Improving the Community-Based Infrastructure to Meet the Developmental Disability Service Needs of Adults with Autism Spectrum Disorder in Georgia

Autism Services Initiative for Adults Project

Final Report - October 31, 2016

Executive Summary

The Autism Services Initiative for Adults Project is a partnership between the Emory Autism Center (EAC), the Emory Rollins School of Public Health (RSPH), and the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD). The Emory team (EAC and RSPH), in collaboration with DBHDD, has completed a gap analysis to describe the current state of developmental disability services provided by DBHDD for adults with an autism spectrum disorder (ASD), and to better understand the needs of stakeholders (individuals receiving services, their family members, and service providers) to identify target service enhancements for meaningful outcomes for adults with ASD receiving or eligible for DBHDD services. The goal was to use existing DBHDD data sources to make informed recommendations regarding training and support materials that will ultimately lead to improved service provision. This analysis was completed through four major components: 1) formation and facilitation of an Autism Advisory Committee for the project; 2) existing data source review, acquisition, and quantitative analysis; 3) completion of a preliminary workforce overview; and 4) qualitative analysis of service needs and experiences from focus groups and presentations in the state. The Emory team completed several prior deliverables that provided the quantitative and qualitative data analysis of the major components of the project. This present *Final Report for the Autism Services Initiative for Adults* synthesizes all information analyzed into five targeted priority areas and presents corresponding recommendations to address them.

Summary of Five Target Priority Findings and Corresponding Recommendations:

1) There is an expected increase in the number of adults with ASD who will be requesting DBHDD services.

Recommendations:

- Facilitate ASD-specific training for families and caregivers, providers, DBHDD crisis services providers, and first responders.
- Develop and pilot programs to train family members in positive behavior support and facilitation of meaningful support plans.
- Train families and providers together on shared areas of service provision. Trainings should be tailored around each individual receiving services.
- Make information on ASD an explicit part of the workforce standards in the *Community Service Standards for Developmental Disability Providers*. Consider expanding training for providers on evidence-based practices for intellectual disability, ASD, and other developmental disabilities.
- Address the severe statewide shortage of qualified advanced practitioners knowledgeable about behavioral, psychosocial, and medication interventions for adults with ASD and other developmental disabilities.

2) Key services relevant to ASD are currently under-used.

- Target family, caregiver, and other provider training to facilitate service coordination and access.
- Target training to anticipate, prevent, and respond to challenging behaviors with regular caregivers and service providers, and increase understanding of when to use the crisis line.
- Improve data-based decision-making through analyses of factors limiting access to services that reduce behavior problems, employment-related services, transportation, and respite care.

3) Families need better access to information.

- Develop a central source of information, such as an information portal that can be accessed via mobile technology.
- Consider how to provide access to families which have limited or no access to computers/internet, or have language barriers or cultural differences in the use of computers and the internet.
- Establish or support networks of families and caregivers.
- Foster interagency collaboration on supporting adults with ASD.

4) A proactive focus on transitions from adolescent to adult services and supports is needed.

- Enhance interagency collaboration/communication to address transitions occurring at adulthood. Work with other agencies to identify the best primary agency to coordinate the development of an individualized life plan for a specific adult.
- Increase efficiency in transition planning to maximize available resources, given scarcity and anticipated increases in demand.
- Identify, adapt, and pilot transition guidance materials and training for families of school-aged children in partnership with the Department of Education and local schools.

5) Measurement of DBHDD ASD service outcome indicators can build on existing current data surveys.

- Enhance the National Core Indicators' (NCI) annual survey that DBHDD currently conducts with adults receiving developmental disability services. To make the best use of this information for adults with ASD, it is recommended that DBHDD capture additional demographic information in the background information collected from administrative records prior to conducting the interviews. The additional information to be collected includes any ASD diagnosis, as well as any other developmental disability or behavioral health diagnoses.
- Add the use of the NCI Staff Stability Survey to address outcome indicators related to staff and systems quality. Include a staff response section to estimate the proportion of the individuals with ASD served by the provider.
- Obtain qualitative feedback annually by reviewing survey results with participants. Solicit corresponding feedback on priority targets for system improvements to include methods, such as focus groups with individuals, caregivers, and staff; input of advisory committees or groups; and public autism meeting presentations (e.g., the annual Autism Conference & Exposition of Georgia).

As follow-up to this project, the Emory team will submit a proposal to DBHDD for further collaboration to address training needs based on the findings of the gap analysis.

