Appendix A: Strategic Plan Goals and Objectives

Multiyear Planning List (MYPLN) Strategic Plan – 5 Year Goals

Programmatic Area	Key Goals	Code
Planning List	Support individuals on the planning list by referring individuals and families to other services	PL.REF.PRM
Planning List	Increase the number of planning list individuals receiving nonwaiver services	PL.SEV.PRM
Planning List	Increase the number of new waiver individuals	PL.NWP.PRM
Planning List	Increase the waiver-entry process efficiency	PL.WEP.PRM
Planning List	Continue to improve the planning list infrastructure and management	PL.CQM.PRM
Medicaid Autism Benefit Plan	Leverage Medicaid Autism Benefit plan and referral to support individuals on the planning list	PL.MAB.PRM
Family Support Services	Improve Family Support Services Program	PL.FSS.PRM
Supported Employment	Leverage GVRA partnership to support individuals on the planning list	PL.GVR.PRM
Respite Services	Expand Respite Services to increase access to respite services for individuals on the planning list	PL.RES.PRM

Annual Targets for Each Goal, organized by the Associated Goal

Planning List

Associated Goal	Key Objectives	Completion Year
PL.REF.PRM	Develop a plan to track and increase the number of planning list individuals referred to other services	Year 1
	All individuals on the planning list interested in Family Support Services will be referred to Family Support Services	Year 1
PL.SEV.PRM	Develop a plan to increase the number of interested planning list individuals receiving nonwaiver services	Year 1
	Increase the Planning List individuals receiving nonwaiver services by 200	Year 2
	Increase the Planning List individuals receiving nonwaiver services by 200	Year 3
	Increase the Planning List individuals receiving nonwaiver services by 200	Year 4
	Increase the Planning List individuals receiving nonwaiver services by 200	Year 5
PL.NWP.PRM	600 NOW/COMP newly admitted waiver participants	Year 1
	650 NOW/COMP newly admitted waiver participants	Year 2
	700 NOW/COMP newly admitted waiver participants	Year 3
	750 NOW/COMP newly admitted waiver participants	Year 4
	800 NOW/COMP newly admitted waiver participants	Year 5

PL.WEP.PRM	Develop a plan to increase waiver-entry process efficiency	Year 1
	Maintain service entry timeline to under 80 business days	Year 2
	Maintain service entry timeline to under 75 business days	Year 3
	Maintain service entry timeline to under 70 business days	Year 4
	Maintain service entry timeline to under 65 business days	Year 5
PL.CQM.PRM	Close out and stabilize the initial planning list redesign efforts	Year 1
	Conduct an analysis to determine the capacity of Family Support Services to serve all new planning list individuals' service needs. This should also include an infrastructure impact analysis to serve as the "front-door"	Year 2
	Develop the 2nd phase of the planning list operations improvement plan; address the gap between the identified needs and the connected services	Year 3
	Develop a workforce development plan to strengthen the planning list team and the impacted provider network capacity	Year 4
	Close out and stabilize ongoing planning list infrastructure and management	Year 5

Medicaid State Plan for Autism Services

The completion year for this plan is dependent upon Department of Community Health's implementation date. It is expected that within the first two years of implementation date that these key objectives would be completed.

Associated Goal	**Key Objectives**	**Completion Year**
PL.MAB.PRM	Strengthen System of Care (SOC) infrastructure for individuals with autism spectrum disorder	TBD
	Enhance data tracking and trending of children and youth with autism spectrum disorder	TBD
	Complement data tracking and trending for adults with intellectual/developmental disabilities with the identified subpopulation of adults with autism spectrum disorder	TBD
	Provide supported employment services to young adults with autism spectrum disorder	TBD
	Increase provider capacity to individualize supported employment services for young adults with autism spectrum disorder	TBD
	Conduct staff training to support referrals of children and youth with autism spectrum disorder for the Medicaid Autism Benefit	TBD

Family Support Services

The completion year for the last three objectives are dependent upon the second phase of DBHDD's system enhancement timeline.

Associated Goal	**Key Objectives**	**Completion Year**
PL.FSS.PRM	Establish an objective assessment tool to determine appropriate resource allocation	Year 1
	Expand $3,000 annual cap for those with a higher level of need	Year 1
	Restructure Family Support Provider administrative fees	Year 1
	Create an interim system to house the new assessment tool	Year 1
	Hold focus groups and listening sessions with key stakeholders	Year 1
	Establish an internal tracking system for applications, assessment tool, and Individual Family Support Plan development and services needed	TBD
	Establish an internal tracking system for tracking and monitoring utilization, and determine and measure outcomes	TBD
	Create outcomes similar to the National Core Indicators for measuring the impact of Family Support Services on individuals receiving support	TBD

Supported Employment Service

Associated Goal	**Key Objectives**	**Completion Year**
PL.GVR.PRM	Develop the strategic plan to increase referrals to Georgia Vocational Rehabilitation Agency (GVRA)	Year 1
	Draft the memorandum of understanding with GVRA	Year 1
	Develop annual targets to refer 480 individuals	Year 1

Respite Service

Associated Goal	**Key Objectives**	**Completion Year**
PL.RES.PRM	Develop a plan to improve access to respite by increasing provider and service capacity	Year 1
	Identify available funding streams to expand respite service	Year 1
	Develop a provider recruitment plan to encourage community providers to provide respite care services	Year 2
	Reduce and eliminate barriers to becoming a respite care service provider	Year 3

Annual Targets for Each Goal, organized by Completion Year

Year 1

Key Objectives	**Associated Goal**
Develop a plan to track and increase the number of planning list individuals referred to other services	PL.REF.PRM
All individuals on the planning list interested in Family Support Services will be referred to Family Support Services	
Develop a plan to increase the number of interested planning list individuals receiving nonwaiver services	PL.SEV.PRM
600 NOW/COMP newly admitted waiver participants	PL.NWP.PRM
Develop a plan to increase waiver-entry process efficiency	PL.WEP.PRM
Close out and stabilize the initial planning list redesign efforts	PL.CQM.PRM
Establish an objective assessment tool to determine appropriate resource allocation	PL.FSS.PRM
Expand $3,000 annual cap for those with a higher level of need	
Restructure Family Support Provider administrative fees	
Create an interim system to house the new assessment tool	
Hold focus groups and listening sessions with key stakeholders	
Develop the strategic plan to increase referrals to GVRA	PL.GVR.PRM
Draft the memorandum of understanding with GVRA	
Develop annual targets to refer 480 individuals	
Develop a plan to improve access to respite by increasing provider and service capacity	PL.RES.PRM
Identify available funding streams to expand respite service	

Year 2

Key Objectives	**Associated Goal**
Increase the planning list individuals receiving nonwaiver services by 200	PL.SEV.PRM
650 NOW/COMP newly admitted waiver participants	PL.NWP.PRM
Maintain service entry timeline to under 80 business days	PL.WEP.PRM
Conduct an analysis to determine the capacity of Family Support Services to serve all new planning list individuals' service needs. This should also include an infrastructure impact analysis to serve as the "front-door"	PL.CQM.PRM
Develop a provider recruitment plan to encourage community providers to provide respite care services	PL.RES.PRM

Year 3

Key Objectives	**Associated Goal**
Increase the planning list individuals receiving nonwaiver services by 200	PL.SEV.PRM
700 NOW/COMP newly admitted waiver participants	PL.NWP.PRM
Maintain service entry timeline to under 75 business days	PL.WEP.PRM
Develop the 2nd phase of the planning list operations improvement plan; address the gap between the identified needs and the connected services	PL.CQM.PRM

Year 4

Key Objectives	**Associated Goal**
Increase the Planning List individuals receiving nonwaiver services by 200	PL.SEV.PRM
750 NOW/COMP newly admitted waiver participants	PL.NWP.PRM
Maintain service entry timeline to under 70 business days	PL.WEP.PRM
Develop a workforce development plan to strengthen the planning list team and the impacted provider network capacity	PL.CQM.PRM

Year 5

Key Objectives	**Associated Goal**
Increase the Planning List individuals receiving nonwaiver services by 200	PL.SEV.PRM
800 NOW/COMP newly admitted waiver participants	PL.NWP.PRM
Maintain service entry timeline to under 65 business days	PL.WEP.PRM
Close out and stabilize ongoing planning list infrastructure and management	PL.CQM.PRM

TBD

Key Objectives	**Associated Goal**
SOC infrastructure for individuals with autism spectrum disorder	PL.MAB.PRM
Enhance data tracking and trending of children and youth with autism spectrum disorder	
Complement data tracking and trending for adults with intellectual and developmental disabilities with the identified subpopulation of adults with autism spectrum disorder	
Provide supported employment services to young adults with autism spectrum disorder	
Establish an internal tracking system for applications, assessment tool, and Individual Family Support Plan development and services needed	PL.FSS.PRM
Establish an internal tracking system for tracking and monitoring utilization, and determine and measure outcomes	
Create outcomes similar to the National Core Indicators for measuring the impact of Family Support Services on individuals receiving support	

Appendix B: General Overview of Disability Services

General Overview of Disability Services

About DBHDD

Created by the governor and General Assembly in 2009, DBHDD and its network of community providers offer treatment and support services to help people with behavioral health challenges (mental illness and emotional disturbances, as well as substance use disorders) achieve recovery. Through uniquely tailored supports and services, DBHDD also assists individuals with intellectual or developmental disabilities attain independence and lead meaningful and fulfilling lives. Organization charts of DBHDD and its Division of Developmental Disabilities are included in Appendix C at the end of this report.

The Division of Developmental Disabilities manages a network of providers for service delivery to people with intellectual or developmental disabilities. A developmental disability is a chronic condition that develops before a person reaches age twenty-two years and substantially limits his or her ability to function in everyday life. DBHDD provides services for people with intellectual and other disabilities, such as severe cerebral palsy and autism, who require services similar to those needed by people with an intellectual disability.

Vision

Easy access to high-quality care that leads to a life of recovery and independence for the people we serve.

Mission

Leading an accountable and effective continuum of care to support Georgians with behavioral health challenges and intellectual and developmental disabilities in a dynamic health care environment.

Funding

Most of DBHDD's programs are funded by either Medicaid dollars (federal and state match) or non-Medicaid state dollars. A breakdown of programs by funding source is shown in figure 1 below.

Fig. B.1. DBHDD Programs by Funding Source

Program	Funding Source	
	Medicaid (Federal/State Match)	**Non-Medicaid State Dollars**
New Options Waiver Program (NOW)	X	
Comprehensive Supports Waiver Program (COMP)	X	
Crisis Services		X
Family Support Services		X
Supported Employment Service		X

Population Served

DBHDD provides numerous services across the state for people living with mental health and emotional disturbances, substance use disorders, intellectual and developmental disabilities, or any combination of these. Services are provided in a variety of locations, including outpatient, inpatient, and community settings. Most often, people served are uninsured or on Medicaid, with few other resources or options.

Roles and Responsibilities

DBHDD relies on subject-matter expertise for program development and administration of services to the three populations noted above. While each of these populations brings different needs and requires different service models and slightly different philosophical and practice theories, all rely on a strong network of sophisticated providers. Recognition that practice areas overlap for some individuals often requires the combined expertise of multiple DBHDD divisions — behavioral health (mental health and substance use), and intellectual or developmental disabilities. All populations are served by regional field offices, state hospitals, forensic programs, crisis-response services, and community-based services.

Regional Field Offices

DBHDD administers six regional field offices across Georgia. Each field office operates a community-based System of Care (SOC) for the people in its catchment area and also works with DBHDD's state hospitals to support transitions into the community. The field offices have community-based partnerships throughout their regions and are the first points of contact for consumers who have questions about accessing services.

Inpatient Facilities

DBHDD operates five hospitals, located in Metro Atlanta, Augusta, Columbus, Milledgeville, and Savannah. The hospitals offer inpatient services in adult behavioral health and forensic needs. The intermediate care facilities for individuals with intellectual or developmental disabilities were closed to admissions in 2011. In lieu of hospital admission, the Division of Developmental Disabilities also operates twelve crisis homes — ten for adults and two for children.

Forensic Programs

Forensic programs serve individuals who have been found not guilty by reason of insanity or incompetent to stand trial (IST) by the criminal justice system. The role of the forensic programs is to treat their underlying condition and, in the case of IST consumers, to restore their competency so that they can stand trial. Individuals may be determined to have intellectual or developmental disabilities while in forensic care and may be admitted to an intellectual or developmental disabilities program for support upon release from a state hospital. The courts determine the timing of release and review plans for support in the community.

Crisis Response Services

Families and providers are often challenged with crises that occur in the intellectual or developmental disabilities population, often related to behavioral issues that may be difficult to manage and may sometimes present a danger to family members or others living with the individual. The goal of the Georgia Crisis Response System for the intellectual or developmental disabilities population is to provide community-based crisis services that support individuals with intellectual or developmental disabilities as an alternative to institutional placement, emergency room care, or law enforcement involvement. These community-based crisis services are provided on a time-limited basis to ameliorate the presenting crisis and provide a safe opportunity for planning and coordination of after-care services.

Mobile crisis services are available twenty-four hours a day, seven days a week to families, providers, and people who have been diagnosed with developmental disabilities. The mobile crisis team assesses the need for a referral for additional community crisis services through an intensive in-home or out-of-home evaluation. Following an evaluation, in-home services include the implementation of behavioral interventions and/or the provision of one-to-one support not only to address the crisis, but also to model interventions with family and/or provider staff. Out-of-home services include the use of crisis homes designed to stabilize the individual through intensive behavioral services and nursing services, when needed. Intensive crisis supports (in-home and out-of-home supports) are specialized services that provide time-limited care and intervention to an individual who would, otherwise, be at risk of imminent harm to self or others or continue to engage in behaviors with serious negative consequences. These supports provide immediate and ongoing services required to stabilize the situation. The outcome of these services should enhance the current family member or provider’s ability to meet the long-term needs of the individual and resolve the acute crisis to avoid individuals having to leave their homes for extended periods.

Community-Based Services

The goal of community-based services is to serve people as close to home as possible in the most integrated setting. This allows them to draw on natural supports, such as family, neighbors, churches, and schools. DBHDD provides and funds a variety of community-based services through community service boards (CSBs) and private-contracted providers. CSBs are the state's safety net for mental health, substance use disorder, and intellectual and developmental disability service management and delivery. The majority of people served by CSBs are uninsured or receive services through Medicaid coverage. There are twenty-six CSBs across Georgia, providing coverage for all 159 counties.

DBHDD funds community services through three primary programmatic areas:

- State-funded contracts for those with intellectual or developmental disabilities
- Family Support Services
- Home- and community-based services (HCBS) waiver programs

State-Funded Contracts

State-funded contracts fund services much like those offered through the Medicaid waiver programs for individuals ineligible for Medicaid or waiting for admission to the waiver programs. State-funded contracts for community programs for persons with intellectual or developmental disabilities began in the 1960s with the establishment of day service centers. Over the decades, state-funded contracts began to fund a variety of community services, including more recently home- and community-based crisis services.

Family Support Services

Family Support Services are offered to families of both children and adults with intellectual or developmental disabilities who meet eligibility criteria for services but whose needs can be met with a small amount of flexible funding for goods and services specific to population needs. Pilots of Family Support Services occurred in the early 1990s prior to the establishment of the Family Support Services program, which grew out of the success of these pilots.

In addition to the primary program areas outlined above, the Division of Developmental Disabilities contracts with additional specialized service providers in areas that require specific expertise or services. Examples of such providers include:

- The Emory Autism Center provides autism-specific psychiatric and behavioral evaluation and services for adults.
- The Marcus Autism Center provides comprehensive evaluation, treatment, and therapy services to Medicaid-eligible children with autism and severe challenging behaviors.
- The Matthew Reardon Center for Autism provides educational programming and behavioral services to children with autism.

- Parent to Parent of Georgia provides support and information services, as well as training and leadership opportunities for families who have children and youth with disabilities or special health care needs.
- Easter Seals of Southern Georgia's Champions for Children program provides services such as Respite Care, recreational, and therapeutic activities to medically fragile children with intellectual or developmental disabilities.
- Georgia Tech Research Corporation provides expertise in assessment and development of customized assistive technology solutions relevant to specific unmet needs of individuals.
- Georgia Microboards Association assists with job training and employment opportunities through development of microenterprise small business opportunities.
- Georgia Association for Prader-Willi Syndrome provides information, education, and training to families supporting someone with this underdiagnosed condition.

HCBS Waivers

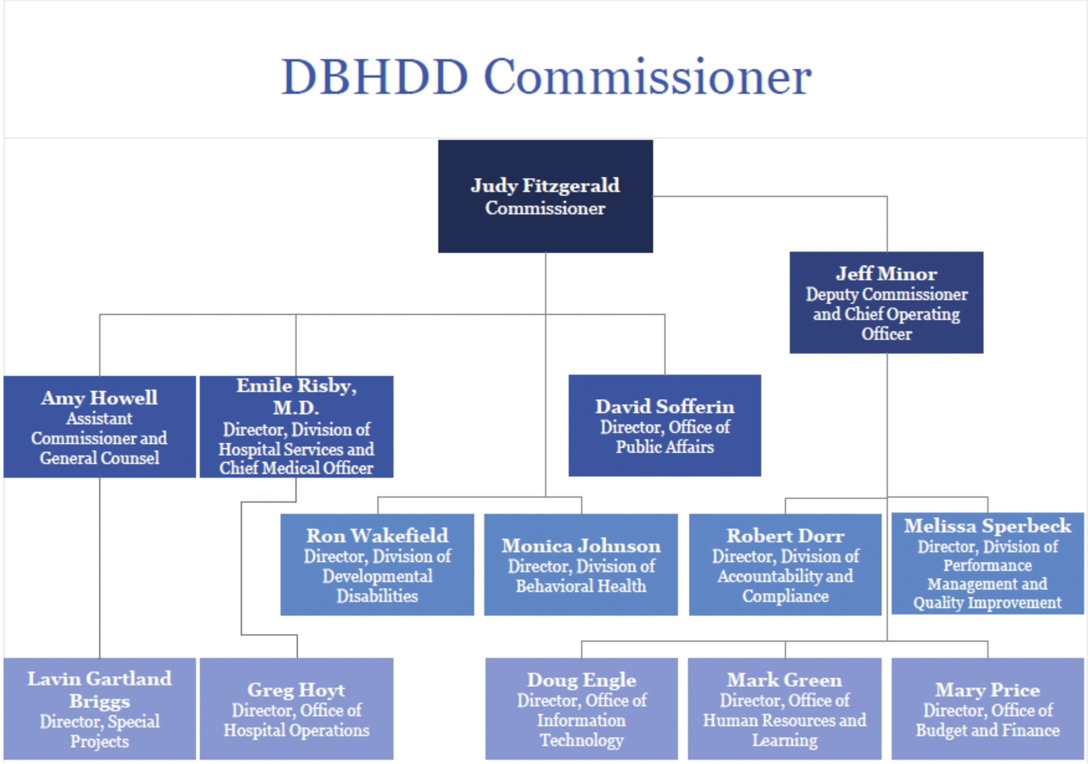
NOW and COMP are two Medicaid waiver programs authorized under the authority of section 1915(c) of the Social Security Act. Traditionally, Medicaid only pays for long-term care for those in nursing homes. However, under section 1915(c) of the Social Security Act, the federal government allows states the option of covering long-term care through HCBS, waiving the requirement that services must be provided to all who qualify. States can limit program participants by the amount of funding available. Hence, these programs usually have a planning list for those waiting for coverage.

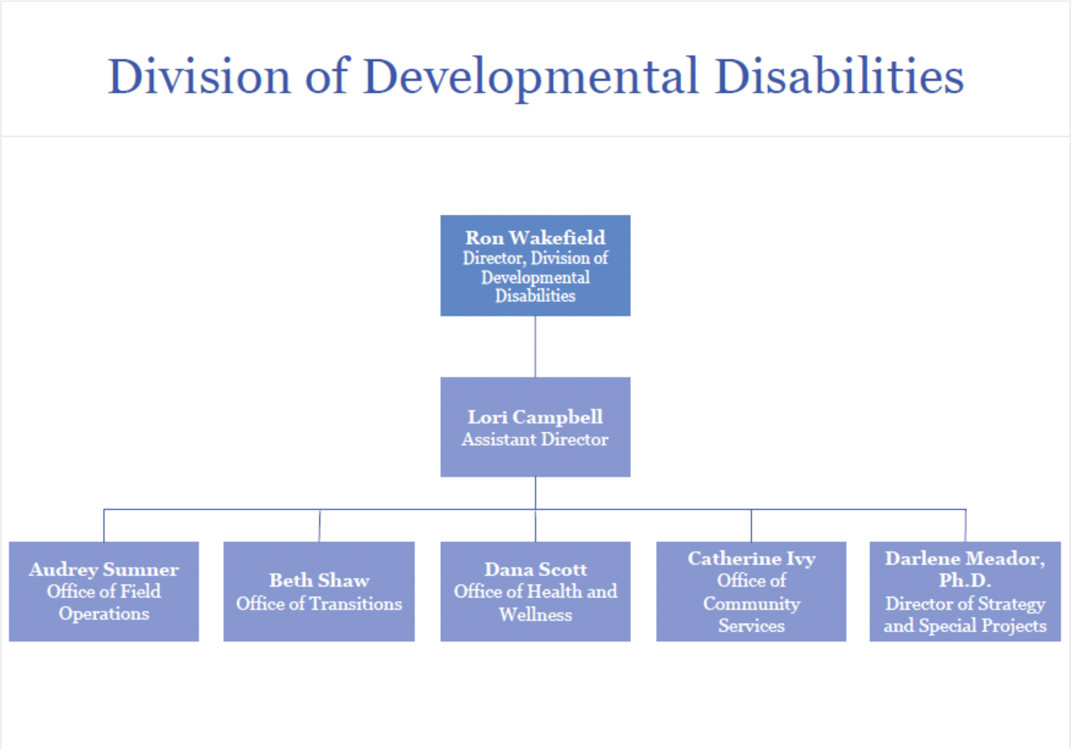
The NOW program serves individuals with less intense or urgent needs than out-of-home residential treatment, allowing individuals to remain in the community. The NOW program replaced the previous Mental Retardation Waiver Program (MRWP), the first HCBS waiver program for individuals with intellectual or developmental disabilities in Georgia, beginning in 1989. The MRWP allowed for the provision of enhanced HCBS to those Medicaid beneficiaries with intellectual or developmental disabilities who would otherwise have required institutional care.

The COMP program is geared toward individuals who need intensive, in-home services to remain in the community. The COMP program replaced the Community Habilitation and Support Services (CHSS), which was originally designed and implemented in 1997 to support the closure of Brook Run, an intermediate care facility for individuals with disabilities that was located in the metro Atlanta area. A list of services provided by both NOW and COMP is attached as Appendix D.

The MRWP and CHSS programs went through several amendments over the years designed to improve HCBS for individuals with intellectual or developmental disabilities. The NOW and COMP programs began in 2008 as a substantial redesign of the Medicaid waiver programs for individuals with intellectual or developmental disabilities. Target populations for the waiver programs were changed, and individuals were moved to either the supports waiver (NOW) or the comprehensive waiver (COMP). In fiscal year 2017, NOW served 4,484 participants, while COMP served 7,918 people. As of December 1, 2017, there are 8,555 individuals on a planning list, waiting for waiver services. Those on the planning lists are classified as either short-term (those presently in need of services) or long-term (those not imminently in need).

Appendix C: DBHDD Organization Charts





Appendix D: NOW and COMP Waiver Services

Additional Residential Staffing is provided on behalf of individuals with a high level of functional, medical, or behavioral needs who require direct support or oversight beyond the level provided within traditional service descriptions. Available in the COMP waiver only.

Adult Nutrition Services include nutrition evaluation; education of participant, family, and support staff; and periodic monitoring and dietary intervention to improve nutrition-related health conditions.

Adult Occupational Therapy Services promote fine motor skill development, coordination, and sensory integration and facilitate the use of adaptive equipment or technology.

Adult Physical Therapy Services address participants' physical therapy needs resulting from developmental disabilities. These services promote gross and fine motor skills and facilitate independent functioning.

Adult Speech and Language Therapy Services address adult participants' speech and language therapy needs, preserving their speech communication capacity and function.

Behavioral Supports Consultation is the professional-level service that assists participants with significant, intensive, and challenging behaviors that interfere with activities of daily living, social interaction, work, or similar situations.

Behavioral Supports Services assist waiver participants with significant, intensive, challenging behavior situations through offering positive behavioral support training and assistance to formal and informal care providers.

Community Access is designed to help participants acquire, retain, or improve self-help, socialization, and adaptive skills required for active participation and independent functioning outside the home.

Community Guide services are only for participants who opt for participant direction. These services help participants to define and direct their own services and supports and to meet the responsibilities of participant direction.

Community Living Support services are individually tailored supports that assist with the acquisition, retention, or improvement of skills related to participants' continued residence in their family homes.

Community Residential Alternatives are available to individuals who require intense levels of residential support in small group settings of four or fewer or in host home/life-sharing arrangements. Services include a range of interventions that focus on training and support in one or more of the following areas: eating and drinking, toileting, personal grooming and health care, dressing, communication, interpersonal relationships, mobility, home management, and use of leisure time. Available in the COMP waiver only.

Environmental Accessibility Adaptation consists of physical adaptations to participants' (or family members') homes that are necessary to ensure health, welfare, and safety, or which enable individuals to function with greater independence in the home.

Financial Support Services are provided to ensure that participant-directed funds outlined in Individual Service Plans are managed and distributed as intended.

Individual Directed Goods and Services that are not otherwise provided through the NOW or Medicaid State Plan may be identified by individuals, support coordinators, and interdisciplinary teams, and include services, equipment, and supplies.

Natural Support Training exists for individuals who provide unpaid support, training, companionship, or supervision to participants.

Prevocational Services prepare participants for paid or unpaid employment and include teaching concepts such as compliance, attendance, task completion, problem–solving, and safety.

Respite Services provide brief periods of support or relief for individuals with disabilities or their caregivers and include maintenance respite for planned or scheduled relief or emergency/crisis respite for a brief period of support for participants experiencing crisis (usually behavioral) or in instances of family emergency.

Specialized Medical Equipment consists of devices, controls, or appliances specified in the Individual Service Plan that enable participants to increase their abilities to perform activities of daily living and to interact more independently with their environment.

Skilled Nursing Services are provided as an extension of the Medicaid State Plan home health services when required to meet the medical needs of the member in the most appropriate setting, including the member's home, a relative's home, or other location where no duplicative services are available.

Specialized Medical Supplies consist of food supplements, special clothing, diapers, bed wetting–protective sheets, and other authorized supplies specified in the Individual Service Plan.

Support Coordination is a set of interrelated activities that identify, coordinate, and review the delivery of appropriate services with the objective of protecting the health and safety of participants while ensuring access to services.

Intensive Support Coordination provides specialized coordination of waiver, medical, and behavioral support services on behalf of waiver participants with exceptional medical and/or behavioral needs. The need for Intensive Support Coordination is determined at initial and annual assessment and is provided as an alternative to traditional Support Coordination.

Supported Employment enables participants, for whom competitive employment at or above the minimum wage is unlikely absent the provision of supports, to work in a regular work setting.

Transportation services enable participants to gain access to waiver and other community services, activities, resources, and organizations typically used by the general population. These services do not include transportation available through Medicaid nonemergency transportation or as an element of another waiver service.

Vehicle Adaptation includes adaptations to participants' (or family members') vehicles approved in the Individual Service Plan, such as hydraulic lifts, ramps, special seats, and other modifications to allow for access into and out of the vehicle as well as safety while moving.

Appendix E: Current Issues with NOW and COMP Waiver Services

Current Issues with NOW and COMP Waiver Services

Since the implementation of the NOW and COMP waiver programs in 2008, demographic shifts in the population and a refocusing on the target population for the waivers has required changes to both programs. Over the past nine years the COMP waiver program, which provides residential and high-level in-home support to individuals with the greatest needs, has seen the most significant changes in population. The average age of individuals served through the COMP waiver program in calendar year 2016 was forty-three years, while the average age of individuals served in the NOW waiver program was forty years. The 2016 Annual Mortality Report indicates that since 2013, there has been a significant increase in the age of the NOW and COMP waiver population, as well as a significant increase in measured health risk in the population. (See Appendix F). In fact, data presented in the 2016 Annual Mortality Report supports increasing age and risk level as the highest predictors of mortality:

- From 2013 to 2015, mortality increased markedly after age fifty-four. In 2016, mortality increased markedly after age sixty-four, a pattern also found in the general U.S. and Georgia populations.
- Life expectancy for the 2016 NOW and COMP waiver population (53.5 years) is comparable to the average age of death for intellectual and developmental disability populations reported in other state mortality reports and in published peer-reviewed research (50.4 to 58.7 years) (DBHDD, 2016).

Changes to the COMP Waiver Program

As Georgia began and has continued aggressive efforts to move individuals living in state hospitals and intermediate care facilities for people with intellectual or developmental disabilities to the community, the COMP waiver program has been in the process of an ongoing redesign to accommodate a more medically and behaviorally fragile population. Previously, one waiver service had been used to design behavior support plans, but over time, there was recognition that the plans required a thorough and sometimes complex understanding of behavior indicators and the timing of strategies and interventions. In 2014, the Centers for Medicare & Medicaid Services (CMS) approved a waiver amendment that enhanced and expanded the availability of nursing services and created a new behavioral service designed to monitor and train staff in residential settings to more effectively understand and use behavior intervention techniques. The 2014 waiver amendment also included a clinical case management service, Intensive Support Coordination, designed to provide an experienced workforce that could recognize and intervene quickly in medical, clinical, and psychosocial concerns that can result in emergency room visits, hospitalization, need for emergency behavioral intervention, and/or failed residential placement.

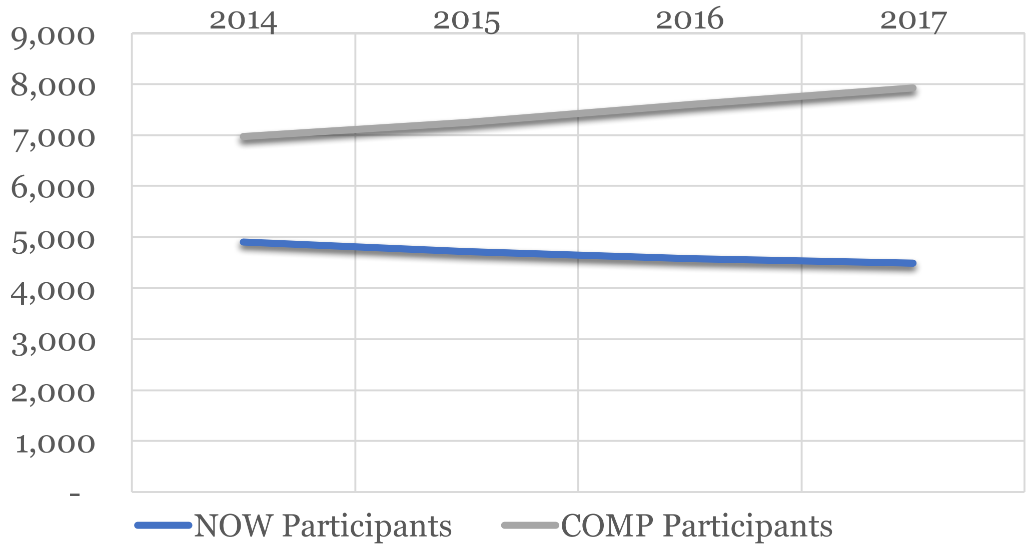
In 2017, CMS approved a COMP waiver renewal application consistent with the federal requirement that all HCBS Medicaid waiver programs be renewed a minimum of every five years. Several changes proposed and approved in the waiver application reflected the need to continue to refine the service system to meet the needs of individuals with high health and safety concerns. The waiver renewal application increased the available funding cap for physical, occupational, and speech/language therapies; added nutrition services; and increased the funding cap for medical supplies. However, the most significant change was the approval to use a tiered structure in residential funding that directly correlates the rate to the direct support staffing needs of the individual served.

The assignment of individuals to a specific tier is determined through a needs assessment and results in individuals being assigned to one of four levels. A small number of individuals whose level of need exceeds the highest tier are accommodated through use of a newly approved service called Additional Residential Staffing. The service is provided and reimbursed on the quarter-hour and allows residential providers to staff very high-risk individuals at levels not available to the general waiver population. The Community Residential Services and Additional Residential Staffing services are only available through the COMP waiver program. A complete list of all approved waiver services is attached in Appendix D.

