Facilitated Discussion Notes
Autism and Mental Health
May 12, 2014

Below are notes distilling the comments made by participants during a Facilitated Discussion of this topic. 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.

General Notes

- Location: Value Options, 3rd Floor, Hartford Room
- Approximately 19 people in attendance

Question 1: Strengths

- We have seen lots of improvements over time. We see improvements in outcomes because we are getting kids into treatment earlier and providing structured education.
- The first sets of outcome studies show that about 5% of those with Autism were independent and self-sufficient and now it's closer to 30-35%. This is a major shift. For instance, we now have kids going to college.
- If you have the means, you can access really good resources.
- We have great resources for families compared to other states.
- We have strengths in teaching schools and programs how to work with kids with Autism.
- For the public schools, there are guidelines in place that help ensure school districts are prepared (but the guidelines do need to be updated).
- We have a lot of dedicated people who have worked hard and we are moving in the right direction. An example includes the development of the CT clinical guidelines for the clinical diagnosis of Autism, based on collaborative work. CT is one of three States in the country to have such guidelines (the other two are CA and WI).
- Some of the professional groups have practice guidelines on working with children with Autism, which can also be helpful.
- We have good infrastructure in CT. For example, the DDS autism plan is one. We also have parental supports and the medical home model.
- We have a lot of cooperation between state agencies. Much better than other states.
- The involvement of the parents and their coordinated efforts of advocacy are great and much better than on the adult side.
- We have good legislative champions and this is essential because of their influence.
- CAAC (CT Autism Action Coalition) is bringing agencies together to communicate & collaborate.
- We have a Medicaid waiver that expands the pool of those able to get services and expands the type of services they can receive.
- DDS has done a great job to build momentum around improving services for children w/ Autism.
- The most important thing is that we have so many wonderful people on the spectrum who are self-advocates and who have sought out their own education.
- Providers are listening to the self-advocates and using that information to guide their work.
- The general public has more of an awareness and understanding of Autism. The awareness is creating more acceptance and respect for a person with Autism. It used to be people with

Autism were hidden away, but now if you bring your child with Autism into the community, people tend to show more support and don't blame the parent.

<u>Question 2: Concerns</u>

- We have a complicated system in this state.
- The state shifted the responsibility of treating Autism to the schools. This gave the insurance companies an out to not support Autism. Not all schools are prepared for this challenge.
- The fundamental problem is with the insurance companies. Medicaid provides a basic level of care and for people who can pay privately, there are good services. However, 60% of the providers out there don't take insurance. This leaves a large group in the middle with very little coverage. Having autism makes you more vulnerable to other mental health problems so not appropriately treating it is a major problem.
- Schools tend to be ambivalent about the problems that children with Autism have. The schools are more mental health focused (e.g., bullying, anxiety, depression screening, suicidality).
- We need better access to early diagnosis. It takes 6 months to first see an autism expert and that's not acceptable.
- Concerns about the Birth To Three program
    - The staff at the Birth To Three program needs to do a better job recognizing which kids need intensive intervention quickly.
    - The interventions that are referred through this program need to be of a long duration and of high quality. The standard recommendation is at least 25 hours/week of treatment. However, Birth to Three staff often recommend as little as 7 hours/month initially, which can be harmful for the child who instead could be improving with the 25 hours/week treatment plan.
    - The services offered are inconsistent. Some staff will recommend 7 hours/month and others will recommend 20/hours week without a clear reason for why one recommendation was different from another.
    - With the transition between Birth To Three to the public schools, there is no guarantee that you will get the same duration and quality of services.
- Access to information about resources is a challenge
    - We are not doing a good enough job at getting the word out about where the good resources are for families. You can start by calling the Birth To Three program but you have to be in that age range.
    - Many people don't have the ability or resources to get information about treatment on their own.
- Sometimes if you move across the street or to a different town, you can get improved services. This is frustrating.
- Currently people are not getting the duration of services they need. Evidence supports that kids with Autism benefit from more hours of intervention. An ideal model is 40 hours/week.
- Local town services are sometimes terrible. You ask for a rationale for the level of services provided and you don't get the answers and clarity you deserve. Providers forced to outplace children into other schools and services where they get intensive ABA services and thrive.
- The majority of families are not able to get the resources their child needs.
- Schools are trying, but we see differences in style and effort from district to district. Sometimes if the children with autism are academically fine, the schools don't help them with psychosocial needs because they perceive them as doing well.

