

# Autism Services Initiative for Adults



DBHDD

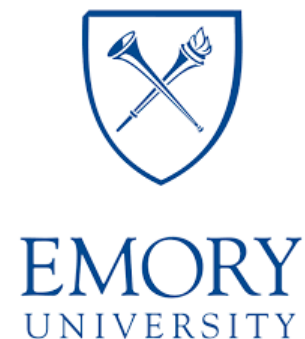
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GEORGIA AUTISM CONFERENCE AND EXPO  
APRIL 14, 2016

# Terminology Preferences

- Preferred linguistic terminology varies widely in the autism and autistic community
  - Many self-advocates prefer the use of “identity first” language rather than “person first” language
  - In recognition of these varying preferences, this presentation will alternate between “adult with autism spectrum disorder” and “autistic adult”
  - See <http://autisticadvocacy.org/home/about-asan/identity-first-language/> for more information

# *What is the Autism Services Initiative for Adults?*

- Partnership of the Georgia Department of Behavioral Health and Developmental Disabilities and Emory Autism Center
  - To improve the quality and effectiveness of DBHDD's services for adults with autism spectrum disorder
  - To fulfill the vision of easy access to high-quality care that leads to a life of independence for the Autistic adults that DBHDD serves
  - To utilize the expertise of the Emory Autism Center as part of a major research university and a national model for family support and innovative services for adults with ASD



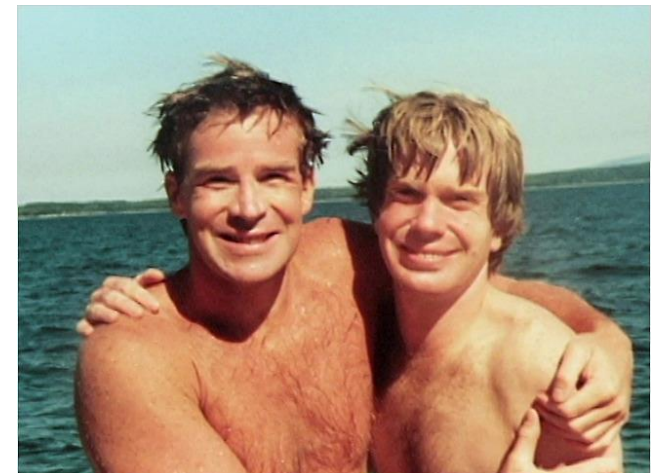
## *Why is there an initiative focused on Autistic adults receiving or eligible for DBHDD services?*

- The decision to conduct this initiative resulted from:
  - Hearing from Georgia families that it is hard to find high-quality developmental disability care for adults living with autism
  - Recognizing that the lack of high-quality developmental disability care for Autistic adults often results in costly and inefficient use of emergency services
  - Knowing that the number of adults with ASD is expected to grow rapidly in the upcoming years



# *What are other factors leading to a project focused on adults with ASD?*

- Research findings (e.g., Ratto & Mesibov, 2015; Steinhausen et al., 2016) show:
  - Poorer adult life outcomes in areas such as:
    - ❖ Independent living
    - ❖ Community inclusion
    - ❖ Employment
- More research is needed to determine:
  - Outcomes with most meaning for:
    - ❖ Autistic adults
    - ❖ Families of Autistic adults



# Other National Findings

- National Core Indicators (NCI)
  - National Association of State Directors of Developmental Disabilities (NASDDDS), Human Services Research Institute (HSRI) & State DD Directors
    - ❖ Multi-state collaboration
    - ❖ Launched in 1997 in 13 participating states – now in 45 states (including DC) and 22 sub-state areas
- Goal of NCI is to measure performance of public systems for people with intellectual and developmental disabilities by looking at outcomes



# NCI Data: Adult Consumer Survey

- Standardized, face-to-face interview with a sample of individuals receiving services
  - Adult can self-identify as having a diagnosis of “Autism Spectrum Disorder (i.e., Autism, Asperger Syndrome, Pervasive Developmental Disorder)”
- NCI Consumer Survey Data, 2013-14 (Bradley & Ne’eman, 2016)
  - 30 states, DC, and 1 sub-state entity
  - 15,525 individual surveys
  - Subsample of Autistic adults from diagnoses in agency records
    - ❖ The total number of records indicating the presence of ASD was 2,277
    - ❖ Subsample of approximately 15% of adults interviewed



Georgia: Member  
since 2005-06

NCI State Participation 2013-14



# NCI Data: Outcomes for Autistic Adults Receiving IDD Services

- Findings from the NCI Consumer Survey Data, 2013-2014 (Bradley & Ne'eman, 2016) indicate that, in comparison to those served without an ASD diagnosis, the following:
  - People with Autism Less Likely to Live in Their Own Home/Apartment
  - Fewer People with ASD Use Words to Speak
  - Autistic Adults Are Less Likely to be Employed
  - People with Autism Are Less Likely to Have Friends
  - Autistic Adults Are Less Likely to Make Choices About Their Lives