Changes to the NOW Waiver Program

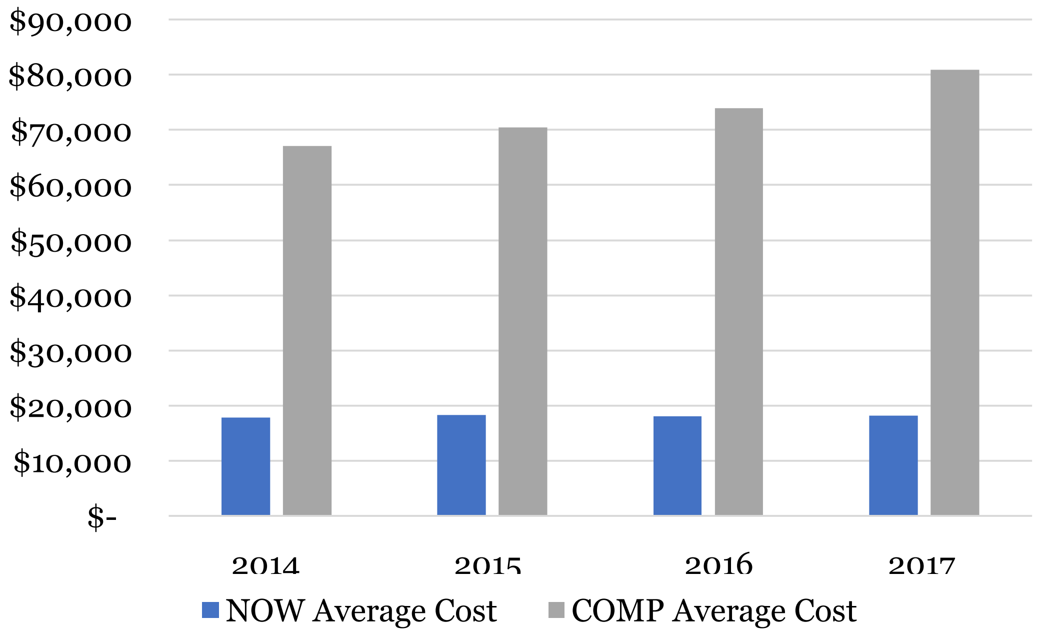
In 2008, the NOW waiver program set an individual cost limit of $25,000 per person per year, which could be exceeded (only under special circumstances) to accommodate a temporary need for additional services for no more than one year. In comparison, the COMP waiver program uses an aggregate cost limit, allowable by CMS and calculated as the annual cost of institutional care were all waiver participants to be served in institutions. Thus, variability of individual costs in the COMP waiver program ranges from just over $25,000 to very high “outlier” costs. The lower funding limit in the NOW waiver program has resulted in the population migration to the COMP waiver program over time as shown in figure E.1 below.

Fig. E.1. Population Migration From NOW to COMP in Georgia, 2014–2017



As depicted in figure E.2 below, the average cost per person on NOW ranged from about $17,900 to a little over $18,000 over a four-year period, while the cost for COMP ranged from about $67,000 to $81,000 over the same period.

Fig. E.2. Average Cost Per Person for NOW and COMP in Georgia, 2014–2017



As previously noted, the migration from the NOW to the COMP waiver program can be partially attributed to the aging waiver population, who need the more intense services provided by COMP that cannot be provided by family caregivers. However, this shift can further be attributed to the increased need at admission to the waiver programs since the admission criteria are designed to admit individuals using “most in need” prioritization. Those “most in need” are usually those that need more extensive services. In 2017, through the NOW waiver renewal application, an increase in the individual cost limit was proposed, in addition to allowing a one-time increase to mitigate temporary situations. In an effort to slow the migration from the NOW to the COMP waiver program, several service changes were proposed and approved by CMS in addition to the increase in individual cost limit. Service additions and service system design changes proposed with the recently approved NOW waiver renewal application include these:

- Synchronizing the model and rates for in-home support services (Community Living Supports) with the COMP waiver program to allow adults with intellectual disabilities to explore more independent living arrangements by sharing staff support in a two- or three-person model. This change will allow young adults with dreams of an independent, but supported, lifestyle to achieve this with

housemates. It will also provide older adults the same option, while they remain relatively healthy and active.
- Adding nutrition services to the NOW waiver assists individuals whose developmental disability causes a predisposition toward obesity to reach the highest level of health.
- Redefining supported employment services allows Medicaid-reimbursed transportation services for accessing work sites daily. Redesign of transportation options will allow greater flexibility in supported travel to and from work sites during nontraditional hours, promoting the use of work settings that operate in nontypical daytime hours.
- Opening all day services, which includes center-based, day supports, prevocational services offered in day centers, and supported employment in integrated business settings, can be used interchangeably as individuals gain more confidence to venture into employment. The redesign will offer the opportunity to move easily from a center-based day setting, where the individual may have friends and experience familiarity, to a less familiar work environment for a few hours a week to a few days each week as the individual gains comfort and confidence with the work setting.

The day service model redesign encourages employment in community settings, as the Division of Developmental Disabilities continues to promote and support employment as a means toward a more independent and meaningful life.

Through these changes, the NOW waiver program is evolving toward a program that supports families in caring for their relatives and one that promotes independence for individuals with intellectual and developmental disabilities.

Looking Ahead

The COMP waiver program will continue to provide supports for individuals with high medical and/or behavioral needs, as well as those who require residential services because of aging or unavailable caregivers. The NOW waiver program changes will further redefine the program to refocus on meaningful support to families by providing sufficient and targeted services to individuals who either live with family members, receive informal support from others, or who wish to live independently with minimal customized support for specific activities of daily living.

As DBHDD continues to shift from an institution-based model of health care delivery to a community-based SOC, individuals with intellectual or developmental disabilities will have greater opportunities to live independently and in the least-restrictive setting possible. As the department has navigated this shift, it has intentionally added to and altered its service array to more effectively meet the needs of a population that is more diverse than it is homogeneous. Despite these efforts, the long planning lists for the NOW and COMP programs are delaying DBHDD’s efforts to shift the care of individuals with intellectual or developmental disabilities away from institutional settings into the community.

Planning list redesign efforts will be supported by the evolution and philosophy of the two waiver programs, and conversely, the planning list redesign will enhance admission to the program best suited to meet individual and family need. By defining the slightly different purposes of the two programs in order to distinguish the best-suited program, DBHDD will be able to target admissions for increased efficiency and cost-effectiveness.

Appendix F: 2016 Annual Mortality Report

2016 Annual Mortality Report

New Options Waiver (NOW) and Comprehensive Supports Waiver (COMP)

DBHDD

Georgia Department of Behavioral Health and Developmental Disabilities

August 22, 2017

This is the third annual report on mortality, mortality trends, and related information pertaining to the health and care received by individuals with intellectual and developmental disabilities served by the Georgia Department of Behavioral Health and Developmental Disabilities. The report focuses on an analysis of mortality data and findings from DBHDD's mortality review process. Reports are scheduled for publication in August of each year and cover the prior calendar year of January 1 through December 31.

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Executive Summary

An analysis of individual deaths and trends in mortality is a component of health and safety oversight and is part of the Georgia Department of Behavioral Health and Developmental Disabilities' ("DBHDD," or "the department") quality management and improvement system. This is the third annual mortality report released by DBHDD. The purpose of this report is to provide information about what DBHDD has learned about deaths, to identify trends or patterns, and to identify indicators that may assist DBHDD in the prevention and treatment of certain illnesses/conditions that may lead to deaths or other disorders/diseases in the future. This report does not issue recommendations, as these will emanate from later processes when DBHDD has had the opportunity to consider findings and observations reported within this document.

This report includes data and information concerning adults who died during calendar year 2016 while receiving intellectual and developmental disability Medicaid waiver services from DBHDD and its contracted providers.

Major Findings

In calendar year 2016, DBHDD served 12,151 adults (at least 18 years of age) with intellectual and developmental disabilities in waiver services. A total of 170 deaths occurred in 2016; the 2016 mortality rate was 14.0 deaths per 1,000 individuals.[1, 2] The respective mortality rates for 2014 and 2015 were 11.1 and 12.5 deaths per 1,000 individuals. The mortality rates do not differ significantly across any years.

Heart disease was the leading cause of death in the general populations of the U.S. (2014), Georgia (2015), and DBHDD 2016 waiver populations. Six of the top 10 leading causes of death in the U.S. and Georgia, and the most prevalent causes of death among people with intellectual and developmental disabilities served by DBHDD in 2016 were similar to past years' findings. Four of the leading causes of death for the 2016 intellectual and developmental disability population that were not common to the top causes of death in the U.S. and Georgia during 2014 and 2015 included disability, aspiration pneumonia, sepsis, and epilepsy/seizures.

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[1] The mortality rate used in this report is a crude mortality rate, which is an unadjusted mortality rate. The mortality rate is a measure of how many people out of every thousand served by DBHDD died within the calendar year. It is determined by multiplying the number of people who died during the year times one thousand and dividing this by the total number of people served in the NOW and COMP waiver program during the same year. The crude mortality rate can be useful when comparing deaths across populations of varying sizes. For the purposes of the remainder of this report, crude mortality rate will be referred to as "mortality rate."

[2] Standard recommended by the U.S. Centers for Disease Control and Prevention, National Vital Statistics Report, *Age Standardization of Death Rates: Implementation of the Year 2000 Standard*, Vol. 47, No. 3, 1998.

Several variables were analyzed to determine their effect on mortality in 2016. These included age, intensity of residential setting, gender, region, and health risk. Major analytical findings from 2013 through 2015 were that increasing health risk and increasing age were most strongly associated with mortality, while gender, intensity of residential setting, region, and other variables were not related to mortality. In 2016, health risk was significantly related to mortality along with increasing age once again.

Most providers had no or very few deficient practices that were identified as posing risk to individuals based on Community Mortality Review Committee (CMRC) findings. DBHDD required providers to submit corrective action plans for 138 deficient practices that were identified as either placing individuals or having the potential to place individuals at critical, high, and moderate risk. As of the date this report was written, most of the reviews identifying deficient practices were closed. The most common provider practices that required corrective action follow:

Health and Wellness Medical (40, 28.9% of all critical/high/moderate deficiencies)

- Deficient response to change in condition
- Deficient response to an emergency
- Deficient response to medical care needs

Neglect (15, 10.9% of all critical/high/moderate deficiencies)

Documentation of Care (23, 16.7% of all critical/high/moderate deficiencies)

- Deficient progress/clinical notes
- Deficient medication documentation

The overlap among the areas above account for 78 of the 138 identified deficient practices that required a corrective action plan. Though corrective action plans are intended to remediate deficient practices and mitigate further risk, the prevalence (57%) of the abovementioned common deficient practices may indicate additional areas for improvement.

Utilization of Mortality Report Findings

The observations and findings in this report will be presented to leadership of DBHDD, the department's Division of Developmental Disabilities, and the Department of Community Health (the Medicaid Authority of Georgia) for consideration in identifying issues that need additional analysis, investigation, and interpretation to improve quality of care in specific areas vital to maintaining health.

The responsibility for the use of the information within this report is that of the director of the Division of Developmental Disabilities. The director will consider these and other mortality data, publicly available national mortality data, and recommendations from the CMRC to develop and implement quality improvement initiatives, including those to reduce mortality rates for individuals with intellectual and developmental disabilities in the community. DBHDD's organizational alignment provides a platform for clarified roles and responsibilities in addressing mortality in the intellectual and developmental disability population in Georgia, including analysis, implementation of targeted action steps, and determination of the impact of selected initiatives. Both expertise and responsibility exist in other areas within the department to help the Division of Developmental Disabilities accomplish improvement strategies; the Division of Developmental Disabilities has the responsibility to use these resources. The Division of Developmental Disabilities has at its disposal department resources to accomplish improvement initiatives with the assistance of support functions provided by the divisions of Accountability and Compliance and Performance Management and Quality Improvement.

Care should be taken when comparing these findings with other mortality reviews and reports that analyzed data from different populations or used different methods. Differences in population definitions, waiver programs, and obligations of other state agencies limit the utility of comparing mortality rates or generalizing findings. DBHDD has used caution when comparing mortality rates across unlike methods and populations.

About DBHDD

The Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) provides for treatment and support services for people with mental health challenges and substance use disorders and assists individuals who live with intellectual and developmental disabilities.

Vision

Easy access to high-quality care that leads to a life of recovery and independence for the people we serve.

Mission

Leading an accountable and effective continuum of care to support Georgians with behavioral health challenges, and intellectual and developmental disabilities in a dynamic health care environment.

About DBHDD Intellectual and Developmental Disability Services

DBHDD is committed to supporting opportunities for individuals with intellectual and developmental disabilities to live in the most integrated and independent settings possible. A developmental disability is a chronic condition that develops before a person reaches age 22 and limits his or her ability to function mentally or physically. DBHDD provides services to people with intellectual and other disabilities, such as severe cerebral palsy and autism, who require services similar to those needed by people with an intellectual or developmental disability. State-supported services help families continue to care for a relative at home or independently in the community when possible. DBHDD also contracts with providers to provide home settings and care to individuals who do not live with their families or on their own. For individuals needing the highest level of care, DBHDD operates five state hospitals across Georgia.

Services are designed to encourage and build on existing social networks and natural sources of support, and to promote inclusion in the community and safety in the home environment. Contracted providers are required to have the capacity to support individuals with complex behavioral or medical needs. The services a person receives depend on a professional determination of level of need.

DBHDD serves as the operating agency for two 1915c Medicaid Waiver Programs, initially approved in 2007 when the two programs transitioned and expanded into their current form. The Medicaid waiver programs operate under the names *New Options Waiver* (NOW) and *Comprehensive Supports Waiver* (COMP). Both waiver programs provide home- and community-based services to individuals who, without these services, would require a level of care comparable to that provided in intermediate care facilities for people with intellectual and developmental disabilities, the costs of which would be reimbursed under the Medicaid State Plan. The Centers for Medicare and Medicaid Services offers the waiver option to states through application, which may be renewed every five years. As in all Medicaid programs, the services and administrative costs are funded through a federal/state match agreement. A complete description of waiver services can be found at www.dbhdd.ga.gov.

Scope of this Report

The focus of the mortality review for this report includes adults with a primary intellectual or developmental disability diagnosis who received services funded by NOW and COMP waivers during the 2016 calendar year. During 2016, data systems for individuals receiving waiver services were maintained separately from state-funded services, and data between these systems vary. This report used the NOW and COMP waiver data because it demonstrated the highest verifiable accuracy and reliability. A description of the chosen method and the analysis conducted in the report can be found in Appendix A. This report also includes data from the Community Mortality Review Committee (CMRC) process from a subset of the deaths that occurred within this population during 2016.

This report does not include data for children under the age of 18. Five deaths of children were reported to DBHDD in 2016. Deaths for children are analyzed on a case-by-case basis and not included in these statistical analyses due to potential differences between children and adults and the small sample size of children.

Several considerations are provided for reading and interpreting the findings from this report. The reader should take care when comparing this report's findings with those from mortality reviews in other states, especially when said reviews included all eligible individuals or analyzed data from different populations. Although DBHDD looked closely at other states' reports, given the differences in waiver programs, obligations of the various state agencies, and other state-specific issues, it is difficult to compare mortality rates or conclusions between states. DBHDD has also used caution when comparing mortality rates across unlike methods and populations. In writing this report, the department strongly cautions the reader to resist the inclination to draw conclusions that cannot be supported due to the limits of information available and the differences in eligibility and populations served in other studies.

Causes of Death among the Intellectual and Developmental Disability Waiver Population

The State of Georgia is a mixed coroner/medical examiner system, making the gathering of information concerning causes and manners of death more difficult than if there were a single statewide system. The state has no uniform method for death reporting (i.e., categorizing the causes of death), and information provided on death certificates varies. Due to this lack of uniformity, it is difficult to aggregate causes of death, and the reliability is somewhat questionable since many death certificates are not completed by medical professionals. Currently, the causes of death are identified by DBHDD through one of the following means: the autopsy report, if an autopsy was conducted; the death certificate issued by the Georgia Department of Public Health's Division of Vital Statistics (if available); the medical examiner or coroner's report (if available); or as reported by law enforcement, the physician, or the family.

In prior years, DBHDD classified and determined primary cause of death based upon physician review and categorization of causes of death. Beginning this year, DBHDD presents an aggregate of all underlying causes of death listed on the death certificate following the methods outlined by the Centers for Disease Control and Prevention (CDC).[3]

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[3] (2017). Retrieved from https://www.cdc.gov/nchs/data/dvs/2a_2017.pdf. Accessed June 8, 2017.

Using CDC direction to create a comprehensive look into the issues and concerns leading to death in the intellectual and developmental disability population, all underlying causes of death listed on the available death certificates were combined and weighted equally. Modes of death were excluded if present. As stated in the CDC's "Instructions for Classifying the Underlying Cause of Death, 2017" (2017, p. 2):

> *A death often results from the combined effect of two or more conditions. These conditions may be completely unrelated, arising independently of each other or they may be causally related to each other, that is, one cause may lead to another which in turn leads to a third cause, etc.*

This method helps to encompass comorbid conditions that could be missed when assigning a singular cause of death.

A summary of the causes of death as recorded in DBHDD's Reporting of Critical Incidents database follows. The leading causes of death reported on death certificates among the intellectual and developmental disability waiver population for 2016 are heart disease, disability, aspiration pneumonia, sepsis, and hypertension. Aspiration pneumonia appeared as a leading cause of death in 2015 and remains a leading cause of death in 2016.

That disability is listed as a leading cause of death is peculiar, as disability typically is not considered to be a fatal condition or cause of death. Disability, though often included as a cause of death on the death certificates, has not been captured for the purposes of this report prior to this year. It is important to note the prevalence of disability being listed as a cause of death on death certificates. This likely is an artifact of using causes of death from death certificates, complicated by the limitations of Georgia's mixed coroner/medical examiner system.

At the time of writing this report, updated U.S. and Georgia causes of death were not available. Comparing the intellectual and developmental disability population to U.S. mortality data (2014) and Georgia mortality data (aggregate 2010-2014), heart disease was the leading cause of death in the general populations of U.S. and Georgia, and heart disease was also the leading cause of death in 2016 for the intellectual and developmental disability population. Chronic lower respiratory disease was the third leading cause of death in U.S. and in Georgia. Respiratory diseases and pneumonia (including aspiration pneumonia) also were in the top leading causes of death in the intellectual and developmental disability population in 2016. Therefore, as in past years, at least half of the top 10 leading causes of death in the U.S. and Georgia and the most prevalent causes of death in the intellectual and developmental disability population in 2016 were similar.

Four of the leading causes of death in 2016 were not common to the top causes of death in the U.S. and Georgia during 2014 and 2015:

- Disability
- Aspiration pneumonia
- Sepsis
- Epilepsy/seizures

Table 1: Leading Causes of Death

	2014	**2015**	**2013**	**2014**	**2015**	**2016**
	U.S.	**Georgia**	**Intellectual and Developemental Disability Population**			
Rank	*All Ages*		*Adult Only*			
1	Heart Diseases *23.4%*	Heart Diseases *28.9%*	Respiratory Disease *18.2%*	Heart Diseases *21.9%*	Respiratory Disease *23.1%*	Heart Diseases 21.2%
2	Malignant Neoplasms *22.5%*	Malignant neoplasms *20.6%*	Heart Diseases *16.4%*	Respiratory Disease *17.4%*	Heart Diseases *15.8%*	Disability 12.4%
3	Chronic Lower Respiratory Diseases *5.6%*	Chronic Lower Respiratory Diseases 9.8%	Sepsis *12.1%*	Epilepsy/ seizures *7.1%*	Sepsis *8.5%*	Aspiration Pneumonia 11.20%
4	Unintentional Injuries *5.2%*	Alzheimer's (Nervous System Diseases) *7.4%*	Pneumonia *7.9%*	Sepsis *8.5%*	Pneumonia *8.5%*	Sepsis 11.2%
5	Cerebrovascular Diseases *5.1%*	Unintentional Injuries *6.2%*	Cancer *7.3%*	Cancer *6.5%*	Aspiration Pneumonia *8.5%*	Hypertension 8.2%
6	Alzheimer's Disease *3.6%*	Mental and Behavioral Disorders 4.3%	Gastrointestinal Disease *6.7%*	Gastrointestinal Disease *6.5%*	Epilepsy/ seizures *3.6%*	Cancer 7.6%
7	Diabetes mellitus *2.9%*	Endocrine, nutritional & metabolic diseases *4.0%*	Epilepsy/ seizures 4.2%	Pneumonia 5.8%	Complications of Cerebral Palsy *3.6%*	Pneumonia 6.5%
8	Influenza and Pneumonia *2.1%*	Digestive system disease *3.5%*	Renal *4.2%*	Renal *3.9%*	Alzheimer's Disease *3.6%*	Respiratory Disease 6.5%
9	Renal *1.8%*	Reproductive & urinary system diseases *3.1%*	Aspiration Pneumonia *3.6%*	Peripheral Vascular Disease *3.9%*	Cancer *2.4%*	Epilepsy/ seizures 6.5%
10	Suicide *1.6%*	Infectious & parasitic diseases *3.0%*	Peripheral Vascular Disease *3.6%*	Aspiration Pneumonia *2.6%*	Peripheral Vascular Disease *2.0%*	Unintentional Injuries 5.9%

NOTE: Percent is given for the overall cause of death, not subcategories within the cause of death.

The information presented above is provided for descriptive purposes only. Due to the lack of consistency in categorizing the causes of death and expertise of those completing the death certificates, readers are strongly cautioned against drawing conclusions based on this information. In order to use this information to make conclusions or recommendations regarding system or practice changes, it is necessary to conduct further exploration into available information about individual cases or groups of cases. It is important to understand and consider information, such as the underlying causes of death, the circumstances of the death, the medical care provided prior to the death, co-morbid conditions, and potentially important early detection, screening, and preventive care practices.

The following sections report statistical analyses. Statistical analyses are useful to identify associations and trends among variables that may be associated to mortality. Statistics commonly refers to "statistical significance." Sometimes associations or patterns occur due to random chance. A "statistically significant" difference for a result or relationship has a "likelihood" that it is caused by *something* other than mere random chance. It is a natural tendency to assume when there is a statistically significant difference or association that it *must* result from the *something* other than a random chance and that the difference *must* have a specific cause. It is important to exercise caution when interpreting statistical significance in this manner, as sufficient facts may not necessarily be present to conclude a specific idea of what that *something* is. It is important that statistical significance should be studied further by gathering additional information and by completing a more extensive analysis through additional steps. It also should be noted that statistical significance does not equate to *importance* or *meaningful significance*. Meaning and importance of findings can only be determined by more careful examination of additional information.

This annual mortality report does not make conclusions about any differences or statistically significant findings. As such, the statistical findings will be presented to DBHDD to be considered along with other information for further exploration to understand the causes and implications of the statistical findings. Where there are specific information, findings, observations, cases, and issues that warrant additional investigation, analysis, and consideration, work is underway to examine possible strategies to address these concerns within DBHDD.

Analysis of Intellectual and Developmental Disability Waiver Data Related to Mortality

This section presents analyses of intellectual and developmental disability waiver data related to mortality. First, the intellectual and developmental disability waiver population is described by presenting analysis of key variables that are associated with mortality. Tables and charts include data from 2014 and 2015 for comparison purposes.

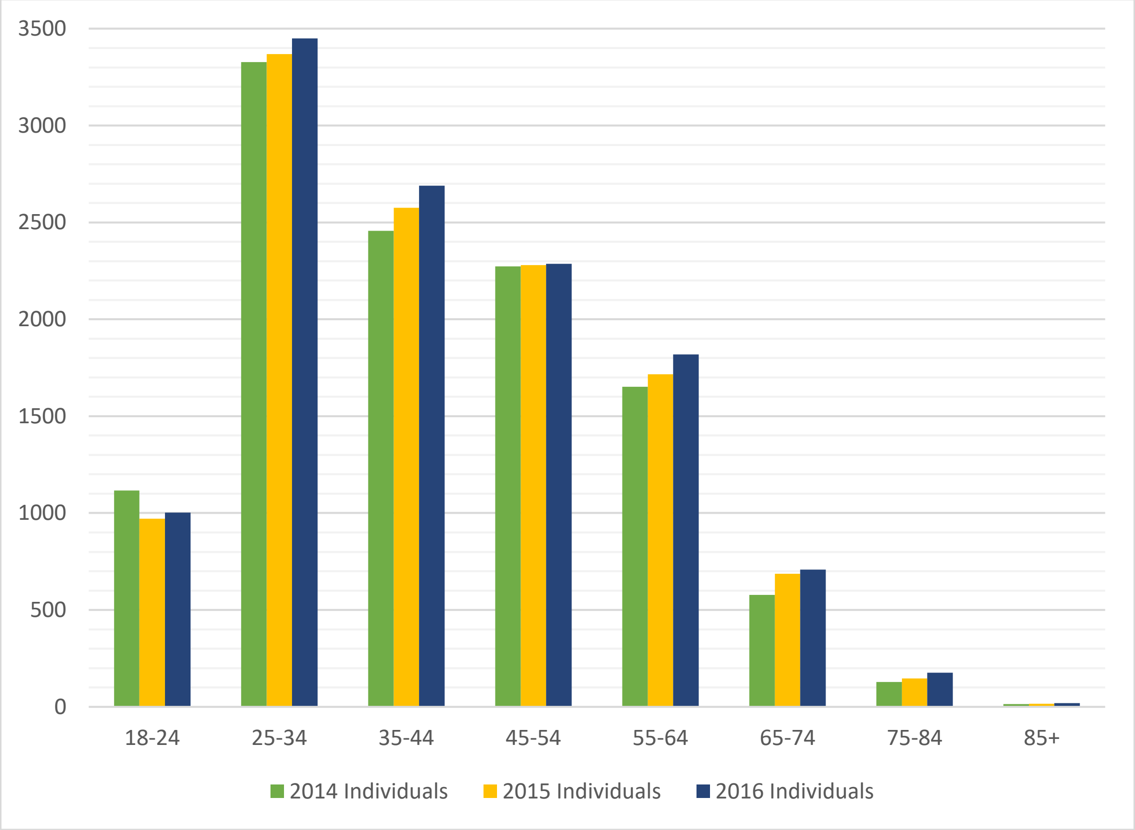
Age

Table 2 and Figure 1 present the distribution of the intellectual and developmental disability population by age groups. Age was calculated as the duration between the individual's birth date and the end of calendar year 2016; when applicable, the age was calculated as the duration between the individual's birth date and their date of death. The average age of the adult intellectual and developmental disability waiver population in 2016 was 42.3 years (SD = 14.3), which was slightly higher than (but not statistically different from) the average age of 42.2 years (SD = 14.1) in 2015 ($|t|$ = .521, df = 23901.09, p= .301). The largest age group in each year was 25-34. More than half (55.91%) of the population is between 35 and 64 years. Approximately one and a half percent of the population is 75 or older.

Table 2: Age Distribution of the Adult Intellectual and Developmental Disability Waiver Population, 2014-2016

Age	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
18-24	1,116	9.67%	971	8.26%	1,002	8.25%
25-34	3,327	28.83%	3,368	28.64%	3,450	28.39%
35-44	2,456	21.28%	2,576	21.90%	2,690	22.14%
45-54	2,273	19.69%	2,280	19.39%	2,286	18.81%
55-64	1,651	14.30%	1,716	14.59%	1,818	14.96%
65-74	577	5.00%	686	5.83%	709	5.83%
75-84	128	1.11%	147	1.25%	176	1.45%
85+	14	0.12%	16	0.14%	20	0.16%
Totals	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 1: Age Distribution of the Adult Intellectual and Developmental Disability Waiver Population, 2014-2016



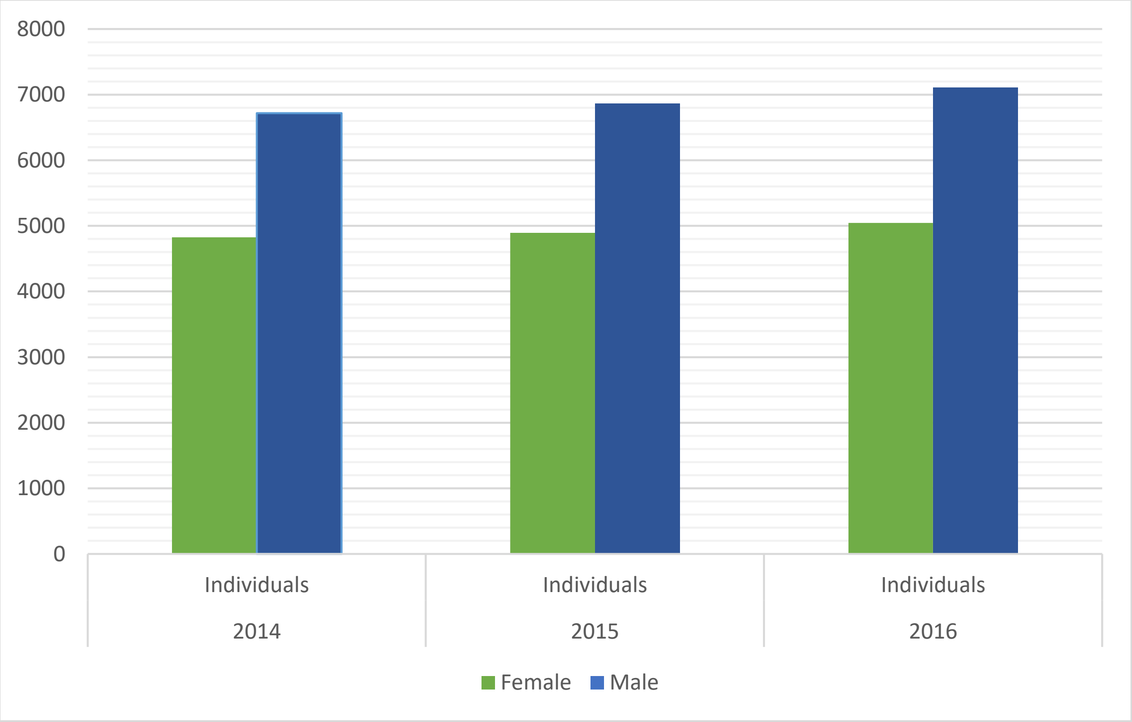
Gender

Table 3 and Figure 2 show that the distributions of gender were equal across the years 2014 to 2016. This null relationship was reinforced by statistical testing.

Table 3: Gender Distribution of the Adult Intellectual and Developmental Disability Waiver Population, 2014-2016

Gender	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Female	4,824	41.80%	4,892	41.59%	5,044	41.51%
Male	6,718	58.20%	6,868	58.41%	7,107	58.49%
Total	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 2: Gender Distribution of the Adult Intellectual and Developmental Disability Waiver Population, 2014-2016



Region

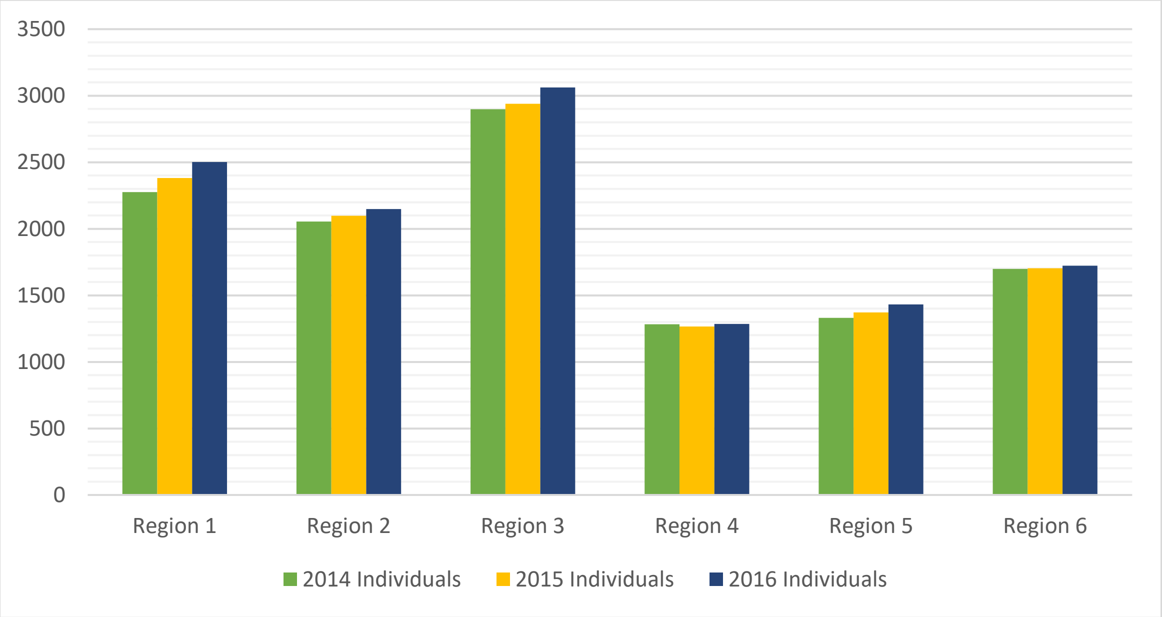
DBHDD serves individuals throughout the state in six geographic regions through a network of contracted providers. See Appendix B for a description of the regions.

Table 4 and Figure 3 show the regional distribution of waiver participants. The percent of individuals being served in each respective region remained uniform between 2014 and 2016. (No statistical differences between proportions were found.) Region 3, the most densely-populated region, had the largest population of individuals served (3,062, 25.20%); regions 4 and 5 are less-populated areas and had the smallest population of individuals served (1,285, 10.58%; 1,431, 11.78%, respectively).