Background

Adults with autism spectrum disorder (ASD) can have substantial needs for disability services, but their needs often differ significantly from the needs of individuals with other developmental disabilities. Many families in Georgia report having difficulty finding high-quality developmental disability care and services appropriate for adults with ASD. Further, the prevalence of ASD is expected to continue to grow, resulting in increasing numbers of adults with ASD. It is anticipated that individuals with ASD will represent an increasing proportion of individuals served by DHBDD, and that this increased demand will place an additional burden on the state and its agencies. There is a need for greater understanding of the service needs of adults with ASD, the provider and caregiver network available to care for them, and of the training needs for stakeholders. Further, there is an urgent need to enhance the quality and efficacy of services delivered by developmental disability providers to Georgia's adults with ASD. DBHDD is searching for solutions for the adult ASD population to ensure that these individuals will be cared for in a developmental disability system that implements best practices for the standard of care, ensuring high quality of care, and effectual use of state funds.

A collaboration between DBHDD, the Emory Autism Center (EAC; part of the Department of Psychiatry), and other Emory doctors on planning services for a young adult with ASD and significant behavioral issues led to a discussion about a partnership to train DBHDD providers in person-centered, evidence-based supports and services for adults with ASD. An agreement for EAC to develop a proposal for a collaboration to begin to address this need was reached, and the first draft of a formal proposal for the first year of the project was completed in April 2014. Proposal development work between EAC and Dr. Darlene Meador of DBHDD continued throughout the remainder of the 2014 calendar year, and the decision was made that a gap analysis of the current developmental disability services provided by DBHDD would be a logical first step to take. To facilitate this analysis, additional team members at Emory Rollins School of Public Health (RSPH) were identified. Once the proposal was finalized and approved by DBHDD leadership, Dr. Meador and her colleagues at DBHDD developed a draft state contract, which was subsequently was approved by DBHDD and Emory University. The executed contract became effective on April 1, 2015. (See Appendix 1, Core Team Members.)

Method

The Emory team (EAC and RSPH), under the guidance of DBHDD, completed a gap analysis to help target service enhancement, make recommendations regarding needed services, and propose development of training and support materials that will ultimately lead to improved service provision. The gap analysis was completed through four major tasks, and resulted in five targeted recommendations.

The key steps involved included:

1. **Formation of an Autism Advisory Committee** to allow stakeholders to respond to, and help shape, the conclusions. The Autism Advisory Committee was formed in early 2015 and consisted of 17 individuals who met bi-monthly with DBHDD staff and the Emory team. This group developed a communications strategy for the initiative and identified data sources and the scope of the analysis. Through discussion and breakout work, recommendations and suggestions were collected on a variety of topics, including quality measures. (See Appendix 2 for members of the Autism Advisory Committee.)

2. **Data Acquisition and Quantitative Analysis**: After obtaining DBHDD and Emory University institutional review board (IRB) approvals, DHBDD supplied the Emory team with key data sources in order to

assess the number of adults with ASD requesting and accessing DBHDD services, and the providers who were available to deliver these services. These data sources included: Case Management Information System (CIS); Health Risk and Screening Tool (HRST); Waiver Information System (WIS); Support Intensity Scale (SIS); National Core Indicators (NCI); Georgia Crisis and Access Line (GCAL); the state hospital transitions and community placements of adults with a primary or secondary ASD diagnosis that were part of the Department of Justice (DOJ) Settlement Agreement; and a list of DBHDD providers who are available to provide intellectual/developmental disability services. (See Appendix 3 for a table presentation.)

A key achievement of the collaboration was the secure collection of electronic data from the state for the fiscal year ending June 30, 2015. The Emory team, working with the Rollins School of Public Health IT Department, set up a secure file transfer protocol on Emory's server to securely transfer data files containing protected health information between DBHDD and Rollins School of Public Health.

The team determined that the downloaded, cleaned and de-duplicated data were sufficient to: identify the target population; identify DBHDD-provided services to adults with ASD; calculate which services the population is authorized to use and which services they are actually using; and define measures of access to services by performing multiple ratio analyses on the cohort.

Based on the available information, the RSPH developed the following indicators of access to DBHDD services:

a. Population prevalence of adults requesting DBHDD services for ASD (i.e., on the long- or short-term planning list, or receiving waiver- or state-funded services)
b. Percentage of adults with ASD and acute service needs who are known to DBHDD (i.e., on the short-term planning list), or who are receiving waiver services
c. Need for crisis services by adults with ASD, as indicated by calls to the crisis line
d. Percentage of adults with ASD who were receiving waiver services who were authorized to receive specific services likely to be of importance for individuals with ASD
e. Proportion of adults with ASD who are authorized to receive specific services who made claims for these services

3. **Workforce Overview**: The Emory team performed a preliminary review of the DBHDD provider workforce in terms of geographic distribution using data provided by DBHDD as well as training requirements indicated in the *Community Service Standards for Developmental Disability Providers,* with an eye toward the clinical care requirements of individuals with ASD.