- They need full day pre-K. Because then you have the same amount of time for intervention with the pre-school children as you do with the school aged children.
- You need a skilled person who is facilitating the child's activities in a classroom.
- Lack of training is a huge problem across disciplines. More training is needed.
- Our funding is locally based which is a problem and there are school to school differences. We need parity across districts and schools.
- Stress on families. Some families fight for more services for their children but some don't even know what to ask for. We have a system that is so individually focused (on the child with Autism) but not meeting the needs of families and siblings.
- We have seen families falling apart because our approach is "one-size fits all." The interventions sometimes don't match needs. We are not doing needs assessments. We are telling them what we have and that's all they can choose from. Because of this, families do not trust the system.
- Transition to adulthood
    - Adults with Autism spectrum disorders are "falling off the face of the earth" after 18. They "are graduating into nothing." They are not able to get the help they need because providers are not taking private insurance or Medicaid. It is the most frustrating thing about my job. Nowhere to send the adults in need. It is a real crisis.
    - You've got some of these kids who go to school and families work hard to keep them included with their peers. Then it comes time for graduation. While in high school, the child may have had a job and they were able to access nice community organizations through school, and then they graduate. School is no longer there for them as a support.
    - You have to look at how adults with Autism are under-employed or unemployed. Most are unemployed. Schools are not doing appropriate transition plans when the child with Autism graduates. Kids who are at the mid to high end of spectrum suffer the most from this transition problem. They are not being trained to develop skills for competitive employment. We need to look at how we are preparing them. They need to be prepared differently than other special populations.
    - Individuals with Autism don't transition from school with social skills, life skills, driving, and housing. Need transition services focused on those areas
- Autism and Behavioral Crisis
    - We really don't have a capacity for individuals with Autism who are in a behavioral crisis. There are limitations with crisis programs (ED or 211) including limited ability to respond and lack of informed care. They do not have trained staff to work with Autism. They are psychiatrically trained with some trauma training only.
    - We know EMPS has been used by families but the staff are not trained in Autism and there is not an alternate system. Not sure it should be the same service for Autism. Maybe something different? If EMPS approaches them wrong, it can exacerbate the situation and lead to medicating the child, which can be more harmful. This experience may make them not come back to that resource and try to deal with it themselves.
- Screening is critical and needs to be implemented universally. Developmental screening and Autism screening should match other screening rates such as collecting vitals, which is close to 100%. A pediatrician and family care doctor should start that journey together with the family. In CT we are at about 38% for screening for Autism in the primary care setting.
- With Birth To Three, it's helpful but at three it stops and then school and Department of Children and Families supports the family. Those schools have challenges providing adequate support. Families don't have a natural support and the services they are being provided don't

flow well. DCF is not an agency that appreciates and works with families effectively but families have to go there. And then at age 8 they have to transition to DDS. This is not a good flow.

- If we all do a more effective job of supporting families and young children who have Autism and start interventions early, then we will have more healthy adults.
- There is over-representation of kids with Autism being restrained at schools. Schools say that is just the way it is, but they are not trained to handle it differently.
- Schools get trained in restraint and seclusion—so that's what they use.

