

# **Georgia Developmental Disabilities Council**

## **Health System Analysis**

### **2017-22 State Plan**

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# Health System Analysis

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## Introduction

Health has a broad set of parameters. Individuals with developmental disabilities have been excluded until recent years from this larger environment. Preventive health care for children and adults, the transition from pediatric to adult health providers and then into the aging system, nutrition, exercise, emotional and mental wellness are all essential to health and well-being.

The health of individuals with developmental disabilities can be understood broadly as a state of complete physical, mental, and social well-being, not merely the absence of disease or disability. The term “health care” encompasses physical, mental, behavioral, vision, hearing, oral and dental health care, substance abuse and addiction services, and services and supports that assist in attaining, maintaining, and improving skills, function, and community participation.<sup>1</sup>

Discussions about health usually start by looking at the insurance available to pay for medical care and services. For individuals with developmental disabilities, that is either Medicaid/SCHIP or their parents’ own private health insurance up to age 26. Within the insurance context, questions about what services are covered, out-of-pocket costs for private insurance, and eligibility for specialty care are all significant subtexts. Medicaid is also the funding source for Home and Community Based Services, permissible through waivers designed by the state and approved by the Centers for Medicare and Medicaid Services (CMS).

As the Georgia Developmental Disabilities Council (GDDC) looks forward to the five-year plan that begins in 2017, there are major themes that will affect the quality of life for individuals with developmental disabilities in their quest for health and well-being. Each of these is discussed further.

1. A number of states are moving rapidly to contain costs in their Medicaid programs by contracting with national insurance companies through managed care organizations (MCO). It is too soon to measure the qualitative impact on the affected client populations, and advocates for persons with disabilities are appropriately apprehensive that cost containment will override quality of services.
2. People with disabilities are a health disparity population.
3. There is a critical lack of primary care, dental and specialty medical personnel to treat the health care needs of individuals with disabilities, especially in Georgia’s rural communities.
4. Transitions from pediatric to adult health care are difficult, at best, and negatively affect health outcomes. The aging of Georgia’s individuals with disabilities adds a further transition to this challenge, one that has received little attention from health care providers.
5. Inter-agency collaboration does not yet function at a system of care level. Resource challenges that affect an individual’s quality of life (i.e. mental health services for individuals with developmental disabilities) are not yet addressed jointly or at a level of detail that resolves problems for individuals.

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<sup>1</sup> <http://www.thearc.org/who-we-are/position-statements/life-in-the-community/health-care>

## **Analysis of Major Themes and Conclusions**

### **Conclusion and implications # 1: Cost Containment and Managed Care Initiatives.**

Advocates for persons with disabilities are appropriately apprehensive that cost containment will override quality of services as states move rapidly to contain costs in their Medicaid programs. The strategy used by other states involves contracting with national insurance companies through managed care organizations (MCO). Most of these conversions have occurred in the past 3 years, and therefore it is too soon to measure the qualitative impact on the affected populations. Georgia currently exempts individuals with developmental delays who are receiving Medicaid HCBS waiver or are on the waiting list. These individuals receive their health care through fee for service state plan services, and their community support services through the Medicaid waiver.

### **State Medicaid Rush to Contain Costs in Long Term Services and Supports**

State legislatures across the country are very concerned that the costs of Medicaid services are driving their state budget. As a result, state Medicaid programs are moving away from traditional fee-for-service delivery systems and toward capitated programs for the delivery of both acute care and long-term services and supports. More than half of the states have embraced this strategy; most are in the initial years of transition, so results are unclear. The newest managed long-term services and supports (MLTSS) programs are focused on providing services to Medicaid's most vulnerable populations, namely seniors and people with disabilities with complex medical, behavioral, and long-term services and supports needs. They seek to integrate basic important goals for serving these individuals, including expanding access to home and community-based services, increasing the quality and experience of care, and promoting efficiency.