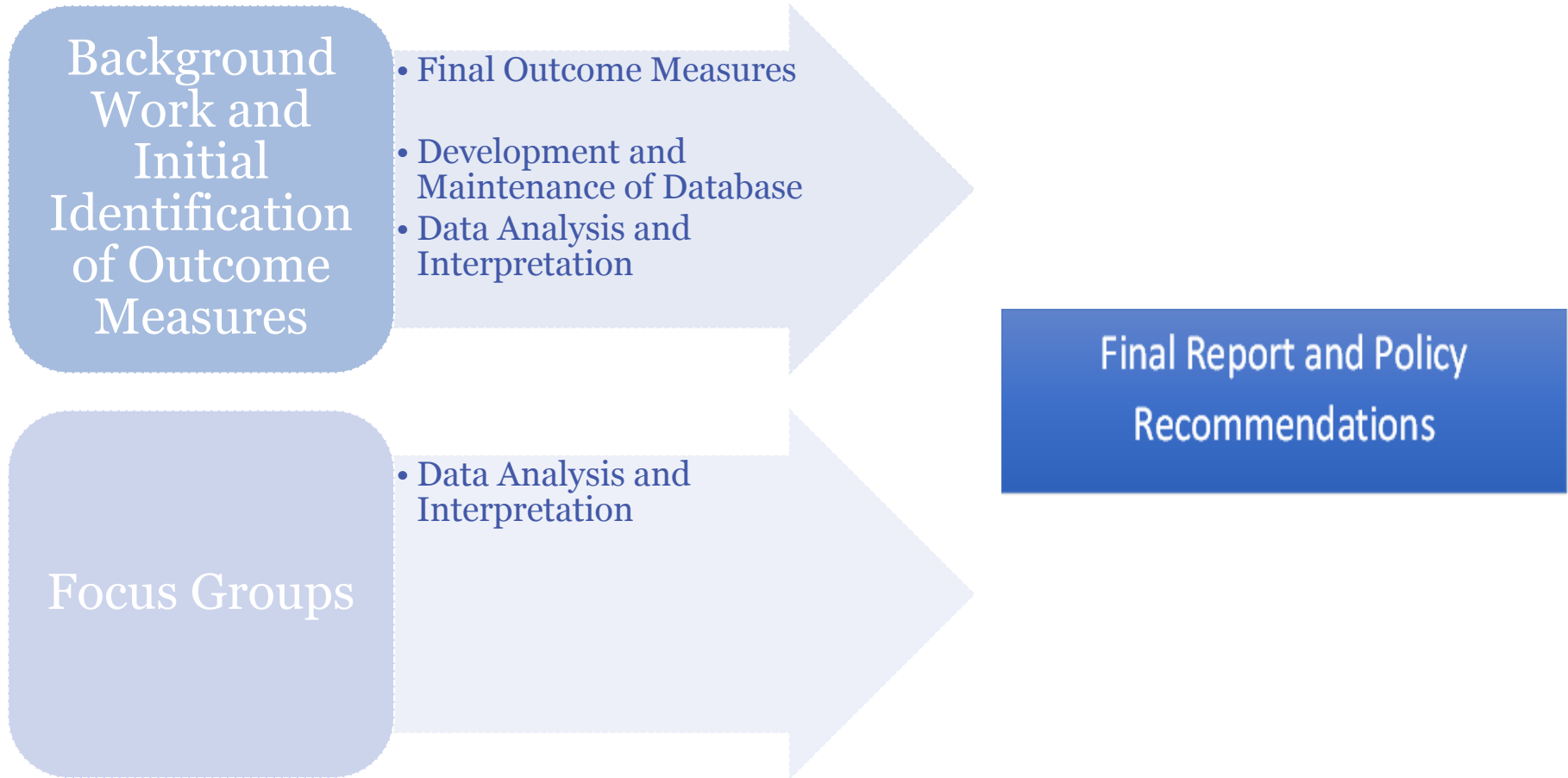


# *Why does the project include a gap analysis of DBHDD services for Autistic adults?*

- The inclusion of a gap analysis resulted from:
  - Recognizing that DBHDD services have a history of being designed to serve individuals with intellectual disabilities
  - Noting that a growing number of adults with ASD served or eligible to be served by DBHDD do not have an intellectual disability
  - Understanding that the needs of Autistic adults vary widely and can be quite complex
  - Realizing the critical need to identify service gaps for Autistic adults who are, or will be, receiving DBHDD services



# Overall Plan for the Gap Analysis



# Autism Advisory Committee

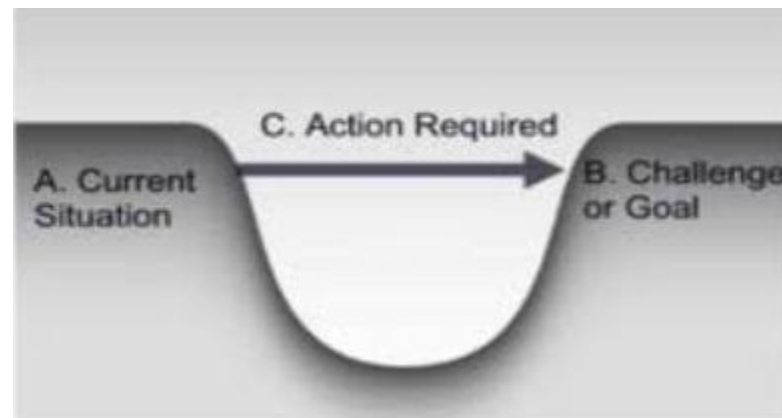
- The Autism Advisory Committee consists of diverse partners, including self-advocates, family members, providers, advocates, and others involved in the system of care for adults with ASD; this committee:
  - Ensures that the initiative is relevant and informs the state's understanding of the comprehensive needs of the target population
  - Serves as our eyes and ears in the community by providing their suggestions and perspective, and disseminating information about the initiative
  - Meets as a committee every two months and participates in subcommittee work

