

**Open Forum Notes**  
**Connecticut College, New London**  
**May 20, 2014**

Below are notes distilling the comments made by participants during an Open Forum. Generally, the comments are listed in the order in which they occurred. 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](mailto:info@plan4children.org).

Summary of Comments

- Speaker 1--parent and foster parent; foster children removed, no support or services for her or her children after that loss.
- Speaker 2--parent of two children, one with a MH need; commercially insured, have fought for 8 years to get services for their child; not system-involved but has MH needs.
  - Getting services: "It's been an uphill battle"
  - So little out there for kids who desperately need services; much less those who have less acute needs but would benefit
  - Serious anxiety and behavioral problems; can't get services until she fails school
  - Suggests that there needs to be something in place for kids with mild to moderate needs to prevent more serious problems later
  - DCF coordinated care worker told them, "You have so many things going for you, call us when you fall apart."
  - "We shouldn't have to fight this hard to get it (services)."
  - It's important to get services when they're 3 and not 18"
- Speaker 3
  - Hope that this plan actualizes the work that many providers have been doing for 20 years to create a comprehensive system of care (commented on KidCare)
  - Hoping this is the time that we develop the comprehensive, culturally and linguistically competent, community-based, family-guided system of care
  - Commercially insured can only get a couple of services, they can't get all the beneficial services in the intermediate sections of the continuum
  - Wants more early childhood and early intervention services; commented on all the families that have told her they knew when their child was 2 years old
  - Fully funded community based system of care; include peer specialists and advocates; community organizers to bring systems change
  - Look at improving access and ensuring that information is available to families
  - Look at how services are financed and how services are paid for
- Speaker 4—teacher; parent of a child with OCD; worked at mental health agencies
  - Has seen people across the developmental lifespan
  - Worked with school dropouts; many dropped out because of unaddressed MH needs; or a child of a parent with MH needs; trauma exposure; academic problems
  - Some kids didn't receive services because the needs were not identified
  - Said that "System is disconnected from human beings."
  - Said that she had worked with great providers, got medications and therapy in place, and got school support and she had to stay on top of it all the time to ensure services were received
  - Teach teachers and pediatricians to recognize, screen and identify problems early
- Speaker 5- parent of a child with MH needs, FSM at FAVOR, previously at various other agencies)

- “It’s very hard to understand what it’s like to live in a family when someone is living with a mental health diagnosis
- If it wasn’t for service providers and DCF Voluntary Services, “I don’t know where we would be.”
- Services are too time limited; when services were not in place she could see her child gradually decompensate
- “I had to get him to the breaking point...where people would start to listen.” “What does that do to us as a family?”
- Child is currently working and living on his own, volunteering, driving, and doing well but it was a lot of work with a lot of providers
- It’s important to take a close look at who you are providing services to and how long services are provided for
- Speaker 6-- works at Walden Behavioral Care; clinician and community outreach/prevention worker
  - Estimated 30 million Americans that are suffering from eating disorders
  - Limited access to prevention and services—by the time she sees some clients, “it’s scary to see how sick they already are.”
  - Need to talk with health education teachers about recognizing symptoms and knowing how to talk about eating disorders
  - We need more education to parents about eating disorders
- Speaker 7-- social worker
  - Need more simple solutions; a drop-in center for low-income and youth with MH needs; alternative and non-traditional (non-clinical) supports and opportunities for youth
  - Not enough use of community education
- Speaker 8-- works for local service agency
  - Need increased access to services
  - His agency turns away commercially insured kids because they are ECCs and they are required to offer enhanced access to Medicaid enrolled youth
  - Prevention is key: need screening at early age; many kids have had years of problems by the time they come to his agency
  - Need more SBHCs, but access is limited there too--they have wait lists after the first couple months of school
  - A real capacity issue
  - Lack of awareness of what services are available to families
  - A “sobering” lack of C/A psychiatrists out there
- Speaker 9--retired physician; representing CT Chapter of National Physician Alliance
  - They have recommendations to solve problems that have been brought up
  - 1 in 10 children will have a MH issue; only about 20% will get treatment
  - Include services that are known to work
  - Important that this plan includes all children and families
  - Every newborn child and family gets resources and materials to get to local services (they use braided state agency funding to support this)
  - NPA supports prevention activities: families need to understand how to relate to children, identify problems, and get to services
  - Take advantage of university system and CHDI to train multiple system stakeholders
  - Access to early developmental specialists and early intervention
  - Interagency blended funding
  - Expansion of the Medical Home model

- Financing: improving salaries among social workers in CT (noted that they are paid much higher in California)
  - NPA willing to help and support with design and delivery of services
- Speaker 10--CT Association of Boards of Education; former foster care parent
  - Need more teacher preparation to improve communication with families
  - Reduce fragmentation across service providers; need coordination across child systems
  - Problems with access are troubling
  - Need to reduce fragmentation
  - Increase personnel preparation for recognizing and delivering services
  - Need healthy coordinated transitions for foster parents—DCF needs to provide more support to foster parents
  - Identify mothers with postpartum depression and other needs
  - Reunite children with families whenever possible
- Speaker 11-- parent of children with MH and dev. needs, HUSKY insured, works with young kids
  - Worst year with HUSKY paperwork, it was in on time but not processed on time, but services were cut off due to their delay
  - Saw her family with no HUSKY reimbursement, but she was fortunate
  - Access CT (ACA enrollment) is not accessible to families
  - Services can't be cut off because of administrative/paperwork problems
  - Wait lists are very long. Many do not take HUSKY because of low reimbursement rates
  - Birth to 3: Services are not as hands-on as they used to be; she knows a lot of parents who have dropped Birth to 3 because they are unhappy with services;
  - Many parents are not aware of their options for getting services
  - Children with Autism have such limited options to meet their MH needs; not enough providers with expertise with Autism; results in long wait for services
  - Schools also do not respond quickly to clear MH needs; they need to listen to parents
- Speaker 12- VO Regional Network Manager
  - Speaking on behalf of a friend with a 7 year old with MH needs
  - Access is problematic, she did not get services through traditional routes;
  - Look at the faith-based community for increased access to services
  - Extreme difficulty getting school system to listen to her and what her child's needs are
    - Several PPTs
    - Child was isolated from other kids in school, no interaction with teachers, students
  - Was successful getting her child in another school with fewer students
  - Fragmented care: medication management requires seeing several psychiatrists with changes to diagnosis and medications all the time
  - Wanted neuropsychological evaluation: Medicaid does not pay for it; can't get a professional to provide it (can't get anyone to approve this evaluation)
  - Special Education Directors and school systems needs to be part of this plan (limited support, they don't understand her concerns, they don't listen to her)
  - IICAPS and Outpatient: Switching to a new outpatient provider and was referred to IICAPS and nobody seems to know if she can get Outpatient and IICAPS at the same time
- Speaker 13-- parent of adults who were once children with MH needs; sibling of an individual with MH needs
  - Participated in Family to Family course through NAMI; taught by family members of people with MH needs
  - Need to educate and train parents about MH and how they can best meet their needs

- Free program, but 12 weeks in duration
  - Help parents understand causes and course of MH and education will help parents cope
- Speaker 14
  - Wanted to talk about problems with Access Health system
  - Concerned about private insurance issues and people getting coverage they need
  - Encouraged strong community voice
  - Thanked DCF and CHDI

#### Event Planning Notes

- Need better signage and parking directions on location at each event
  - Especially at University of New Haven
  - New Britain and Stamford are at schools and should be more straightforward