States with existing programs for the adult, blind and disabled (ABD) population are:

1. Arizona Medicaid-- ALTCS (Arizona's Managed Long Term Care) program has continued to grow through the end of 2015 and into 2016, primarily in the state's Acute Care managed care program.
2. Hawaii Medicaid-- On January 1, 2015, Hawaii implemented its integrated Medicaid managed care program, combining QUEST managed Medicaid and QUEST Expanded Access (QExA), which provides managed Medicaid to the aged, blind, and disabled (ABD) populations.
3. Minnesota Medicaid-- Special Needs BasicCare
4. New York Medicaid-- Managed LTC
5. Ohio Medicaid
6. Wisconsin Medicaid—Family Care, in place for 20 years, and Respect, I Self-Direct (IRIS) program (2008) offers adults with disabilities and frail elders to determine the services and supports they need and how they want those services and supports to be delivered. These programs are currently operated by local government or regional collaborative organizations. Family Care/IRIS 2.0 will establish a coordinated-care model that focuses on the overall health of the individual and will coordinate all of an individual's care needs, including long-term care, primary

and acute care, and behavioral health care. It will require CMS waivers, a bidding process to select vendors, and transition of existing populations.<sup>2</sup>

**Georgia’s Challenge**

In FY 2016, the ABD population accounts for 18.9% of the Medicaid beneficiaries, but consumes 53.1% of the expenditures. FY 2016 expenditures for the total ABD population are estimated as \$1,638,816,761<sup>34</sup>.

**Table 1: ABD Eligibility by Age--February 2016<sup>5</sup>**

Grouping by age	Member Count
<b>Total</b>	315,508
0 to 5	11,090
6 to 10	16,194
11 to 17	24,260
18 to 25	23,808
26 to 39	38,443
40 to 64	118,009
65 to 74	39,572
greater 75	40,551
Katie Beckett	2,970

Analyzing the Medicaid claims and expenses for persons enrolled in the NOW and COMP waivers, identifies 46,553 claims for a total expense of \$523,063,971.25 from April 2015 to February 2016.

A significant number of persons with various disabilities are waiting for the six Georgia waiver services. Their health needs are provided by basic Medicaid.

**Table 2: ABD population Enrolled in Medicaid, by Primary Diagnosis (not on Support Waivers)<sup>6</sup>**

Developmental Disabilities as Primary Diagnosis Code	10,518
Traumatic Brain Injury as Primary Diagnosis Code	7,491
Autism Spectrum Disorder as Primary Diagnosis Code	8,419

<sup>2</sup> Family Care/IRIS 2.0 Concept Paper. Wisconsin Department of Health Services. March 2016

<sup>3</sup> DCH Budget Update, FY 2016 and FY 2017 Requests, PowerPoint presented to DCH Board, August 27, 2015, pages 4 and 7.

<sup>4</sup> DCH Budget Update, FY 2016 and FY 2017 Requests, PowerPoint presented to DCH Board, April 14, 2016. Page 4.

<sup>5</sup> Report is based on eligibility data for Feb-2016 provided by Medicaid Program office

<sup>6</sup> Unduplicated count of members based on claims paid from April 1, 2015 through March 2016, and not in COS 680 (NOW) or 681 (COMP). Data provided by Medicaid Program office May 13, 2016,

**Table 3: Georgia Waiver Wait List Summary**

Waiver Name <sup>7</sup>	Population Served	Institution Waived	Active as of 9/30/15	Active as of 12/31/15	Wait List as of 12/31/15
<b>Community Care Services Program</b>	Elderly and disabled	Nursing facility	8,866	8,330	2,503
<b>SOURCE</b>	Elderly and disabled	Nursing facility	15,311	15,678	0
<b>Independent Care Waiver Program</b>	Severely physically disabled	Nursing facility Hospital	1,375	1380	115
<b>New Options Waiver</b>	Developmental disabilities	ICF-MR	4,620	4,570	STPL: 3,007 LTPL: 5,297 Total: 8,304
<b>Comprehensive Supports Waiver</b>	Developmental disabilities	ICF-MR	7,297	7,399	
<b>Georgia Pediatric Program</b>	Medically fragile children under age 5	Nursing facility/ Hospital	0	0	No Waiting list No current enrolled providers
<b>Total</b>			<b>37,469</b>	<b>37,357</b>	<b>19.226</b>