Table 4: Distribution of Adults Receiving Intellectual and Developmental Disability Waiver, 2014-2016

Region	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Region 1	2,275	19.71%	2,381	20.25%	2,501	20.58%
Region 2	2,055	17.80%	2,098	17.84%	2,148	17.68%
Region 3	2,899	25.12%	2,940	25.00%	3,062	25.20%
Region 4	1,284	11.12%	1,265	10.76%	1,285	10.58%
Region 5	1,331	11.53%	1,372	11.67%	1,431	11.78%
Region 6	1,698	14.71%	1,704	14.49%	1,724	14.19%
Total	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 3: Adult Intellectual and Developmental Disability Waiver Population by Region, 2014-2016



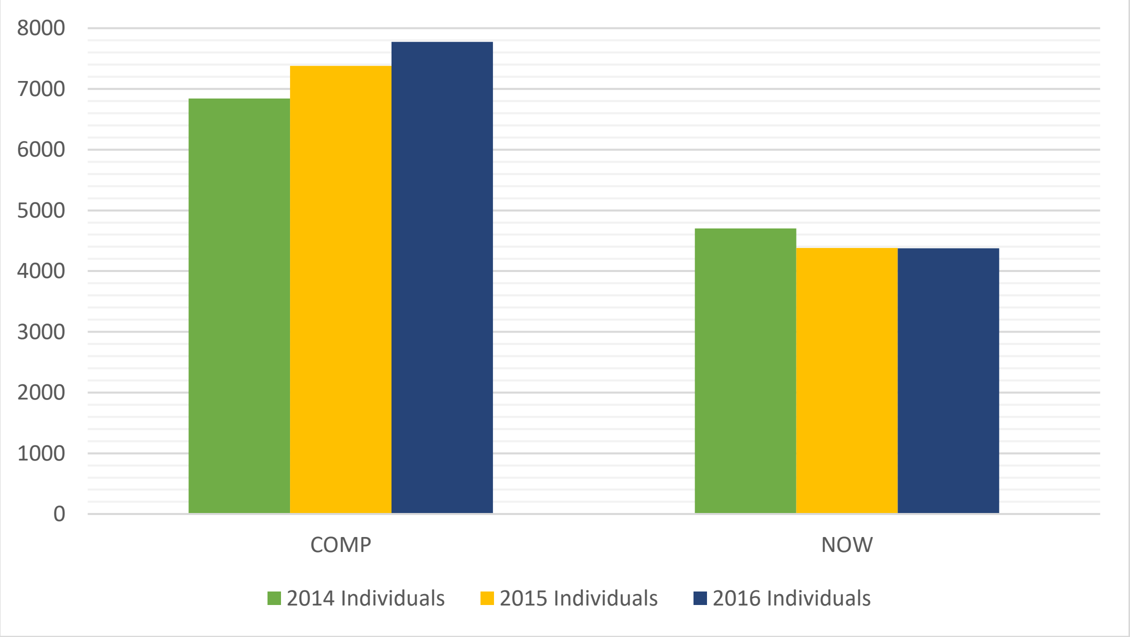
Type of Medicaid Waiver

The number (and percent) of individuals receiving COMP waivers increased by 392 (5.3%) in 2016. The number of individuals receiving NOW waivers decreased by one (0.02%). The only statistically significant difference in proportions was between calendar years 2014 and 2016 (|z| = 7.437, p < .0001).

Table 5: Distribution of Adult Intellectual and Developmental Disability Waiver Population, 2014-2016

Waiver	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
COMP	6,841	59.27%	7,381	62.76%	7,773	63.97%
NOW	4,701	40.73%	4,379	37.24%	4,378	36.03%
Total	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 4: Distribution of Adult Intellectual and Developmental Disability Waiver Population, 2014-2016



Residential Setting

Individuals who receive intellectual and developmental disability services from DBHDD live in a variety of settings. Many live independently or with family members, friends, or caretakers/caregivers. Individuals may also receive services in small group settings in any of the following arrangements:

- Host Home (life-sharing): The individual resides and receives services in an owner-occupied home, where the owner includes the individual in household routines and provides training, support, and supervision.
- Community Living Arrangement: "Community Living Arrangement" means any residence, whether operated for profit or not, that undertakes through its ownership or management to provide or arrange for the provision of daily personal services, supports, care, or treatment exclusively for two or more adults who are not related to the owner or administrator by blood or marriage and whose residential services are financially supported, in whole or in part, by funds designated through DBHDD. Provider agencies must hold a Community Living Arrangement License from the Georgia Department of Community Health's Healthcare Facilities Regulation Division.
- Personal Care Home: "Personal Care Home," "home," or "facility" means any dwelling, whether operated for profit or not, which undertakes through its ownership or management to provide or arrange for the provision of housing, food service, and one or more personal services for two or more adults who are not related to the owner or administrator by blood or marriage. Agencies providing this service must hold a Georgia Personal Care Home Permit/License from the Georgia Department of Community Health's Healthcare Facilities Regulation Division.
- Independent: The individual resides and receives services in a residence which he or she owns, leases, or rents.
- Live with Family/Relative/Other: The category combines several residential setting categories that do not live independently or in higher-intensity residential settings. Specifically, the individual lives and receives services in a residence owned, leased, or rented by a family member or relative. "Other" refers to individuals who reside with a caretaker/caregiver who is not a relative, friend, or immediate family member. This category also includes 12 individuals whose residence in the Waiver Information System (WIS) is designated as "foster care." Finally, 44 individuals' residential setting was designated in WIS as "other."

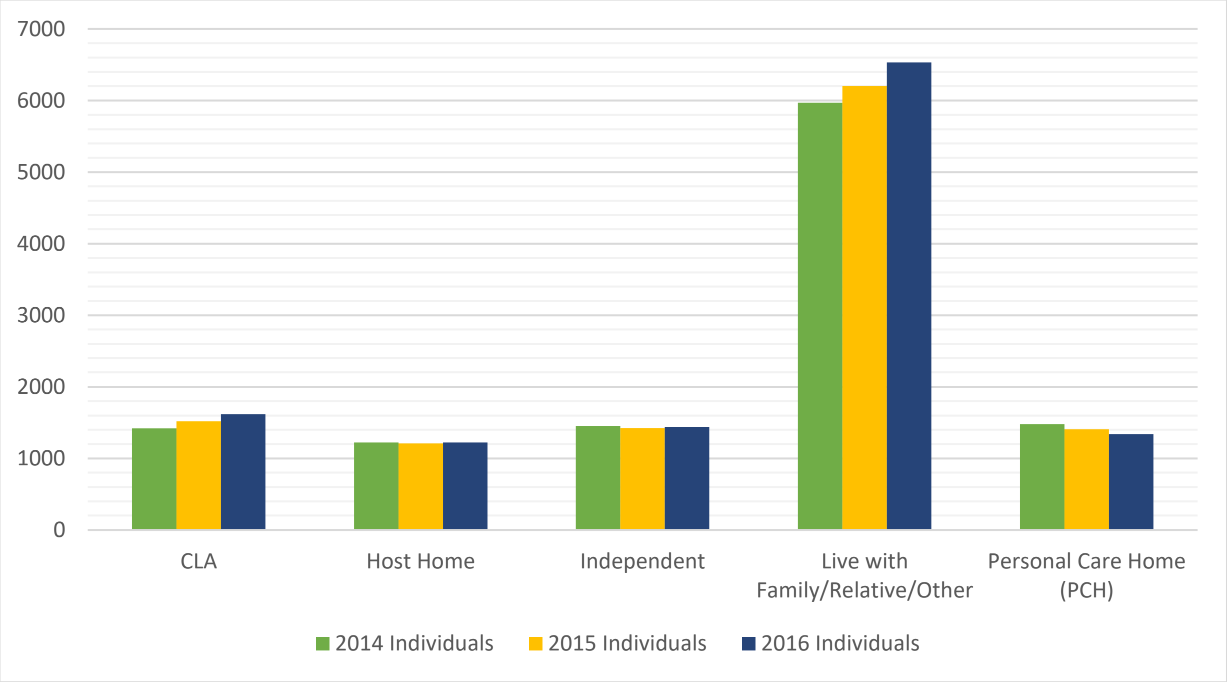
Host homes, community living arrangements, and personal care homes are residential settings that can provide more intensive services and supports. Generally, individuals with greater support needs tend to reside in host homes, community living arrangements, and personal care homes, though individuals and families may choose these settings to allow individuals the opportunity for increased independence and socialization. It is important to note that "higher intensity" and "lower intensity" are used in this report to categorize for analytical purposes. It also is important to understand that individuals living in "lower intensity" residential settings may also receive higher-intensity services, such as 24/7 nursing, for example. The level of intensity of the services are based on individual needs, not the residential setting.

The number and percent of individuals living in each type of residential setting was similar across all years besides two categories in 2014 and 2016. The percent of people who were living in personal care homes changed from 12.78% in 2014 to 11.00% in 2016; that change was statistically significant (|z| = 4.225, p < .0001). The proportion of people who were living independently changed from 12.60% in 2014 to 11.88% in 2016; that change was also statistically significant (|z| = 3.158, p < .001). Slightly fewer than 65% lived independently or with a family/relative/other in 2016, and approximately 35 percent resided in more intensive service settings (host homes, community living arrangements, and personal care homes).

Table 6: Distribution of Adults in Residential Settings in Intellectual and Developmental Disability Waivers, 2014-2016

Residential	2014		2015		2016	
	Individuals	Percent	Individuals	Percent	Individuals	Percent
Community Living Arrangement	1,420	12.30%	1,519	12.92%	1,615	13.29%
Host Home	1,223	10.60%	1,210	10.29%	1,222	10.06%
Independent	1,454	12.60%	1,425	12.12%	1,443	11.88%
Live with Family/Relative/Other	5,970	51.72%	6,200	52.72%	6,534	53.77%
Personal Care Home	1,475	12.78%	1,406	11.96%	1,337	11.00%
Total	11,542	100.00%	11,760	100.00%	12,151	100.00%

Figure 5: Distribution of Adults in Residential Settings in Intellectual and Developmental Disability Waivers, 2014-2016



Health Risk

The Health Risk Screening Tool (HRST) is a standardized mechanism used to determine an individual's vulnerability to potential health risks and the supports she or he needs to enable early identification of deteriorating health. The HRST measures health risk using a distinct rating scale related to functional status, behavior, physiological condition, and safety. HRST results are incorporated into the ongoing health care surveillance process. The HRST is completed to facilitate an individual's approval for community intellectual and developmental disability services. After its initial completion, the HRST is conducted annually and whenever an individual experiences significant health events or changes in health, functional, or behavioral status. The HRST guides providers in determining the individual's need for further assessment and evaluation, services, or modifications to his or her service plan to address identified health risks.

The HRST assigns points to rated items. The resulting numerical total is assigned a health care level (HCL) associated with degrees of health risk. Table 7 below shows the risk level designations and points associated with each of the six health care levels used as a part of the HRST.

Table 7: HRST Health Care Levels

HRST: Health Care Levels		
Level 1:	(Low Risk)	0 to 12 points
Level 2:	(Low Risk)	13 to 25 points
Level 3:	(Moderate Risk)	26 to 38 points
Level 4:	(High Moderate Risk)	39 to 53 points
Level 5:	(High Risk)	54 to 68 points
Level 6:	(Highest Risk)	69 or greater

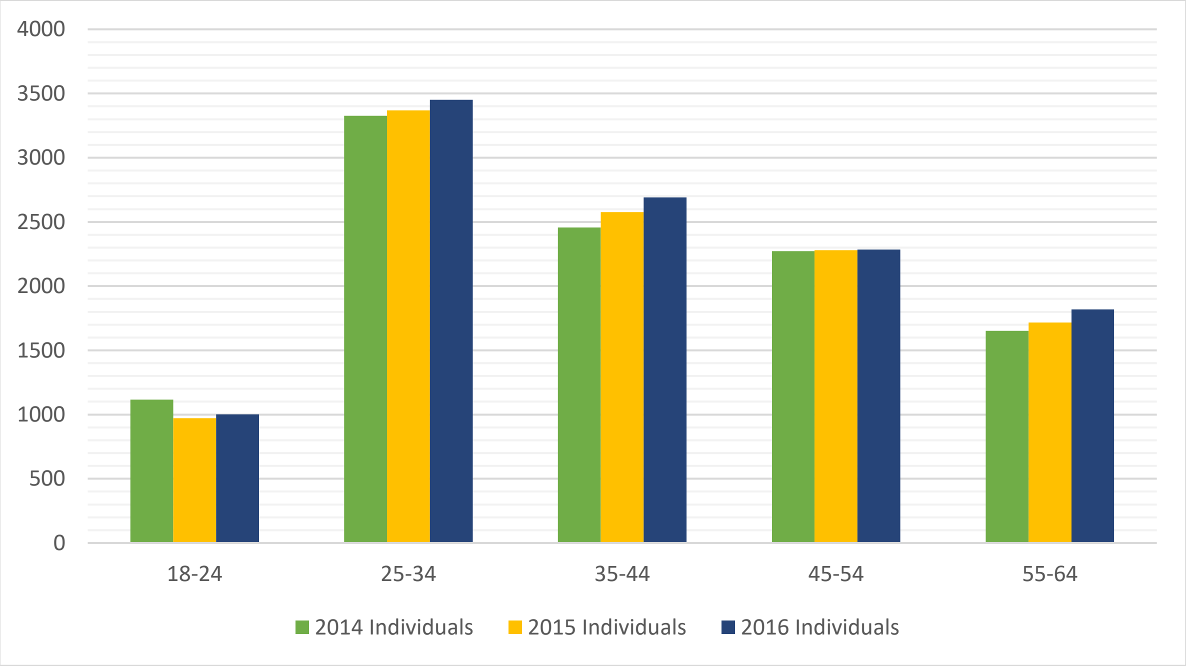
Table 8: Distribution of HRST Scores for Adults Receiving Intellectual and Developmental Disability Waivers, 2014-2016

HRST	2014		2015		2016		Significance of 2015-2016 Change
	Count	% of population	Count	% of population	Count	% of population	
1	5,053	43.8%	4,799	40.8%	4,733	38.97%	|z = 2.895|, p < .01
2	3,332	28.9%	3,500	29.8%	3,627	29.87%	NS
3	1,405	12.2%	1,497	12.7%	1,645	13.55%	NS
4	719	6.2%	802	6.8%	833	6.86%	NS
5	476	4.1%	545	4.6%	588	4.84%	NS
6	557	4.8%	617	5.2%	718	5.91%	NS
Total	11,542	100.0%	11,760	100.0%	12,144	100.00%	

The most current HRST during 2016 was used for this analysis. Seven individuals had missing values for the HRST field; so, the totals for tables involving HRST will be 12,144 instead of 12,151. Those individuals' other data were used in all non-HRST analysis. To manage the health and wellness of individuals, DBHDD considers the individual assessment data and reasons for each score in addition to the actual HRST score. For the purposes of this report, HRST scores of 1, 2, and 3 are considered to be low-risk scores; HRST scores of 4, 5, and 6 are considered to be high risk. Low-risk HRST scores accounted for 82.4 percent of the population; high-risk HRST level accounted for 17.6 percent of the population. The distribution of each HRST remained similar across all levels except for HRST = 1, in which the number of individuals decreased significantly, by 1 percent (|z| = 2.895, p < .01).

The average HRST score for 2016 was 2.26 (SD = 1.453); the average HRST score for 2015 was 2.20 (SD = 1.422); and the average HRST score for 2014 was 2.13 (SD = 1.392). The average HRST scores across these three years were statistically different from each other, 2016 to 2015 (|t| = 3.226, df = 23,902, p = .013), 2016 to 2014 (|t| = 7.025, df = 23,684, p < .001). This means that, on the whole, there is a statistically significant increase in the amount of measured health risk in this population over time.

Figure 6: Distribution of HRST Scores for Adults Receiving Intellectual and Developmental Disability Waivers, 2014-2016



Multiple Variable Analyses

The previous analysis section described the intellectual and developmental disability waiver population by looking at one variable at a time. This section looks at relationships between two or more variables and their association to mortality.

Health Risk and Residential Setting

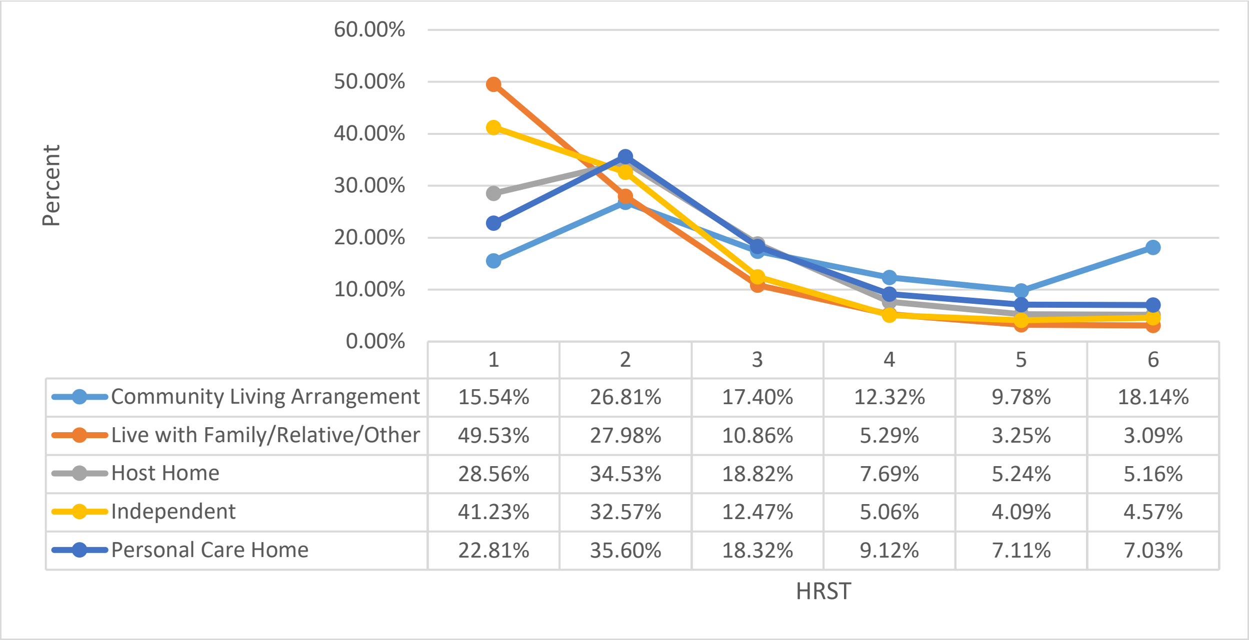
It is useful to consider the distribution of health risk scores across residential settings. Because host homes, personal care homes, and community living arrangements were categorized as the "high-intensity" residential settings, it is logical that higher HRST scores are distributed differently within those residential settings. For example, approximately 18 percent of people living in community living arrangements had a HRST score of six; in contrast, approximately three percent of people living with family, relatives, or other had a health care level of six. The percentages for other health care level groups within different living situations are presented in Figure 7. The percentages show that both low- and high-health risk individuals as categorized by health care level are present in all settings.

Categorized by type of residential setting, community living arrangements had the highest average HRST score 3.28 (SD = 1.720); personal care homes had the second highest average HRST score 2.63 (SD = 1.464), and live with family/relative/other had the lowest 1.94 (SD = 1.265). To compare the means across more than two groups, a statistical analysis using a one-way analysis of variance (ANOVA) indicated that the average HRST scores were different for the different residential settings. This result is concurrent with the information in Figure 7 which shows that a larger proportion of the high-intensity HCLs are in community living arrangements and personal care homes.

Table 9: Residential Setting by HRST Score, 2016

HRST	Residential Setting					Total
	Community Living Arrangement	Live with Family/ Relative/ Other	Host Home	Independent Apartment/ Home	Personal Care Home	
1	251	3,233	349	595	305	4,733
2	433	1,826	422	470	476	3,627
3	281	709	230	180	245	1,645
4	199	345	94	73	122	833
5	158	212	64	59	95	588
6	293	202	63	66	94	718
Total	1,615	6,527	1,222	1,443	1,337	12,151
Percentage	13.29%	53.72%	10.06%	11.88%	11.00%	100%

Figure 7: Residential Setting by HRST Score, 2016



	1	2	3	4	5	6
Community Living Arrangement	15.54%	26.81%	17.40%	12.32%	9.78%	18.14%
Live with Family/Relative/Other	49.53%	27.98%	10.86%	5.29%	3.25%	3.09%
Host Home	28.56%	34.53%	18.82%	7.69%	5.24%	5.16%
Independent	41.23%	32.57%	12.47%	5.06%	4.09%	4.57%
Personal Care Home	22.81%	35.60%	18.32%	9.12%	7.11%	7.03%

Health Risk and Age

Health risk and age are important factors that need to be considered when investigating mortality. Within this population, high-level risk is present across all age categories, as well as varying degrees of lower-health risks across all age categories. The relationship between health risk and age is not uniform. HRST scores are distributed similarly within each age group. Correlations between age (both as continuous and ordinal variables) indicate the association between HRST and age is weak (Pearson's r = .08, p < .001). Though this is statistically significant, the total variance explained in the association between age and health risk is less than one percent, which indicates that for this population, health risk and age are not necessarily meaningfully associated. Therefore, one would also expect that if health risk and age were related to mortality, these variables would have independent (not interactive) effects.

Table 10: HRST by Age Category, 2016

Age	Count by HRST						Total	Percent by HRST						Total
	1	2	3	4	5	6		1	2	3	4	5	6	
18-24	275	329	154	87	57	94	996	5.8%	9.1%	9.4%	10.4%	9.7%	13.1%	8.2%
25-34	1,552	999	383	209	139	167	3,449	32.8%	27.5%	23.3%	25.1%	23.6%	23.3%	28.4%
35-44	1,215	773	319	151	103	129	2,690	25.7%	21.3%	19.4%	18.1%	17.5%	18.0%	22.2%
45-54	896	667	342	148	111	122	2,286	18.9%	18.4%	20.8%	17.8%	18.9%	17.0%	18.8%
55-64	570	582	298	145	99	124	1,818	12.0%	16.0%	18.1%	17.4%	16.8%	17.3%	15.0%
65-74	189	219	110	73	60	58	709	4.0%	6.0%	6.7%	8.8%	10.2%	8.1%	5.8%
75-84	34	49	35	19	18	21	176	0.7%	1.4%	2.1%	2.3%	3.1%	2.9%	1.4%
85+	2	9	4	1	1	3	20	0.0%	0.2%	0.2%	0.1%	0.2%	0.4%	0.2%
Total	4,733	3,627	1,645	833	588	718	12,144	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Mortality During 2016

This section contains information on deaths reported to DBHDD among the intellectual and developmental disability waiver population during calendar year 2016. Calendar years 2014 and 2015 are included for comparison purposes. Appendix A describes the method used to collect and analyze information and data contained in this section.

The respective mortality rates for 2014 and 2015 were 11.1 and 12.5 deaths per 1,000 individuals. The 2016 mortality rate was 14.0 deaths per 1,000 individuals; the mortality rates do not differ significantly across any years.

As stated earlier: caution should be used in comparing mortality rates across populations that may differ in terms of inclusion criteria for study. States vary in the eligibility and enrollment criteria, yielding unlike populations, which may complicate meaningful comparisons of mortality rates. For example, Massachusetts[4] included all individuals who were eligible for services in the study population, regardless of whether or not they were receiving services. Ohio, Connecticut, and Louisiana include individuals with an IQ above 70 who have functional support needs; however, some of these individuals were receiving only case coordination.[5] DBHDD's report includes only those individuals who have an IQ below 70 and have the higher functional support needs required to receive more intensive services within the NOW or COMP waivers. Reports that include only individuals with a demonstrated, verified higher level of functional impairment (as does this report) may yield higher mortality rates than reports with a more expanded population that includes individuals with less severe functional or support needs. Because eligibility and enrollment criteria are not consistent across states, generalizations and comparisons may lead to insupportable conclusions.

A search for peer-reviewed research for comparison data yielded data from four states. Compared to research that used data from Connecticut, Louisiana, Ohio, and New York, the combined crude mortality rate for these states was 14.96 deaths per 1,000 individuals in 2009, which is not significantly different from the 2016 intellectual and developmental disability mortality rate for DBHDD, 14.0 deaths per 1,000. The mortality rate for these states combined in 2011 was 9.37,[5] which is significantly lower than the DBHDD 2016 mortality rate ($|z| = 4.999$, $p < .001$).

This report also compared mortality findings from other states' mortality reports that were available. Tennessee reported mortality rates of 27.4 (fiscal year 2013) and 21.1 (fiscal year 2014),[6] which were significantly higher than the 2016 DBHDD mortality rates ($|z| = 6.736$, $p < .001$; $|z| = 3.898$, $p < .001$, respectively). Massachusetts reported mortality rates of 19.2 and 17.4 deaths per 1,000 in 2012 and 2013, respectively.[4] DBHDD's 2016 mortality rates were significantly lower compared to Massachusetts' mortality rates in 2012 ($|z| = 3.465$, $p < .001$) and in 2013 ($|z| = 2.382$, $p = .009$). This difference is particularly striking in that Massachusetts included in the denominator all individuals receiving services, as well as those *eligible* for services, but included mortality information for only those individuals who

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[4] Commonwealth of Massachusetts, Executive Office of Health & Human Services, Department of Developmental Services. 2012 & 2013 Mortality Report.

[5] Lauer, E & McCallion, P. (2015). Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data. Journal of Applied Research in Developmental Disabilities, 28, 394-405.

[6] Tennessee Department of Intellectual and Developmental Disabilities, Annual Mortality Report, 2013-2014 Fiscal Year.

actually *received* services in the numerator. DBHDD also searched for additional states' mortality reports as well as peer-reviewed mortality statistical reports, to no avail.

Age and Mortality

The average age of death in 2015 was 53.69 (SD = 15.40). The average age of death in 2016 was 53.54 years (SD = 15.40). The average age of death decreased by .15 years from 2015 to 2016; however, that change was not statistically significant. This means that as a whole, individuals who died in 2016 lived about the same length of time as those who died in 2015. The average age of death reported here falls within the 2009-to-2011 range for Connecticut, Louisiana, Ohio, and New York (combined), which was 50.4 to 58.7 years.

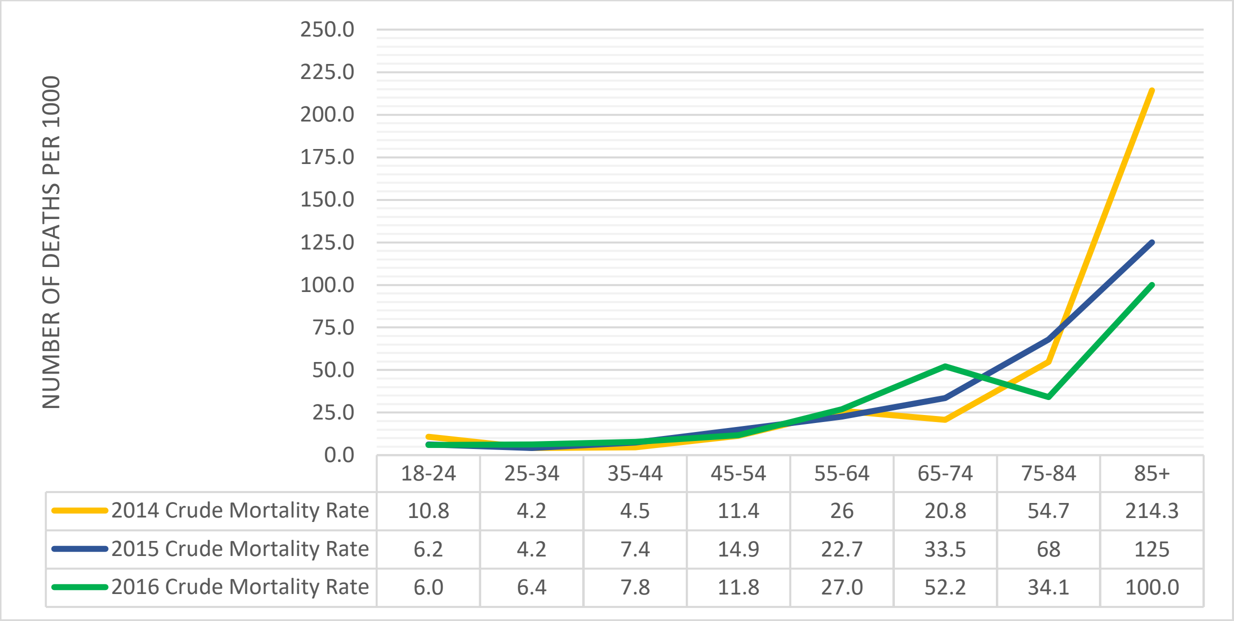
Table 11: Mortality Rates by Age Category, 2014-2016

		Age Category								Total
		18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
2014	Adult Waiver Population	1,116	3,327	2,456	2,273	1,651	577	128	14	11,542
	No. of Deaths	12	14	11	26	43	12	7	3	128
	Percent of Deaths	9.4%	10.9%	8.6%	20.3%	33.6%	9.4%	5.5%	2.3%	100.0%
	Crude Mortality Rate	10.8	4.2	4.5	11.4	26	20.8	54.7	214.3	11.1
2015	Adult Waiver Population	971	3,368	2,576	2,280	1,716	686	147	16	11,760
	No. of Deaths	6	14	19	34	39	23	10	2	147
	Percent of Deaths	4.1%	9.5%	12.9%	23.1%	26.5%	15.6%	6.8%	1.4%	100.0%
	Crude Mortality Rate	6.2	4.2	7.4	14.9	22.7	33.5	68	125	12.5
2016	Adult Waiver Population	1,002	3,450	2,690	2,286	1,818	709	176	20	12,151
	No. of Deaths	6	22	21	27	49	37	6	2	170
	Percent of Deaths	3.5%	12.9%	12.4%	15.9%	28.8%	21.8%	3.5%	1.2%	100.0%
	Crude Mortality Rate	6.0	6.4	7.8	11.8	27.0	52.2	34.1	100.0	14.0

As in 2014 and 2015, mortality rates increase with increasing age (Table 11, Figure 8). In particular, between 2014 and 2015, the mortality rate for individuals between ages 45 and 54 exceeded the overall mortality rate for the entire population. In 2016, however, the mortality rate increase above this population level occurred in the 55-64 population.

Statistical comparisons of mortality rates between corresponding age categories from 2016 to 2015 were not significantly different, with the exception of the 65-74 group. The trends in Figure 8 are visually striking due to the absolute difference among 2014, 2015, and 2016 mortality rates for the 85+ age category, which were 214.3, 125.0, and 100.0 deaths per 1,000, respectively. The differences among proportions, however, were not statistically significant due to the small numbers of individuals in the 85+ age category. It is difficult to generalize mortality rate differences for the 85+ age group due to the low number of individuals in this category, as well as the small number of deaths. Also remarkable is the increase in the mortality rate in the 65-74 group. The difference between mortality rates in these groups is statistically significant between 2014 and 2016, indicating that this group's mortality rate has increased in recent years.

Figure 8: Mortality Rate by Age Category, 2014-2016



	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+
2014 Crude Mortality Rate	10.8	4.2	4.5	11.4	26	20.8	54.7	214.3
2015 Crude Mortality Rate	6.2	4.2	7.4	14.9	22.7	33.5	68	125
2016 Crude Mortality Rate	6.0	6.4	7.8	11.8	27.0	52.2	34.1	100.0

As noted above, the mortality rate for the age group 55-64 increases above the overall mortality rate for the population. From there, the mortality rate increases with age. (This pattern did not occur for the 75-84 group in 2016, but such a fluctuation is not abnormal for such a small subgroup.)

Other research[7] found that mortality rates increase with increasing age, such that younger groups had lower mortality rates, and significant increases in mortality rates were found to begin at 45-54 and increased dramatically with increasing age. For the U.S. population, mortality rates also increase more rapidly with increasing years after about 55 years of age.[7] The 2015 Georgia mortality rate for the 55-64-year-old category is 11.6 deaths per 1,000, and it increases with increasing age after 55.[8]

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[7] National Vital Statistics Report, Vol. 64 No. 2, February 16, 2016, p. 7. http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf, accessed June 8, 2017.

[8] https://oasis.state.ga.us/oasis/webquery/qryMortality.aspx, accessed June 8, 2017.

These data combined indicate that age-specific mortality rates are similar for intellectual and developmental disability populations across states. The pattern of significantly increasing mortality rates with increasing ages after 55 is similar for the U.S., Georgia, and the DBHDD intellectual and developmental disability population, though the intellectual and developmental disability mortality rate is higher than those of the U.S. and Georgia.

Gender and Mortality

Gender was not an explanatory variable in mortality in 2014-2016. The 2016 mortality rate for females was 15.3 and 13.1 for males; the difference between the two was not statistically different. The average age of death for females was 56.4 and 51.2 for males.

