Adults with Autism Work Group Notes – 8/6/15

Participants: Joyce Millard Hoie (Raising Special Kids), Jon Meyers (The Arc of Arizona), Nancy White (Parent), Denise Resnik (SAARC and First Place), Daniel Openden (SAARC); on phone: Elanie Estrada (DDD). Facilitated by Sharon Flanagan-Hyde. Notes taken by Chris Vinyard (AHCCCS).

What are the areas of focus of this work group?

Need to compile research and data that is already available to establish a better starting point. This should include a 360 degree view of the parent, provider and system in order to give a better perspective on what is needed.

Outcome based results and developing mechanisms to support that will be needed for the long-term.

Identifying all members that have ASD and where they are currently located within the system.

Any indicator if members with ASD are being missed within the system.

Additional areas of focus: residential living, transportation, healthcare (Acute/Behavioral Health) services currently being utilized.

System design should have a focus on identifying those in the system with ASD, but there should be an equally significant focus on whether or not the system is meeting the needs of each member.

Economic effects of inadequately addressing ASD

The potential fiscal impacts of providing adequate support to individuals with ASD

Steps to begin collecting data – specifically robust and reliable outcome data (What is their life like: employment, social contacts, transportation, healthcare, and housing).

Data on those working directly with adults – from community forum, we know that those providing services have high turnover rates (50-80% a year), low wages, less training, less than optimal outcomes

Looking at the population of adults that is undiagnosed but would be diagnosed had they been born at the right time (Historical Data) – the diagnostic tools did not exist 20-30+ years ago. Is it useful to look at this population and is it possible?

Communication and relational therapies once individuals no longer become at-risk for institutionalization – the need is still there

Indicators of good health and how do we know if we have achieved them?

Promoting direct care provider curriculums to ensure an adequate work force

Finding mechanisms to gauge the population that has gone undiagnosed

Services lacking for those extremely close to being at risk for institutionalization

Renewed focus on what the overall group is truly working towards: Strengthening the healthcare systems ability to respond. See Governor's memo on establishment of the workgroup.

What data do we have?

It has been a challenge collecting data on this population. AHCCCS may not have been collecting data at all, or in a manner sufficient to support policy initiatives.

Joyce will send e-mail with information from DDD about numbers served. Small number of members representative of being frustrated with the system and dropping out altogether, or frustrated due to primary language being non-English.

Other

AHCCCS from the beginning stated we did not want to focus solely on the ALTCS population, but the piece that is missing is the population not captured within the current population. Members who may not qualify for ALTCS – high functioning (Asperger's).

Targeted case management population has dropped significantly

Finding all the pieces and parts of those with all forms of autism

UCP study and AZ being ranked #1 looked good because we are keeping people at home – more interpretation is needed. Because of home-health care, there are no waiting lists. Conversely, employment and quality of life issues has AZ at the bottom of the list

Report produced by UC Davis on the economic effects of ASD and not addressing it or inadequately addressing the problem.

AARP study on economic effects of family caregivers for those enrolled in home and community based services.

Are there therapies and interventions needed for those after 18? Currently, there are significant communication/relational issues

Even when individuals progress to a point of not being at risk for institutionalization, there is still a diagnosis of Autism – it never goes away

Adult programs do not function for continual education – and there is not a one size fits all approach, but current programs is more to kill time rather than continually progress. Medicaid will not pay for "education," so the potential for coverage needs to be phrased differently. (Interventions, therapies, etc.). Could potentially be included in an integrated group home.

Once members turn 18, they are somewhat discarded from the system. What services will be paid for whether in AHCCCS or DDD for members beyond 18? Everything is driven by the individuals ISP.

Infrastructure needs as well as others extremely underfunded. Need to go where the group can win in getting valuable data due to state likely underfunding any initiative.

Members who may be enrolled in DDD but are not ALTCS eligible would benefit from expanded services that members in ALTCS receive.

Opportunities for further reimbursement of services where the state will not pay and member is forced into private pay

“Home” is just one part of the concern for adults. Services for adults with autism should focus on “life” (joy, health, education, finances, focus on independence, connected to community, greater circle of support (shrinks as they get older).

Fears of those living with ASD include stigma, abuse, medication management and loss of skills and abilities.

With CMS’ ruling, the group wants to focus on more than just housing or what is defined as a “home.”