**Table 4: Average Expenditure Per Month for Enrolled Waiver Members<sup>8</sup>**

Number of enrollees	11,969
Average Expenditure per month (11 months)	\$47,551,270.11
Average expenditure per member per month	\$3,972.87
Annualized average expenditure per member	\$47,674.43

Persons on the Comprehensive Supports Waiver (COMP) and New Options Waiver (NOW) waiting lists may be on either a long term or short term planning list, determined by the complexity of their needs. The data for 2016 by region and type of waiver is below.

<sup>7</sup> Source: Brian Dowd, Georgia Department of Community Health, Medicaid Program, 4/8/16

<sup>8</sup> Marcey Alter, May 1, 2016

**Table 5: Planning List--Numbers of Persons on Short Term & Long Term Lists by Regions as of January 1, 2016<sup>9</sup>**

Region	LTPL	STPL Immediate	STPL Level 1	STPL Level 2	STPL Level 3	Total
Region 1	1,254	5	10	92	214	1,575
Region 2	579	23	70	114	286	1,072
Region 3	1,698	7	10	90	911	2,716
Region 4	453		22	83	220	778
Region 5	617	27	69	158	343	1,214
Region 6	696	7	48	39	159	949
<b>Total</b>	<b>5,297</b>	<b>69</b>	<b>229</b>	<b>576</b>	<b>2,133</b>	<b>8,304</b>

**Table 6: Service Needs of Planning List Members as of November 1, 2015<sup>10</sup>**

Services Need	LTPL	STPL	Total
Adult Occupational Therapy Services	40	38	78
Adult Physical Therapy Services	35	38	73
Adult Speech and Language Therapy Services	66	64	130
Behavioral Support Services	318	190	508
Behavioral Supports Consultation	4	11	15
Community Access Group Services	2,435	1,361	3,796
Community Access Individual Services	448	301	749
Community Living Support Services	1,394	854	2,248
Community Residential Alternative	1,068	603	1,671
Environmental Accessibility Adaptation	27	25	52
Financial Support Services	16	16	32
Georgia Crises Response System (GCRS)	4	22	26
Individual Directed Goods and Services	90	27	117
Natural Support Training Services	346	94	440
Prevocational Services	241	205	446
Respite Services	796	563	1,359
Specialized Medical Equipment	114	66	180
Specialized Medical Supplies	326	234	560
Supported Employment Group Services	938	429	1,367
Supported Employment Individual Services	449	233	682
Transition Services	9	10	19
Transportation	182	132	314

<sup>9</sup> Source data: CIS as of January 1, 2016

<sup>10</sup> Source data: CIS as of November 1, 2015

Services Need	LTPL	STPL	Total
Vehicle Adaptations	15	10	25
<b>Total</b>	<b>9,361</b>	<b>5,526</b>	<b>14,887</b>

### **CARE-M recommendations**

The Georgia Developmental Disabilities Council has supported the Coalition to Assure Redesign Effectiveness in Medicaid (CARE-M) since 2012. This is a coalition of consumers, advocacy organizations and providers that meets periodically to examine promising practices in managed care for special need populations, called the Aged, Blind and Disabled (ABD) population

In early 2012, the Department of Community Health received a report from Navigant titled “Medicaid and PeachCare for Kids® Design Strategy Report”. CARE-M members reviewed this report thoroughly, and developed an extensive set of recommendations to the Department for its consideration in developing a managed care plan. That July 2012 report was incorporated extensively into RFPs by the state in 2013.