Advisory Committee



# *How is the gap analysis of DBHDD services for adults with ASD being conducted?*

- Data on adults with ASD receiving or eligible for DBHDD, DD services are being analyzed
  - Demographic information, health characteristics and risks, support needs, and service authorization and utilization
- Focus groups discussions on frequency of use of DD services and barriers to accessing these services
- Development of outcome measures for access and quality of DBHDD provided services to adults with ASD



# *Who are the group of Autistic adults included in the gap analysis?*

- For the purposes of the gap analysis, the cohort of Autistic adults are:
  - Adults with a primary or secondary diagnosis of Autism Spectrum Disorder who were at a point in time in 2015:
    - ❖ Receiving state or waiver funded services from DBHDD
    - ❖ Waiting for waiver services



Georgia Department of Behavioral Health  
and Developmental Disabilities



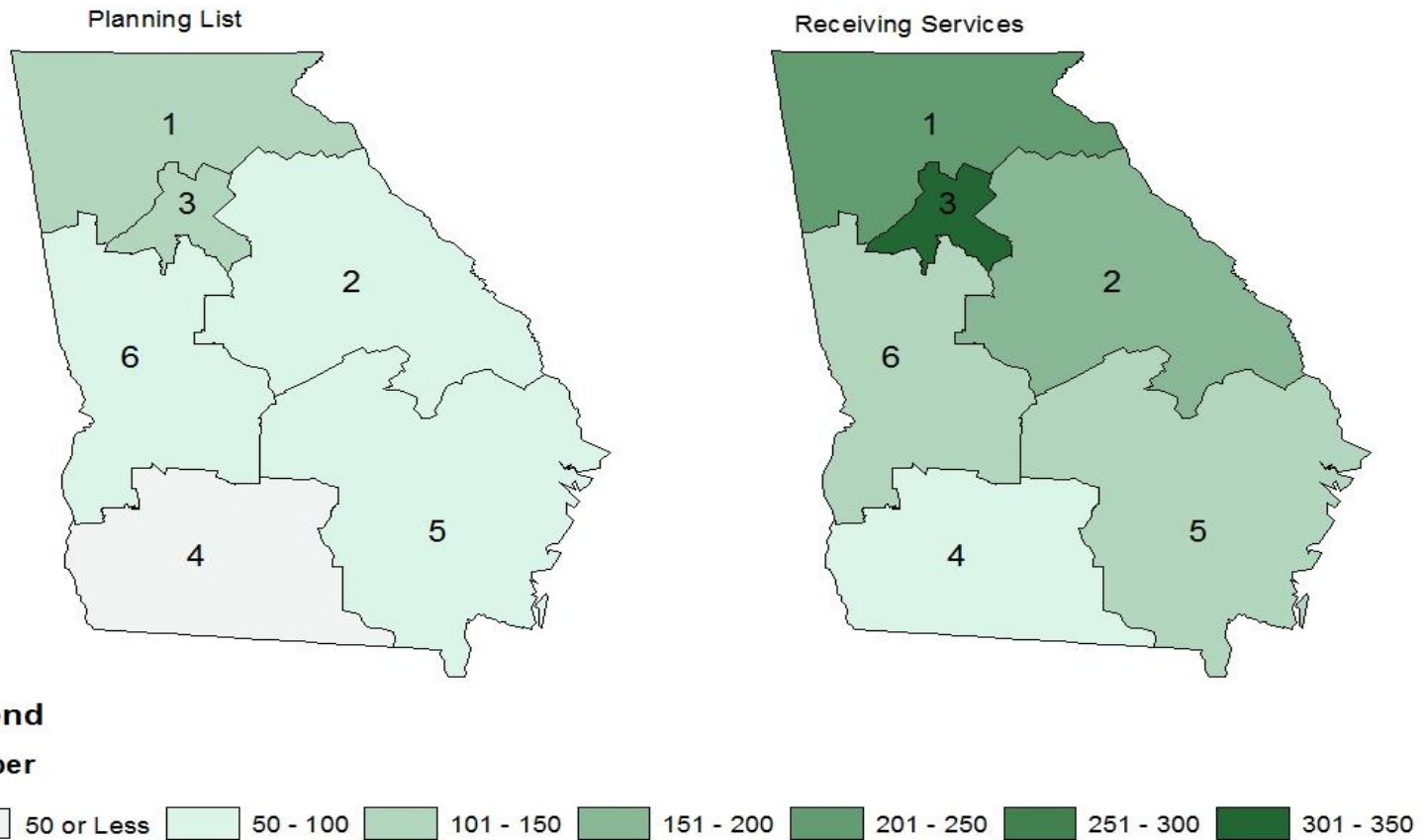
# Region Based Data for Cohort of Adults with Autism Spectrum Disorder

