ASD Workgroup- Building Network Capacity
8/7/15

- **Overview of ASD Workgroup Timeline & Activity of other workgroups**

- **Review of July Workgroup Discussion**

Where do you see areas of focus for this workgroup?

- No additional comments

What additional information is needed?

- Geomap of ASD population
- Information detailing the population already in DDD
- Data Subsets
    - RBHAS (individuals under age 18 and those transitioning into adulthood)
    - SMI
    - RBHA entire pop with special focus on age 16-24 (transition population)
- CDC Data (ADDM Survey) – CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network
- Through PC and Acute Health plan (EPSDT studies)
- Wait list for diagnosis
- Department of Education data sets- need to determine what information is available
- Empowerment Scholarship Account (ESA) data
- Subsets for ages 16-18 and 19-23
- Subsets for ages 0-5 (services may be different and more than those available for ages 5-15)
- The number of services approved versus services actually received
- How many 504 plans are being offered through education?
- Health Exchange plans- with parity, number of kids who are receiving services through health exchanges (account for kids with dual coverage)
- The RBHA may have a diagnosis for autism but DDD doesn't- we need to identify how many cases like this exist. Also, a pediatrician may diagnose a child with autism, but the child does not qualify for ALTCS.
- Average insurance carrier rates for certain services vs. DDD

- How many providers have autism experience?

What other barriers exist that impact network capacity?

- Rates- reimbursement is essential in surveying issues with health disparity, particularly in rural areas.
- Habilitation consultation is supposed to expand upon current services to include a broader age range and across diagnoses (any DD individual) - the governing rules for this service have been put on hold per AHCCCS pending the ASD Workgroup's activity. These evidence-based consultation services are essential to families and it will allow DDD to tap into a much broader network of service providers.
- There are two rates- one if you have a behavioral health license and one if you don't.
- Has there been discussion about using telemedicine in rural areas? Individuals used to be able do telemedicine for hab, but can't do it anymore. (Behavior Change Institute)

- There is a need for providers for higher functioning teens- more counseling on social skills, independent living, job skills and making friends.
- We are not able to quickly bring in speech, OT and PT. As we move towards integration and value-based purchasing- we need to get there quicker.
- It is hard to find providers for adult ASD. There not many physicians who can provide good medical care for this population.
- We need to make certain nutrition is included- we sometimes have to refer kids to pediatricians for nutritional care.
- We need providers who can address sensory issues.
- We need kids to get dental care- some people are not able to brush their teeth- parents don't get to dentists because they are so focused on behaviors.
- There are often wait times for other specialists.
- For children who need augmentative communication devices, there is long wait time (as much as 2 years). Additionally, there are not enough people to do evaluations. If you have a private speech therapist, it is easier.
- Recruiting
- It is a challenge to keep providers in Arizona.
- There are problems with reimbursement.
- There is too much complexity in the behavioral health system.
- It is almost impossible to see a psychiatrist- complicated by the fact there are frequent medication changes for these patients.
- There was a previous task force through the RBHA.
- There is a tendency to put kids in front of a medical professional and ask to control their behavior with a chemical instead of behavioral analysis and therapy. It took until 2000 to get providers to stop being critical of parents and change the conversation.
- There are differences in 3 RBHAs in terms of how referrals are managed.
- There is a shortage of providers who know how to treat ASD behaviors (medications don't always work on behaviors).
- There are child psychiatrists who don't feel comfortable treating children with an autism diagnosis, even though this is included in their training.
- Many kids are taking other medications that affect behaviors due to an interaction between the chemicals in those drugs.
- Symptoms cannot be evaluated in a 15-20 minute review- the provider is often reacting to a parent, depending on how stressed they are.
- Nationwide we are not producing enough child psychiatrists. This is a workforce issue.
- We need more developmental pediatricians. There is competition for same workforce in Arizona. Additionally, grads don't want to stay in AZ- they express that they only stay to pay down their debt.
- There should be specialized training for child psychiatrists. Right now they may or may not know how to deal with ASD. It would be an excellent idea to require continuing education on this topic. However, if a big company is contracting with these professionals by the hour, they will not want them offline in training.
- At ASU, there is a certificate program to train people in swallowing and feeding disorders- professionals can either take all courses to gain full certification or a la carte to gain more familiarity (less time and more appealing to companies). There is also an online option with a practicum component- look to replicate this program for other professions.
- It is hard to find professionals with a lot of real-life experience.
- We need to make it so it so it is not cost-prohibitive to develop professionally.

- How do we eliminate wait list for speech therapy? Why is the ASU program so small? The program is big compared to other schools (36 students/year). The training is intense- students must have a set number of hours of supervised practice- this limits professors' availability. The program's numbers are increasing- they just started working with East Carolina University (students take courses online, but do their practicum in Arizona).
- There are also speech language pathology assistants- we could get more in different settings to increase capacity.
- There is a new Masters in ABA- all practicum take place through the year with rotations to different sites.

Are there other provider areas not discussed?

- Dieticians and nutrition
- In-home support habilitation (coaching, respite)
- Some agencies have great training and some have no clue. We need transparency on agencies' training and focus. These agencies need licensed professionals and special skills training, and support staff with training. Funding makes it difficult to do extra training and support. There has to be a balance between higher rates and higher standards.
- Having highly qualified in-home support providers helps.
- Parents need to know who the qualified providers are. There should be a review site people can go to for information- similar to yelp.
- What are parents looking for?
  - Someone with a BCBA
  - For transition age children- someone who knows how to address behaviors
  - Provider options and what each provider actually does
  - What are providers' training?
  - A supervision log- if using extenders, it is important to know they are supervised well.
- There is a more robust schedule of service codes through RBHAs- if you go to DDD it titrates down. Commercial service codes are all over the place. Often, the family must decide whether to pay out of pocket. Many people move from one system to another.
- There should be a grading system for providers that include parent surveys and data driven outcome information or evidence-based practices.
- It is easier to measure outcomes easier with BHA, but with habilitation, outcomes are harder to measure- it is hard to make it a fair comparison.
- It is important to ensure quality as well as progress- you must look at the individual (plateau or progress) to determine quality.
- There should be CARF- like accreditation standards (including quality elements) for providers.
- Some agencies have habilitators in house? There are better outcomes when habilitators are directly employed by the agency.
- The more we can train people, the more successful they will be and the lower the turnover.
- Do positive reinforcement. There should be incentives for additional training.
- Is it wise to keep loading students with debt or ask the Legislature to start creating the workforce, similar to what happened with Cox and Century Link? They could bring back the loan repayment program.

What are the key bullet points for entire committee?

1. Push through habilitation consulting service- huge impact
2. Increase who can diagnose to include pediatricians using STAT-MD.
3. Increase the number and competency of providers and ability to provide effective services that are currently inhibited by reimbursement rates.

4. Increase our level of training for all providers.
5. Increase supervision for fidelity of training
6. Include someone from Arizona Dept. of Education in all workgroups to gain additional information on the rules and services available to children with ASD. For example, right now, providers cannot ride on a bus with a child.