In 2016, CARE-M has reassembled and accepted the task of identifying critical transitions and health issues of the various ABD populations, and identifying promising practices in managed care that address these populations qualitatively. The group plans to make recommendations to the Department of Community Health if they again decide to implement managed care for this population. The last RFP was the summer of 2013, but was canceled without awarding any contracts. Only Georgia Families 360, services for children in state custody, has been implemented.

### **Georgia Families 360®--Georgia Department of Community Health MCO initiative<sup>11</sup>**

Georgia Families 360<sup>SM</sup>, the state’s managed care program for approximately 25,000 children, youth, and young adults in foster care, children and youth receiving adoption assistance, and select youth involved in the juvenile justice system, launched on March 3, 2014. Amerigroup Community Care of Georgia, one of the state’s CMOs, will provide health care coverage for these populations.

Georgia Families 360° program goals are to:

- Improve access to health care services, particularly for physical and behavioral health services covered by the Medicaid program.
- Increase continuity of care, including when members transition in and out of foster care.
- Enhance health outcomes, providing additional care coordination, and improved physical and behavioral health oversight.

Results from the first full year of operation (Q4 2014 to Q4 2015) shows a 13% decrease in inpatient hospital admissions; 15% decrease in emergency room visits; a 6% reduction in psychological treatment residential center (PRTF) admissions, and a 2% reduction in the PRTF readmission rate. Complex care coordination is provided for children with intensive needs, including medically fragile children, those

<sup>11</sup> <http://dch.georgia.gov/foster-care-adoption-assistance-juvenile-justice-%E2%80%93-georgia-families-360>



with multiple needs (often including behavioral challenges), and those admitted to/discharged from PRTS facilities. A total of 696 children received this care on the most recent report from AmeriGroup.<sup>12</sup>

Members of the Georgia Families 360° program receive a number of services to improve care coordination, access to care, and health outcomes:

- Members have a medical and dental home to promote consistency and continuity of care. A primary care provider and primary dental provider is selected or assigned for each member.
- Regional Care Coordination Teams to help coordinate care and schedule appointments.

Each member has an assigned care coordination team to work closely with Division of Family and Children Services (DFCS) and Department of Juvenile Justice (DJJ) personnel and affiliated providers across the state.

The collaboration of the care coordination teams and agency staff involve the development of health care plans and the monitoring and measurement of each member's health outcomes. Providers, foster parents, adoptive parents and other caregivers will be involved in the ongoing health care plans to ensure that the physical and behavioral health needs of these populations are met.

New initiatives since the program's inception include initiatives focused on timely early, periodic screening, detection and treatment (EPSDT) and follow-up services:

- Group home clinic days
- Mobile Assessment Unit for the urban counties of Fulton and DeKalb
- Trauma informed care training by Children's Healthcare of Atlanta
- Judges Court Healthcare Integration Program (J-CHIP) in Bartow/Newton Counties
- Region 5 (DFCS) Home in 5 Collaboration

Complex care coordination initiatives include:

- Pathways to Permanency pilot program, a partnership with CHRIS Kids, Youth Villages Inner Harbour, and the Multi-Agency Alliance for Children (MAAC). A total of 62 youth have been served to date.
- Care Management partnership between View Point Health and Lookout Mountain Community Services Board to provide intensive Customized Care Coordination to members with high intensity social/medical/behavioral needs. This program began in September 2015. Enrollment to date is 31.

24/7 Intake Line for calls from foster and adoptive parents, caregivers, providers and members. Ombudsman staff are available at both DCH and Amerigroup to support caregivers and members, and assist them in navigating the health care system.

Additionally, the medication management program focuses on appropriate monitoring of the use of psychotropic medications and ADD/ADHD medications in the Georgia Families 360° population. In the first full year it has focused on tracking members' prescription use; identifying therapeutic

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<sup>12</sup> Monitoring and Oversight Committee, April 20, 2016, PowerPoint presentation by AmeriGroup.

appropriateness, identifying whether behavioral health treatment has been initiated, and outreach to the prescribing physician to educate them on clinical practice guidelines. The result to date has been a significant decrease in medication regimens for children age 4 and under.