Table 12: Number of Deaths, Average Age at Death and Mortality Rate by Gender 2014-2016

		Female	Male	Total
2014	Adult Waiver Population	4,824	6,718	11,542
	No. of Deaths	59	69	128
	Percent of Deaths	46.1%	53.9%	100.0%
	Average Age at Death	51.9	51.4	
	Crude Mortality Rate	12.2	10.3	11.1
2015	Adult Waiver Population	4,892	6,868	11,760
	No. of Deaths	63	84	147
	Percent of Deaths	42.9%	57.1%	100.0%
	Average Age at Death	55.4	52.4	
	Crude Mortality Rate	12.9	12.2	12.5
2016	Adult Waiver Population	5,044	7,107	12,151
	No. of Deaths	77	93	170
	Percent of Deaths	45.3%	54.7%	100.0%
	Average Age at Death	56.4	51.2	
	Crude Mortality Rate	15.27	13.09	14.0

Age, Residential Setting, and Mortality

The average age of death was 53.5 (SD = 15.40) in 2016. The average age of death for residential settings ranged between 44.0 and 59.0 years. The average age of death for individuals who lived in less-intensive residential settings was 46.4 (SD = 15.56). The average age of death for individuals who lived in more-intensive settings was 57.83 (SD = 16.67). The difference between the average age of death for these two groups is statistically different ($|t| = 4.863$, df = 119.79, $p < .001$). This means that individuals who died in 2016 who resided in more-intensive residential service settings lived longer than those who received services in less-intensive service settings.

It should be noted, however, that individuals living with family, friends, or others had the second lowest mortality rate (8.3 deaths per 1,000); combined, the lower-intensity residential setting group had a mortality rate of 8.02, which is significantly lower than the rate for the total population 14.0 deaths per 1,000 ($|z| = 3.863$, $p < .001$). The lowered average age at death in the living with family friends or others group makes it seem like those living at home may have a higher risk of death than others. That is not the case: the population of people living at home is much younger on average than those in other settings; so, the average age of death is naturally lower regardless of the mortality rate. This result and further analysis are presented in Appendix C.

Residential-setting-specific mortality rates range from 6.9 to 36.5. The mortality rate for the three higher-intensity residential settings combined is 25.4. In 2015, the mortality rate for these three high-intensity residential setting combined was 20.6. The mortality rate for the two lower-intensity residential settings combined was 8.0 in 2016 and 8.1 in 2015. The mortality rates for 2015 and 2016 do not differ significantly between similar categories of residential settings. The mortality rate for the high-intensity service setting, however, is significantly higher than the lower-intensity service setting mortality rate in 2016 ($|z| = 7.743$, $p < .0001$).

Table 13: Average Age at Death and Mortality Rate by Residential Setting, 2016

Residential Setting	Adult Population	Percent	% of Population 65+	No. Deaths	Average Age at Death	Crude Mortality Rate
Personal Care Home (PCH)	1,337	11.0%	14.73%	31	58.2	23.2
Community Living Arrangement (CLA)	1,615	13.3%	11.64%	59	57.6	36.5
Host Home	1,222	10.1%	10.88%	16	58.2	13.1
Independent Apartment/ Home	1,443	11.9%	12.54%	10	59.0	6.9
Live with Family/ Relative/Other	6,534	53.8%	3.15%	54	44.0	8.3
Total	12,151	100.0%	7.45%	170	53.5	14.0

Health Risk and Mortality

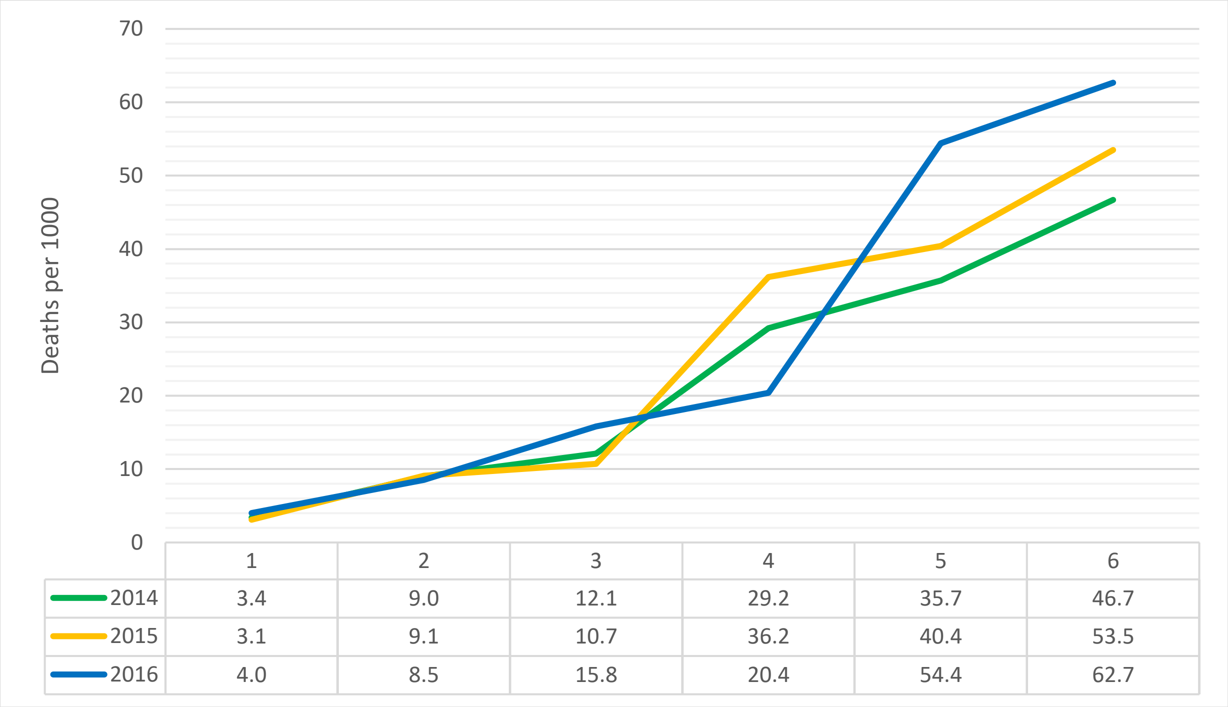
Similar to previous years, there is statistical association between health risk score and mortality rate in 2016. Lower HRST scores (1-3) have a group mortality rate (7.6 deaths per 1,000) that is below the population mortality rate in 2016 (14.0 deaths per 1,000). The mortality rates associated with an HRST score of (4-6) exceed the overall population mortality rate by a large margin (29.9 deaths per 1,000).

The mortality rate for lower HRST scores (1-3) is 7.6; the mortality rate for the higher HRST scores (4-6) is 43.95, which is significantly higher ($|z| = 12.958$, $p < 0.001$). The disparity between consecutive levels four and five was the largest (20.4 and 54.42 deaths per 1,000 individuals, respectively) ($|z| = 3.461$, $p < 0.001$). It should be noted that despite the visual separation of mortality rates between health care levels five and six (Figure 9), these two mortality rates are not statistically different. These analyses clearly indicate that increasing health risk was significantly associated with mortality, which is especially true for health care levels five and six. In other words, particular attention should be given to health care levels five and six due to their significant association with mortality.

Results from previous years have consistently indicated that a two-point increase in health care level scores is associated with a significant association with mortality. Analysis of 2016 data indicate that this pattern holds still, though there is a significant increase in the mortality rate between health care levels one and two. Therefore, consistent with previous years, it is important to consider a one-point change in health risk scores to address the increased association between increasing health risk and mortality that occurs with a two-point health risk score increase. Furthermore, particular attention should be given to health care level four (in addition to health care levels five and six). First, health care level four is the health risk level that moves above the overall population mortality rate. Secondly, an increase of one health care level score above four would move individuals into a level of risk more significantly associated with mortality (i.e., health care level five/six).

DBHDD has begun further analyses to identify additional information that may provide further understanding of the relationship among health status, health risk, and mortality. For example, mortality analyses of 2013-2016 data have used the health care level of the HRST to understand the relationship between health risk and mortality; the health care level is a summary score. The HRST also provides subscale- and item-level information that may indicate particular health conditions or risks that may be related to mortality, even when the overall summary score provided by the health care level does not. DBHDD is undertaking careful analyses of these subscales and items in the context of mortality outcomes, along with analysis of additional information, to attempt to identify additional findings that may be useful to reduce the risk of unnecessary deaths. These analyses, observations, and findings will be presented to the Division of Developmental Disabilities and DBHDD when they become available.

Figure 9: Mortality Rate by HRST Score, 2014-2016



	1	2	3	4	5	6
2014	3.4	9.0	12.1	29.2	35.7	46.7
2015	3.1	9.1	10.7	36.2	40.4	53.5
2016	4.0	8.5	15.8	20.4	54.4	62.7

Table 14: Mortality Rate by HRST Score, 2016

HRST Score	2016				
	Adult Waiver Population	No. Deaths	Percent of deaths	Crude Mortality Rate	Statistical significance between HRST Scores
1	4,733	19	11.2%	4.0	(|z| = 2.664, p = 0.003)
2	3,627	31	18.2%	8.5	(|z| = 2.361, p = 0.009)
3	1,645	26	15.3%	15.8	NS
4	833	17	10.0%	20.4	(|z| = 3.461, p < 0.001)
5	588	32	18.8%	54.4	NS
6	718	45	26.5%	62.7	
Grand Total	**12,144**	**170**	100.00%	14.0	

The Importance of Age and Intensity of Residential Setting

Data analyses to this point have examined the relationship of age, gender, region, residential setting, and health risk as they individually, or in pairs, relate to mortality. Examining the contribution of one variable or a small set of variables at a time to mortality rates is useful. However, it also is important to consider all variables of interest at once to determine the individual effect of each variable on the occurrence of death, while controlling for the influence of other variables. Subsequent discussion in this report considers how age, gender, region, residential setting, and health risk together are associated with mortality to determine which variables may be of key importance in understanding it.

Several advantages of using logistic regression exist. First, logistic regression allows one to determine the association of a variable without the influence of other variables. That means, logistic regression analysis about, for example, age, pertains only to the effects of age and mortality without the effect of other variables. In this way, each variable is risk-adjusted so that the effects of other variables do not affect it.

Another advantage is that logistic regression can be used to determine the importance of each variable in that the information from the model can be used to calculate the odds ratio that an event occurred given the effect of one or more variables. An odds ratio is a measure of association between a variable and an outcome occurring, such as death in these analyses. The odds ratio represents the odds of death occurring given a particular event or condition compared to the odds of death occurring in the absence of that variable. An odds ratio of 1 indicates that the variable of interest does not affect the odds of death occurring; odds ratios greater than 1 indicate that the variable is associated with higher odds of death occurring; odds ratios less than 1 indicate that the variable is associated with lower odds of death occurring.

Age, gender, region, intensity of residential intensity setting, and HRST score were used together to analyze which variables were associated with death in 2016. Only age and health risk scores were significantly associated with occurrence of death. This means that when controlling for age and health risk level, region, gender, and residential setting were not significantly associated with the occurrence of death. It should be noted that the logistic regression analysis for 2013-2016 are very similar.

Table 15: Final Logistical Regression Model with Death as Outcome, 2016

Variable	B	S.E.	Wald	df	Sig.	Exp(B)
Age	.044	.005	8.560	1	.000	1.045
HCL	.527	.044	11.970	1	.000	1.695

The odds of dying increase significantly with increasing age. According to the logistic regression model estimates of association, at 20 years old, the odds of dying are small (i.e., .0008797). However, with each 10-year increase in age, the odds of dying increase multiplicatively, such that the odds of dying at 40 almost triples compared to age 20; the odds of dying at 50 are more than four times greater than at 20. Finally, by age 70, the odds of dying are almost 10 times higher than they are at 20. The main point made here is that increasing age has a very strong, exponential relationship to the likelihood that death may occur. (The referent age for Table 17 is 18. Each odds ratio represents the increase in odds from that age.)

The odds of dying increase significantly with increasing health care level scores. Those with an HRST score of 3 had an estimated five times higher increase in odds of having died in 2016. Those with HRST scores of six had 23.62 times increased odds of having died in 2016. This relationship indicates that the odds of death increases exponentially with increasing HRST scores in 2016.

It is worth noting that death is a relatively rare outcome; so, even a large increase in odds (such as with the upper values of HRST and age), does not mean that someone with these attributes is in great danger of death; it only means that people in those groups were more *likely* than others to experience the death. It is also worth noting that statistical association does not indicate causation. (Refer back to the discussion about statistical analysis on page 11.)

Table 16: Odds Ratio for 10 Year Age Difference, 2013-2016

HCL	OR 2013	OR 2014	OR 2015	OR 2016
1	1.65	1.61	1.66	1.69
2	2.72	2.60	2.77	2.87
3	4.48	4.20	4.60	4.86
4	7.39	6.77	7.66	8.23
5	12.18	10.91	12.74	13.94
6	20.09	17.60	21.20	23.62

Table 17: Odds Ratio for 10 Year Age Difference, 2013-2016

Age	OR 2013	OR 2014	OR 2015	OR 2016
20	1.07	1.08	1.08	1.09
30	1.52	1.61	1.71	1.69
40	2.16	2.41	2.41	2.63
50	3.06	3.60	4.22	4.08
60	4.35	5.37	6.62	6.34
70	6.17	8.00	10.38	9.86

The sections above presented findings and observations based on a statistical analysis of all adults with a primary intellectual or developmental disability diagnosis who received services funded by NOW and COMP waivers during the 2016 calendar year. Statistical analyses are useful for identifying factors or variables and trends that are associated with mortality, which provides information for improvement of service quality. It is also helpful to consider other, more detailed mortality data from mortality reviews that were conducted in 2016, which is presented next.

Community Mortality Review Committee and Deficient Practice Analysis

DBHDD's Community Mortality Review Committee (CMRC) uses a standard process to conduct reviews of deaths of individuals receiving services by or through DBHDD community providers. The purpose of the mortality review is to identify opportunities to reduce morbidity or mortality and evaluate and provide information that may improve the quality of services. The overall goals of the mortality review are to provide insight into the way the DBHDD system works; share lessons and learn from an individual's death; discover if the same or similar situations may affect others served; assist in prevention or mitigation of future harm; and improve overall quality of care. The CMRC policy was effective November 1, 2015.

Categories of Deaths

The department's incident management policy, Reporting and Investigating Deaths and Critical Incidents in Community Services, 04-106, is an integral part of the CMRC process. This policy requires providers to self-report deaths (and other critical incidents). It identifies categories of deaths and incidents based on risk and establishes reporting timeframes and investigation requirements accordingly. Not all deaths require an investigation or a review by the CMRC.

The CMRC reviews deaths of individuals served by the DBHDD who meet the following criteria:

- Receive residential services or 24/7 community living support;
- Die on the site of a community provider or in the company of staff of a community provider; or
- Are absent without leave from residential services.

Further, the deaths identified above may be unexpected—not attributed to the natural course of a diagnosis or a diagnosed disease where the reasonably expected outcome is death (Category 1)—or expected—attributed to a terminal diagnosis or a diagnosed disease where the reasonably expected outcome is death (Category 2). The CMRC reviews all Category 1 deaths and Category 2 deaths identified for review by the DBHDD medical director or director of Office of Incident Management and Investigations.

Purpose of CMRC

The CMRC reviews factual information to determine ways to improve the quality of services. The goals of the CMRC include the following:

- To conduct mortality reviews using a clinical and systematic interdisciplinary review of deaths;
- To evaluate the quality and efficiency of services and supports to the individual;
- To evaluate compliance of the provider with applicable laws, rules, regulations, and standards;
- To identify possible gaps in services;
- To make referrals to other governmental entities of identified individual and system issues;
- To monitor support systems and programmatic operations to ensure reasonable medical; educational, legal, social, or psychological interventions were being provided prior to deaths;
- To ensure that risk factors for mortality are identified and prevention strategies implemented; and
- To recommend statewide action based on mortality information to improve care systematically.

Membership

The CMRC represents a multidisciplinary, inter-professional team consisting of physicians, including the DBHDD medical director, nurses and other health care professionals, quality improvement staff, legal staff, program staff, investigative staff, representatives from advocacy organizations, and representatives from the provider community. The variety of professionals with differing experiences and responsibilities brings different knowledge and perspectives to the mortality review process and serves to improve the quality of the mortality review findings.

Process

The CMRC is a significant source of information and a major component of DBHDD's quality improvement system, and reflects the department's ongoing commitment to reviewing and learning from critical information gathered during investigations of deaths of individuals served by the department. DBHDD is committed to a systematic, thoughtful, and detailed review of deaths and the opportunity such a review presents for organizational learning and corrections at the provider, department, and system levels.

The CMRC meets at least monthly to review all internal and external investigative reports and mortality reviews. The CMRC seeks to determine whether necessary and reasonable measures were taken to provide for the health, safety, and welfare of the individual receiving services; what statewide actions may reduce risks, including provider training, communication with providers relative to risks, alerts, and opportunities for learning and training; identify and mitigate any findings that could affect the health, safety, and welfare of other individuals; and make recommendations to providers and DBHDD. These recommendations are evaluated to identify deficient practices. When deficient practices are identified, they are managed by DBHDD through a corrective action plan tracking system.

Corrective Action Plans

A corrective action plan is a plan developed by the reviewed entity as a response to deficient practices/problems identified in a written report. The following elements are present in an acceptable corrective action plan:

> **Identified Cause**: The cited entity's determined cause of the deficient practice and the method that the entity used to determine the cause;
>
> **Corrective Action**: A plan that contains the steps or actions that have been or will be taken to correct the deficient practice and address the identified cause;
>
> **Target Date**: An anticipated date for the accomplishment of the corrective action; and
>
> **Measures of Effectiveness/Monitoring**: A description of how the entity will monitor the corrections to ensure that the corrective actions have successfully resolved the issues.

Deficiency Tracking

Deficiencies are tracked in DBHDD's Corrective Action Tracking System (CATS). This database maintains information about deficient practices, entities cited, categorization of the deficiencies (e.g., critical, high, moderate, or low risk), and any corrective actions implemented for those deficiencies. CMRC reviews may reveal no deficient practices, and CMRC reviews may reveal multiple deficient practices for each death, resulting in tracking multiple deficiencies and corrective actions. More information about the deficiency determinations and tracking processes can be found in DBHDD policy Internal and External Reviews and Corrective Action Plans, 13-101.

The analysis of deficient practices and deficiency tracking presented below is based on data from CATS. These 2016 CMRC and CATS data and analysis are presented as baseline performance. Not all deaths are reviewed by the CMRC, and DBHDD has requested an external agency review 11 cases that were not completed at the time of this report were written and, therefore, not included in these analyses.

The CMRC purposively selects deaths for review based on policy. Deaths reviewed are not selected to be a representative sample of deaths for the DBHDD intellectual and developmental disability population each year.

Due to small sample sizes, not having all data from some external reviews, not having a representative sample of all intellectual and developmental disability deaths reviewed by CMRC, and having only one year of data, statistical analysis is not advisable at this time. Finally, the reader is cautioned from generalizing findings and observations from the CMRC analysis below to the DBHDD intellectual and developmental disability population.

Statewide Analysis of Number and Type of Deficient Practices

DBHDD distinguishes between “deficient practices” and “recommendations.” At a minimum, DBHDD requires providers to correct deficient practices that have the potential for causing minimal harm, which include critical-, high-, and moderate-risk practices. A corrective action plan is required for critical-, high-, and moderate-risk practices. DBHDD required providers to submit corrective action plans for 138 deficient practices that were identified as either placing the individual or having the potential to place individuals at critical-, high-, and moderate-risk levels.

Seventy-nine practices were deemed to have low risk. (Providers were requested to correct these.) Recommendations made as the result of a CMRC review are sent to the provider. DBHDD requests providers respond or comment to recommendations identified as the result of CMRC reviews.

Critical Risk: Statewide

Provider practices identified in 2016 with the potential for causing or having caused serious injury, harm, impairment or death to individuals were related to health and safety. The most common critical-risk provider practices centered on health and wellness/medical, including failure to respond to an apparent change in individuals’ health condition and failure to respond to an emergency in a manner that would protect the welfare of the individual. In 10 instances, provider practices were classified as neglectful, which also was a commonly-identified critical-risk practice. (DBHDD refers instances of abuse, neglect, and exploitation to external investigative agencies, as appropriate.) As mentioned earlier, DBHDD requires providers to submit a corrective action plan to address critical-risk provider practices. At the time this report was written, most issues were resolved/closed.

Table 18: Critical-Risk Count: Statewide

CRITICAL RISK	**29**
Health & Safety	**29**
Abuse/Neglect/Exploitation	10
Neglect	10
Coordination of Care	1
Communication/Collaboration	1
Health and Wellness/Medical	13
Response to change in condition	6
Response to emergency	7
Medication Management	3
Medication errors	2
Storage, dispensing, administration	1
Physical Environment and Life Safety/Emergency Planning	1
Emergency and disaster planning	1
Staff Issues	1
Scheduling/availability of staff	1

High Risk: Statewide

Deficiencies at the high-risk level have resulted in a negative outcome to an individual. A closer examination of the high-risk provider practices that may cause harm to individuals shows similarities with the critical-risk practices: health and safety is the most common high-risk practice area. Again, health and wellness/medical had the most areas of concern, specifically, providers failing to respond to changes in individuals' condition, attending to medical care needs, and failure to respond appropriately to emergencies. Four instances of neglectful provider practices were identified as high risk. (DBHDD refers instances of abuse, neglect, and exploitation to external investigative agencies, as appropriate.)

Table 19: High-Risk Count: Statewide

HIGH RISK	25
Compliance	4
Abuse/Neglect/Exploitation	1
Neglect	1
Health and Wellness/Medical	1
Physical care, wellness, preventative	1
Leadership/Governing Body	1
Supervision and Oversight	1
Planning and Program Integrity	1
Scope of Practice	1
Health & Safety	21
Abuse/Neglect/Exploitation	3
Neglect	3
Coordination of Care	2
Communication/collaboration	2
Health and Wellness/Medical	9
Medical care needs	3
Response to change in condition	4
Response to emergency	2
Leadership/Governing Body	1
Oversight of Service Provision	1
Medication Management	1
Monitoring	1
Provision of Care and Treatment	4
Assessment/treatment planning	1
Special Needs Issues	2
Adherence to treatment plan	1
Training	1
Training for Individualized Care	1

Moderate Risk: Statewide

Deficiencies at the moderate-risk level have the potential to result in no more than minimal physical, mental, or psychosocial discomfort. The most common moderate-risk provider practice area was related to provider practices concerning the health and safety of individuals. Health and safety-deficient practices including failure to attend appropriately to medical care needs, failure to respond to changes in condition, and failure to respond to emergencies. Overall, however, the single most common deficient practice was failure to document care adequately.

Table 20: Moderate-Risk Count: Statewide

MODERATE RISK	**84**
Compliance	**19**
Documentation of Care	1
Progress/Clinical note	1
Financial	1
Billing integrity, justification	1
Leadership/Governing Body	3
Oversight of Service Provision	1
Policy, procedure, protocol development	2
Planning and Program Integrity	4
Adherence to service guidelines/requirements	2
Information Management	1
Screening, referral, eligibility processes	1
Provision of Care and Treatment	1
Individual Engagement	1
Risk Management/Quality Improvement	7
Failure to report incidents	5
Failure to conduct investigation	1
Quality Improvement Process and Systems Issues	1
Staff Issues	2
Staff Credentialing, qualifications, competence	2
Health & Safety	**62**
Abuse/Neglect/Exploitation	1
Neglect	1
Coordination of Care	3
Communication/collaboration	3
Documentation of Care	21
Medication documentation	6
Miscellaneous	1
Progress/Clinical notes	12
Tracking sheets	2
Health and Wellness/Medical	17
Medical care needs	7
Response to change in condition	6
Response to emergency	4
Infection Control	1
Universal Precautions	1
Leadership/Governing Body	2
Oversight of Service Provision	1
Policy, procedure, protocol development	1

Medication Management	3
Medication Errors	2
Storage, dispensing, administration	1
Provision of Care and Treatment	10
Adherence to treatment plan	3
Assessment/treatment planning	3
Individual Engagement	1
Miscellaneous	1
Special Needs Issues	1
Unauthorized Service Provision	1
Risk Management/Quality Improvement	1
Failure to report incidents	1
Training	3
Policy & Procedure training	1
Required Training/Licensure/Certification	1
Training for Individualized Care	1
Operational	**3**
Documentation of Care	1
Progress/Clinical notes	1
Provision of Care and Treatment	2
Billing Integrity, justification	2

Regional Analysis of Number and Type of Deficient Practices

Region 2 had the largest number of identified critical deficient practices and accounted for 24.1 percent of critical-risk provider practices identified. Region 5 had 20.7 percent of the critical deficient provider practices identified. Regions 2 and 3 had the highest number of deficient practices that were identified as having high risk to individuals (8, 32.0%; 7, 28%, respectively). Regions 4 and 2 had the most deficient practices that were identified as posing moderate risk to individuals (30, 35.7%; 21, 25%, respectively).

When one considers the 138 total number of critical-, high-, and moderate-risk practices that were identified during the CMRC (recalling that these levels of deficient practices require corrective actions to be submitted to DBHDD), Regions 2 and 4 have the highest number of these levels of deficient practices (each having 36, 26.1%), which account for 52.2 percent of all critical-, high-, and moderate-level risk practices identified. Region 3 had 30 critical-, high-, and moderate-level deficiencies combined, which accounted for 21.7 percent of all deficiencies of these levels. It should be noted, however, that Region 3 has the highest number of individuals being served, as well as the highest number of CMRC reviews where no deficiencies were identified. In comparison, then, Regions 2 and 4 are consistently identified as standing out from other regions in terms of having deficient practices that place individuals at critical-, high-, and moderate-risk levels of potential harm. It should be noted that Region 2 served 863 more individuals than Region 4, indicating that Region 4 stands out most as having deficient provider practices identified as part of mortality reviews.

Table 21: Regional Analysis of Number and Type of Deficient Practices

Region	Count					
	Population	**Critical** Deficiencies	**High** Deficiencies	**Moderate** Deficiencies	**Low** Deficiencies	No Deficiencies Found
1	2,501	3	3	8	13	9
2	2,148	7	8	21	16	10
3	3,062	4	7	19	18	9
4	1,285	4	2	30	24	8
5	1,431	6	4	2	1	3
6	1,724	5	1	4	7	3
Total	12,151	29	25	84	79	42

Region	Percent				
	Critical Deficiencies	**High** Deficiencies	**Moderate** Deficiencies	**Low** Deficiencies	No Deficiencies Found
1	10.3%	12.0%	9.5%	16.5%	21.4%
2	24.1%	32.0%	25.0%	20.3%	23.8%
3	13.8%	28.0%	22.6%	22.8%	21.4%
4	13.8%	8.0%	35.7%	30.4%	19.0%
5	20.7%	16.0%	2.4%	1.3%	7.1%
6	17.2%	4.0%	4.8%	8.9%	7.1%

The main points concerning deficient practices identified in the course of CMRC reviews, when considering the 138 combined critical-, high-, and moderate-risk practices conjointly (that require a corrective action plan), one notices substantial overlap in three areas:

Health and Wellness Medical (40, 28.9% of all critical/high/moderate deficiencies)

- Deficient response to change in condition
- Deficient response to an emergency
- Deficient response to medical care needs

Neglect (15, 10.9% of all critical/high/moderate deficiencies)

Documentation of Care (23, 16.7% of all critical/high/moderate deficiencies)

- Deficient progress/clinical notes
- Deficient medication documentation

The overlap among the areas above account for 78 of the 138 identified deficient practices that require a corrective action plan. Though corrective action plans are intended to remediate deficient provider practices and mitigate further risk, the prevalence (57%) of the abovementioned common deficient practices may indicate additional areas for improvement.

Key Findings

- The 2016 DBHDD NOW and COMP waiver mortality rate was 14.0 deaths per 1,000 individuals. The 2016 mortality rate did not differ significantly from the DBHDD NOW and COMP waiver mortality rates in 2014 and 2015.
- The 2016 DBHDD NOW and COMP waiver mortality rate of 14.0 in all except one comparison with other states' mortality rates was significantly lower; however, caution should be used in interpreting or generalizing these differences.
- Increasing age (as in previous years) is significantly associated with the occurrence of mortality.
- Increasing health risk was associated with mortality in 2013-2016.
- In 2013-2015, mortality increased markedly after the age group of 45-54. This year, mortality increases markedly after ages 55-64—a pattern also found in the general U.S. and Georgia populations.
- Life expectancy for the 2016 NOW and COMP waiver population (53.5 years) is comparable to the average age of death for intellectual and developmental disability populations as reported in other state mortality reports and in published, peer-reviewed research (50.4 to 58.7 years).
- Heart disease was the leading cause of death in the general populations of U.S. (2014), Georgia (2015), DBHDD 2016 NOW and COMP waiver population. As in past years, at least half of the top 10 leading causes of causes of death in the U.S. and Georgia and the most prevalent causes of death in the NOW and COMP waiver population in 2016 were similar.
- Four of the leading causes of death for the 2016 NOW and COMP waiver population were not common to the top causes of death in the U.S. and Georgia during 2014 and 2015 included disability, aspiration pneumonia, sepsis, and epilepsy/seizures.
- DBHDD required providers to submit corrective action plans for 138 deficient practices that were identified as either placing the individual or having the potential to place individuals at risk. As of the date this report was written, most of the reviews identifying deficient practices were closed.
- The most common deficient provider practices that required corrective action centered on health and wellness/medical, including failure to respond to an apparent change in individuals' health condition, such as failures in responding to a person's medical needs, failure to respond to an emergency in a manner that would protect the welfare of the individual.
- Fifteen provider actions were identified as neglectful, and deficient practices regarding documentation of progress/clinical notes/medication were also among most common.
- Most providers had none or very few deficient practices (from CMRC reviews) that were identified to pose risk to individuals.

Appendix A: Method for Mortality Review and Analysis

This mortality report analyzes information on individuals and deaths reported to DBHDD that meet the following criteria:

- At least 18 years of age during the calendar year of review
- Primary diagnosis of an intellectual or developmental disability
- Medicaid waiver recipient (NOW or COMP)

Other reports (e.g., 2010 & 2011 Mortality Report, Massachusetts) included all individuals that were eligible for services to calculate mortality rates. This report included only those receiving NOW and COMP waivers, who may have a higher level of disability and need for services and supports. Including data from only those individuals receiving services may have produced upwardly biased mortality rates relative to those studies that included all of the population eligible for services. Due to data limitations mentioned earlier, it was not possible to investigate this possible bias.

Individuals who moved between the NOW and COMP waiver during 2016 were categorized into the waiver where they were last enrolled.

The data used to calculate mortality rates per 1,000 people by age group and type of residence was supplied by the Waiver Information System (WIS) Medicaid information system and Reporting of Critical Incidents (ROCI). WIS Medicaid information was the primary source for identifying, demographic, and payer information, as well as residential setting. Health risk information was extracted from the Columbus Information System (CIS). Death and incident information was extracted from ROCI. ROCI and CIS do not track individuals by a common unique identifier stored in WIS. All efforts were made to match individuals using related identifying information, including name, age, address, and region.

For these analyses, the following information was included:

- Region (WIS)
- Medicaid number (WIS)
- Date of birth (WIS)
- Date of death (ROCI)
- Residential setting (WIS)
- Cause of death (if known) (ROCI)
- Whether death was referred for investigation (ROCI)
- Whether a mortality review was completed (CMRC)
- Health Status Risk Screening Tool (HRST) score (CIS)
- Tracking of deficient practices and corrective action plans related to CMRC (CATS)

Due to the large number of statistical comparisons, the statistical significance level was set at $\alpha = .01$. Setting $\alpha = .01$ as the significance level is to compensate for finding significance due to increased chances afforded by multiple comparisons.

The specific methodology employed by this report to calculate mortality rates per 1,000 people throughout this report appears on the following page.

$$\text{Crude Mortality Rate} = \frac{\text{(Number of people who died in calendar year x 1,000)}}{\text{(Number of adults who received waiver service during the calendar year)}}$$

Caution should be used when comparing mortality rates across unlike methods and populations.

Deaths were included, regardless of death category, for all population-eligible adults who died in 2016.

Analyses were conducted using R,[9] including tests of significance and logistic regression. In order to facilitate the interpretation of coefficients, variables were not transformed. The variables used for the logistic regression follow:

Death (outcome): 0 = No death 1 = Death

Age: Continuous

Gender: Female = 0 Male = 1

HRST: Continuous (1-6)

Intensity of Residential Setting

- Lower Intensity = 0
  - Independent apartment/home
  - Live with family/relative/caretaker/friend
- Higher Intensity = 1
  - Personal care home
  - Community living arrangement
  - Host home

All variables were entered into a single step, and the variables were examined for significant association with death. Variables that were indicated as not being significantly associated with death were removed, and the model was recomputed. Those variables that were indicated as significantly associated with death were retained in the model. This process continued until only significantly-associated variables with death remained. Finally, the model was examined for meaningful relationships and interpretation.

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[9] R Core Team. (2016). R: A Language and Environment for Statistical Computing. R Foundation for Statistical Computing, Vienna, Austria. https://www.R-project.org.

