

ASD Advisory Committee Adults with ASD Work Group—10/1/15

Participants: Jim Adams (on phone), Joyce Millard Hoie, Denise Resnik (on phone)

Note-taker: Chris Vinyard

1. Updates

a. Online Survey:

- Survey results could be published in a research article. Will need approval by ASU since it will be human subjects research, but this shouldn't take long because this is an anonymous survey.
- If results are promising, there is no objection from work group to pursuing publication.
- Moving forward, group will need to identify who is doing the survey – needs to be either ASU or the work group. *Group will proceed with the survey being a collaboration between ASU and the work group.
- Will need to determine how the survey research will be advertised to groups that focus on ASD. Survey will be disseminated through all the organizations affiliated with the overall committee. *Sharon will provide list.
- Survey data will be analyzed during the month of November with the committee recommendations due in December.

b. Discussion questions for site visits:

- Denise and Joyce shared their draft notes from a conversation they had. Discussion questions, and the work group's report to the Committee, could follow this format: housing, employment, health, community life, and general.
- Likely those filling out the survey will be parents and family members.
- Will also be an opportunity to get responses directly from members with ASD.
- Work group wants the voices of members prominent in the recommendations put forward.
- Discussion questions should be brief and those asking the questions should not appear as being forceful or a looming presence.
- Patience is key to garner quality input.
- Health, housing, employment, community, and general aspects should be prominent in the discussion questions. Additionally, personal aspects of friendships (boyfriend/girlfriend/other) need to be included.
- Questions are structured with a voice for members and parents.
- *Jim will provide input on the questions before Joyce and Denise disseminate the questions to the rest of the work group.
- When feedback comes in, there may be specific next steps on actionable items, but it will still need a collaborative effort to effectuate any change. Potential strategies and "next steps" will need to be included, specifically to how government can be involved and make appropriate changes to better serve members and families.

2. Developing Recommendations:

- The group will need to work towards a unified vision of what next steps will and should be.

- The big question is what is needed to inform policy and policymakers.
 - Choice, community involvement and acceptance should be utilized as principles or guardrails to help guide the report.
 - Specifically, guardrails in the report should be home, stepping stones (transitioning), person-centered culture, integrity and efficacy to get results, inclusive, collaborative, and pioneering.
 - Higher education and trade programs offered at the university or community college level. – Of the 100 or so students with autism at ASU, the graduation rate is well below the university average. Need to strive towards the Marshall University model of having a 90%+ graduation rate.
 - Look at National Housing Indicators Report.
- a. Comprehensive data on AHCCCS members (children and adults) with ASD and where they are (or are not) receiving services within the system:
- What numbers of incidents are being reported in group homes and if it is proportionately higher with members who are diagnosed with ASD.
 - There is no real evaluation process for group homes and their effectiveness.
 - Little to no members identified as living in an “independent living” facility under DDD agency statistics.
 - Data presented on total cost of care to members with ASD under the AHCCCS system – but did not include a separation of where exactly money is funneled.
 - If the group was able to identify how money was being spent, there may be opportunities to better spend in order to realize better outcomes within the system.
 - How does DDD allocate funding within the program – day programs, respite, vocational, etc.? Information would be used to gauge whether funding is appropriate.
 - Respite is more difficult to find with adults, which may be a primary reason parents encounter difficulties and end up sending their children to group homes. – Would help to quantify this number, but it may be answered in the survey.
 - Turnover rates for staff who are employed by facilities treating or interacting with members with ASD.
- b. Integration of medical care, behavioral health, and support services:
- Medical home model is a goal to pursue.
 - The benefit of electronic medical records aligns with AHCCCS initiatives around care coordination.
 - Greater use of technology will go a long way in aligning care.
- c. Effective training and education for community members who interact with adults with ASD (e.g., judicial system, emergency personnel, employers, neighbors):
- When the city or state employs individuals with ASD, there should be mechanisms in place so there is an understanding and awareness.
 - All organizations should have the opportunity to expand awareness when engaging with members with ASD.
 - The question remains whether or not awareness of community is necessary or can be entertained by AHCCCS. Information should be included in the report to at least have the conversation.