Both the Georgia Department of Community Health/Medicaid program and AmeriGroup have learned useful lessons about the transition of a client population to a managed care environment. Priorities to date have been on enrolling an appropriate network statewide, profiling the health experience and needs of enrolled children, improving documentation, tracking members over time, improved care coordination documentation, more robust crisis plans, evidence of progress towards goals, and a decrease in late chart entries. Monitoring and oversight priorities in the next year will be on quality and documentation of health outcomes.

## **Conclusion and implications # 2: People with disabilities are a health disparity population.**

Health disparities refer to differences in health outcomes at the population level, differences that are linked to a history of social, economic, or environmental disadvantages, and for which there is general agreement that these differences are avoidable.

Adults with intellectual or other developmental disabilities face a cascade of health disparities. They often:<sup>13</sup>

- have complex or difficult-to-treat medical conditions;
- have difficulty accessing health care;
- may receive inadequate health care;
- may have difficulties expressing their symptoms and pain;
- receive little attention to wellness, preventive care, and health promotion.

Yet these adults deserve quality, patient-centered health care as well as the general population.

The fragmentation of the health care financing resources for individuals with developmental disabilities aggravates these disparities. Consumers are not the “customer” of Medicaid; the providers of services who are paid to provide care are the customers.

### **National Core Indicators**

NCI™ is a voluntary effort by public developmental disabilities agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety. The NCI program is also recognized as a uniquely valuable source of information about individuals with developmental disabilities receiving services across a large sample of states. The NCI database includes randomly-selected representative samples by state, with 39 states planning to contribute data this year.

NCI states and project partners continue to work toward a broader vision of utilizing NCI data not only to improve practice at the state level but also to add knowledge to the field, to influence state and national policy, and to inform strategic planning initiatives for NASDDDS. Data from NCI are aggregated

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<sup>13</sup> <http://vkc.mc.vanderbilt.edu/etoolkit/resources/>

and used to support state efforts to strengthen long term care policy, inform the conduct of quality assurance activities, and compare performance with national norms.

Through participation in the program, NCI states make a commitment to share information with stakeholders so that data can be used for policy change and quality improvement. Surveys are done with individuals with developmental disabilities who are enrolled in the Medicaid Home and Community-Based Services waiver (HCBS).

The most recent results from Georgia are based on data collected in 2014-15. The following data represents items where Georgia varies from the national average. (See Data section for detailed graphs).

1. Georgia is doing very well on several indicators. 98% of respondents reported they have a primary care doctor, and only 2% reported in poor health. 93% had a physical exam in the past year, and 77% had a dental exam.
2. It is important to note that on the preventive screening and vaccination questions, individuals with developmental disabilities are not receiving these measures at an adequate rate. Only 29 percent have been vaccinated for pneumonia; 71 percent have had a flu vaccine in the last year. This is significantly below the national average.
3. Georgia individuals with developmental disabilities reported somewhat higher participation in other health screenings. Only 31 percent of individuals age 50 or older had a Colorectal Cancer screening in the past year; 56 percent of men had a PSA test. For women age 40 and over, 81percent had a mammogram in the past two years, but 77 percent had a pap test.
4. Hearing screening in the past five years (54 percent) and vision (66 percent) screening in the past year results were also low.
5. Georgia respondents ranked somewhat lower than the national average on exercise, but both rates are below desired levels. Respondents from Georgia went out for exercise an average of 7.3 times in the past month, and respondents across NCI states went an average of 10.5 times. 45% of respondents from Georgia and 55% across NCI states reported that they went out for exercise in the past month
6. Mental health issues were addressed in several ways. In the 2014-15 NCI data, the percentage of individuals taking at least one medication for mood disorders, anxiety, behavior challenges and/or psychotic disorders is 47 percent, on a par with the national data. Georgia has a higher percentage, however, of respondents taking 3-4 medications (32%) and 5-10 medications (11%).
7. Overall, 22 percent rated their health as excellent, 52 percent rated their health as very good, and 24 percent ranked it as fairly good.