4. **Qualitative Analysis and Focus Groups:** The Emory team gathered and analyzed data on user feedback regarding the disability services provided by DBHDD to adults with autism in the state of Georgia; performed a detailed analysis; reported findings; and formulated solution-focused recommendations. The structured interview and focus group discussions included frequency of use of developmental disability services, barriers, and facilitators to accessing the services appropriate for persons with ASD and focused on possible solutions for improving service delivery to families caring for individuals with ASD.

The purpose of the qualitative data collections was to assess a variety of stakeholders' experiences related to access and delivery of developmental disability services provided by the DBHDD service system to adults with ASD. Discussions included frequency of use of developmental disability services and barriers and facilitators to accessing such services appropriate for persons with ASD. The methodology consisted of individual structured interviews and family focus groups (61 individuals; 47 households) held throughout the state from February to August, 2016. To prepare for this phase, the team identified stakeholder

participants with DBHDD and Autism Advisory Committee assistance, and designed a framework which was used in focus group discussions.

Primary Conclusions and Targeted Recommendations

The team analyzed and synthesized the service data and the qualitative data collected for this project. Based on a comprehensive review undertaken by the team, target priority gaps were identified, as noted in the project's original objectives, using all information obtained from quantitative, qualitative, and DBHDD data sources. The recommendations that follow identify five proposed high-need areas, and propose high-impact actions to address them. A special emphasis has been placed on training targets for an initial staff and family training and support plan.

1) There is an expected increase in the number of adults with ASD who will be requesting DBHDD services.

Evidence: The number of adults with ASD who are likely to need DBHDD services is on the increase (see Deliverable 5 report). In the current DBHDD data, 1,505 individuals with ASD are either receiving waiver- or state-funded services from DBHDD or on the planning lists for waiver services but may be receiving family support or other state-funded services from DBHDD. The vast majority of these individuals are under the age of 30. That equates to a service prevalence of 0.19 per 1,000. Current population prevalence estimates, including data from metropolitan Atlanta, estimate identified ASD prevalence to now be between 1.5-2.5% of the population with increases of 30-50 fold over the past 20 plus years. The median age of individuals with ASD who are receiving services is 25, and those on the short-term planning list are younger still. Further, very few of the individuals on either planning list is over the age of 30 (Figure 1). In contrast, among those between the ages of 18 and 25, there are more than 35 individuals with ASD who are on the short- or the long-term planning list per 100,000 individuals in Georgia. Additionally, while more than 80% of adults with ASD over the age of 25 who are known to DBHDD are receiving waiver services, less than two-thirds of the adults under that age have access to these services. It should be noted that individuals under the age of 22 years may be continuing to receive special education services, currently not needing waiver services, and therefore on the planning list for waiver services.
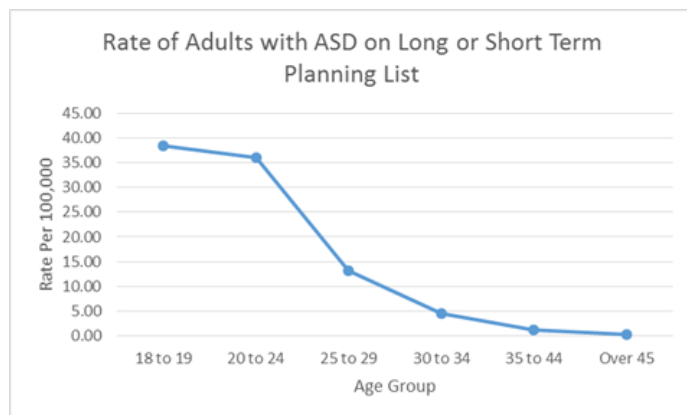
Policy Implications: The most important implication of the rise in identified ASD prevalence is the increasing number of adults with ASD who will need services. Until recently, only a relatively modest proportion of the population served by DBHDD has been diagnosed with ASD. However, data from these analyses highlight the rapidly growing number of young adults with ASD who are beginning to access the system. The "wave" of adolescents and young adults just beginning to access the system and the long-term impact of this shift is only beginning to be felt, but national data indicate that it will continue to increase steadily and dramatically. Certainly, not everyone with an ASD diagnosis will seek or be eligible for intellectual/developmental disability

services from DBHDD, and not everyone with the characteristics of ASD will have a diagnosis; however, the impact of the changing population will be increasingly felt in the adult service systems. It is likely that the new, higher numbers of individuals who will need and be eligible for intellectual/developmental disability services from DBHDD will quickly exceed the capacity of the existing system, especially the provider base which is already strained in places, and not readily available in some places. The data strongly suggest a pressing need to build DBHDD's intellectual/developmental disability system capacity to serve an increasing number of eligible adults with ASD. It should be noted that individuals on the planning list(s) for waiver services may receive DBHDD family support services, which help to support the individual and family.