Appendix B: Regions of DBHDD

The DBHDD system of services is administered through six regional field offices. Each field office is responsible for the following:

- Communicating and implementing department policy at the local level;
- Developing annual regional plans in conjunction with the regional advisory councils;
- Managing allocated funds and contracting with providers for mental health, substance use disorder, and intellectual and developmental disability services for individuals eligible to receive these services through the public sector;
- Facilitating and determining eligibility for intellectual and developmental disability services, managing the planning lists, and authorizing services;
- Managing the provider network by routinely meeting with providers to improve existing services, plan for the implementation of new services, ensure consumer access to services, and improve quality of services;
- Developing and promoting effective working relationships with all stakeholders in the region, through regular meetings with providers, consumers, individuals, family members, advocates, elected officials, regional advisory council members, and other social service agencies; and
- Investigating and resolving complaints and conducting special investigations as needed.

Region Descriptions (map on following page):

Region 1 covers 31 predominantly rural counties of Northwest and Northeast Georgia (total population: more than 2.5 million).

Region 2 covers 33 counties of East and Central Georgia (total population: 1.27 million).

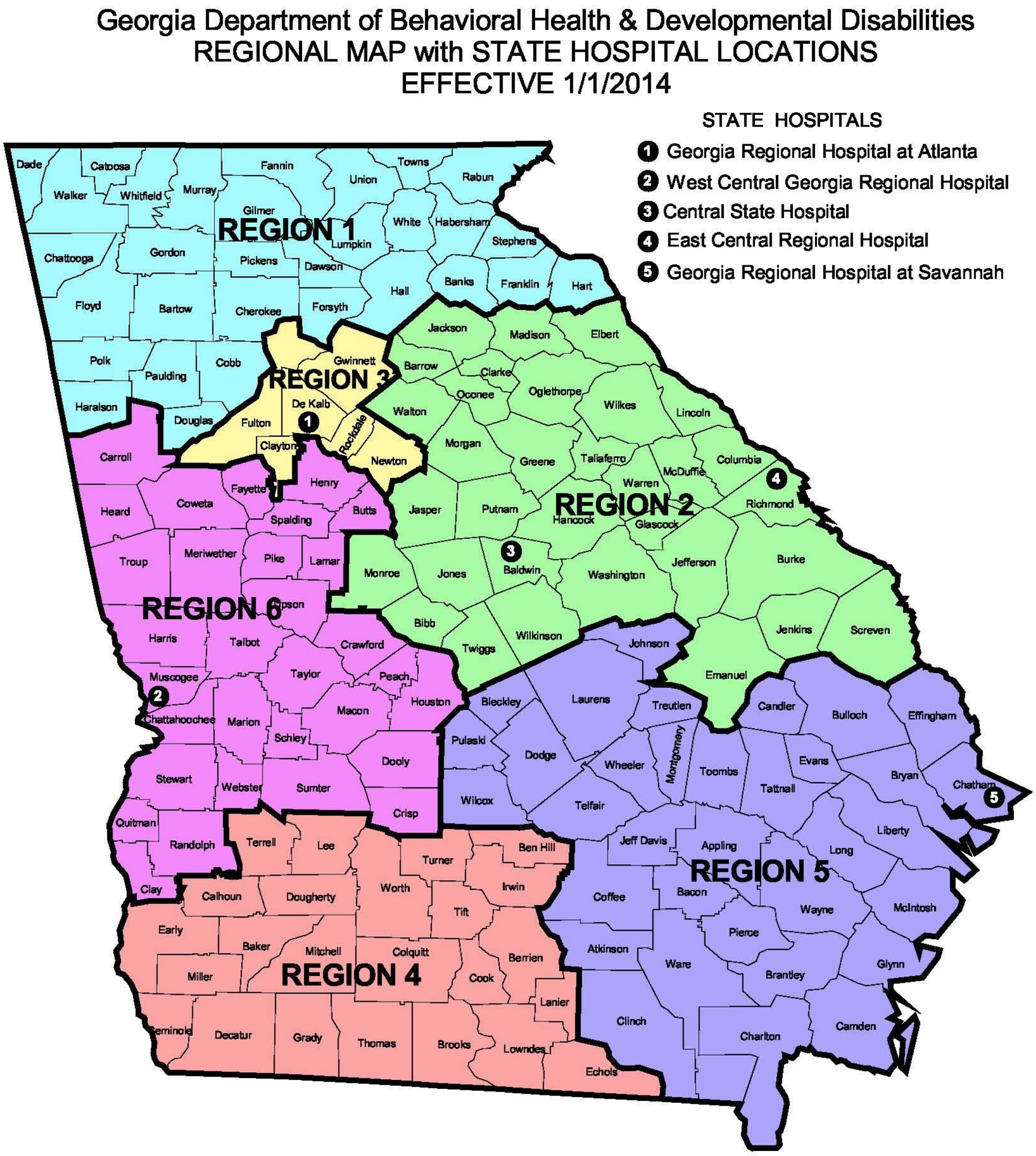
Region 3 covers 6 counties, which includes the capital city of Atlanta (total population: 2.9 million).

Region 4 covers 24 predominantly rural counties in Southwest Georgia (total population: 611,590).

Region 5 covers 34 counties in Southeast Georgia (total population: 1.1 million).

Region 6 covers 31 counties in West-Central Georgia (total population: 1.37 million). Two-thirds of the region is rural.

Figure 10: DBHDD Regional Map with State Hospital Locations



Appendix C: Logistic Regression for Living at Home

The population of individuals living at home with their family, a friend, or someone else had lower mortality rates in 2016 than many of the other more-intensive living situations; yet, the population's average age of death was lower than others. A logistic regression model was generated using only the individuals in the family, friend, or other residential setting category. The results are the same as those for the overall population. The association between age and mortality remained much like the overall model. The association between HRST and mortality was also largely the same; so, there are no differences between variables and their respective associations to mortality for those in the aforementioned population and others in the waiver population examined in the primary analysis.

It was found, however, that the distribution of individuals living at home with family/relative/other had a lower average age than any of the other living situations. The average ages of death are presented in Table 22. Their low average age of death is an effect of the low age of the population. This way, the population can have a low mortality rate yet a low average age of death.

Table 22: Logistic Regression Model with Death as Outcome, 2016

Variable	B	S.E.	Wald	df	Sig.	Exp(B)
HCL	.492	.079	6.218	1	.000	1.636
Age	.039	.009	4.170	1	.000	1.039

Table 23: Statistics on Age Stratified by Living Situations

Living Situation	Mean	SD	Median
Independent	48.106	13.557	47.675
Live with Family/Relative/Other	37.871	12.647	35.071
PCH	49.881	13.738	51.180
CLA	47.235	14.487	47.949
Host Home	44.269	15.361	42.852

Appendix G: Planning List Redesign

Planning List Redesign

The planning lists for the NOW and COMP waivers include a variety of individuals, such as those who actively require services (short-term needs) and people who may need services in the future (long-term needs). One of the changes in the redesign is to convert these categories into a list for the COMP waiver and a list for the NOW waiver, rather than maintaining the short- and long-term designations.

DBHDD recognizes benefits from maintaining planning lists. Knowing who may need supports, and what kind of support, helps the department to plan and understand the types of providers that may need cultivating. Rather than eliminating the planning lists, the department is committed to increasing the number of people who are moved onto the NOW and COMP waivers, improving the efficiency of the process, and providing referrals to other types of services that will meet the needs of people who have intellectual or developmental disabilities.

The planning lists have recently been under redesign to streamline the process, reduce barriers, add a navigator role, and change the role of the planning list administrators (PLAs) to achieve these goals. The PLA navigator in each region has specialized training and is focused on customer service, answering questions related to the planning lists, providing referrals, and completing screenings. PLAs work with an individual to complete the process of starting services, arranging providers for services, assisting with Medicaid issues, and developing the individual's first service plan. Within the redesign efforts, PLAs work with fewer individuals with the goal of moving individuals into appropriate services rather than providing case management for people who are not moving into services.

DBHDD also set goals to improve customer service, reduce the amount of time it takes to complete the process, and increase the number of people receiving the NOW or COMP waiver each year. In the following sections, measurable objectives for each goal are provided at the beginning of each section and are listed more comprehensively in Appendix A. Goals and objectives are addressed in three categories: those on the planning lists not yet needing services, alignment of resources, and technology.

Through the planning list redesign project, DBHDD developed a linear process from application to service entry (figure G.1). The redesign addresses many of the barriers, including reducing the number of days the process takes and increasing the number of people each PLA places into services in a year. After this redesign process is implemented, additional increases in the number of people placed into services will likely be related to the number of employees assigned to move people to the NOW or COMP waivers.

Fig. G.1. Application for Services Process

1 An individual or his representative completes and submits an application to the nearest region. **Application**

2 **Pre-eligibility** Intake and Evaluation reviews the application and all relevant materials to ensure everything is complete and correct. The individual is determined to be pre-eligible or not based on a psychologist's review of all the documentation and possibly a face-to-face interview.

3 The PLA navigator contacts the individual within 4 days of being determined pre-eligible to discuss the process and complete screening using tools including the Determination of Need-Revised (DON-R). The PLA navigator makes appropriate referrals for support, such as vocational rehabilitation, family support etc. **Planning list**

4 **Funding** Depending on an individual's needs, the most appropriate source of funding for services is identified. An individual may be recommended for the NOW or COMP waiver, as well as different state-funded programs.

5 Individuals are reviewed by Georgia Medical Care Foundation to determine level of care for eligibility for the NOW or COMP waiver. **Medicaid eligibility**

6 **Evaluations** The assessments required for proper support of an individual based on the person's specific needs are completed.

7 The PLA, along with the individual and identified service providers, complete the first annual service plan, identifying goals and services based on the individual's strengths, needs, hopes, and dreams. **Individual service plan**

8 **Service entry** The individual begins receiving services.

The redesign of the planning lists improves efficiency, consistency throughout the state, and customer service. In addition to improved efficiencies in processes and use of technology, DBHDD will continue to evaluate and leverage all other forms of support to reduce the demand for the NOW and COMP waivers.

Individuals on Planning Lists but Not Currently in Need of Services

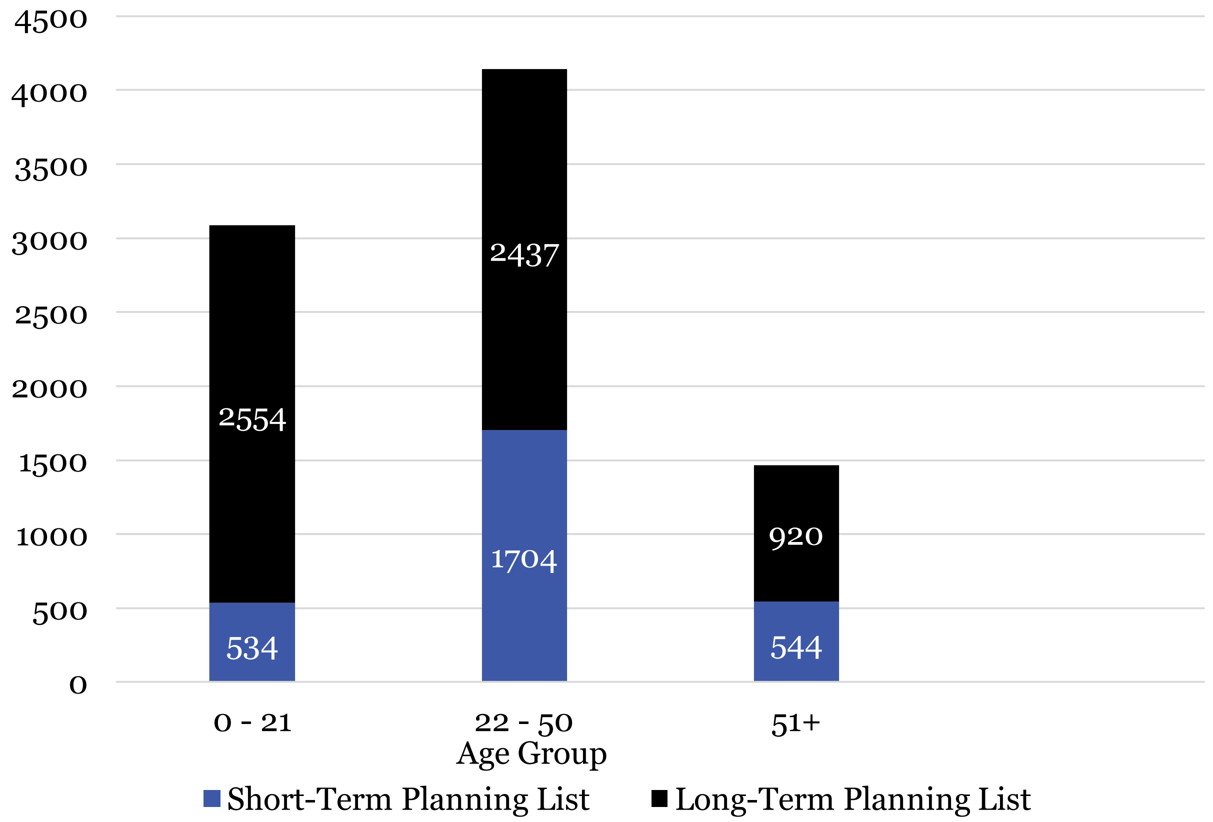
Individuals who are on the planning lists, but may not currently need services, include children who are still attending school and have most of their needs met through the school system. It should be noted that parents often apply for the NOW or COMP waiver programs with the expectation that being on a list will facilitate the admissions process, although they do not want or need the services at the time of application.

Individuals can continue in public education until the age of twenty-two when they "age out" of school. As indicated in figure G.2 below, as of December 2017, 3,088 people under the age of twenty-two are on a planning list for services. Presently, need assessments are being completed for everyone on the planning lists using the Determination of Need-Revised (DON-R) assessment tool and other assessment instruments, which include a set of standards used for consistency in determining who receives funding for waiver services.

Screens for medical needs and behavioral needs are also used in determining an individual's total needs. The DON-R is a tool used in many areas of human services, including the Georgia Department of Human Resources Division of Aging, to identify both strengths and needs in function, and level of required support for completing activities of daily living and instrumental activities of daily living. The DON-R can be conducted in person or over the phone and should be completed whenever there is a significant change in functioning. With respect to children, screens have been developed based on the DON-R format. The Division of Developmental Disabilities is contracting with an outside research organization to validate new screening tools and determine what predictive capabilities the tools may provide.

Currently, the process for determining most-in-need status for individuals who are applying for services includes the population of individuals aging out of the school system.

Fig. G.2. Number of Individuals on the Planning Lists by Age



Another group of people who are on a planning list who do not currently need services through the NOW and COMP waivers are people who receive needed support through programs such as Family Support, Vocational Rehabilitation, State Funded Services, and the Service Options Using Resources in a Community Environment (SOURCE) Medicaid waiver program. Often, individuals receiving these types of services choose to remain on a planning list with the belief that it will facilitate getting the NOW or COMP waiver if the individuals' needs change.

To improve efficiency of the waiver-entry process and increase the number of new participants, the following goals and objectives have been identified.

Goals	Objectives	Timeline
Increase waiver-entry process efficiency	Develop a plan to increase waiver-entry process efficiency	6/30/2019
	Maintain service entry timeline to under 80 business days	6/30/2020
	Maintain service entry timeline to under 75 business days	6/30/2021
	Maintain service entry timeline to under 70 business days	6/30/2022
	Maintain service entry timeline to under 65 business days	6/30/2023
Increase the number of new waiver individuals	Increase NOW/COMP newly admitted waiver participants by 600	6/30/2019
	Increase NOW/COMP newly admitted waiver participants by 650	6/30/2020
	Increase NOW/COMP newly admitted waiver participants by 700	6/30/2021
	Increase NOW/COMP newly admitted waiver participants by 750	6/30/2022
	Increase NOW/COMP newly admitted waiver participants by 800	6/30/2023

To achieve its objectives, DBHDD will address the processes associated with the assessment of needed support, the identification of providers, and the assurance of consistency and uniformity in the prioritization process. While assessments used to identify the appropriate types of support the person needs are still required prior to entry to the waiver program, completing only the most critical assessments prior to initiating services is intended to reduce the amount of time required to obtain services through the NOW and COMP waivers.

The development of the PLA navigator role will ensure that staff are available to complete the initial DON-R assessment, as well as to promptly complete an updated assessment after a change in an individual's needs occurs. Because the order people are being moved into services is based on an objective measure, and reviewed at the central office, decisions will be more consistent throughout the state.

In addition, all identified services previously had to have a corresponding provider prior to start of a service. Now, a person can begin services with as few as one service provider identified. The PLA will work to identify providers for up to sixty days in collaboration with Support Coordination for the other service needs. After the initial sixty days, Support Coordination will manage the identification of any remaining providers. This additional support provided by the PLAs, as well as increased coordination between staff, will enable faster admission into service for newly admitted individuals.

Alignment of Resources

Goal	Objectives	Timeline
Continue to improve the planning list infrastructure and management	Close out and stabilize the initial planning list redesign efforts	6/30/2019
	Conduct an analysis to determine the capacity of Family Support Services to serve new planning list individuals' service needs, including an infrastructure impact analysis to serve as the "front door"	6/30/2020
	Develop the second phase of the planning list operations improvement plan and address the gap between the identified needs and the connected services	6/30/2021
	Develop a workforce development plan to strengthen the planning list team and the impacted provider network capacity	6/30/2022
	Close out and stabilize ongoing planning list infrastructure and management	6/30/2023

To achieve objectives for better alignment of resources, DBHDD intends to improve the role clarity and expectations of the PLAs as well as increase statewide oversight of their efforts. Previously, all short-term planning list individuals were assigned to a PLA's caseload, which resulted in PLAs managing more than 100 individuals at a given time. To provide the most appropriate support to individuals in the NOW and COMP waiver entry process, DBHDD will create a new position of PLA navigator to serve as specialists in understanding and describing the planning list process and in assessing available resources for those on the planning lists. In addition, PLAs themselves will better manage their caseload assignments by focusing on those prioritized to actively move into the NOW or COMP waiver program.

DBHDD has developed new performance indicators and measures for the PLAs. The state's admission services manager, who will oversee the PLA supervisor in each region, will monitor these measures on a regular basis for continued improvement.

Technology

Goal	Objectives	Timeline
Support individuals on the planning list by referring individuals and families to other services	Develop a plan to track and increase the number of planning list individuals referred to other services	6/30/2019
	Refer all individuals on the planning list interested in Family Support Services to Family Support Services	6/30/2019

To reduce delays due to administrative burdens and to better track performance, in addition to the objectives and activities identified under Process Redesign and Alignment of Resources sections, DBHDD will use technological advances to reduce administrative burdens and implement performance and process tracking.

A comprehensive case management system is currently in development to improve efficiency and performance tracking. Some of the key system enhancements expected are electronic tracking of assessments and management of data points for analysis, including tracking and monitoring of provided resources and referrals. The system will also include tools to track performance and processes such as communications, productivity, work queue, and status. Leveraging an enhanced case management system will allow DBHDD to remain accessible to the community, while optimizing the opportunity to remotely support the individuals and families.

With the additional data collected through the system enhancements, DBHDD will partner with a third-party academic institution to test for reliability and validity of the needs assessments proposed to better assess the individuals' needs on the planning lists. Furthermore, the proposed partnership includes developing a predictive analysis model that would allow the department to better manage the planning lists. It is expected that these data would enable improved understanding of needs, patterns or shifts in needs, and potential triggers that indicate expected changes in demand for support. In the next few years, DBHDD will work closely with an academic institution in Georgia with experiential knowledge in technology to clarify the next steps and define the scope of the partnership.

Appendix H: Addressing the Planning Lists through Other Programs and Services

Addressing the Planning Lists through Other Programs and Services

DBHDD is committed to addressing the planning lists by braiding nonwaiver DBHDD services and non-DBHDD services to better support those individuals on the planning lists. Specifically, DBHDD plans to target five primary programs: Medicaid State Plan Autism Services Benefit, Crisis Services, Family Support Services Program, Supported Employment Services, and Respite Services. In addition to these five programs, the department has leveraged the NOW and COMP waiver renewal and amendment processes to further support these individuals. In each section, the respective programmatic area includes the goals and objectives of the Multiyear Planning List Strategic Plan.

Addressing the Planning Lists through the Medicaid State Plan Autism Services Benefit

Goal	Objectives	Timeline*
Leverage Medicaid Autism Benefit plan and referral to support individuals on the planning lists	Enhance data tracking and trending of children and youth with autism spectrum disorder (ASD)	6/30/2019
	Complement data tracking and trending for adults with intellectual or developmental disabilities within the identified subpopulation of adults with ASD	6/30/2019
	Provide supported employment services to young adults with ASD	6/30/2019
	Increase provider capacity to individualize supported employment services for young adults with ASD	6/30/2019
	Conduct staff training to support referrals of children and youth with ASD	6/30/2019
	Strengthen System of Care (SOC) infrastructure for individuals with ASD	6/30/2019
	Conduct staff training to support referrals of children and youth with ASD for the Medicaid Autism Benefit	6/30/2019

*Timeline dependent on implementation of the plan

The Medicaid State Plan Autism Benefit, to be implemented in FY 2018 by the Georgia Department of Community Health (DCH), includes a comprehensive array of assessment and treatment services according to severity and based on medical necessity. Covered individuals are to include children and youth with autism spectrum disorder (ASD). Some of these children currently receive DBHDD state-funded services (e.g., Family Support Services) or are currently on the planning lists. In addition, a small number of these children receive NOW or COMP waiver services. This section of the plan provides an overview of the rising prevalence of ASD and its impact on the planning lists and waiver admissions. Specific actions of DBHDD to leverage the Medicaid State Plan Autism Services Benefit to address the planning lists are outlined. In addition, specific actions by DBHDD are delineated to address an increasing number of adults with ASD on the planning lists.

Autism Spectrum Disorder Overview

ASD is a neurodevelopmental condition with essential features of impairment in social communication and interaction as well as restricted, repetitive patterns of behavior (American Psychiatric Association, 2013). The severity of ASD symptoms vary from mild to severe. Individuals with ASD, who are eligible for the NOW and COMP waiver services, exhibit severe functional impairment in several areas of daily living due to their ASD symptoms and require substantial support (Georgia Department of Community Health, 2017). These individuals may or may not have a co-occurring intellectual disability.

The number of children, youth, and adults with ASD who are expected to need DBHDD intellectual or developmental disabilities services is increasing dramatically. ASD prevalence in the U.S. population, including data from metropolitan Atlanta, currently ranges from 1.5 to 2.5 percent of the population, with substantial increases over the past couple of decades (Emory University, 2016). More children and youth currently receive services in the disability category of autism for special education than previously documented, with a threefold increase occurring from 2000 to 2010 (Penn State, 2015). In addition, ASD as an identified disability by the Social Security Administration is showing considerable and consistent growth (National Academy of Sciences, 2015). As a result of the increased prevalence of ASD, more individuals with ASD are eligible for and need NOW and COMP services. In fact, almost one-fifth of all NOW and COMP new participants in FY 2017 have ASD, a 10 percent increase over FY 2016 (see Appendix N). Moreover, ASD as an eligibility category for DBHDD intellectual or developmental disabilities services (historically, a relatively small category), is growing, particularly as more individuals transition from special education to adult services. The rising prevalence of ASD, therefore, is a critical factor to consider in this strategic plan to reduce and eliminate the planning lists.

Individuals with Autism Spectrum Disorder and the Planning Lists

The planning lists recently show an increasing proportion of individuals with ASD. Many of the individuals with ASD added to the planning lists are children. The planned FY 2018 implementation of a Medicaid State Plan Autism Services Benefit by DCH will allow DBHDD to leverage this benefit to address the needs of children with ASD on the planning lists. The availability of this benefit will also allow for the redirecting of Family

Support and other state-funded programs to address the needs of other individuals on the planning lists. Children, including those with ASD, represent only a small proportion of waiver entries (e.g., about 7 percent of waiver entries in FY 2017; see Appendix O). The implementation of the Medicaid State Plan Autism Services Benefit, therefore, impacts certain programs like Family Support Services more than the NOW and COMP waiver programs.

DBHDD recently partnered with Emory University, specifically the Emory Autism Center and the Emory Rollins School of Public Health, on a gap analysis of intellectual and developmental disability services provided by DBHDD for adults with ASD. The gap analysis was based on DBHDD demographic and service data for the fiscal year ending June 30, 2015. The final report, titled *Improving the Community-Based Infrastructure to Meet the Developmental Disability Service Needs of Adults with Autism Spectrum Disorder in Georgia*, was completed on October 31, 2016 (See Appendix M). The findings included a review of the adults with ASD on the planning lists for NOW and COMP waiver services. These findings reflected the rising prevalence of ASD. Most of the adults with ASD on the planning lists are under the age of twenty-five. Figure 1 below from the final report illustrates the overall rate (per 100,000) of adults with ASD on the planning lists.

Fig. H.1. Rate of Adults with ASD on Short- or Long-Term Planning Lists, 2015

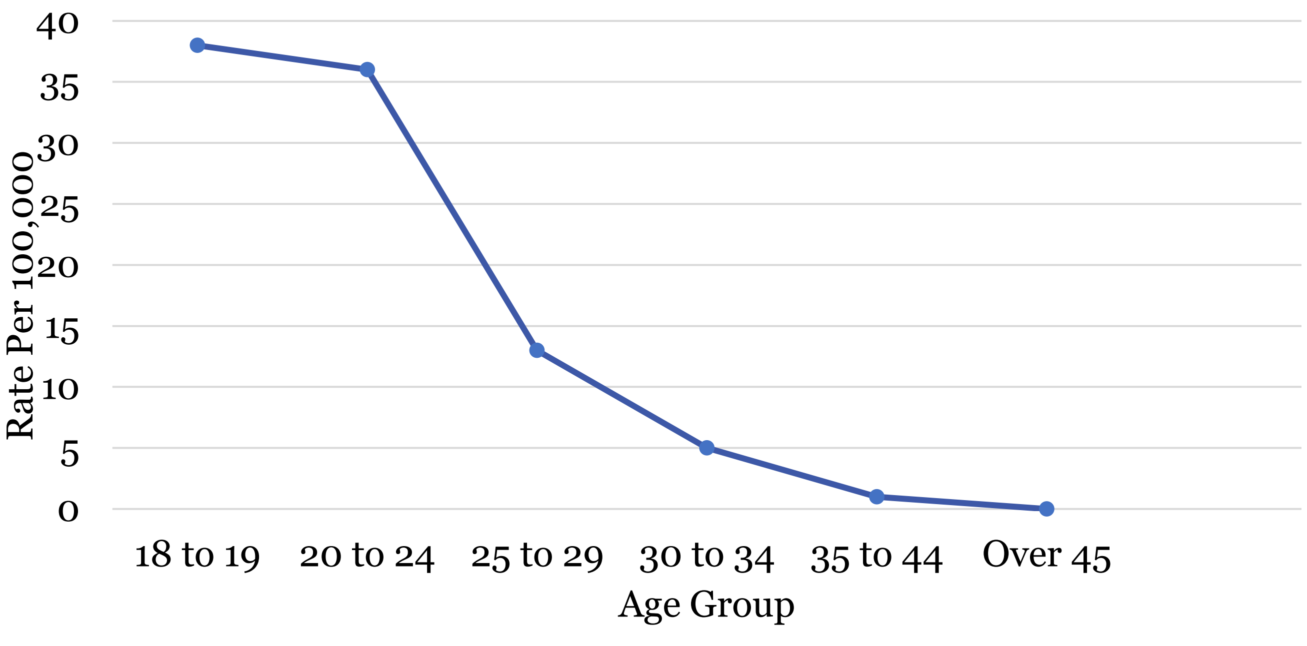


Figure H.1 suggests that the number of individuals needing intellectual or developmental disability services from DBHDD is likely to grow substantially over the next few years as there are so many young adults in need of services today. In fact, as of October 2017, individuals with ASD represented one-third of those under the age of eighteen years on the planning lists, and young adults with ASD were almost one-fifth of those from eighteen years through twenty-one years on the planning lists. In contrast, individuals with ASD represented only one-tenth of those from twenty-two years through thirty-five years on a planning list and were less than 7 percent of those thirty-six years and older. These data support the need to consider the ASD population in this strategic plan to address the planning lists for NOW and COMP waiver services.

Impact of Medicaid State Plan Autism Services Benefit for Children and Youth

DCH is planning to implement in FY 2018 a Medicaid State Plan Autism Services Benefit that includes Adaptive Behavior Services to assess and treat ASD in Medicaid-eligible individuals under age twenty-one and PeachCare for Kids®-eligible members under age nineteen years.

DBHDD provides intellectual or developmental disabilities behavioral services to children and youth with ASD (i.e., behavioral supports consultation services and behavioral supports services), which are similar to the Adaptive Behavior Services to be included in the Medicaid State Plan Autism Benefit offered by DCH. Therefore, services currently provided to children and youth with ASD as NOW and COMP waiver services can be provided through the Medicaid program, freeing up space in these programs for those waiting on the planning lists. Thus, the availability of the Medicaid State Plan Autism Benefit will allow DBHDD resources currently used for behavioral services for children and youth with ASD to be redirected to address the needs of other individuals on the NOW and COMP planning lists. Nevertheless, it should be noted that as children with severe symptoms of ASD age out of the Medicaid autism benefit at age twenty-two, they will need the services provided by the NOW and COMP programs and may end up back on a planning lists for those services.

To accomplish the objectives outlined above, specific actions are required by DBHDD to maximize the opportunities for addressing the NOW and COMP planning lists, as well as actions to address an increasing number of adults with ASD requiring intellectual or developmental disabilities services provided by DBHDD. These actions include data tracking and trending, adult supported employment services, staff and provider training, and evaluation.

Data Tracking and Trending

DBHDD will develop a system of data tracking specific to children and youth with ASD receiving or eligible to receive DBHDD state or waiver services. DBHDD will track children and youth who become eligible for the Medicaid State Plan Autism Benefit and begin to receive Adaptive Behavior Services and no longer need behavioral services through the Family Support Services program. Children and youth with ASD applying for waiver services will be referred to the Medicaid State Plan Autism Benefit to meet their behavioral service needs. The comprehensiveness of the autism services in the Medicaid State Plan will allow for children and youth with severe impairments and ASD to have their behavioral service needs met without waiting on the planning lists.

In addition, data tracking and trending will occur for adults with ASD receiving or eligible for state and waiver services. DBHDD will need to track youth aging out of the Medicaid State Plan Autism Benefit as well as youth transitioning from special education to adult services. The data tracking and trending specific to adults with ASD will tie into the data tracking and trending occurring for the NOW and COMP waivers, the Family Support Services program, and Supported Employment Services. The data tracking and trending will be reviewed for the subpopulation of those with ASD as well as for the entire intellectual or developmental disabilities population eligible for or receiving services from DBHDD.

Supported Employment Services

DBHDD plans to address the increasing number of adults with ASD with a focus on the critical years immediately after high school, which form the foundation for all the adult years (Shattuck et al., 2012). Research is limited on outcomes for adults with ASD, but the available research supports positive benefits from employment of adults with ASD, including positive impacts on their quality of life, cognitive functioning, and well-being (Walsh, Lydon, and Healy, 2014). Supported employment services, including vocational rehabilitation services and supported employment services through DBHDD, are a key part of planning for youth aging out of the Medicaid State Plan Autism Benefit, as well as for youth with ASD transitioning from special education to adult services.

The evidence-based research on services for young adults with ASD is limited. Available research, however, shows the benefits of supported employment services (Walsh et al., 2014) and provides descriptions of successful supported employment programs for individuals with ASD (Hendricks, 2010). The unique social, communication, and behavioral characteristics of adults with ASD call for specific strategies to help them achieve employment success (Hendricks, 2010). Interpersonal, communicative, and behavioral difficulties experienced by adults with ASD may present challenges to employment success. Some research evidence supports the effectiveness of supported employment services designed to address the distinctive needs of adults with ASD (Hendricks, 2010).

DBHDD plans to coordinate with the Georgia Vocational Rehabilitation Agency to develop training for provider staff on strategies for successful implementation of supported employment services for adults with ASD. DBHDD will develop informational documents on the benefits of supported employment for young adults with ASD.

Provider/Staff Training and Family Education

DBHDD clinicians and PLAs will be trained on the Medicaid Autism Benefit and referral processes. Training will include in-person events as well as webinars. Materials from the training will be made available on the DBHDD website. An informational sheet and frequently asked questions (FAQ) document on the Medicaid State Plan Autism Benefit will be developed in collaboration with DCH. These informational documents will assist DBHDD clinicians and PLAs to inform families about the Medicaid State Plan Autism Benefit.

System of Care Evaluation

DBHDD will conduct a System of Care (SOC) evaluation of all DBHDD resources and other resources used or available to address the intellectual or developmental disabilities needs of children, youth, and adults with ASD. This evaluation will involve DBHDD contracts with Marcus Autism Center, Matthew Reardon Center for Autism, and Emory Autism Center, which include deliverables for services to children or youth with ASD. The expectations of these deliverables will transition to align appropriately with the autism service expansion of the Medicaid State Plan Autism Benefit and will support the SOC for children and youth with ASD. DBHDD will also evaluate crisis service use by children, youth, and adults with ASD. The SOC evaluation will incorporate the data tracking and trending reports, including data on the NOW and COMP waivers, the Family Support Services program, and Supported Employment Services. DBHDD will use the SOC evaluation to identify ways to maximize available resources to address the growing population of individuals with ASD requiring intellectual or developmental disabilities services provided by DBHDD.