Question 3: Recommendations

- With the young children, CT made a decision to move away from State services to the contracted Birth To Three program. There is no oversight with this program and so we see variation in quality. CT also made a decision to move away from center-based treatment to home-based treatment but the evidence for that being better is limited and out of date. Center-based treatments have the possibility of providing more intensive opportunities and socialization opportunities. This will give children more time with services. The programs can provide more services and make the transition from age three to schools. The centers can more easily coordinate with the schools because they would be more like the school-based programs.
- Improve screening. American Academy of Pediatrics (AAP) supports training regarding screening so we need to make it happen. "Birth to Five—Watch me Thrive"—is a national initiative to make sure developmental screening and ADS screening is happening. Consider looking at the "Birth to Five—Watch me Thrive" model and think about how we can implement that in CT. Other initiatives from CDC should be looked at and possibly integrated in CT. We know early intervention is critical. Representatives from AAP would be good to have at the table to talk about implementation in the primary care setting.
- State could sponsor Grand Rounds for medical residents on early identification and screening. You could reach every resident in CT this way.
- Explore ways to mandate training in Autism across professional disciplines
- Yale has a course on the internet on Autism and anyone can view it. Yale undergraduate students know more about Autism than those coming out of psychiatry programs. Suggestion: Statewide package of options to get training using a single centralized system.
- A comprehensive list of resources for Autism is coming through a collaborative effort. All state agencies were involved in a feasibility study. They came up with recommendations and broken down to sub-committees. One training working group/subcommittee is focused on having a central repository of information on resources.
- Expanding and enhancing rates of screening is important but pediatricians don't have time.
- Schools and pediatricians are the main sources for kids for professional services and they don't have time to do screening and referral.
- Like with Utah, consider initiatives that emphasize including people, tolerance, training, community, and religion.
- Medicaid and private insurance also should do better in reimbursement. If practices take private insurance, they are overbooked and appointments are 6 months out. This is a problem.
- Having all services in one place.
- Create a transition program for youth with Autism entering college. At the University of Toronto, if you are a college student with Autism, they provide you with a 2-3 week introduction to the school in the summer, they know about your disorder.
- There are family support groups out there but it is hard to keep them going with no or limited funds. We need support for family support organizations. This would make the people doing

the work feel like they have buy-in from the state agencies. Business and churches may sponsor these groups too.

- There are models in other states (e.g., SC, NC, Maine) to help communities put together a family/local program to help families navigate the system in a culturally, appropriate way. We have people who could do this but there are no resources/funds to support it.
- The transition from Birth To Three to DCF (Age 4-7) to DDS (8-18) is not good. Families can apply for autism waivers but it takes too long. We need to consolidate services under one agency. Families have to go from culture to culture to culture and this is very hard for them.
- We need to look at how to develop successful transition programs in the high school. Southern CT has the CT Center for Excellence and they could develop this transition program.
- Need to diagnose early. We have children being diagnosed late and this overwhelms families.
- Things can be therapeutic without being therapy. Boy Scouts for example. A little teaching about Autism to these local community organizations could make a big difference.
- Commercial Insurance Specific Recommendations:
  - Self-funded insurance plans that don't have to follow a mandate—these are federally regulated. People on these plans have trouble getting services covered for Autism. Self-funded employers don't want to fund these services. You can advocate for services at your place of employment but you might worry about losing your job and it takes a lot of time.
  - Sometimes services are only covered for 16 weeks or some limited time. It shouldn't be time limited.
  - Questions about who is on the insurance companies Provider Panel. There needs to be a mandate to have appropriate providers on the panel. Some companies won't put certain people on the panel if they are not licensed and that is limiting.
- Need appropriate funding for DDS as an agency so they can do more. There is a waitlist and we can't serve everyone. Need more money for DDS.
- Design <u>one</u> system that covers everyone--- Medicaid, non-Medicaid, private, non-private, no insurance, etc.
- Assist the family who is usually the constant. What about having a parent do the screenings in a primary care setting—get creative.
- Need funding for training. The training should be for the whole team (e.g., teachers, speech professionals, counselors) and it needs to be funded by the State.
- Every teacher has been trained but they get one class on disabilities and then one lecture on Autism which is not enough (unless they specialize in it).
- Please remember <u>adults</u> on the spectrum. We are graduating our youth from high schools and they are not prepared for adulthood.
- Training—developing some online didactic material and then adding on the coaching and modeling components. There could be cost sharing between State and district.
- Transition should start when you are starting a system. Even when they are in kindergarten, start thinking about when they are adults. It starts at the beginning.
- One-size does not fit all. Each disability needs different types of services.

<u>General Feedback on the Discussion</u>

- Have people from the State Department of Education & Office of Early Childhood provide input.
- This was enough time to share. Two hours was good.