Adults with ASD have significant, and sometimes intense, individualized developmental disability service needs that often differ from those individuals with intellectual disability or other forms of developmental disabilities. To effectively care for and help individuals with ASD develop to their full potential, care strategies particular to the ASD population should be employed. DBHDD service providers and caregivers will need training on specific service needs and strategies for supporting eligible adults with ASD to maximize their quality of life. As the proportion of individuals with ASD served by DBHDD increases, the service needs and provider base needs to adapt to provide services that specifically address the medical, behavioral, and psychosocial needs of individuals with ASD and their families. These needs include: behavioral support services, natural support training, respite care and supported employment, all of which appear to be underused by individuals with ASD. Thus, these findings suggest the value of additional review by DBHDD of the services available to eligible adults with ASD.

Recommendations:

- Facilitate ASD-specific training for

    1. Families and Caregivers

    2. Developmental Disability Providers

    3. DBHDD Crisis Services Providers

    4. First Responders

- Develop pilot training programs for families in positive behavior support and facilitation of meaningful support plans.
- Target training simultaneously toward families plus providers.
- Make ASD an explicit part of the workforce standards in the *Community Service Standards for Developmental Disability Providers*, and consider expanding training for providers on evidence-based practices for features of intellectual disability, ASD, and other developmental disabilities.
- Address the severe statewide shortage of qualified advanced practitioners knowledgeable about behavioral, psychosocial, and medication interventions for adults with ASD and/or developmental disabilities.

2) Key services relevant to ASD are currently under-used.

Evidence: There are a number of key services that are critical to the support of individuals with autism, and these service needs often differ from the needs of individuals with other types of disabilities. Further, as a 2005 report from Delaware noted, adults with ASD are often provided services through programs designed "for individuals with cognitive disabilities or mental illness. Such services do not take into consideration the unique behavioral, communication, and sensory challenges presented by autism"(Best Practices for Serving Adults with Autism, Autism Society of Delaware, http://www.delautism.org/wp-content/uploads/2015/01/

Adult-Best-Practices.pdf). Specifically, the hallmarks of ASD include difficulties in social interaction, social communication, and social imagination. Further, ASD is associated with sensory issues, difficulty with stress and anxiety, behavioral problems including a lack of sense of danger, high risk of self-harm and physical aggression. Additionally, many individuals with ASD have difficulty sleeping, which results in caregiver exhaustion. As the Delaware report says, "If we do not provide effective adult services and supports, we will be failing a generation of individuals by wasting considerable financial resources; years of time and effort invested by these individuals and their families; and the tremendous dedication of many staff who prepared them for a life of independence and productivity. We cannot simply terminate the supports for improved communication and behavior, management of sensory challenges, and social and community integration and not expect marked deterioration in skills."

As a result, we analyzed the authorization and use of services that are likely to be of benefit to adults with ASD by the cohort of adults who have ASD and were receiving DBHDD waiver services in FY 2015. These include:

1. **Financial Support Services** as an indication of self-direction of services.
2. **Community Living Support Services** and **Community Residential Alternative Services** as an indication of individuals who are receiving some type of residential or in-home support services.
3. **Prevocational and Supported Employment** since individuals with ASD may be able to work, given adequate **transportation** and support, and may be less resistant to boredom in completing repetitive tasks than other individuals.
4. **Behavioral Support Services** and **Natural Support Training** given the often significant behavioral challenges that individuals with ASD often present for caregivers.
5. **Respite Care** to provide caregivers with needed breaks, especially given the frequency of sleep disorders in this population.

Table 1

Anaysis of Service Needs

Type of Service	% of those with waiver who are authorized to receive service	% of those authorized to receive service who have one or more claims for service	Average % of authorized funds claimed
Financial Support Services	28.3%	92.4%	75.3%
Community Living Support Services	42.7%	93.6%	70.7%
Community Residential Alternative	30.3%	97.4%	92.7%
Prevocational Services	7.1%	85.7%	64.3%
Supported Employment	6.7%	89.8%	50.0%
Transportation	1.2%	63.6%	40.3%
Behavioral Support Services	7.1%	41.3%	29.4%
Natural Support Training	1.1%	30.0%	24.5%
Respite Services	13.2%	60.7%	46.5%

More than one-quarter of the cohort of adults with ASD are authorized to receive financial support services, suggesting that a significant number of these individuals are self-directing at least some care. Further, nearly all (92%) of these individuals are accessing these services. Similarly, nearly three-quarters of the cohort of adults with ASD are authorized to receive either community living support services (43%) or community residential alternative services (30%), and more than 90% of those authorized to receive such services are accessing them as indicated by one or more claims for such services. Thus, these services appear to be available for adults with ASD who are receiving waiver services.

