Adults with ASD Work Group Meeting: August 31, 2015

Participants: Jon Meyers, Joyce Millard Hoie, Jim Adams; On Phone: Aaron Blocher-Rubin, Denise Resnik

Facilitator: Sharon Flanagan-Hyde Note-taker: Chris Vinyard

Thoughts on summary document sent by Sharon:

Data is helpful, but further follow up needed:

- For employment options, who is taking advantage of those options?
- How many hours actually working – check with SAARC
- Average hourly wage of those working – check with SAARC
- Identifying average wage levels of members enrolled in AHCCCS and currently employed.
- Number of individuals actually looking for employment opportunities – additional and even higher level work – may result in the need to draft a survey because people do give up, or continually look for work.
- Survey could be conducted using email list that contains thousands of individuals, or using social media outlets with a minimal marketing budget.
- How different is Arizona regarding employment compared nationally?

Overall Issues

Do not want to lose focus on the great number of undiagnosed individuals living with ASD and those who do not qualify for ALTCS.

Needing to better understand how the new CMS rules apply to the entire spectrum.

Parents may not be aware of the options for adults with ASD.

Member-Directed Services

Member-directed services can provide flexibility in segmentation – are other states pursuing such innovative approaches? This might be an opportunity for innovation in Arizona. What might this look like? A system that supports individuals and their families designing and directing services that work best for each individual. We need to understand the trajectories of different types of individuals and what works with different segments.

We need to find ways to help individuals make good decisions based on the specific and unique parameters of each individual – other communities and industries do it, but innovative options need to be implemented to get individuals connected to proper resources.

Medical Home

Medical home for adults with autism is a necessary approach given the personal experiences of members on the committee. Care coordination is huge in getting the necessary services in a timely manner – coordination of preventive physical heath, acute physical health, and behavioral health needs.

In the report, the distinction between “group home” and an individual “medical home” needs to be made to avoid any confusion. Perhaps “health home” is a better term.

Helping members understand the significance of their own health and the awareness needed to maintain a healthy life. Reminder phone calls, postcards, or other regular follow-up notices are needed regarding preventive services.

Residential Issues

Residential options – high proportion of members living with parents at home. What is the degree of satisfaction with residential options for both caregivers (parents) and members?

What is the turnover rate at group homes for employees – pay may be higher in other types of facilities geared for different populations. What types of models are more successful and may be innovative?

Need to find and summarize any data that can lead to quality indicators of satisfaction, and put plainly, what is actually working.

ADHs (Adult Developmental Homes), which are individually designed living arrangements, are the potentially best option. Because residents live in the homes of staff, there is lower turnover.

Employment Issues

Availability of working options — the disabilities faced by members can create barriers (interview process is often challenging and intimidating) – job placement, job coaches, navigators, or other similar services may be beneficial in connecting members to the right resources to find employment, housing, and connecting to the community.

Agencies may need dedicated employees to find jobs for members. For members, Centers should be just a stepping stone to community-based employment.

Having a centralized location or resource for members to go to in order to find employment opportunities – will also allow businesses to connect to the community to fill openings. Workability (Tucson) or Untapped Arizona (AHCCCS grant) may be a good starting point.

Expanding the definition and scope of a “navigator” and explaining the many options to members and parents – not just finding a job, but finding the right job will be extremely important. Job shadowing should be encouraged by the navigator.

Should navigators be viewed as case managers, or something different? Navigators could potentially be a service that case managers authorize, but specific training needs to be a part of the navigator’s qualifications.

Consider the idea of tax credits for businesses that hire individuals with disabilities – not knowing the current tax codes, this may already be an option. The more individuals hired, the less support will be necessary.

Social Life

Adding an umbrella organization to help schedule social activities which is a quality of life issue.

The social isolation that individuals with autism feel is tremendous – when asked, one young man said a job and friends are what constitutes a quality and happy life. Social connection and the skills needed to develop and maintain those social networks is paramount.

Social groups or social organizing would be a helpful service - both big and small events– even just one or two activities a week.

The HCBS rules and the social aspect is extremely important – but it will be difficult to achieve because the first inclination of members is to socially disengage.

When children become adults, the social activities and settings need to be somewhat different in order to avoid any sort of burnout.

Social therapy, or community therapy, addresses the issues that are at the core of autism — social therapists need to be brought into the system as they are currently being paid for privately outside of the system.

Community navigation in the form of social activities and being able to navigate the community is very important and often times based on the generation of members, the manner in which these services are packaged and presented needs to be specific to adult populations.

Look at Program for the Education and Enrichment of Relational Skills for Young Adults (PEERS-YA) developed at UCLA to assist children and young adults with ASD in navigating the world of social skills and peer relationships. Evidence-based program, emulated in other locations.

Emulating evidenced based friendship or social programs based on studies presented by UCLA.

Need to address how to bill for social support services. Potential providers: speech pathologists, psychologists, and those supervised by these providers.

Education for Adults

One roadblock to members is the availability of education – resources are very limited. Lack of interest and willingness to change across many different campuses (community colleges and universities) is prevalent throughout the state.

One of the more successful models is at Marshall University. A premium is paid each semester and a certain benefit package is made available that involves intensive support. This has resulted in a 95% graduation rate, compared to a 50% graduation rate by students not facing disabilities. Northridge is also providing similar one-to-one intensive services.

Community Outreach – Awareness of Autism

Community outreach to emergency services, employers/coworkers, neighbors, etc., to help better identify and understand the autism disorder. Educating first responders may be the most beneficial (parents who are older sometimes cannot effectively restrain and calm down individuals who are having a meltdown).

Dennis Debbaudt has provided training programs for first responders – however, there are thousands of policemen and other first responders to reach out to.

Members with autism may have a driver's license or state identification card and the state can enter into the system that they have social disabilities which will result in first responders being better able to serve and address the situation. – see personal story of car crash and police phone call.

Perspectives of Adults with Autism

Going forward, what is the best way to include the perspectives of adults with autism in the work group? What are the logistics? The work groups wants adults with autism to provide an authentic, member-specific opinions on what barriers are being faced and solutions they would recommend.

During September, Jim will draft discussion questions. Questions will focus on health, employment, and community living (residential and social aspects).

What level of services are they receiving in these areas, and what is their satisfaction level?

Considered whether parents of adults should be included. Decided that perspectives of parents are already represented in work group.

At October 1 work group meeting, will review the questions that Jim develops. Work group members have connections with sites that serve adults with autism; will arrange to visit these sites and talk with adults, using standardized set of questions. Will bring information back to the work group for discussion at the November 2 work group meeting.

ACTIONS:

- Sharon will ask AHCCCS if they have any information on employment status and salaries of AHCCCS members.
- Sharon will check with SAARC: any information on how many hours people are actually working and average hourly wage of those working?
- Jim will draft discussion questions for adults with ASD