so we can work with them early.
 - There are individuals up there (representatives) that are listening and want to help.
- Speaker 15--Director of clinical research at a center
 - We have to write grants to get kids help.
 - One major problem—Patient centered medical home—we need to get them in practice. No one is listening to the parents and families. There is a true lack of communication. The clinicians are communicating with themselves. The plan has to integrate a communication network!! The network needs to be built so that all parties are communicating.
- Speaker 16-- Manager of team that helps practices transform into medical homes.
 - We have people that come up with ideas on how to solve issues, people dealing with the issues, researchers---but there is a disconnect because they are not teaching the providers on how to integrate all of these great ideas. We need to create tools and resources for primary care providers to help them do the things that you all are recommending. We go to primary care providers to show them how to use new ideas and tools to help you.