In contrast, some of the services identified above that are likely to be of targeted importance for individuals with ASD appear to be authorized for only a relatively limited number of these adults. For example, prevocational services and supported employment are authorized for only a relatively small number of the cohort of adults with ASD (7% and 6.7%, respectively). Further, on average, even among adults with ASD who are authorized for such services, less than two-thirds of the authorized funds for these services were claimed. This finding of the limited availability of adults with ASD to access these services may result from a lack of transportation (which was authorized for less than 2% of adults with ASD) for those receiving supported employment services, or because of a lack of available programs to provide these services.

Programs to mitigate behavioral challenges associated with ASD are similarly under-used. Safety was a central concern reported by families who participated in the focus groups, especially if their child was an adult male. A number of families reported being worried about situations escalating to violent and fatal levels, and reported having "close calls" with law enforcement and members of the public. However, fewer than one in ten adults are authorized to receive behavioral support services or natural support training (7% and 1%, respectively), and fewer than half of those who are authorized to receive these services made even a single claim for these services (41% and 30%, respectively). Again, it is unclear whether the lack of use of these services represents the limited availability of service providers; the inclusion of authorization and claims for these services as part of the daily rate for community residential alternative services; or limitations in caregiver and/or provider awareness of the utility and/or necessity of these services.

Additionally, although it is well known that adults with ASD present significant challenges for their caregivers because of behavioral challenges and because of sleep concerns, respite services appear to be under-used. Only 13% of the cohort of adults with ASD are authorized to receive these services, and fewer than two-thirds of adults who are authorized to receive respite services have made a single claim for these services. This finding suggests that the caregivers of only 8% of all adults with ASD who were receiving waiver services made a single claim for respite care. The need for respite services was echoed by families in focus group discussions. Families reported a heavy financial, physical, and emotional burden caring for their family member with ASD, especially during the transition from high school to adult services. In addition to resulting in caretaker "burnout," having untrained family members providing care was reported to result in the "backsliding" of the skills, especially maintenance and acquisition of life skills, of the adult family member with ASD.

Overall, fewer than 4% of the 1,505 adults with ASD in Georgia made a call to the crisis line in 2015 (n=59). Further, among those who made at least one call, most made only one call to the crisis line. However, one individual made 23 calls to the crisis line. Additionally, only 39 individuals (2.5% of the population) called the crisis line for an urgent or emergent problem. As with all calls to the crisis line, most individuals only made one such call, but there were a number of individuals for whom multiple calls to the crisis line were made. Nearly 15% (n=24) of all of these calls involved a potentially life-threatening situation (e.g., suicidal or homicidal threats).

These findings are supported by the comments of focus group members. In all regions, families reported difficulties with accessing appropriate, consistent, and timely identification of providers, as well as having

providers with limited understanding of ASD and the services likely to benefit adults with ASD. DBHDD provider organizations reported concerns with recent regulations that were drafted to increase care quality, but may inadvertently exacerbate provider shortages.

Policy Implications: The findings suggest some misalignment in the services that are provided to adults with ASD, and those that may be of greatest benefit to adults with ASD. It is likely that targeted training for families, support coordinators, and service providers can help improve access by providing them with greater understanding of the service needs for these adults. Additionally, training of caregivers can help them understand the types of services that may improve the quality of their lives, as well as the lives of those for whom they are caring. Although only a relatively small proportion of the population is using the crisis line, it appears to be filling an important need as many of these calls are for urgent and emergent reasons, including potentially life-threatening situations. It does not appear that any one group is using these services more than other groups. However, young adults and those with co-occurring psychiatric illness appear to have a need for these services more than other groups.

However, it is not clear, at this point, if training will completely mitigate these problems, as there is a need for additional information about factors that limit access to these services. Specifically, it is not clear whether there is adequate capacity to provide a person-centered match of the services for adults with ASD and/or if the quality of services provided is sufficient. It will also be important to examine the policies dictating which services adults with ASD are authorized to receive and the corresponding availability of services targeted to the needs of adults with ASD.

Recommendations:

- Target family, caregiver, and other provider training to facilitate service coordination and access.
- Target training to anticipate, prevent, and respond to challenging behaviors with regular caregivers and service providers and improve the specificity of when the crisis line is used.