Addressing the Planning Lists through Crisis Services

Goal	Objective	Timeline
Implement the Crisis Strategic Plan	Implement the Crisis Strategic Plan	6/30/2023

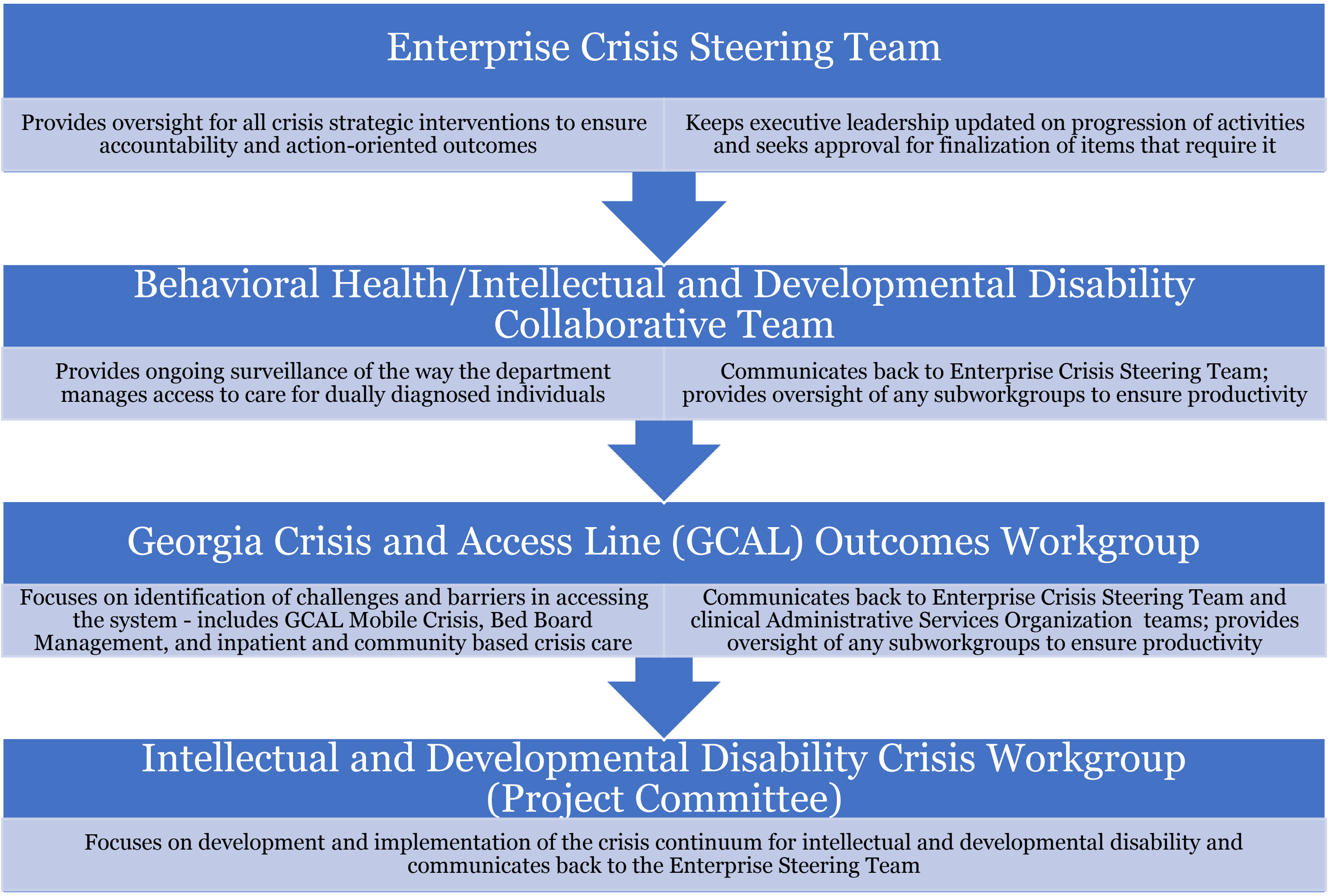
Crisis Services Overview

In 2016, the Extension of Settlement Agreement with the U.S. Department of Justice required DBHDD to assess and enhance the intellectual or developmental disabilities crisis system, including minimizing the occurrence of individuals leaving their homes during crisis and limiting individuals' out-of-home lengths of stay in crisis support homes. Recognizing that individuals with intellectual or developmental disabilities require specialized response and intervention, the department first implemented a crisis-response system specifically for individuals with intellectual or developmental disabilities in June 2011. In 2016, Division of Developmental Disabilities staff began to analyze the current crisis system and make recommendations on design improvements. The analysis included the solicitation of internal and external stakeholder input on the current system and the following recommendations for improvement:

- Identification of information technology solutions for data collection and analysis
- Identification of gaps in the crisis services array
- Identification of funding opportunities to maximize resources

DBHDD and the Division of Developmental Disabilities have developed a crisis-planning structure and workgroups to further advance the work, as depicted in figure 2 below.

Figure H.2: Crisis Planning Structure



Enterprise Crisis Steering Team

Provides oversight for all crisis strategic interventions to ensure accountability and action-oriented outcomes

Keeps executive leadership updated on progression of activities and seeks approval for finalization of items that require it

Behavioral Health/Intellectual and Developmental Disability Collaborative Team

Provides ongoing surveillance of the way the department manages access to care for dually diagnosed individuals

Communicates back to Enterprise Crisis Steering Team; provides oversight of any subworkgroups to ensure productivity

Georgia Crisis and Access Line (GCAL) Outcomes Workgroup

Focuses on identification of challenges and barriers in accessing the system - includes GCAL Mobile Crisis, Bed Board Management, and inpatient and community based crisis care

Communicates back to Enterprise Crisis Steering Team and clinical Administrative Services Organization teams; provides oversight of any subworkgroups to ensure productivity

Intellectual and Developmental Disability Crisis Workgroup (Project Committee)

Focuses on development and implementation of the crisis continuum for intellectual and developmental disability and communicates back to the Enterprise Steering Team

Implementation of the strategic plan for Redesign of the Crisis Response System was to accomplish the following:

- Enhancement of the crisis system to improve efficiency and effectiveness, including reducing the need for out-of-home services and the length of stay in out-of-home services
- Maximization of resources for crisis diversion as well as resolution
- Improvement of data collection and analyses, and using data on successful strategies and interventions to guide future work.

Current work is also designed to provide greater assistance with coordination of follow-up care and services, particularly since individuals who have experienced a recent crisis rise to an “urgent priority” status on the planning lists. In the past, discharge planning for individuals in crisis support homes was the responsibility of regional field offices. With the realignment of functions that occurred departmentwide, resources were allocated for enhanced collaboration in discharge planning and follow-up postdischarge from the crisis setting. Support coordination agencies now provide Intensive Support Coordination services to individuals in crisis support homes who are not current waiver participants upon admission. Individuals already receiving waiver services also receive Intensive Support Coordination while in a crisis support home to enhance behavioral and other support services, ultimately reducing the length of stay in crisis homes.

The increased focus on planning for ongoing support at the time of admission to crisis services results in a major improvement to the crisis system. The emphasis on transition of crisis services to traditional intellectual or developmental disabilities services to reduce risk of future crises directly relies on timely planning list activities, admission to waiver or nonwaiver services, and intensive coordination of postdischarge supports. Designing it as a continuum in which prevention, early intervention, and transition back to precrisis placement or service, or a new placement or service, is as important as the response to the crisis episode itself.

Addressing the Planning List through the Family Support Services Program

Goals	Objectives	Timeline*
Improve Family Support Services Program	Establish an objective assessment tool to determine appropriate resource allocation	6/30/2019
	Expand $3,000 annual cap for those with a higher level of need	6/30/2019
	Restructure family support provider administrative fees	6/30/2019
	Create an interim system to house the new assessment tool	6/30/2019
	Hold focus groups and listening sessions with key stakeholders	6/30/2019
	Establish an internal tracking system for applications, assessment tool, and Individual Family Support Plan development and services needed	TBD*
	Establish an internal tracking system for tracking and monitoring use, and determine and measure outcomes	TBD*
	Create outcomes similar to the National Core Indicators for measuring the impact of Family Support Services on individuals receiving support	TBD*
Continue to improve the planning list infrastructure and management	Conduct an analysis to determine the capacity of Family Support Services to serve new planning list individuals' service needs, including an infrastructure impact analysis to serve as the "front door"	6/30/2020
Increase the number of planning list individuals receiving nonwaiver services	Develop a plan to increase the number of interested planning list individuals receiving nonwaiver services	6/30/2019
	Increase the planning list individuals receiving nonwaiver services by 200	6/30/2020
	Increase the planning list individuals receiving nonwaiver services by 200	6/30/2021
	Increase the planning list individuals receiving nonwaiver services by 200	6/30/2022
	Increase the planning list individuals receiving nonwaiver services by 200	6/30/2023

*Dependent upon DBHDD's ASD plan for the second phase of the system implementation

The Family Support Services program serves individuals with intellectual or developmental disabilities or ASD. Supported through state funds, the Family Support Services program is not considered an entitlement program; it is flexible and family-friendly, with a broader set of eligibility criteria than the NOW and COMP waiver eligibility. This program focuses on providing immediate access to services and assisting individuals and families in maintaining a cohesive family unit while living at home, linking families to other available resources within the respective community.

Family Support Services Overview

Family Support Services are meant to help sustain and enhance the quality of family and home life so the individual with intellectual or developmental disabilities or ASD can remain at home. The program is intended to:

- Provide goods and services to assist the identified individual or their family
- Prevent crises that could lead to out-of-home placement or higher intensity of services
- Keep the family together
- Enhance the individual's or family's ability to meet the needs of the identified individual
- Improve the quality of supports to the individual or family while minimizing the needs and cost of out-of-home placement
- Allow the individual or family to participate in recreational and social activities
- Make a positive difference in the life of the person with disabilities, as well as the lives of the family members

There are currently 36 providers that broker individualized goods and services (See Appendix L). These providers preapprove the services for individuals and families, working closely with the family to create a fully developed service plan. During this planning time, providers are encouraged to explore community resources and services, help families and individuals gain access to services that are otherwise not available, or assist with extraordinary expenses. This service planning process is family-driven and focused, respectful of cultural differences, and community-integrated.

The most used Family Support Services in 2017 were:

- Social and recreational services
- Family Support Coordination
- Respite Care
- Medical supplies
- Incontinence supplies

After a review of the FY 2017 data, the Office of Performance Analysis indicated that about 22 percent of individuals on the planning lists were receiving Family Support Services. However, individuals on the planning lists are also likely to receive other services, in addition to Family Support Services, such as services available through the

Georgia Department of Education and State Plan Medicaid benefits. Additionally, in FY 2016 and FY 2017, the majority of individuals who received Family Support Services were either defined as children under the age of eighteen years or adults between the ages of twenty-two and thirty-five years.

Enhancement and Expansion of the Family Support Services Program

Due to the program's flexibility and its focus on leveraging community resources as a primary source of support in maintaining a strong community integrated service design, DBHDD encourages the use of the Family Support Services program as a "front door" for individuals on the planning lists while waiting for the NOW or COMP waiver services.

The program is designed to reduce the need for out-of-home placement, maintain the individual at home with their family, and provide a level of support and services to prevent crises from occurring. By implementing the above-mentioned goals and objectives, DBHDD, in partnership with its network of community service providers, will be better able to plan for those individuals needing long-term supports, respond to requests for assistance, provide immediate access to services, and ensure that services are not being duplicated.

With a growing desire to leverage the Family Support Services program to support individuals on the planning lists, continued improvements will be made to strengthen the program. In anticipation of the increased referrals to the Family Support Services program, DBHDD will develop a strategic plan to build and strengthen the current programmatic infrastructure, develop provider capacity, and create quality measures for ongoing improvement opportunities. DBHDD will continue to explore the feasibility and appropriateness of further integration of nonwaivered services for individuals on the planning lists.

Technical enhancements for better tracking and monitoring, as well as other improvements, will assist in prudent resource allocation, support objective decision-making, restructure the reimbursement mechanism, and monitor outcomes. In order to further support this strategic plan, the Family Support Services program will develop a reasonable benchmark of success to measure the outcome of its implementation. Although Family Support Services cannot duplicate the services provided by many of the other public agencies, DBHDD will strive to assist individuals and families in navigating the various available resources to help them get connected.

Addressing the Planning List through Additional Programs

Supported Employment Services

Goal	Objectives	Deadline
Leverage the Georgia Vocational Rehabilitation Agency (GVRA) partnership to support individuals on the planning list	Develop the strategic plan to increase referrals to GVRA	6/30/2019
	Draft the memorandum of understanding with GVRA	6/30/2019
	Develop annual targets to refer 480 individuals	6/30/2019

DBHDD has historically supported people with intellectual or developmental disabilities to obtain and maintain jobs through supported employment services. Today, employment services for Georgians with intellectual or developmental disabilities are optimized through a partnership between Georgia DBHDD and the Georgia Vocational Rehabilitation Agency (GVRA). Through this partnership, GVRA uses federal funding for job development and initial job support, and DBHDD draws upon a combination of state and federal funding to provide long-term support to people with intellectual or developmental disabilities.

Each year GVRA provides vocational services to thousands of Georgians with disabilities, including people with intellectual or developmental disabilities. These services include:

- Vocational assessment
- Vocational counseling and guidance
- Physical and mental restoration services
- Vocational training
- School-to-work transition
- Rehabilitation technology
- Supported employment
- Job search and job placement
- Referral to other agencies for needed services

The demand for GVRA's services is growing. In 2014, GVRA served 1,440 persons with intellectual or developmental disabilities. In 2015 and 2016, GVRA served 1,861 and 2,343 individuals, respectively. Based on the annual increase in the clients with intellectual or developmental disabilities served through GVRA, it can be assumed that GVRA has the capacity and skilled provider network to serve additional individuals with intellectual or developmental disabilities on the planning lists.

DBHDD and GVRA Strategic Partnership

DBHDD's Division of Developmental Disabilities is partnering with GVRA to provide many individuals on the planning lists with the support they need to be a successful part of Georgia's workforce. In addition to the benefit of increased independence people gain through employment, employed individuals may also have a decreased demand for other, much more expensive, publicly funded services. It is anticipated that through this strategic partnership with GVRA, DBHDD will be able to allocate funding for approximately 480 individuals per year from the planning lists to receive supported employment services.

Respite Services

Goal	Objectives	Timeline
Expand respite services to increase access to respite services for individuals on the planning list	Develop a plan to improve access to respite by increasing provider and service capacity	6/30/2019
	Identify available funding streams to expand respite services	6/30/2019
	Develop a provider recruitment plan to encourage community providers to provide Respite Care services	6/30/2020
	Reduce and eliminate barriers to becoming a Respite Care service provider	6/30/2021

In addition to other services that support the individuals on the planning list, DBHDD is committed to evaluating opportunities to expand respite services. DBHDD will develop a plan to improve access to respite services by targeting the community service providers. While individuals and families on the planning lists may not have access to a full array of services through the NOW and COMP waivers, DBHDD hopes to provide access to respite services through the above listed goal and objectives.

Appendix I: Six-Month Planning Lists Trend

With the changes implemented through the initial process and operations improvement plan, the number of individuals entering waiver services has increased and the number of individuals on planning lists has begun to decrease in the last six months. Figure I.1 illustrates the number of individuals on the planning lists in fiscal year 2017. Over the six-month period there is a decrease in individuals waiting for services, with the peak of the count in July 2017.

Fig. I.1. Individuals on the Planning Lists in FY 2017

Appendix J: Service Impact to the Planning Lists

The following tables provide an outline of available services or those that can be referred.

Family Support Services
Provide support for individuals while on the planning lists Provide support for some individuals, eliminating the need for NOW or COMP waiver.

Medicaid Autism Benefit
Referred for comprehensive assessments and treatment for children and youth with Autism Spectrum Disorder Robust services eliminating or postponing the need for the NOW or COMP Waiver

Supported Employment Vocational Rehabilitation
Referred for comprehensive initial employment development and support through Vocational Rehabilitation DBHDD provides continued long-term support for employment

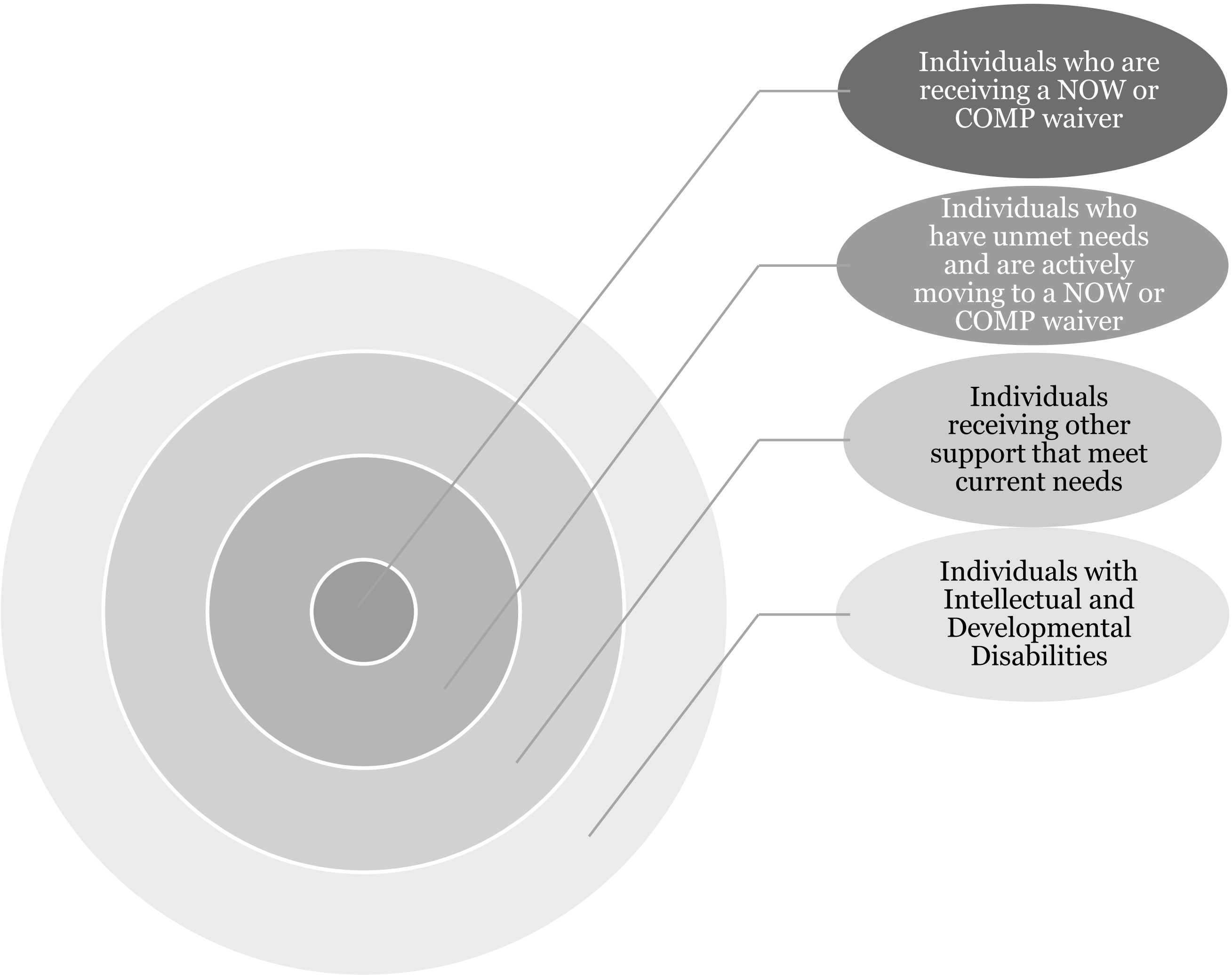
Respite Services
Provide relief for unpaid caregivers of individuals on the planning lists

Crisis Services
Provide crisis support to reduce the need for out-of-home placement

Provider Network Development
Additional provider development to respond to the increased demand for services from new waiver recipients based on identified needs.

Appendix K: Services' Relative Relationship Overview

The figure below describes the general relative relationship of the individuals with intellectual and developmental disabilities to those who receive the NOW or COMP waiver services.

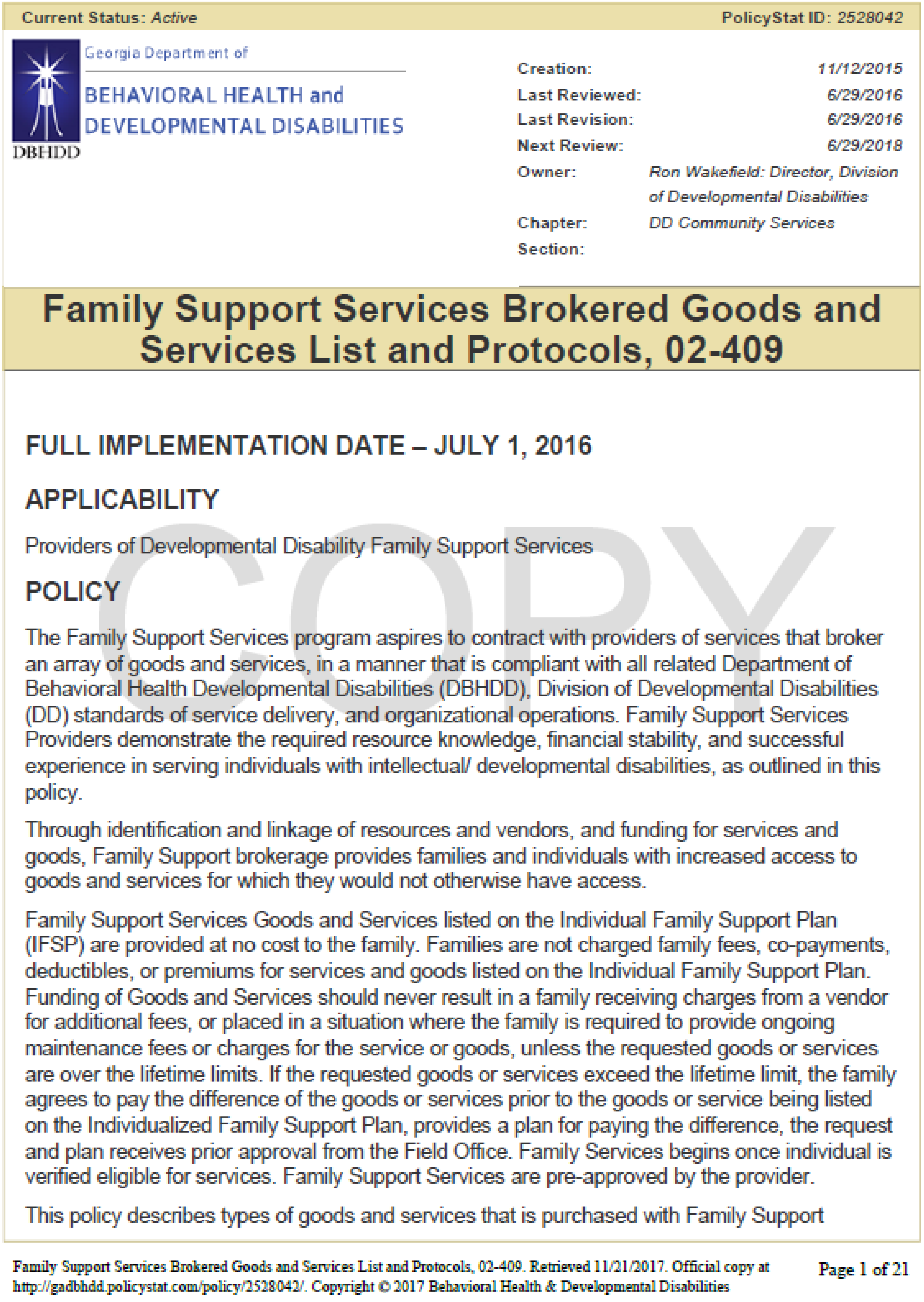


Appendix L: Family Support Services

Family Support Services Authorized Goods & Services

Family Support Respite Care
Family Support Community Living Support
Family Support Community Access
Family Support Supported Employment
Dental Services
Medical Care
Vision Care
Specialized Clothing
Specialized Diagnostic Services
Recreation and Social Community Integration Activities
Environmental Modifications
Specialized Equipment/Assistive Technology Device
Therapeutic Services
Counseling
Parent/Family Training
Specialized Nutrition
Supplies
Incontinent Supplies
Behavioral Consultation and Support
Financial and Life Planning Assistance
Exceptional Disability Related Living Costs
Family Support Transportation
Vehicle Adaptation Services
Child Day Care/After-School Services
Other Family Support Services

Family Support Services Brokered Goods and Services List and Protocol



Current Status: *Active*

PolicyStat ID: *2528042*

Georgia Department of
BEHAVIORAL HEALTH and
DEVELOPMENTAL DISABILITIES
DBHDD

Creation:	*11/12/2015*
Last Reviewed:	*6/29/2016*
Last Revision:	*6/29/2016*
Next Review:	*6/29/2018*
Owner:	*Ron Wakefield: Director, Division of Developmental Disabilities*
Chapter:	*DD Community Services*
Section:	

Family Support Services Brokered Goods and Services List and Protocols, 02-409

FULL IMPLEMENTATION DATE – JULY 1, 2016

APPLICABILITY

Providers of Developmental Disability Family Support Services

POLICY

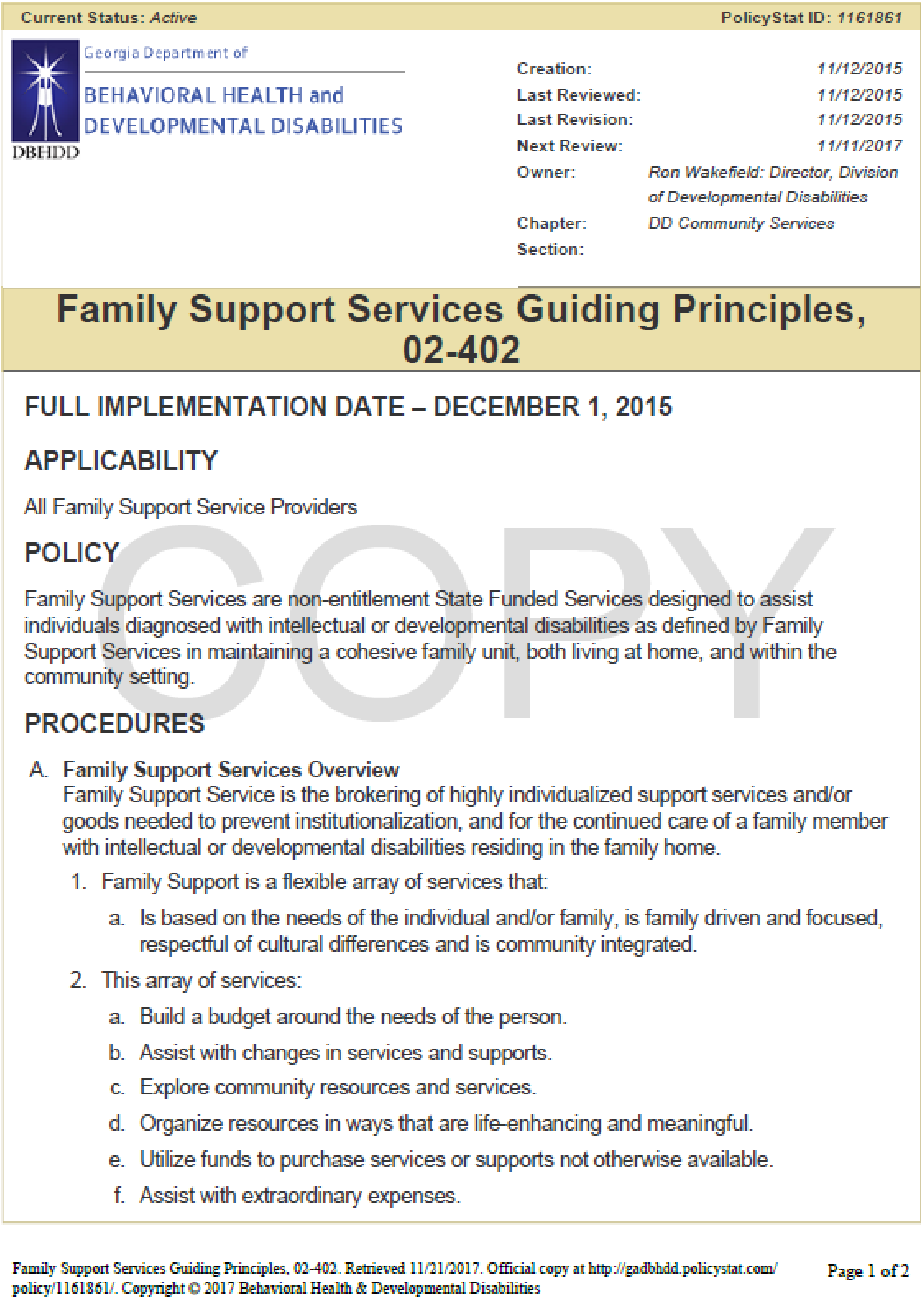
The Family Support Services program aspires to contract with providers of services that broker an array of goods and services, in a manner that is compliant with all related Department of Behavioral Health Developmental Disabilities (DBHDD), Division of Developmental Disabilities (DD) standards of service delivery, and organizational operations. Family Support Services Providers demonstrate the required resource knowledge, financial stability, and successful experience in serving individuals with intellectual/ developmental disabilities, as outlined in this policy.

Through identification and linkage of resources and vendors, and funding for services and goods, Family Support brokerage provides families and individuals with increased access to goods and services for which they would not otherwise have access.

Family Support Services Goods and Services listed on the Individual Family Support Plan (IFSP) are provided at no cost to the family. Families are not charged family fees, co-payments, deductibles, or premiums for services and goods listed on the Individual Family Support Plan. Funding of Goods and Services should never result in a family receiving charges from a vendor for additional fees, or placed in a situation where the family is required to provide ongoing maintenance fees or charges for the service or goods, unless the requested goods or services are over the lifetime limits. If the requested goods or services exceed the lifetime limit, the family agrees to pay the difference of the goods or services prior to the goods or service being listed on the Individualized Family Support Plan, provides a plan for paying the difference, the request and plan receives prior approval from the Field Office. Family Services begins once individual is verified eligible for services. Family Support Services are pre-approved by the provider.

This policy describes types of goods and services that is purchased with Family Support

Family Support Services Guiding Principles



Current Status: *Active* PolicyStat ID: *1161861*

Georgia Department of
BEHAVIORAL HEALTH and
DEVELOPMENTAL DISABILITIES
DBHDD

Creation:	*11/12/2015*
Last Reviewed:	*11/12/2015*
Last Revision:	*11/12/2015*
Next Review:	*11/11/2017*
Owner:	*Ron Wakefield: Director, Division of Developmental Disabilities*
Chapter:	*DD Community Services*
Section:	

Family Support Services Guiding Principles, 02-402

FULL IMPLEMENTATION DATE – DECEMBER 1, 2015

APPLICABILITY

All Family Support Service Providers

POLICY

Family Support Services are non-entitlement State Funded Services designed to assist individuals diagnosed with intellectual or developmental disabilities as defined by Family Support Services in maintaining a cohesive family unit, both living at home, and within the community setting.

PROCEDURES

A. **Family Support Services Overview**
Family Support Service is the brokering of highly individualized support services and/or goods needed to prevent institutionalization, and for the continued care of a family member with intellectual or developmental disabilities residing in the family home.

1. Family Support is a flexible array of services that:
   a. Is based on the needs of the individual and/or family, is family driven and focused, respectful of cultural differences and is community integrated.
2. This array of services:
   a. Build a budget around the needs of the person.
   b. Assist with changes in services and supports.
   c. Explore community resources and services.
   d. Organize resources in ways that are life-enhancing and meaningful.
   e. Utilize funds to purchase services or supports not otherwise available.
   f. Assist with extraordinary expenses.

3. Family Support Services are neither an entitlement nor a grant, and are provided as services to assist in maintaining a cohesive family unit and to assist the individual to live at home in the community.
4. Family Support Services are not a crisis program. These services are provided to families with the goal of preventing crises, which can result in the need for out-of-home placements, or higher intensity services.

B. **Family Support Services Program Goals**

1. Family Support Services are intended to help sustain and enhance the quality of family/home life so the individual with an Intellectual Disability, Developmental Disability, and/or Autism Spectrum Disorder can remain within the family/home through the following goals:
    a. Provide goods and services to assist the identified individual and/or their family.
    b. Prevent crises that could lead to out-of-home placement or higher intensity of services.
    c. Keep the family together.
    d. Enhance the individual/families ability to meet the needs of the identified individual.
    e. Improve the quality of supports to the individual/family while minimizing the needs and cost of out of home placement.
    f. Allow the individual/families to participate in recreational and social activities.
    g. Make a positive difference in the life of the person with disabilities as well as the lives of the family members.