**Table 1: Waiver and Planning List Information for Cohort of Adults with Autism Spectrum Disorder in Georgia**

| Number                    | Region |     |     |    |     |     |
|---------------------------|--------|-----|-----|----|-----|-----|
|                           | 1      | 2   | 3   | 4  | 5   | 6   |
| <b>Total Number</b>       | 359    | 253 | 464 | 88 | 161 | 179 |
| <b>Receiving Services</b> | 239    | 166 | 317 | 65 | 102 | 116 |
| <b>Planning List</b>      | 120    | 87  | 147 | 23 | 59  | 63  |
| <b>Long Term</b>          | 61     | 30  | 43  | 9  | 31  | 44  |
| <b>Short Term</b>         | 59     | 57  | 104 | 14 | 28  | 19  |

# Distribution of Cohort of Autistic Adults by Region

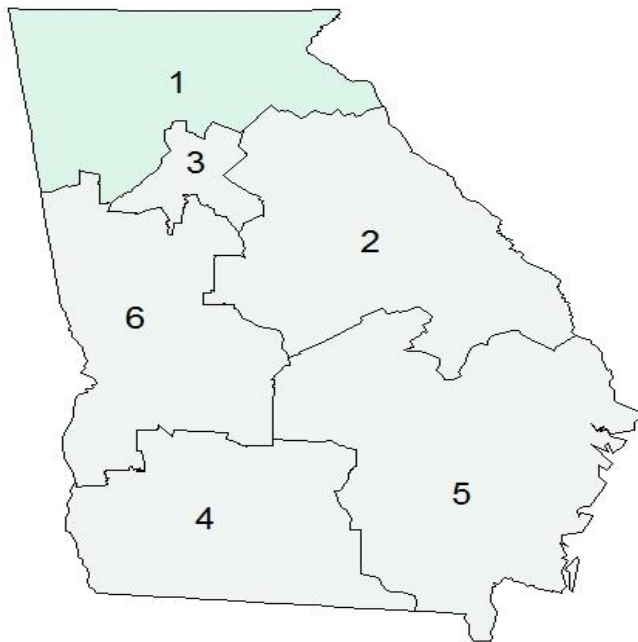
Number of Adults with Autism Receiving or Eligible for DBHDD Services  
Planning List vs Receiving Services



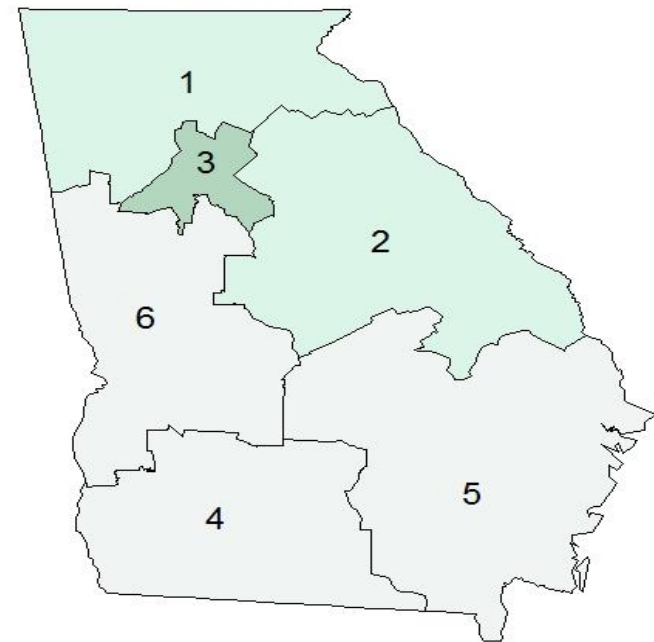
# Distribution of Cohort of Autistic Adults by Planning List

Number of Adults with Autism Receiving or Eligible for DBHDD Services  
Planning List