  - Familiarize caregivers with typical ASD-related behaviors.

  - Teach and practice positive interactions and behavior management.

  - Provide training on diffusing meltdowns and other behavioral crises.

  - Teach life skills that increase satisfaction, and that foster independence and community participation.

  - Train providers to look for areas of talent or strength in individuals with ASD that could facilitate job or career training.

- Improve data-based decision-making through analyses targeted to understanding factors limiting access to services that reduce behavior problems, employment-related services, transportation, and respite care to enhance the work already completed by providing more targeted recommendations and training.

3) Families need better access to information.

Evidence: In each of the focus groups, families reported having difficulties finding accurate information about the clinical diagnosis of ASD, effective treatments and interventions, and available state and non-state resources. It was clear that many families were unaware of existing services and resources, indicating an information flow or uptake issue between the state agencies and the families. For instance, many families

reported not having heard about the waiver until right before the age cut-off for educational services, or not having heard of it at all. Families need improved dissemination of information about services and resources.

Families reported collecting information from a variety of sources, including the internet, medical professionals, mental health providers, and intellectual and developmental disability providers, as well as other families that agree to release information. Currently, there is no consolidated, one-stop source of information for families. Families reported that the creation of an information portal with a complete list of resources and providers would be very helpful for families who seek to create a roadmap addressing the needs of the individuals in their care. Through partnership of DBHDD with advocacy organizations for adults with ASD listed as resources, the information portal could facilitate the establishment of a network of families for support and information sharing, an important step towards the creation of a sustainable support infrastructure. The parent network could include parent-to-parent peer support positions, modeled on the education peer model currently employed in the education system.

The use of online or app-based resources was generally considered a good idea by families. However, the "digital gap" observed in the focus groups suggests that digital resources cannot be solely relied upon for information dissemination and training. Families had differing levels of knowledge about how to gather and evaluate information. While families in urban, mostly white, focus groups reported being well versed in finding good quality information online, families in rural and mostly African-American families reported having difficulty with accessing information. While most families were aware of at least some electronic and provider resources, information sharing with other families was considered the most useful source of information. In each focus group, it became clear quickly who in the group had the highest level of information finding skills, and knew how to use this information to advocate for their family member.

Policy Implications: Currently, unlike the child autism parenting networks, there is no centralized source for families of adults with ASD to find other families with more experience and/or higher advocacy level skills, nor are there formal family-run resource groups or ways to find them. Encouraging and increasing networking and knowledge transfer between the families will be a crucial component to maximize the utilization, efficiency, and effectiveness of DBHDD intellectual/developmental disability services. As part of this knowledge transfer, there is a need for interagency initiatives (e.g., Department of Education) to encourage a seamless flow of information and resource identification.

Recommendations:

- Develop a central source of information, such as an information portal that can be accessed via mobile technology.
- Consider how to address:
  - The "digital gap," whereby some families have limited or no access to computers and internet, but may have access to smart phones.
  - Language barriers and cultural differences in the use of computers and the internet.
- Establish or support peer networks of families and caregivers.
- Foster interagency collaboration on the needs of adults with ASD.

4) Proactive focus on transitions from adolescent to adult services and supports is needed.

Evidence: As noted above, the majority of adults with ASD are young, suggesting a large and growing need for services to support the transition from school-based services to those provided for adults with disabilities

provided by DBHDD and other state agencies. The relative urgency of this need is supported by calls to the crisis line. Adults with ASD who are under the age of 25 make 70% more calls to the crisis line than do those who are over that age, and are 150% more likely to make an urgent or emergent call to the crisis line. Further, most of young adults with ASD (90% of those aged 18-19, 84% of those aged 20-24 and 80% of those aged 25-29) live with a parent or other family member reinforcing the notion that these individuals are transitioning from educationally-based services. Further, it is likely that these families have limited prior experience with obtaining services for adults with disabilities.

The area of biggest concern reported by the participating families was finding reliable information about successful transitioning to adulthood, and how to create a viable and flexible long-term plan for their family member with ASD. Given the anticipated increases in demand for DBHDD services and the scarcity of available resources, efficient transition planning is a means toward maximizing the benefits of available resources.

Families reported that the transition between the educational system and DBHDD was a particularly challenging time for them to find information and navigate available resources. Having received more or less useful guidance and coordination within the educational system, families are faced at that point with a relative lack of guidance and sharp drop-off of resources. Many families reported frustration with being able to identify providers for their adult children, with many providers and self-directed families not being able to recruit willing and well-trained caregivers. Families reported that it would have been helpful to start the transition far earlier in their children's time in school, with a stronger emphasis on balancing academic training and life skills training in order to prepare their child for the next phase of their life. Caregivers emphasized that it will be necessary to provide individualized, interactive transition support and training to families to serve the unique needs of their families. The transition period was also considered another potentially fruitful point of intervention by family-to-family peer supports (e.g., Parent System Navigator).