RELATED POLICIES

Family Support Services for Developmental Disabilities Services - All Procedures, 02-401

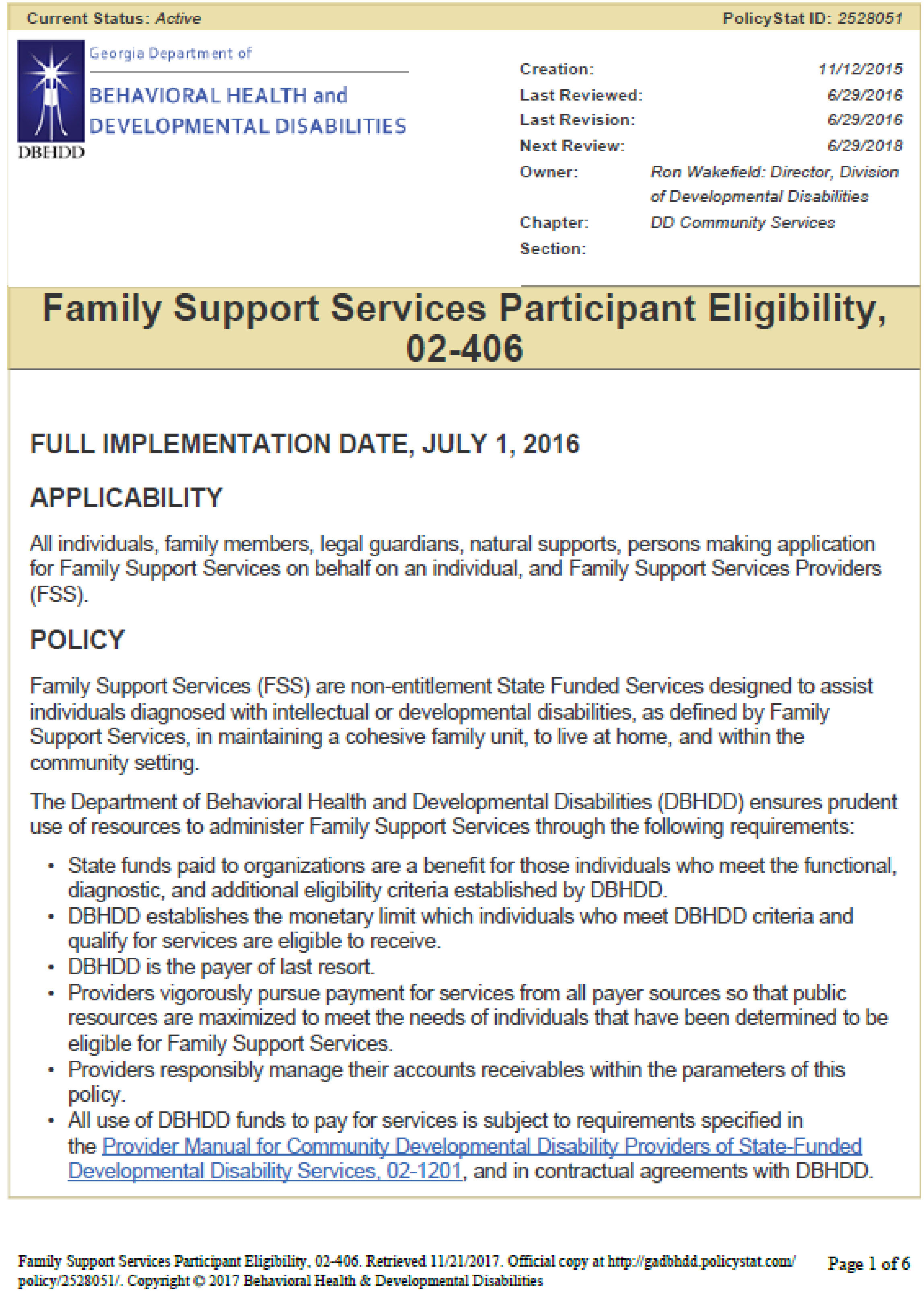
Attachments:

No Attachments

Approval Signatures

Approver	Date
Anne Akili, Psy.D.: Policy Director	11/12/2015
Dan Howell: Director Division of Developmental Disabilities	11/11/2015
Frank Kirkland: Assistant Division Director for DD	11/5/2015
Ron Wakefield: Director, Office of Field Operations for DD	11/4/2015
Robert Bell: Director of Community Supports	11/3/2015
Anne Akili, Psy.D.: Policy Director	9/25/2015
Terah Harris-Tessier: DD Program and Policy Development	9/25/2015

Family Support Services Participant Eligibility



Current Status: *Active* **PolicyStat ID:** *2528051*

Georgia Department of
BEHAVIORAL HEALTH and
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DBHDD

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Chapter:	*DD Community Services*
Section:	

Family Support Services Participant Eligibility, 02-406

FULL IMPLEMENTATION DATE, JULY 1, 2016

APPLICABILITY

All individuals, family members, legal guardians, natural supports, persons making application for Family Support Services on behalf on an individual, and Family Support Services Providers (FSS).

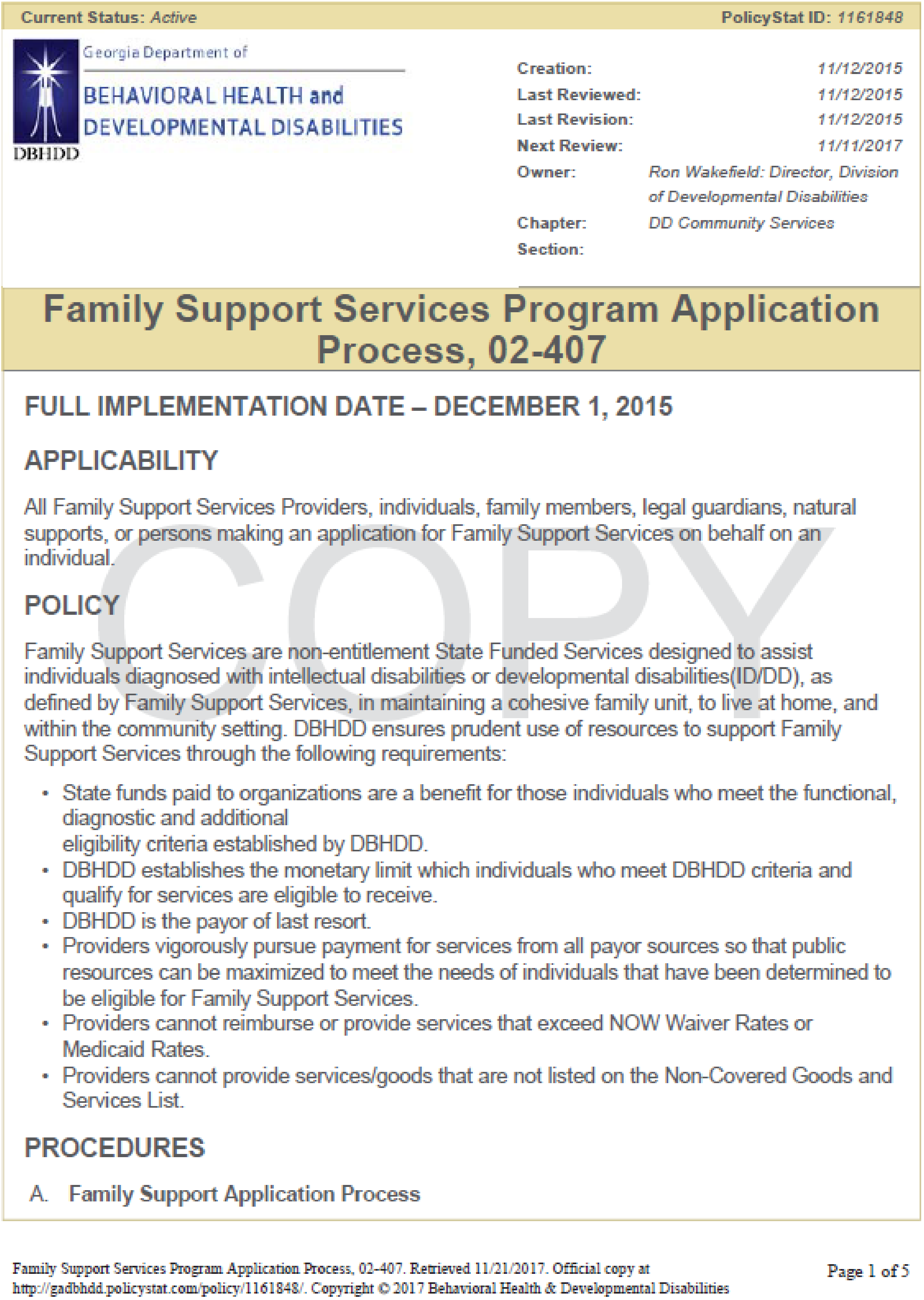
POLICY

Family Support Services (FSS) are non-entitlement State Funded Services designed to assist individuals diagnosed with intellectual or developmental disabilities, as defined by Family Support Services, in maintaining a cohesive family unit, to live at home, and within the community setting.

The Department of Behavioral Health and Developmental Disabilities (DBHDD) ensures prudent use of resources to administer Family Support Services through the following requirements:

- State funds paid to organizations are a benefit for those individuals who meet the functional, diagnostic, and additional eligibility criteria established by DBHDD.
- DBHDD establishes the monetary limit which individuals who meet DBHDD criteria and qualify for services are eligible to receive.
- DBHDD is the payer of last resort.
- Providers vigorously pursue payment for services from all payer sources so that public resources are maximized to meet the needs of individuals that have been determined to be eligible for Family Support Services.
- Providers responsibly manage their accounts receivables within the parameters of this policy.
- All use of DBHDD funds to pay for services is subject to requirements specified in the Provider Manual for Community Developmental Disability Providers of State-Funded Developmental Disability Services, 02-1201, and in contractual agreements with DBHDD.

Family Support Services Program Application Process



Current Status: *Active* **PolicyStat ID:** *1161848*

Georgia Department of
BEHAVIORAL HEALTH and
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Chapter:	*DD Community Services*
Section:	

Family Support Services Program Application Process, 02-407

FULL IMPLEMENTATION DATE – DECEMBER 1, 2015

APPLICABILITY

All Family Support Services Providers, individuals, family members, legal guardians, natural supports, or persons making an application for Family Support Services on behalf on an individual.

POLICY

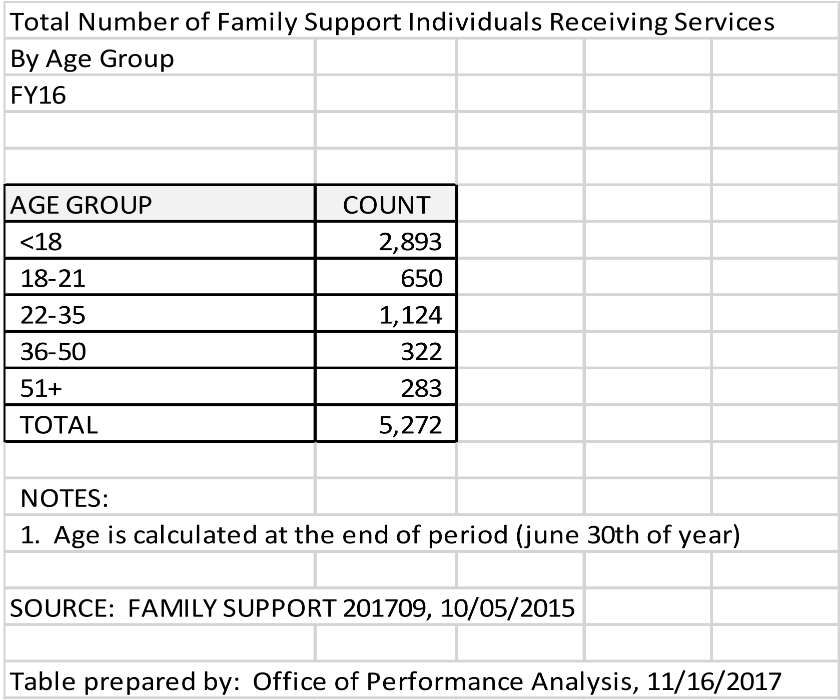
Family Support Services are non-entitlement State Funded Services designed to assist individuals diagnosed with intellectual disabilities or developmental disabilities(ID/DD), as defined by Family Support Services, in maintaining a cohesive family unit, to live at home, and within the community setting. DBHDD ensures prudent use of resources to support Family Support Services through the following requirements:

- State funds paid to organizations are a benefit for those individuals who meet the functional, diagnostic and additional eligibility criteria established by DBHDD.
- DBHDD establishes the monetary limit which individuals who meet DBHDD criteria and qualify for services are eligible to receive.
- DBHDD is the payor of last resort.
- Providers vigorously pursue payment for services from all payor sources so that public resources can be maximized to meet the needs of individuals that have been determined to be eligible for Family Support Services.
- Providers cannot reimburse or provide services that exceed NOW Waiver Rates or Medicaid Rates.
- Providers cannot provide services/goods that are not listed on the Non-Covered Goods and Services List.

PROCEDURES

A. **Family Support Application Process**

FY16 and FY17 Total Number of FS x Age Group



Total Number of Family Support Individuals Receiving Services
By Age Group
FY16

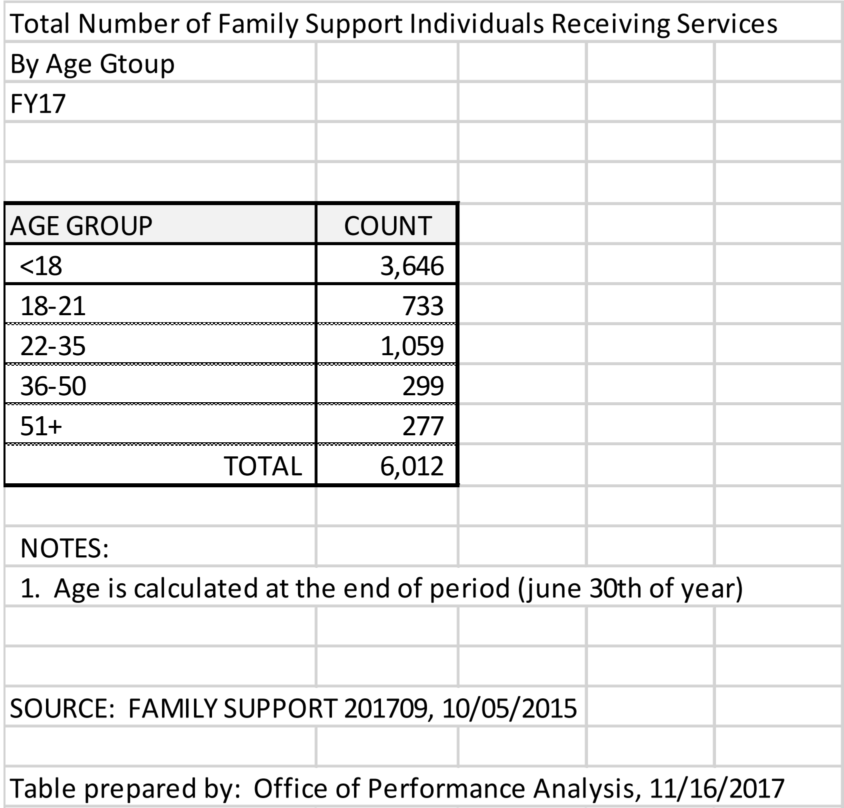
AGE GROUP	COUNT
<18	2,893
18-21	650
22-35	1,124
36-50	322
51+	283
TOTAL	5,272

NOTES:

1. Age is calculated at the end of period (june 30th of year)

SOURCE: FAMILY SUPPORT 201709, 10/05/2015

Table prepared by: Office of Performance Analysis, 11/16/2017



Total Number of Family Support Individuals Receiving Services
By Age Gtoup
FY17

AGE GROUP	COUNT
<18	3,646
18-21	733
22-35	1,059
36-50	299
51+	277
TOTAL	6,012

NOTES:

1. Age is calculated at the end of period (june 30th of year)

SOURCE: FAMILY SUPPORT 201709, 10/05/2015

Table prepared by: Office of Performance Analysis, 11/16/2017

Specific FSS Eligibility Criteria Crosswalk

If I am currently receiving…	Can I also receive Family Support Services?
New Options Waiver (NOW)	No
Comprehensive Supports Waivers (COMP)	No
Inpatient Hospitalization* (FS needed for transition services, to family home)	No
Skilled Nursing Facilities*	No
Individuals living in Community Living Arrangements	No
Children, 19 years and younger, that are in DFCS custody, and are in Foster Care placement in an approved foster home operating under a licensed Child Placing Agency	No

Service Limitations for families that are receiving other Waiver or Medicaid supports:

If I am currently receiving…	Can I also receive Family Support Services?	What are the limitations?
Medicaid or Medicare State Plan	Yes; see limitations	Services cannot be duplicative
Services Options Using Resources in a Community Environment (SOURCE)	Yes; see limitations	Services cannot be duplicative
Deeming Waiver	Yes; see limitations	Services cannot be duplicative
Community Care Services Program (CCSP)	Yes; see limitations	Services cannot be duplicative
Independent Care Waiver Program (ICWP)	Yes; see limitations	Services cannot be duplicative
Georgia Pediatric Program (GAPP)	Yes; see limitations	Services cannot be duplicative
Children Intervention Services	Yes; see limitations	Services cannot be duplicative
Children's Medical Services	Yes; see limitations	Services cannot be duplicative

Service limitations for families that are receiving other support programs services:

If I am currently receiving…	Can I also receive Family Support Services?	What are the limitations?
Early Intervention: Babies Can't Wait funding	Yes; see limitations	Children who are 0 to 3 years of age are approved if funding has been exhausted in the region where the family resides

State Funded Services through DBHDD	Yes; see limitations	Services cannot be duplicative; must be community integrated, and correspond to the Developmental Disability related needs

Service limitations for individuals in public education for children and young adults under the Individuals with Disabilities Education Act (IDEA) includes but is not limited to the following:

1. Education and services provided by schools as part of a free and appropriate public education for children and young adults under the Individuals with Disabilities Education Act (IDEA) includes but is not limited to the following:

If I request the following supports	Can Family Support Services provide funding?
Private school tuition (as related to IDEA)	No
Augmentative communication devices for school use	No
Computer/assisted technology applications for school use	No
IEP identified and listed therapies	No
Applied behavior Analysis (ABA) in schools	No
Accommodating school supplies	No
Tutors related to services identified on the IEP	No
Home schooling activities and supplies	No

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.

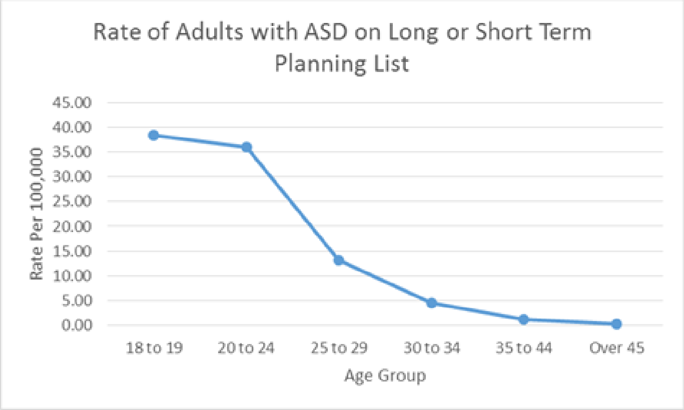
   The purpose of the qualitative data collections was to assess a variety of stakeholders' experiences related to access and delivery of developmental disability services provided by the DBHDD service system to adults with ASD. Discussions included frequency of use of developmental disability services 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
○ **Individual Outcomes**
○ **Health, Welfare, and Rights**
○ **System Performance**
○ **Staff Stability**
○ **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

Joseph F. Cubells, MD, PhD Emory Autism Center	Associate Professor, Departments of Human Genetics and Psychiatry and Behavioral Sciences, and Director of Medical and Adult Services, Emory Autism Center.	Co-Principal Investigator, Co-Director
Silke von Esenwein, PhD Rollins School of Public Health	Assistant Research Professor, Health Policy and Management, Rollins School of Public Health Specialty: Public Sector Health Services Research	Co-Principal Investigator, Co-Director
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
Active Community Volunteer

Deborah Conway
Executive Director
Cross Plains Community Partner

Rena Harris
Provider
Jewish Family and Community Services

Theresa Heard
Director of Clincal Services
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Ray Johnson
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Stacey Lane
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Kim Lucker-Greene
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Regional/Field Representative
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Michelle Robison (alternate with G. O'Dell)
Chairperson
CSB Association

Michelle Schwartz
Support Coordinator
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Pauline Shaw
Family Support Coordinator
B & B Care Services, Inc., Savannah

April Umstead
Clinical Training Director
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

Appendix N: Individuals with ASD Admitted to NOW and COMP Waivers FY2016 and FY2017

Numbers of Individuals with Autism Spectrum Disorder Admitted to NOW and COMP Waivers in FY 2016 and FY 2017

The determination of the percentage of individuals with Autism Spectrum Disorder (ASD) receiving NOW and COMP waiver services was based on data tables from the DBHDD Office of Performance Analysis. This appendix contains the applicable data tables.

To determine the percentage increase from FY 2016 to FY 2017, the total of individuals with ASD on the NOW and COMP on the last page of the table on autism participants for FY 2016 (July 1, 2015 to June 30, 2016) was compared to the last page of the table on autism participants for FY2017 (July 1, 2016 to June 30, 2017) as follows:

FY 2016	FY 2017
424 (NOW)	434 (NOW)
635 (COMP)	736 (COMP)
1059 (Total)	1170 (TOTAL)

1170 – 1059 = 111

111 / 1059 = 10.5 % increase in one fiscal year in the numbers of individuals with ASD served in the waivers.

The following comparison was made to determine the proportion of new 2017 NOW and COMP admissions of individuals with ASD. The number of individuals with ASD newly admitted to the NOW/COMP waivers as derived above (i.e., 111) was compared to the total number of first time admissions indicated on the last page of the table entitled Waiver Demographics Report for NOW/COMP Waiver Participants in Authorized Services 7/1/2017 to 6/30/2017 Statewide (i.e., 579) as follows:

111 (those with autism admitted to waivers in FY17)/579 (total admitted to waivers in FY17) = 19.2 % or about one fifth of those admitted to waivers in FY17 had autism

DBHDD

WAIVER DEMOGRAPHICS REPORT
FOR NOW/COMP WAIVER PARTICIPANTS IN AUTHORIZED SERVICES
7/1/2016 to 6/30/2017
STATEWIDE

	FIRST TIME ADMISSIONS			DISCHARGES		
	NOW	COMP	TOTAL	NOW	COMP	TOTAL
TOTAL NUMBER OF WAIVER PARTICIPANTS						
REGION 1						
AGE						
<18	2	5	7	2	2	4
18-21	9	14	23	16	0	2
22-35	59	22	81	16	11	27
36-50	5	12	17	9	6	15
51+	14	22	36	7	30	37
REGION 1 TOTAL	89	75	164	36	49	85
REGION 2						
<18	0	8	8	1	1	1
18-21	3	9	12	0	1	1
22-35	18	20	38	7	7	14
36-50	0	7	7	8	7	15
51+	5	11	16	9	31	40
REGION 2 TOTAL	26	55	81	24	47	71
REGION 3						
<18	7	6	13	0	0	0
18-21	1	7	8	0	0	0
22-35	71	16	87	3	1	4
36-50	5	4	9	1	6	8
51+	8	13	21	2	6	6
REGION 3 TOTAL	92	46	138	6	6	19
REGION 4						
<18	0	4	4	0	0	0
18-21	1	6	7	5	0	1
22-35	5	10	15	5	4	9
36-50	0	1	1	8	5	8
51+	1	9	10	23	15	8
REGION 4 TOTAL	7	30	37	17	24	41
REGION 5						
<18	0	6	6	0	0	0
18-21	5	9	14	0	0	0
22-35	30	17	47	1	8	9
36-50	8	10	18	2	18	20
51+	24	20	24	2	18	20
REGION 5 TOTAL	47	62	109	9	27	36
REGION 6						

DBHDD

WAIVER DEMOGRAPHICS REPORT
FOR NOW/COMP WAIVER PARTICIPANTS IN AUTHORIZED SERVICES
7/1/2016 to 6/30/2017
STATEWIDE

	FIRST TIME ADMISSIONS			DISCHARGES		
	NOW	COMP	TOTAL	NOW	COMP	TOTAL
<18	0	5	5	0	0	0
18-21	0	5	5	0	0	0
22-35	5	15	20	5	5	10
36-50	4	4	8	3	4	7
51+	2	9	11	15	15	30
REGION 6 TOTAL	11	38	49	23	24	47
GRAND TOTAL	273	306	579	116	185	301

NOTES

1\. Total number of unduplicated authorizations x waiver type = total number of authorizations during report period

2\. Unduplicated totals of participants do not equal totals x waiver since some participants can be active in both.

3\. Number of participants prior to report period - FYTD through previous month.

4\. Transfers includes those who transfer from one waiver to another.

5\. Living Situation includes the following categories: (1) Community Living Arrangement = Community Living Arrangement (CLA), Community Living Arrangement (CLA) - 3 Person, Community Living Arrangement (CLA) - 4 Person; Community Living Arrangement (CLA) - 5 Person; (2) Personal Care Home = Personal Care Home (PCH), Personal Care Home (PCH) - 3, Person Personal Care Home (PCH) - 4 Person ;Person Personal Care Home (PCH) - 5 Person ; (3) Indpendent = Independent Apartment/Home; (4) Host Home = Host Home and Foster Care; and (5) Family Friends Other =(a) 'Live with Family/Relative/Caretaker,(b) Other,and (c) 'Live with Friends/Others Non-Caretaker.

5\. Age is calculated at beginning of period.

6\. Discharge data has not been validated with other data sources; therefore sdhould be used with cauthion

SOURCE: HISTORICAL AUTHORIZTION DATAFILE 20171005 TABLE PREPARED BY: Office of Performance Analysis.

DBHDD

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
ADULT OT SENSORY INTEGRATIVE TECHNIQUES SELF-DIRECTED				
22-35	0	1	$ 0	$ 1,786
TOTAL	0	1	$ 0	$ 1,786
ADULT OT THERAPEUTIC ACTIVITIES SELF-DIRECTED				
22-35	0	1	$ 0	$ 2,608
36-50	0	1	$ 0	$ 1,759
TOTAL	0	2	$ 0	$ 4,367
ADULT PT THERAPEUTIC PROCEDURE SELF-DIRECTED				
22-35	0	3	$ 0	$ 3,653
TOTAL	0	3	$ 0	$ 3,653
ADULT SPEECH LANGUAGE EVALUATION SELF-DIRECTED				
22-35	1	1	$ 55	$ 110
TOTAL	1	1	$ 55	$ 110
ADULT SPEECH LANGUAGE THERAPY				
22-35	0	1	$ 0	$ 1,876
TOTAL	0	1	$ 0	$ 1,876
ADULT SPEECH LANGUAGE THERAPY SELF-DIRECTED				
22-35	1	5	$ 1,563	$ 6,378
36-50	0	1	$ 0	$ 3,502
TOTAL	1	6	$ 1,563	$ 9,880
ADULT SPEECH-GENERATING DEVICE THERAPY SELF-DIRECTED				
22-35	0	4	$ 0	$ 4,763
TOTAL	0	4	$ 0	$ 4,763
BEHAVIORAL SUPPORT CONSULTATION SELF-DIRECTED				
<18	4	9	$ 9,643	$ 19,375
18-21	0	2	$ 0	$ 3,600
22-35	0	5	$ 0	$ 9,503
51+	0	1	$ 0	$ 3,600
TOTAL	4	17	$ 9,643	$ 36,078
BEHAVIORAL SUPPORTS CONSULTATION SELF-DIRECTED				
<18	13	15	$ 41,277	$ 46,382
18-21	2	7	$ 1,988	$ 27,521
22-35	3	20	$ 9,048	$ 61,450
51+	0	2	$ 0	$ 6,786
TOTAL	18	44	$ 52,313	$ 142,139
BEHAVIORAL SUPPORTS SERVICES				

NOTES:
1. SSN was used to intersect those individuals from CIS with Authorization Data.
2. The following primary or secondary diagnosis were used to identify Autism participants: 'Autism','Autistic Disorder','Pervasive Developmental Disorder'
3. Report uses authorizations for services
4. If there are no age category for a service then there were no participants in that age category/service.
5. Age is calculated at the end of the period.

SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

DBHDD

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
<18	1	8	$ 488	$ 14,625
18-21	2	8	$ 1,238	$ 11,850
22-35	3	56	$ 2,006	$ 90,694
36-50	0	6	$ 0	$ 6,825
51+	2	7	$ 1,125	$ 10,538
TOTAL	8	85	$ 4,856	$ 134,531
COMMUNITY ACCESS GROUP				
<18	0	3	$ 0	$ 45,101
18-21	7	13	$ 53,534	$ 366,047
22-35	189	273	$ 4,722,227	$ 8,539,945
36-50	28	61	$ 807,776	$ 1,947,154
51+	18	64	$ 402,954	$ 1,686,961
TOTAL	242	414	$ 5,986,491	$ 12,585,208
COMMUNITY ACCESS GROUP CO-EMPLOYER				
<18	33	20	$ 253,840	$ 98,866
18-21	16	8	$ 115,126	$ 48,385
22-35	12	36	$ 168,727	$ 308,063
36-50	0	3	$ 0	$ 19,796
51+	2	3	$ 1,702	$ 56,975
TOTAL	63	70	$ 539,395	$ 532,085
COMMUNITY ACCESS INDIVIDUAL				
<18	7	5	$ 36,887	$ 37,509
18-21	7	8	$ 55,508	$ 92,870
22-35	49	97	$ 456,812	$ 1,146,327
36-50	7	16	$ 52,818	$ 242,255
51+	4	23	$ 27,054	$ 267,264
TOTAL	74	149	$ 629,079	$ 1,786,225
COMMUNITY ACCESS INDIVIDUAL CO-EMPLOYER				
<18	40	28	$ 493,602	$ 350,871
18-21	19	16	$ 233,014	$ 179,446
22-35	26	73	$ 259,868	$ 980,573
36-50	0	4	$ 0	$ 50,958
51+	2	4	$ 27,685	$ 48,929
TOTAL	87	125	$ 1,014,169	$ 1,610,777
COMMUNITY GUIDE CO-EMPLOYER				
<18	0	1	$ 0	$ 4,000
TOTAL	0	1	$ 0	$ 4,000

NOTES:

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3. Report uses authorizations for services
4. If there are no age category for a service then there were no participants in that age category/service.
5. Age is calculated at the end of the period.

SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

DBHDD

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
COMMUNITY LIVING SUPPORT - 15 MINUTES				
<18	13	27	$ 233,815	$ 4,385,861
18-21	8	22	$ 120,529	$ 3,824,635
22-35	12	102	$ 152,832	$ 19,026,369
36-50	4	18	$ 69,555	$ 2,938,227
51+	1	19	$ 6,418	$ 3,705,363
TOTAL	38	188	$ 583,148	$ 33,880,456
COMMUNITY LIVING SUPPORT - 15 MINUTES - EXTENDED SERVICES				
<18	0	10	$ 0	$ 1,215,632
18-21	0	6	$ 0	$ 657,241
22-35	0	45	$ 0	$ 6,191,389
36-50	0	6	$ 0	$ 529,551
51+	0	9	$ 0	$ 832,277
TOTAL	0	76	$ 0	$ 9,426,090
COMMUNITY LIVING SUPPORT - 15 MINUTES CO-EMPLOYER				
<18	52	52	$ 1,064,899	$ 1,665,008
18-21	28	17	$ 531,926	$ 891,289
22-35	33	110	$ 631,173	$ 3,558,218
36-50	1	5	$ 32,136	$ 158,773
51+	3	13	$ 40,818	$ 426,271
TOTAL	117	197	$ 2,300,952	$ 6,699,559
COMMUNITY LIVING SUPPORT - DAILY				
<18	0	12	$ 0	$ 558,184
18-21	0	14	$ 0	$ 1,310,536
22-35	0	52	$ 0	$ 4,691,253
36-50	0	15	$ 0	$ 1,820,537
51+	0	7	$ 0	$ 577,689
TOTAL	0	100	$ 0	$ 8,958,200
COMMUNITY LIVING SUPPORT - DAILY CO-EMPLOYER				
<18	0	18	$ 0	$ 507,908
18-21	0	10	$ 0	$ 418,691
22-35	0	43	$ 0	$ 2,027,135
36-50	0	3	$ 0	$ 153,682
51+	0	9	$ 0	$ 363,791
TOTAL	0	83	$ 0	$ 3,471,207
COMMUNITY LIVING SUPPORT LPN				
<18	0	2	$ 0	$ 30,975

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SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER BY AGE CATEGORY,and SERVICE and WAIVER FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
22-35	0	5	$ 0	$ 403,821
36-50	0	5	$ 0	$ 359,380
51+	0	2	$ 0	$ 357,700
TOTAL	0	14	$ 0	$ 1,151,876
COMMUNITY LIVING SUPPORT RN				
<18	0	2	$ 0	$ 1,360
22-35	0	10	$ 0	$ 22,200
36-50	0	5	$ 0	$ 16,480
51+	0	2	$ 0	$ 177,120
TOTAL	0	19	$ 0	$ 217,160
COMMUNITY RESIDENTIAL ALTERNATIVE - DAILY				
<18	0	3	$ 0	$ 204,367
18-21	0	14	$ 0	$ 1,584,597
22-35	0	157	$ 0	$ 14,696,855
36-50	0	53	$ 0	$ 4,383,499
51+	0	51	$ 0	$ 4,528,460
TOTAL	0	278	$ 0	$ 25,397,777
COMMUNITY RESIDENTIAL ALTERNATIVE LPN				
22-35	0	2	$ 0	$ 98,123
36-50	0	9	$ 0	$ 555,669
51+	0	8	$ 0	$ 1,108,616
TOTAL	0	19	$ 0	$ 1,762,408
COMMUNITY RESIDENTIAL ALTERNATIVE RN				
22-35	0	2	$ 0	$ 4,430
36-50	0	8	$ 0	$ 20,070
51+	0	8	$ 0	$ 20,870
TOTAL	0	18	$ 0	$ 45,370
COMMUNITY RESIDENTIAL ALTERNATIVE SERVICES – HOST HOME - CATEGOI				
<18	0	1	$ 0	$ 52,308
18-21	0	6	$ 0	$ 214,012
22-35	0	55	$ 0	$ 2,231,079
36-50	0	10	$ 0	$ 458,214
51+	0	13	$ 0	$ 636,358
TOTAL	0	85	$ 0	$ 3,591,970
COMMUNITY RESIDENTIAL ALTERNATIVE SERVICES – HOST HOME – CATEGOI				
22-35	0	5	$ 0	$ 278,801
36-50	0	2	$ 0	$ 135,788

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NUMBER and AUTHORIZED AMOUNTS FOR SERVICES AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER BY AGE CATEGORY,and SERVICE and WAIVER FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
51+	0	3	$ 0	$ 84,659
TOTAL	0	10	$ 0	$ 499,249
Community Residential Alternative Services (3 Person - Tier 1)				
22-35	0	4	$ 0	$ 256,369
36-50	0	1	$ 0	$ 10,176
TOTAL	0	5	$ 0	$ 266,545
Community Residential Alternative Services (3 Person - Tier 2)				
22-35	0	5	$ 0	$ 360,567
36-50	0	3	$ 0	$ 310,971
51+	0	3	$ 0	$ 151,372
TOTAL	0	11	$ 0	$ 822,910
Community Residential Alternative Services (3 Person - Tier 3)				
22-35	0	12	$ 0	$ 944,727
36-50	0	9	$ 0	$ 629,382
51+	0	4	$ 0	$ 216,244
TOTAL	0	25	$ 0	$ 1,790,354
Community Residential Alternative Services (3 Person - Tier 4)				
18-21	0	1	$ 0	$ 29,131
22-35	0	8	$ 0	$ 722,616
51+	0	3	$ 0	$ 240,902
TOTAL	0	12	$ 0	$ 992,649
Community Residential Alternative Services (4 Person - Tier 1)				
22-35	0	9	$ 0	$ 296,172
36-50	0	1	$ 0	$ 58,337
51+	0	1	$ 0	$ 36,054
TOTAL	0	11	$ 0	$ 390,564
Community Residential Alternative Services (4 Person - Tier 2)				
18-21	0	1	$ 0	$ 33,294
22-35	0	8	$ 0	$ 470,842
36-50	0	6	$ 0	$ 250,672
51+	0	3	$ 0	$ 220,814
TOTAL	0	18	$ 0	$ 975,622
Community Residential Alternative Services (4 Person - Tier 3)				
18-21	0	1	$ 0	$ 28,768
22-35	0	17	$ 0	$ 1,113,777
36-50	0	8	$ 0	$ 517,995
51+	0	7	$ 0	$ 536,516

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AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
TOTAL	0	33	$ 0	$ 2,197,055
Community Residential Alternative Services (4 Person - Tier 4)				
22-35	0	11	$ 0	$ 867,589
36-50	0	5	$ 0	$ 267,841
51+	0	5	$ 0	$ 495,663
TOTAL	0	21	$ 0	$ 1,631,094
Community Residential Alternative Services (5 Person)				
18-21	0	1	$ 0	$ 7,934
22-35	0	3	$ 0	$ 117,098
36-50	0	6	$ 0	$ 106,626
51+	0	6	$ 0	$ 139,471
TOTAL	0	16	$ 0	$ 371,129
ENVIRONMENTAL ACCESSIBILITY ADAPTATION				
<18	0	1	$ 0	$ 7,700
TOTAL	0	1	$ 0	$ 7,700
ENVIRONMENTAL ACCESSIBILITY ADAPTATION SELF-DIRECTED				
<18	0	1	$ 0	$ 10,400
22-35	0	2	$ 0	$ 13,171
TOTAL	0	3	$ 0	$ 23,571
FINANCIAL SUPPORT SERVICES				
<18	63	58	$ 107,025	$ 81,600
18-21	37	27	$ 57,675	$ 41,250
22-35	51	136	$ 76,500	$ 218,100
36-50	2	9	$ 3,600	$ 16,200
51+	4	17	$ 4,575	$ 23,625
TOTAL	157	247	$ 249,375	$ 380,775
INDIVIDUAL DIRECTED GOODS AND SERVICES				
<18	7	3	$ 7,050	$ 4,453
18-21	1	4	$ 3,000	$ 5,700
22-35	4	20	$ 5,096	$ 31,410
36-50	0	1	$ 0	$ 1,200
TOTAL	12	28	$ 15,146	$ 42,763
INTENSIVE SUPPORT COORDINATION				
<18	4	15	$ 14,752	$ 66,845
18-21	1	13	$ 2,305	$ 51,171
22-35	2	78	$ 5,993	$ 369,722
36-50	0	19	$ 0	$ 116,173

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AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
51+	0	20	$ 0	$ 102,803
TOTAL	7	145	$ 23,050	$ 706,714
NATURAL SUPPORT TRAINING SELF-DIRECTED				
<18	4	10	$ 7,354	$ 18,489
18-21	1	4	$ 800	$ 11,452
22-35	2	4	$ 1,276	$ 11,354
51+	0	1	$ 0	$ 3,574
TOTAL	7	19	$ 9,430	$ 44,869
PREVOCATIONAL SERVICES				
18-21	1	3	$ 13,944	$ 62,874
22-35	33	20	$ 424,802	$ 365,533
36-50	5	5	$ 60,115	$ 107,449
51+	1	3	$ 2,809	$ 26,598
TOTAL	40	31	$ 501,670	$ 562,455
RESPITE CARE SERVICES IN THE HOME				
<18	2	3	$ 4,800	$ 11,232
18-21	3	2	$ 4,896	$ 5,568
22-35	9	11	$ 34,944	$ 47,616
36-50	3	2	$ 7,488	$ 6,336
51+	1	1	$ 1,920	$ 3,744
TOTAL	18	19	$ 54,048	$ 74,496
RESPITE SERVICES - 15 MINUTES				
<18	1	0	$ 3,743	$ 0
18-21	1	0	$ 4,101	$ 0
22-35	8	6	$ 29,167	$ 12,150
51+	0	2	$ 0	$ 11,240
TOTAL	10	8	$ 37,010	$ 23,390
RESPITE SERVICES - 15 MINUTES CO-EMPLOYER				
<18	13	13	$ 42,568	$ 36,886
18-21	7	9	$ 26,969	$ 44,975
22-35	4	29	$ 10,048	$ 113,524
36-50	1	2	$ 4,006	$ 8,726
51+	2	5	$ 171	$ 12,270
TOTAL	27	58	$ 83,762	$ 216,381
RESPITE SERVICES - OVERNIGHT CO-EMPLOYER				
<18	15	12	$ 50,112	$ 34,656
18-21	10	6	$ 22,368	$ 25,356

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AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
22-35	8	31	$ 25,536	$ 102,528
36-50	0	5	$ 0	$ 14,496
51+	1	6	$ 96	$ 21,216
TOTAL	34	60	$ 98,112	$ 198,252
SPECIALIZED MEDICAL EQUIPMENT SELF-DIRECTED				
<18	1	1	$ 2,237	$ 389
22-35	1	0	$ 200	$ 0
TOTAL	2	1	$ 2,437	$ 389
SPECIALIZED MEDICAL SUPPLIES				
<18	6	17	$ 16,279	$ 66,577
18-21	4	8	$ 10,232	$ 25,086
22-35	12	92	$ 30,999	$ 337,921
36-50	1	22	$ 3,468	$ 172,308
51+	2	33	$ 1,938	$ 202,383
TOTAL	25	172	$ 62,916	$ 804,275
SPECIALIZED MEDICAL SUPPLIES SELF-DIRECTED				
<18	22	18	$ 54,467	$ 44,624
18-21	3	14	$ 6,670	$ 26,381
22-35	7	36	$ 14,281	$ 88,846
36-50	1	2	$ 3,468	$ 5,427
51+	2	2	$ 1,501	$ 7,472
TOTAL	35	72	$ 80,387	$ 172,750
SUPPORT COORDINATION				
<18	76	82	$ 258,061	$ 229,779
18-21	47	60	$ 146,612	$ 177,952
22-35	255	413	$ 817,908	$ 1,298,410
36-50	32	83	$ 110,991	$ 263,871
51+	23	88	$ 59,012	$ 247,207
TOTAL	433	726	$ 1,392,584	$ 2,217,219
SUPPORTED EMPLOYMENT - GROUP				
22-35	14	6	$ 125,718	$ 43,045
36-50	0	2	$ 0	$ 26,849
51+	1	0	$ 14,131	$ 0
TOTAL	15	8	$ 139,849	$ 69,894
SUPPORTED EMPLOYMENT - INDIVIDUAL				
<18	1	0	$ 7,180	$ 0
18-21	0	1	$ 0	$ 10,670

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AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2016 TO June 30, 2017

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
22-35	33	23	$ 349,678	$ 234,638
36-50	2	2	$ 5,217	$ 15,613
51+	1	1	$ 20,274	$ 6,447
TOTAL	37	27	$ 382,349	$ 267,368
SUPPORTED EMPLOYMENT - INDIVIDUAL CO-EMPLOYER				
<18	0	2	$ 0	$ 41,816
18-21	0	2	$ 0	$ 9,657
22-35	1	3	$ 15,135	$ 20,389
36-50	0	1	$ 0	$ 6,882
51+	1	0	$ 10,670	$ 0
TOTAL	2	8	$ 25,805	$ 78,744
SUPPORTED EMPLOYMENT SELF-DIRECTED				
<18	1	0	$ 2,450	$ 0
TOTAL	1	0	$ 2,450	$ 0
THERAPEUTIC BEHAVIORAL SERVICES PER 15 MINUTES (INDIVIDUAL)				
<18	5	12	$ 14,984	$ 26,741
18-21	2	13	$ 1,955	$ 37,131
22-35	5	71	$ 13,170	$ 167,323
36-50	1	11	$ 2,262	$ 22,806
51+	2	10	$ 1,414	$ 16,572
TOTAL	15	117	$ 33,785	$ 270,572
TRANSPORTATION SERVICES				
22-35	3	1	$ 7,276	$ 5,595
TOTAL	3	1	$ 7,276	$ 5,595
TRANSPORTATION SERVICES - TRIP CO-EMPLOYER				
18-21	0	1	$ 0	$ 5,594
22-35	4	2	$ 9,819	$ 4,137
TOTAL	4	3	$ 9,819	$ 9,731
GRAND TOTAL	434	736	$ 14,332,924	$127,574,622

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PRINT DATE: 11/16/2017PAGE

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2015 TO June 30, 2016

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
ADULT OT THERAPEUTIC ACTIVITIES SELF-DIRECTED				
22-35	1	1	$ 2,625	$ 178
TOTAL	1	1	$ 2,625	$ 178
ADULT PT THERAPEUTIC PROCEDURE				
22-35	0	1	$ 0	$ 1,786
TOTAL	0	1	$ 0	$ 1,786
ADULT PT THERAPEUTIC PROCEDURE SELF-DIRECTED				
22-35	0	3	$ 0	$ 4,055
TOTAL	0	3	$ 0	$ 4,055
ADULT SPEECH LANGUAGE EVALUATION SELF-DIRECTED				
22-35	0	2	$ 0	$ 165
TOTAL	0	2	$ 0	$ 165
ADULT SPEECH LANGUAGE THERAPY				
22-35	0	1	$ 0	$ 3,502
TOTAL	0	1	$ 0	$ 3,502
ADULT SPEECH LANGUAGE THERAPY SELF-DIRECTED				
22-35	0	6	$ 0	$ 7,066
36-50	0	1	$ 0	$ 3,502
51+	1	1	$ 863	$ 625
TOTAL	1	8	$ 863	$ 11,193
ADULT SPEECH-GENERATING DEVICE THERAPY SELF-DIRECTED				
22-35	0	4	$ 0	$ 3,559
TOTAL	0	4	$ 0	$ 3,559
BEHAVIORAL SUPPORT CONSULTATION SELF-DIRECTED				
<18	0	2	$ 0	$ 2,700
22-35	0	1	$ 0	$ 1,620
TOTAL	0	3	$ 0	$ 4,320
BEHAVIORAL SUPPORTS CONSULTATION SELF-DIRECTED				
<18	16	17	$ 43,922	$ 47,424
18-21	1	4	$ 972	$ 14,527
22-35	2	20	$ 7,108	$ 51,626
51+	1	5	$ 3,980	$ 14,986
TOTAL	20	46	$ 55,982	$ 128,563
BEHAVIORAL SUPPORTS SERVICES				
18-21	0	2	$ 0	$ 3,600
22-35	0	8	$ 0	$ 18,750

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AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
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FROM July 01, 2015 TO June 30, 2016

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
36-50	0	1	$ 0	$ 713
51+	0	3	$ 0	$ 3,413
TOTAL	0	14	$ 0	$ 26,475
COMMUNITY ACCESS GROUP				
<18	0	4	$ 0	$ 45,852
18-21	6	8	$ 67,323	$ 225,396
22-35	166	224	$ 4,107,565	$ 6,777,005
36-50	29	55	$ 779,021	$ 1,651,825
51+	17	56	$ 273,274	$ 1,448,666
TOTAL	218	347	$ 5,227,183	$ 10,148,745
COMMUNITY ACCESS GROUP CO-EMPLOYER				
<18	37	14	$ 279,938	$ 64,954
18-21	15	5	$ 104,839	$ 21,888
22-35	13	24	$ 105,765	$ 214,669
36-50	0	3	$ 0	$ 24,751
51+	0	1	$ 0	$ 12,802
TOTAL	65	47	$ 490,542	$ 339,064
COMMUNITY ACCESS INDIVIDUAL				
<18	7	9	$ 55,983	$ 84,185
18-21	4	8	$ 26,935	$ 111,106
22-35	45	76	$ 401,081	$ 901,619
36-50	8	23	$ 44,905	$ 270,591
51+	4	26	$ 46,661	$ 284,099
TOTAL	68	142	$ 575,564	$ 1,651,600
COMMUNITY ACCESS INDIVIDUAL CO-EMPLOYER				
<18	50	25	$ 540,538	$ 295,581
18-21	13	12	$ 194,046	$ 106,420
22-35	34	61	$ 269,835	$ 777,053
36-50	0	4	$ 0	$ 50,957
51+	5	6	$ 56,311	$ 78,072
TOTAL	102	108	$ 1,060,730	$ 1,308,083
COMMUNITY GUIDE CO-EMPLOYER				
<18	1	1	$ 500	$ 4,000
TOTAL	1	1	$ 500	$ 4,000
COMMUNITY LIVING SUPPORT - 15 MINUTES				
<18	18	26	$ 276,167	$ 1,534,557
18-21	6	7	$ 103,417	$ 349,661

NOTES:
1. SSN was used to intersect those individuals from CIS with Authorization Data.
2. The following primary or secondary diagnosis were used to identify Autism participants: 'Autism','Autistic Disorder','Pervasive Developmental Disorder'
3. Report uses authorizations for services
4. If there are no age category for a service then there were no participants in that age category/service.
5. Age is calculated at the end of the period.

SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

DBHDD

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2015 TO June 30, 2016

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
22-35	10	61	$ 115,499	$ 3,799,273
36-50	5	8	$ 79,167	$ 516,446
51+	1	16	$ 4,804	$ 767,202
TOTAL	40	118	$ 579,054	$ 6,967,139
COMMUNITY LIVING SUPPORT - 15 MINUTES CO-EMPLOYER				
<18	64	38	$ 1,261,566	$ 1,703,136
18-21	24	18	$ 453,081	$ 784,074
22-35	38	95	$ 547,875	$ 3,740,661
36-50	1	7	$ 32,137	$ 171,467
51+	9	9	$ 198,153	$ 387,153
TOTAL	136	167	$ 2,492,812	$ 6,786,491
COMMUNITY LIVING SUPPORT - DAILY				
<18	0	11	$ 0	$ 490,400
18-21	0	12	$ 0	$ 1,114,551
22-35	0	42	$ 0	$ 4,607,742
36-50	0	16	$ 0	$ 2,243,436
51+	0	9	$ 0	$ 681,547
TOTAL	0	90	$ 0	$ 9,137,676
COMMUNITY LIVING SUPPORT - DAILY CO-EMPLOYER				
<18	0	13	$ 0	$ 501,173
18-21	0	12	$ 0	$ 624,613
22-35	0	45	$ 0	$ 2,300,058
36-50	0	4	$ 0	$ 279,047
51+	0	3	$ 0	$ 103,428
TOTAL	0	77	$ 0	$ 3,808,319
COMMUNITY LIVING SUPPORT LPN				
<18	0	1	$ 0	$ 1,680
18-21	0	1	$ 0	$ 153,300
22-35	0	3	$ 0	$ 228,559
36-50	0	3	$ 0	$ 129,299
51+	0	1	$ 0	$ 39,296
TOTAL	0	9	$ 0	$ 552,134
COMMUNITY LIVING SUPPORT RN				
<18	0	1	$ 0	$ 960
18-21	0	1	$ 0	$ 87,600
22-35	0	7	$ 0	$ 15,710
36-50	0	3	$ 0	$ 13,280

NOTES:
1. SSN was used to intersect those individuals from CIS with Authorization Data.
2. The following primary or secondary diagnosis were used to identify Autism participants: 'Autism','Autistic Disorder','Pervasive Developmental Disorder'
3. Report uses authorizations for services
4. If there are no age category for a service then there were no participants in that age category/service.
5. Age is calculated at the end of the period.

SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

DBHDD

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2015 TO June 30, 2016

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
51+	0	1	$ 0	$ 1,440
TOTAL	0	13	$ 0	$ 118,990
COMMUNITY RESIDENTIAL ALTERNATIVE - DAILY				
<18	0	4	$ 0	$ 371,922
18-21	0	16	$ 0	$ 1,809,089
22-35	0	146	$ 0	$ 17,259,077
36-50	0	52	$ 0	$ 5,833,333
51+	0	49	$ 0	$ 5,737,826
TOTAL	0	267	$ 0	$ 31,011,247
COMMUNITY RESIDENTIAL ALTERNATIVE LPN				
18-21	0	2	$ 0	$ 58,914
22-35	0	2	$ 0	$ 87,588
36-50	0	9	$ 0	$ 824,469
51+	0	7	$ 0	$ 748,248
TOTAL	0	20	$ 0	$ 1,719,218
COMMUNITY RESIDENTIAL ALTERNATIVE RN				
18-21	0	2	$ 0	$ 32,960
22-35	0	2	$ 0	$ 3,640
36-50	0	9	$ 0	$ 26,510
51+	0	7	$ 0	$ 20,340
TOTAL	0	20	$ 0	$ 83,450
ENVIRONMENTAL ACCESSIBILITY ADAPTATION SELF-DIRECTED				
<18	1	0	$ 8,000	$ 0
22-35	0	1	$ 0	$ 2,189
TOTAL	1	1	$ 8,000	$ 2,189
FINANCIAL SUPPORT SERVICES				
<18	79	44	$ 127,125	$ 61,950
18-21	30	24	$ 49,650	$ 36,750
22-35	55	119	$ 73,275	$ 184,350
36-50	2	10	$ 3,600	$ 17,175
51+	9	10	$ 14,100	$ 13,275
TOTAL	175	207	$ 267,750	$ 313,500
INDIVIDUAL DIRECTED GOODS AND SERVICES				
<18	7	4	$ 11,290	$ 6,840
18-21	1	2	$ 3,000	$ 2,552
22-35	7	19	$ 8,175	$ 26,298
36-50	0	2	$ 0	$ 2,037

NOTES:

1. SSN was used to intersect those individuals from CIS with Authorization Data.
2. The following primary or secondary diagnosis were used to identify Autism participants: 'Autism','Autistic Disorder','Pervasive Developmental Disorder'
3. Report uses authorizations for services
4. If there are no age category for a service then there were no participants in that age category/service.
5. Age is calculated at the end of the period.

SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

DBHDD

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2015 TO June 30, 2016

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
51+	3	2	$ 2,766	$ 2,399
TOTAL	18	29	$ 25,231	$ 40,126
NATURAL SUPPORT TRAINING SELF-DIRECTED				
<18	5	9	$ 6,469	$ 23,487
18-21	1	1	$ 836	$ 3,574
22-35	3	2	$ 3,165	$ 2,993
51+	1	3	$ 1,000	$ 8,648
TOTAL	10	15	$ 11,471	$ 38,702
PREVOCATIONAL SERVICES				
18-21	2	2	$ 3,143	$ 36,989
22-35	32	23	$ 402,470	$ 338,548
36-50	6	6	$ 62,415	$ 124,589
51+	1	4	$ 28,737	$ 41,636
TOTAL	41	35	$ 496,766	$ 541,762
RESPITE CARE SERVICES IN THE HOME				
<18	4	1	$ 8,160	$ 2,880
18-21	1	0	$ 5,568	$ 0
22-35	7	11	$ 28,896	$ 28,992
36-50	2	1	$ 6,720	$ 1,248
51+	2	2	$ 3,456	$ 7,392
TOTAL	16	15	$ 52,800	$ 40,512
RESPITE SERVICES - 15 MINUTES				
<18	1	0	$ 472	$ 0
18-21	1	1	$ 1,558	$ 7,401
22-35	7	6	$ 27,546	$ 8,782
36-50	1	1	$ 522	$ 42
TOTAL	10	8	$ 30,097	$ 16,225
RESPITE SERVICES - 15 MINUTES CO-EMPLOYER				
<18	18	9	$ 60,464	$ 32,236
18-21	8	6	$ 28,293	$ 30,509
22-35	5	29	$ 13,273	$ 103,279
36-50	1	3	$ 4,011	$ 6,579
51+	2	4	$ 4,321	$ 23,704
TOTAL	34	51	$ 110,362	$ 196,307
RESPITE SERVICES - OVERNIGHT CO-EMPLOYER				
<18	19	9	$ 57,890	$ 31,222
18-21	6	5	$ 10,657	$ 18,528

NOTES:
1. SSN was used to intersect those individuals from CIS with Authorization Data.
2. The following primary or secondary diagnosis were used to identify Autism participants: 'Autism','Autistic Disorder','Pervasive Developmental Disorder'
3. Report uses authorizations for services
4. If there are no age category for a service then there were no participants in that age category/service.
5. Age is calculated at the end of the period.

SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

DBHDD

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2015 TO June 30, 2016

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
22-35	9	27	$ 27,648	$ 78,076
36-50	0	5	$ 0	$ 18,624
51+	2	3	$ 4,416	$ 6,624
TOTAL	36	49	$ 100,611	$ 153,074
SPECIALIZED MEDICAL EQUIPMENT SELF-DIRECTED				
<18	0	1	$ 0	$ 2,093
22-35	0	1	$ 0	$ 250
TOTAL	0	2	$ 0	$ 2,343
SPECIALIZED MEDICAL SUPPLIES				
<18	11	16	$ 23,377	$ 55,620
18-21	2	11	$ 6,764	$ 49,236
22-35	13	72	$ 32,281	$ 244,436
36-50	2	24	$ 3,469	$ 186,903
51+	2	24	$ 1,547	$ 135,050
TOTAL	30	147	$ 67,438	$ 671,245
SPECIALIZED MEDICAL SUPPLIES SELF-DIRECTED				
<18	26	17	$ 67,854	$ 39,048
18-21	3	10	$ 6,719	$ 17,211
22-35	6	32	$ 10,106	$ 85,756
36-50	1	3	$ 3,468	$ 10,796
51+	2	2	$ 4,342	$ 5,136
TOTAL	38	64	$ 92,489	$ 157,947
SUPPORT COORDINATION				
<18	96	74	$ 304,690	$ 211,433
18-21	39	49	$ 131,018	$ 161,136
22-35	230	350	$ 743,150	$ 1,170,296
36-50	34	81	$ 107,780	$ 277,020
51+	25	79	$ 69,713	$ 247,207
TOTAL	424	633	$ 1,356,351	$ 2,067,091
SUPPORTED EMPLOYMENT - GROUP				
22-35	13	5	$ 112,063	$ 29,769
36-50	0	2	$ 0	$ 26,849
51+	0	2	$ 0	$ 10,057
TOTAL	13	9	$ 112,063	$ 66,676
SUPPORTED EMPLOYMENT - INDIVIDUAL				
18-21	1	0	$ 20,274	$ 0
22-35	25	18	$ 281,728	$ 156,521

NOTES:
1. SSN was used to intersect those individuals from CIS with Authorization Data.
2. The following primary or secondary diagnosis were used to identify Autism participants: 'Autism','Autistic Disorder','Pervasive Developmental Disorder'
3. Report uses authorizations for services
4. If there are no age category for a service then there were no participants in that age category/service.
5. Age is calculated at the end of the period.

SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

DBHDD

NUMBER and AUTHORIZED AMOUNTS FOR SERVICES
AUTISM PARTICIPANTS RECEIVING NOW AND COMP WAIVER
BY AGE CATEGORY,and SERVICE and WAIVER
FROM July 01, 2015 TO June 30, 2016

	NOW PARTICIPANTS	COMP PARTICIPANTS	NOW AUTHORIZED AMOUNT	COMP AUTHORIZED AMOUNT
36-50	1	2	$ 3,083	$ 20,333
51+	3	4	$ 18,984	$ 13,027
TOTAL	30	24	$ 324,069	$ 189,881
SUPPORTED EMPLOYMENT - INDIVIDUAL CO-EMPLOYER				
<18	0	2	$ 0	$ 41,816
18-21	1	1	$ 1,502	$ 5,222
22-35	2	2	$ 15,880	$ 10,951
36-50	0	1	$ 0	$ 13,764
TOTAL	3	6	$ 17,382	$ 71,753
SUPPORTED EMPLOYMENT SELF-DIRECTED				
<18	1	0	$ 2,450	$ 0
TOTAL	1	0	$ 2,450	$ 0
THERAPEUTIC BEHAVIORAL SERVICES PER 15 MINUTES (INDIVIDUAL)				
<18	3	5	$ 11,874	$ 10,013
18-21	1	9	$ 94	$ 32,876
22-35	4	30	$ 11,309	$ 87,337
36-50	1	2	$ 2,262	$ 6,715
51+	0	5	$ 0	$ 9,777
TOTAL	9	51	$ 25,539	$ 146,718
TRANSPORTATION SERVICES				
22-35	1	1	$ 1,323	$ 2,797
51+	1	0	$ 5,595	$ 0
TOTAL	2	1	$ 6,918	$ 2,797
TRANSPORTATION SERVICES - TRIP CO-EMPLOYER				
18-21	0	1	$ 0	$ 4,196
22-35	5	3	$ 15,481	$ 5,312
TOTAL	5	4	$ 15,481	$ 9,508
GRAND TOTAL	424	635	$ 13,609,122	$ 78,548,307

NOTES:
1. SSN was used to intersect those individuals from CIS with Authorization Data.
2. The following primary or secondary diagnosis were used to identify Autism participants: 'Autism','Autistic Disorder','Pervasive Developmental Disorder'
3. Report uses authorizations for services
4. If there are no age category for a service then there were no participants in that age category/service.
5. Age is calculated at the end of the period.

SOURCES: AUTISM: CIS DATAFILE, 11/11/2017
AUTHORIZATIONS: HISTORICAL AUTHORIZATIONS DATAFILE 201709, 10/05/2017

TABLE PREPARED BY: Office of Performance Analysis, 11/15/2017.

Appendix O: Number of Children Admitted to NOW and COMP Waivers in FY2017

Number of Children Admitted to NOW and COMP Waivers in FY 2017

The determination of the number of children admitted to the NOW and COMP waiver services was based on a data table from the DBHDD Office of Performance Analysis. This appendix contains the applicable data table.

The number of individuals below 18 admitted to the NOW and COMP wavier in FY 2017 (7/1/2016 to 6/30/2017) is provided by ages for each of the six DBHDD regions in the table entitled Waiver Demographics Report for NOW/COMP Waiver Participants in Authorized Services 7/1/2017 to 6/30/2017 Statewide. The numbers of children (those less than 18 years old) for each region were added to obtain the statewide total number of children with first time admissions to the NOW and COMP waivers (i.e., 43). This total number was compared to the statewide total number of individuals added to the waivers as indicated on the second page of the table. The percentage of children was determined as follows:

Number of children (<18 years) with waiver admissions in FY 2017 = 43/579 or 7.4%

DBHDD

WAIVER DEMOGRAPHICS REPORT
FOR NOW/COMP WAIVER PARTICIPANTS IN AUTHORIZED SERVICES
7/1/2016 to 6/30/2017
STATEWIDE

	FIRST TIME ADMISSIONS			DISCHARGES		
	NOW	COMP	TOTAL	NOW	COMP	TOTAL
TOTAL NUMBER OF WAIVER PARTICIPANTS						
REGION 1						
AGE						
<18	2	5	7	2	2	4
18-21	9	14	23	16	0	2
22-35	59	22	81	16	11	27
36-50	5	12	17	9	6	15
51+	14	22	36	7	30	37
REGION 1 TOTAL	89	75	164	36	49	85
REGION 2						
<18	0	8	8	1	1	1
18-21	3	9	12	0	1	1
22-35	18	20	38	7	7	14
36-50	0	7	7	8	7	15
51+	5	11	16	9	31	40
REGION 2 TOTAL	26	55	81	24	47	71
REGION 3						
<18	7	6	13	0	0	0
18-21	1	7	8	0	0	0
22-35	71	16	87	3	1	4
36-50	5	4	9	1	6	8
51+	8	13	21	2	6	6
REGION 3 TOTAL	92	46	138	6	6	19
REGION 4						
<18	0	4	4	0	0	0
18-21	1	6	7	5	0	1
22-35	5	10	15	5	4	9
36-50	0	1	1	8	5	8
51+	1	9	10	23	15	8
REGION 4 TOTAL	7	30	37	17	24	41
REGION 5						
<18	0	6	6	0	0	0
18-21	5	9	14	0	0	0
22-35	30	17	47	1	8	9
36-50	8	10	18	2	18	20
51+	24	20	24	2	18	20
REGION 5 TOTAL	47	62	109	9	27	36
REGION 6						

WAIVER DEMOGRAPHICS REPORT
FOR NOW/COMP WAIVER PARTICIPANTS IN AUTHORIZED SERVICES
7/1/2016 to 6/30/2017
STATEWIDE

		FIRST TIME ADMISSIONS			DISCHARGES	
	NOW	COMP	TOTAL	NOW	COMP	TOTAL
<18	0	5	5	0	0	0
18-21	0	5	5	0	0	0
22-35	5	15	20	5	5	10
36-50	4	4	8	3	4	7
51+	2	9	11	15	15	30
REGION 6 TOTAL	11	38	49	23	24	47
GRAND TOTAL	273	306	579	116	185	301

NOTES
1. Total number of unduplicated authorizations x waiver type = total number of authorizations during report period
2. Unduplicated totals of participants do not equal totals x waiver since some participants can be active in both.
3. Number of participants prior to report period - FYTD through previous month.
4. Transfers includes those who transfer from one waiver to another.
5. Living Situation includes the following categories: (1) Community Living Arrangement = Community Living Arrangement (CLA), Community Living Arrangement (CLA) - 3 Person, Community Living Arrangement (CLA) - 4 Person; Community Living Arrangement (CLA) - 5 Person; (2) Personal Care Home = Personal Care Home (PCH), Personal Care Home (PCH) - 3, Person Personal Care Home (PCH) - 4 Person ;Person Personal Care Home (PCH) - 5 Person ; (3) Indpendent = Independent Apartment/Home; (4) Host Home = Host Home and Foster Care; and (5) Family Friends Other =(a) 'Live with Family/Relative/Caretaker,(b) Other,and (c) 'Live with Friends/Others Non-Caretaker.
5. Age is calculated at beginning of period.
6. Discharge data has not been validated with other data sources; therefore sdhould be used with cauthion

SOURCE: HISTORICAL AUTHORIZTION DATAFILE 20171005 TABLE PREPARED BY: Office of Performance Analysis.