Long Term Planning List



Short Term Planning List



## Legend

### Number





# Population Based Rates for Cohort of Adults with Autism Spectrum Disorder

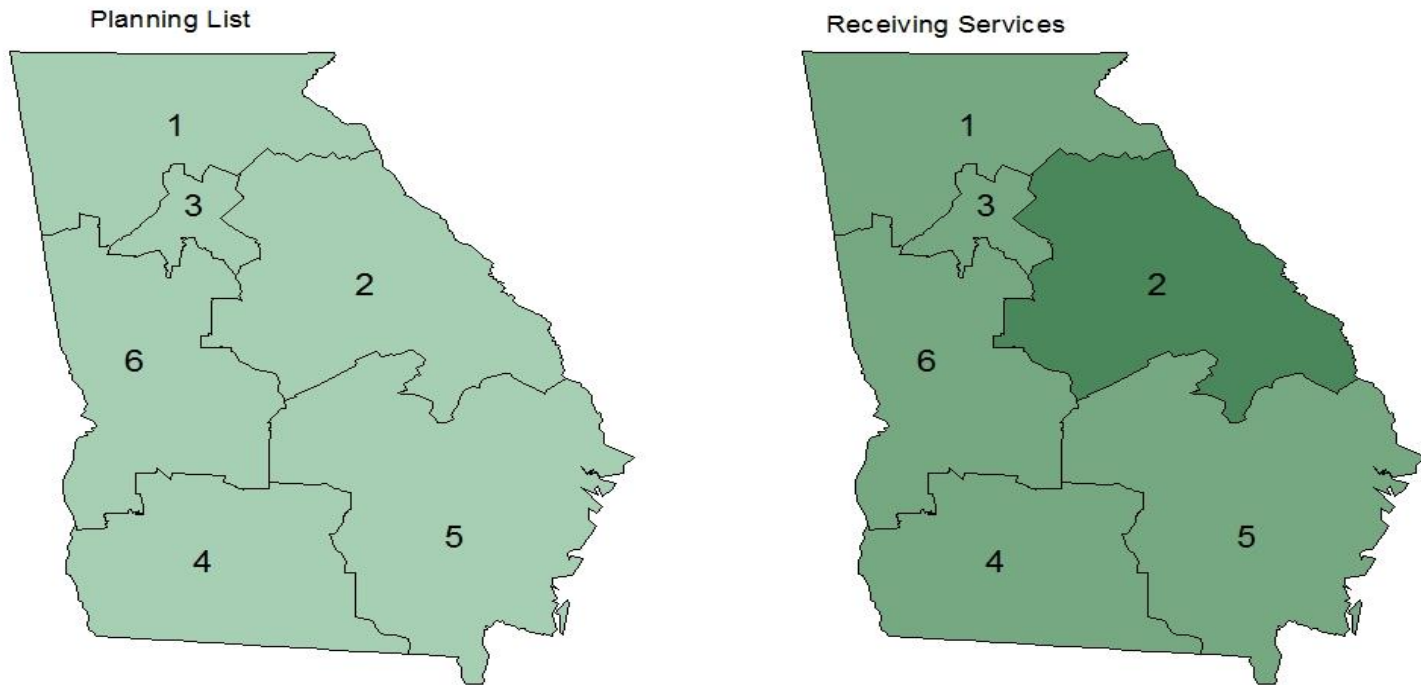
**Table 2: Population-Based\* Rates for Cohort of Adults with Autism Spectrum Disorder in Georgia**

| Rate per 100,000 Persons  | Region |       |       |       |       |       |
|---------------------------|--------|-------|-------|-------|-------|-------|
|                           | 1      | 2     | 3     | 4     | 5     | 6     |
| <b>Total Rate</b>         | 19.31  | 26.71 | 21.91 | 19.52 | 19.87 | 17.91 |
| <b>Receiving Services</b> | 12.85  | 17.52 | 14.97 | 14.41 | 12.51 | 11.61 |
| <b>Planning List</b>      | 6.45   | 9.18  | 6.94  | 5.1   | 7.24  | 6.3   |
| <b>Long Term</b>          | 3.28   | 3.17  | 2.03  | 2     | 3.8   | 4.4   |
| <b>Short Term</b>         | 3.17   | 6.02  | 4.91  | 3.1   | 3.43  | 1.9   |

\*Population data taken from 2010 Area Health Resource File (AHRF)

# Rate of Autistic Adults Receiving or Eligible for DBHDD Services

Rate of Adults with Autism Receiving or Eligible for DBHDD Services  
Planning List vs Receiving Services



## Legend

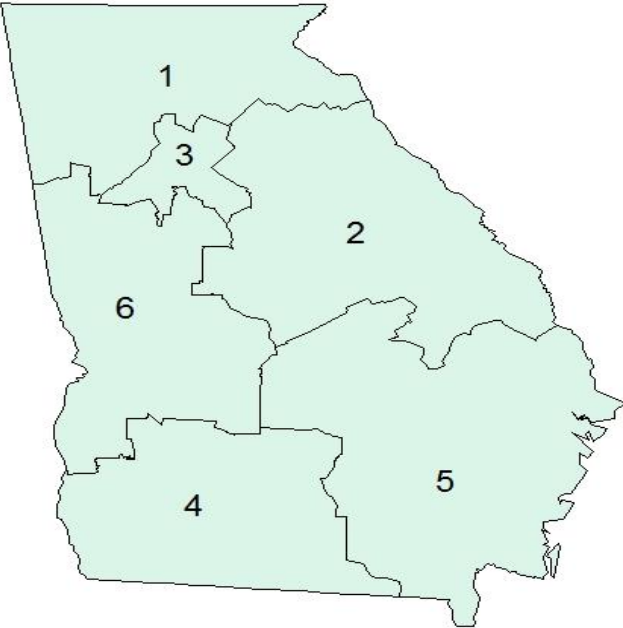
Rate per 100,000

|           |        |         |         |         |
|-----------|--------|---------|---------|---------|
| 5 or less | 6 - 10 | 11 - 15 | 16 - 20 | 21 - 25 |
|-----------|--------|---------|---------|---------|