A central concern for families was creating a long-term care plan for the individual with ASD once the present guardian/caregiver was gone. Most of the families reported fears about the individual being taken advantage of, not being properly taken care of by other guardians, and the individual losing benefits due to improperly created estate planning. African-American families reported being very concerned about their children/family member being taken advantage of financially and/or sexually, and having difficulties finding providers and direct care staff that they trusted. Safety was a central concern for families, especially if their child was an adult male. A number of families reported being worried about situations escalating to violent and fatal levels, and reported having "close calls" with law enforcement and members of the public. The data collected from African-American families emphasizes the importance of addressing cultural differences and individual family needs when developing or improving intellectual/developmental disability services for this population.

Policy Implications: Our findings indicate that the transition from services based in the educational system to a range of potential service systems (DBHDD being one of them) in young adulthood, represents a substantial and predictable stress point for individuals with ASD and their families. Unlike the "base" of support provided through the educational system during the school years, adults have no agency that serves as a primary hub to organize the individual support needs across major domains of life (educational, vocational, residential, health and wellness, etc.). Individuals making the transition from school-based to DBHDD-based services are most likely to be on the short-term planning list and most likely to make calls, including urgent and emergent calls, to the crisis line. These findings suggest that: (1) the Georgia Crisis and Access Line (GCAL) is an important safety net for individuals with ASD who are exiting the school system, and (2) GCAL workers need better training in how to respond helpfully to individuals with ASD, since such individuals are likely to represent a growing proportion of crisis calls. Thus, these findings support DBHDD partnering with other state agencies

(Georgia Department of Education and Georgia Vocational Rehabilitation Agency) to develop services that support individuals with ASD in their transition from school-based services.

Recommendations:

- Enhance interagency collaboration/communication to address the transition occurring at adulthood. Work with other agencies to identify the best coordinating "hub" for an adult to develop his or her individualized life plan.
- Increase efficiency of transition planning as a means toward maximizing the benefits of available resources given the anticipated increases in demand for DBHDD services and the scarcity of available resources.
- Identify, adapt, and pilot transition guidance materials and training for families of school-aged children in partnership with the Department of Education and local schools.

5) Measurement of DBHDD ASD service outcome indicators can build on existing current NCI data surveys.

Evidence: Knowledge of who is accessing services, the type of services available, and the providers who furnish them is an important first step in defining quality. Individual service needs are likely to vary by age, living situation and co-occurring disabilities, and service delivery is likely to vary by regional needs, population concentration, and services available. It will be important to have ongoing indicators to monitor the changes in access, services, and quality in DBHDD services over time.

To identify ASD-specific adult access and quality outcome indicators, the data available through DBHDD, the recommendations of the Autism Advisory Committee, and the existing literature on ASD outcome measures were considered. The National Core Indicators (NCI) (http://www.nationalcoreindicators.org/) provides guidance on outcome indicators for adults with developmental disabilities receiving services from state developmental disability service systems. The NCI outlines five primary domains upon which state developmental disability services should be evaluated for quality:

National Core Indicator (NCI) Quality Indicator Domains
o **Individual Outcomes**
o **Health, Welfare, and Rights**
o **System Performance**
o **Staff Stability**
o **Family Indicators**

Currently, DBHDD collects satisfaction data from families and adults with developmental disabilities, including adults with ASD, using the NCI through two family satisfaction surveys (the Adult Family Survey and the Adult Guardian Survey) and an Adult Consumer Satisfaction Survey based on the NCI (http://www.nationalcoreindicators.org/states/GA/). However, the family satisfaction surveys do not collect information that allows the identification of families with individuals with ASD, and thus cannot currently be used to address any family issues particular to adults with ASD. In the Adult Consumer Satisfaction Survey, although individuals can self-identify with autism, there is no way or knowing how many with ASD simply did

not self-identify as having ASD, or were not able to participate in the NCI interview (for example, due to limited language skills). Therefore, it is difficult to generalize results from self-identified individuals with ASD capable of participating in the interview to all individuals with ASD. In addition, of all of the NCI core indicators, Georgia does not currently report on the NCI Staff Stability Survey, with information about this survey located at the following website:
http://www.nationalcoreindicators.org/upload/coreindicators/2014_Staff_Stability_Report_11_13_15.pdf.
This survey would provide additional information on the personnel delivering services and would be informative for identifying training targets. Thus, the NCI data, as they are currently collected in Georgia, inform some training needs broadly for the developmental disability population, but are of limited use for the identification of training needs specifically for ASD care personnel.

Policy Implications: Based on the data collected currently through DBHDD individual and family surveys and feedback from the Autism Advisory Committee and literature review, the greatest gaps in quality indicators are in the ability to make ASD-specific conclusions, and in the evaluation of staff and family outcomes. Based on all of the information collected and analyzed, it is clear that DBHDD has a robust basis for collecting developmental disability individual and family feedback, and that evaluation of ASD-specific service access and quality can be accomplished through enhancements to these methods.

Recommendations:

- Enhance current annual surveys that DBHDD currently conducts based on the National Core Indicators (http://www.nationalcoreindicators.org/states/GA/). In order to make the most use of this information for adults with ASD, it is recommended that DBHDD capture additional demographic information in the background information collected from administrative records prior to the interview with the adults. The additional information to be collected on these adults is any diagnosis of autism spectrum disorder as well as any other developmental disability or behavioral health diagnoses.
- Fill in gaps in recommended outcome indicators of staff and systems quality not collected by adding the NCI Staff Stability Survey (http://www.nationalcoreindicators.org/upload/core-indicators/2014_Staff_Stability_Report_11_13_15.pdf). Include a staff respondent item estimating the proportion of individuals with ASD served by the provider.
- Obtain qualitative feedback on an annual basis through review of survey results with individuals and solicit corresponding feedback on priority targets for system improvements to include methods, such as focus groups with individuals, caregivers, and staff, input of advisory committees or groups, and public autism meeting presentations (for example, the annual Autism Conference & Exposition of Georgia).

Follow Up - Next Steps

As follow-up to this project, the Emory team will submit a proposal to DBHDD for further collaboration to address training needs based on the findings of the gap analysis.

Appendix 1
ASIA Core Team

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Catherine Rice, PhD Emory Autism Center	Professor, Department of Psychiatry and Behavioral Sciences; Director, Emory Autism Center Specialty: identification and intervention of autism; developmental disabilities epidemiology	Co-investigator
Carolyn Drews-Botsch, PhD Rollins School of Public Health	Professor, Epidemiology, Rollins School of Public Health. Specialty: developmental disabilities epidemiology	Co-investigator
Katherine Roeder, MBA, MHA Emory Autism Center	Writing & Editing, Meeting Planning, Assurance of Contract Compliance, Autism Advisory Committee Relationship, Payments	Project Coordinator
Darlene Meador, PhD DBHDD	Director of Strategy and Special Projects, Division of Developmental Disabilities	Conceptualization, development and implementation of the project

Appendix 2
Autism Services Initiative for Adults
Advisory Committee Members

Scott Bales
Self-Advocate
Active Community Volunteer

Jennifer Briggs (alternate with E. Myers)
Provider
Briggs & Associates

Tim Cartledge
Family Member
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Deborah Conway
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Rena Harris
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April Umstead
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DBHDD Office of Learning & Organizational
Development

Appendix 3 - Data Sources and Uses

Data Source	Description	Proposed Use	Extraction Date
Case Management Information System (CIMS)	Application for Services; Eligibility Status; Demographic Information; Individual Service Plan (ISP)	Identify eligible adults with ASD receiving or awaiting developmental disability services from DBHDD	12/07/2015
Health Risk Screening Tool (HRST)	Details on health and risk including ICD9 Scores	Describe health characteristics and risks of eligible adults with ASD receiving or awaiting developmental disability services from DBHDD	01/05/2016
Waiver Information System (WIS)	Service authorization and utilization data	Determine Waiver Services authorized and Waiver Services provided	01/13/2016 (authorization data) 2/3/2016 (utilization data)
Supports Intensity Scale (SIS)	Record of periodic review of level of supports required	Describe support needs of eligible adults with ASD receiving or awaiting developmental disability services from DBHDD	01/08/2016
National Core Indicators (NCI)	National developmental disability quality report by the state from surveys	Individual outcomes, health welfare and rights, system performance	2/3/2016
Crisis Data	Record of crisis events from Georgia Crisis Access Line (GCAL); information on services received, diagnoses and other demographics	Describe characteristics of cohort of adults with ASD accessing the Georgia Crisis Line, referral sources, and crisis services received	03/22/2016
Hospital & Community Placement	Subset of community placement of individuals per DOJ Agreement	Examine service needs of high risk group	05/26/2016
Provider Sites	List of providers and services they provide by region	Identify the distribution of provider locations available to serve individuals with ASD	08/16/2016