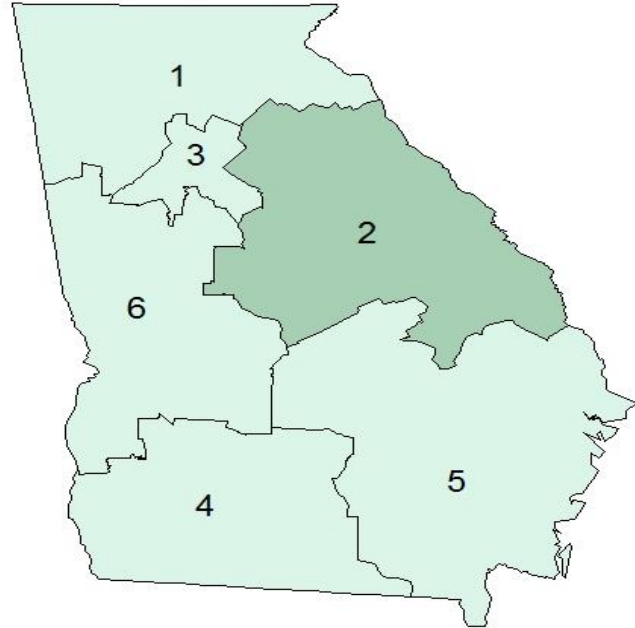
# Rate of Autistic Adults Eligible for DBHDD Services by Planning Lists

Rate of Adults with Autism Receiving or Eligible for DBHDD Services  
Planning List

Long Term Planning List



Short Term Planning List



### Legend

Rate per 100,000

|           |        |         |         |         |
|-----------|--------|---------|---------|---------|
| 5 or less | 6 - 10 | 11 - 15 | 16 - 20 | 21 - 25 |
|-----------|--------|---------|---------|---------|

# Median Age Data for Cohort of Adults with Autism Spectrum Disorder

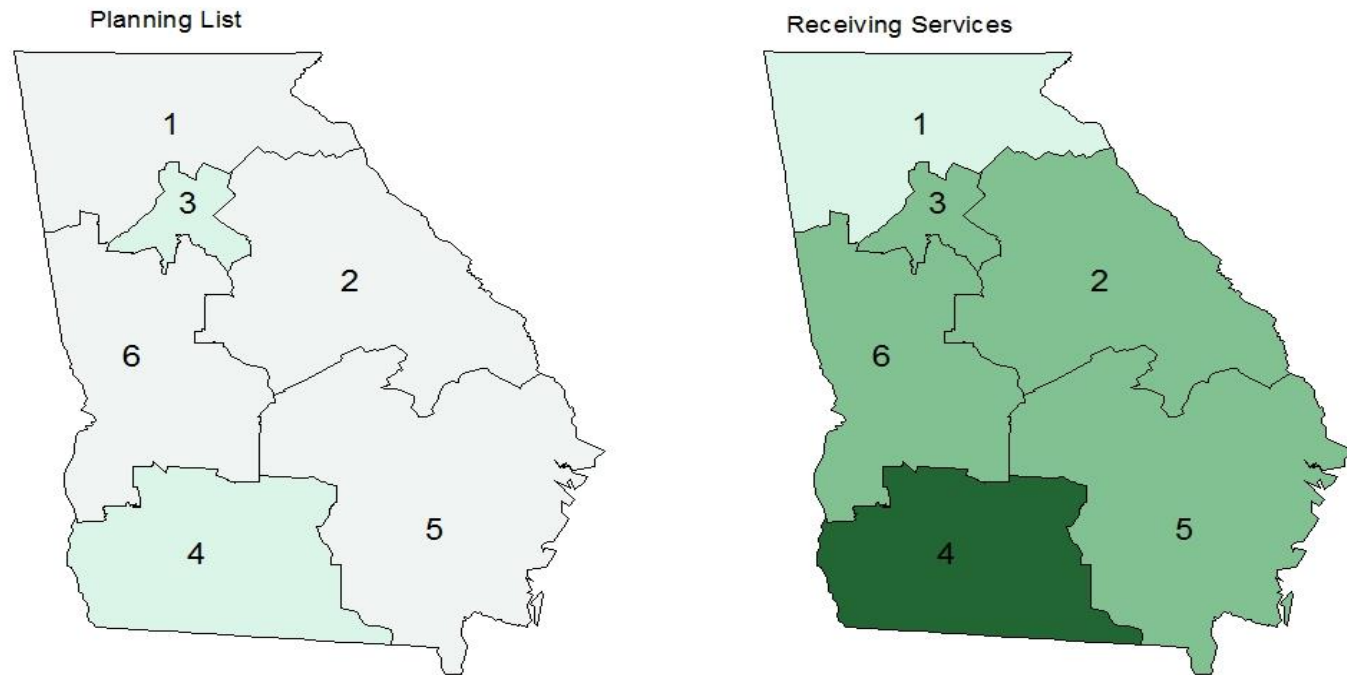
**Table 3: Median Age for Cohort of Adults with Autism Spectrum Disorder in Georgia**

| Median Age         | Region |    |    |      |    |    |
|--------------------|--------|----|----|------|----|----|
|                    | 1      | 2  | 3  | 4    | 5  | 6  |
| Receiving Services | 25     | 26 | 26 | 32   | 26 | 26 |
| Planning List      | 21     | 22 | 23 | 23   | 21 | 22 |
| Long Term          | 20     | 21 | 22 | 23   | 21 | 21 |
| Short Term         | 22     | 22 | 23 | 22.5 | 21 | 22 |

# Median Age of Cohort of Autistic Adults Receiving or Eligible for Services

Median Age of Adults with Autism Receiving or Eligible for DBHDD Services

Planning List vs Receiving Services



## Legend

Median Age

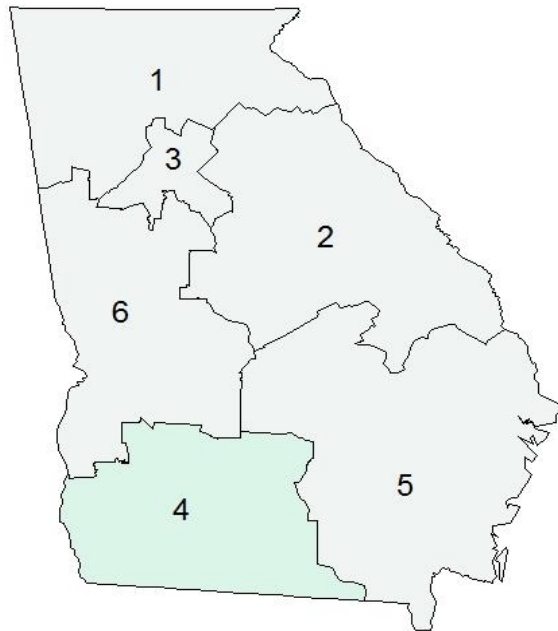
|         |         |         |         |         |
|---------|---------|---------|---------|---------|
| 20 - 22 | 23 - 25 | 26 - 28 | 29 - 31 | 32 - 35 |
|---------|---------|---------|---------|---------|

# Median Age of Cohort of Autistic Adults by Planning Lists

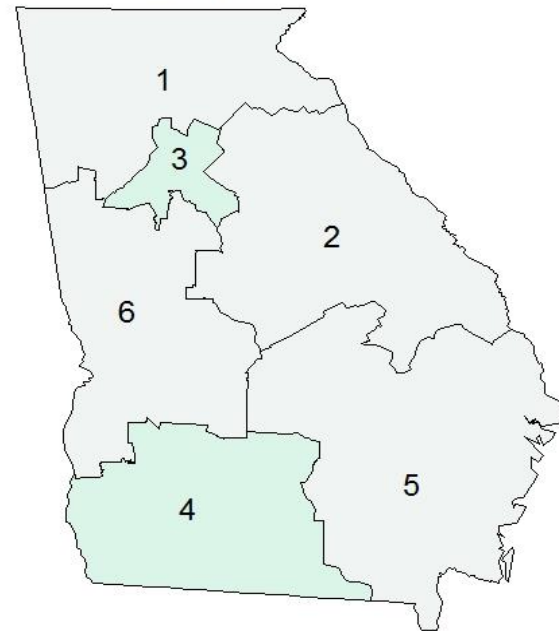
Median Age of Adults with Autism Receiving or Eligible for DBHDD Services

Planning List

Long Term Planning List



Short Term Planning List



## Legend

Median Age

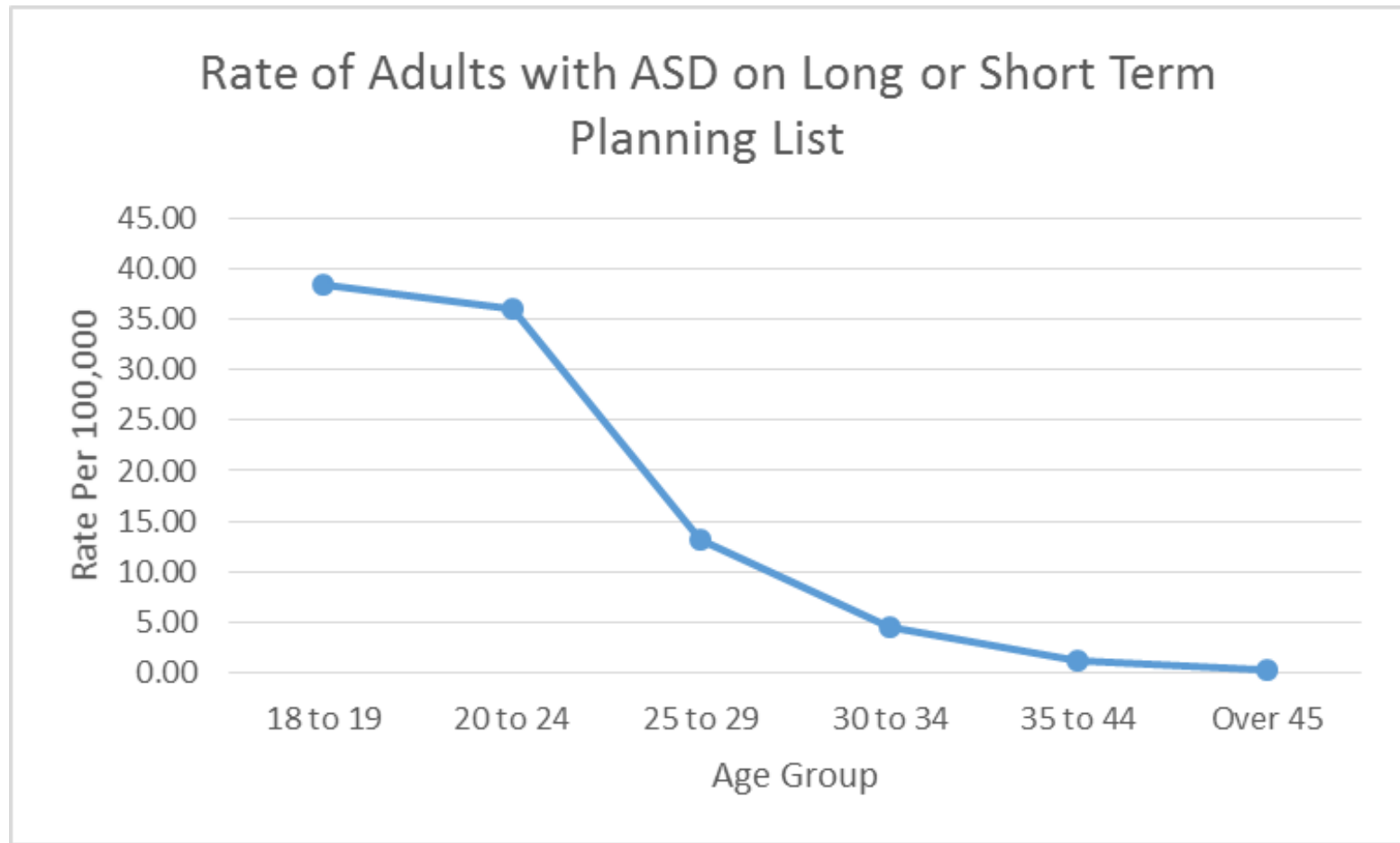
|         |         |         |         |         |
|---------|---------|---------|---------|---------|
| 20 - 22 | 23 - 25 | 26 - 28 | 29 - 31 | 32 - 35 |
|---------|---------|---------|---------|---------|

# Overall Georgia Planning List Information by Age Group for Cohort of Adults with Autism Spectrum Disorder

**Table 4: Planning List Information by Age for Cohort of Adults with Autism Spectrum Disorder in Georgia**

| Characteristic                                      | Age Group |          |          |          |          |         |
|---|-----------|----------|----------|----------|----------|---------|
|   | 18 to 19  | 20 to 24 | 25 to 29 | 30 to 34 | 35 to 44 | Over 45 |
| <b>Number on Planning List (Long or Short term)</b> | 109       | 245      | 89       | 30       | 18       | 8       |
| <b>Rate Per 100,000</b>                             | 38.38     | 36.03    | 13.21    | 4.53     | 1.29     | 0.23    |

# Overall Planning List Rate (Long or Short Term) by Age Group for Cohort of Adults with Autism Spectrum Disorder in Georgia





# Next Steps for Data Analysis

- Compare service authorization and utilization information across regions
- Compare National Core Indicator data for Georgia for those who identify as having ASD vs those who do not
- Explore both service provider information and data from the Georgia Crisis Access Line



# Focus Groups

- Qualitative data about frequency of use of DD services and barriers to accessing these services are being collected by:
  - Small focus groups of self-advocates, family members, providers, advocates, and others involved in the system of care for adults with ASD
  - Plan for diversity in gender, age, rural v. city, degree of impairment, and geographic location
  - Individual interviews at the outset helped to form questions for focus groups



# Identification of Outcome Measures

Eligible adults with ASD receiving DD services in the DBHDD system and those on the planning list

## Access

- Breakdown of the specific services approvals
- Provider location

## Services

- Breakdown of the specific services received
- Utilization of emergency services

## Quality

- Provider credentialing and training
- Family and individual satisfaction data
- Match between services received and standards of care

# Plan for Final Report



- The final report will include:
  - Results of the data analysis
  - Findings of the focus groups
  - Preliminary training goals
  - Policy recommendations for community based services for adults with ASD

# Information on the Autism Services Initiative for Adults

- Information on the Autism Services Initiative for Adults can be obtained by:
  - Accessing the Georgia DBHDD website at <http://dbhdd.georgia.gov/autism-services-initiative-adults>
  - Emailing Darlene Meador ([Darlene.Meador@dbhdd.ga.gov](mailto:Darlene.Meador@dbhdd.ga.gov)) or April Umstead ([April.Umstead@dbhdd.ga.gov](mailto:April.Umstead@dbhdd.ga.gov))



# References

Bradley, V. J., & Ne'eman, A. (2016, March 10). Outcomes for adults on the autism spectrum receiving services in 31 states: Putting the research in context [Webinar]. Retrieved from <http://www.nationalcoreindicators.org/resources/presentations>.

Ratto, A. B., & Mesibov, G. B. (2015). Autism spectrum disorders in adolescence and adulthood: Long-term outcomes and relevant issues for treatment and research. *Science China Life Sciences*, *58* (10), 1010-1015.

Steinhausen, H. C., Mohr-Jensen, C., & Lauritsen, M. B. (2016). A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. *Acta Psychiatrica Scandinavica*. Advance online publication. doi: 10.1111/acps.12559

# Questions?