### **Health Issues for Individuals Waiting for LTSS**

More than half of the individuals with developmental disabilities who are enrolled in the basic state plan are on the waiting list for the HCBS waiver, and have little interaction with a case manager except to update their eligibility. The person working with individuals on the HCBS waivers is focused primarily on the services paid by the waiver, not health care received on a fee for service basis. To address this, *Annual Health Screening Recommendations* are now included for all adults with intellectual/

developmental disabilities in the Medicaid nursing services policy. When wheelchairs or other assistive technology is inadequate for the individual's need, those expenditures are driven by the federal Medicaid rules, and there is no authority by either the Agency for Health Care Administration (ACHA) or the Department of Community Health's Medicaid program to challenge those rules.

Every major report addressing the poor health of people with disabilities has called for improvements in training of health care providers about adults with disabilities. Improved training of health care providers can support earlier identification and intervention for children with disabilities, improved services for youths with disabilities transitioning into the adult care system, and improved health care and health promotion for adults with disabilities. During times of emergency or in disaster situations, people with disabilities are less likely to be evacuated and can be especially vulnerable. Emergency preparedness means planning for the different phases of multiple disaster scenarios that could be natural or man-made. It also requires individual-level planning and training in advance of, during, and following events. Coordinated efforts and explicit planning across HHS agencies could lead to better addressing the needs of people with various limitations.

As a group, people with disabilities experience more chronic diseases and conditions, and experience them at earlier ages, making this a critically important population to include to achieve success in health promotion campaigns.

Disability is an emerging field within public health; people with significant disabilities account for more than 12 percent of the US population. People with disabilities are a diverse group who share the experience of living with significant limitations in functioning and, as a result, often experience exclusion from full participation in their communities.

Because people with some disabilities require more health care for management of their disabling conditions or increased risk of some chronic conditions, measurement of failure or delay in receiving needed care is as important as comparing receipt of care. People with disabilities consistently report higher rates of obesity, lack of physical activity, and smoking. Some also have higher rates of newly diagnosed cases of diabetes, and their percentages of cardiovascular disease are 3 to 4 times higher.<sup>14</sup> Although they have higher rates of chronic diseases than the general population, adults with disabilities are significantly less likely to receive preventive care. As an illustration, people with cognitive limitations are up to 5 times more likely to have diabetes than the general population<sup>15</sup> while potentially receiving less adequate management care.<sup>16</sup> Inclusion of people with disabilities is critically important as agencies coordinate efforts to prevent and manage chronic diseases and conditions like diabetes, cardiovascular disease, and hypertension.

The Healthy People 2020 objectives in disability and health are distributed across 4 areas: systems and policies, barriers to health care, environment, and activities and participation. Without action on these

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<sup>14</sup> Reichard A, Stolze H, Fox MH. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disabil Health J.* 2011;4 (2):59--67.

<sup>15</sup> Reichard A, Stolze H. Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. *Intellect Dev Disabil.* 2011;49(3):141---154.

<sup>16</sup> Balogh R, Brownell M, Ouellette-Kuntz H, Colantonio A. Hospitalization rates for ambulatory care sensitive conditions for persons with and without an intellectual disability---a population perspective. *J Intellect Disabil Res.* 2010;54(9):820---832

objectives, health disparities can be expected to continue and possibly increase for people with disabilities.

### **Quality Improvement Initiatives**

The Developmental Disabilities Program within the DBHDD has instituted a number of initiatives to address the health care needs of this population through the Medicaid services array and improvements in federally approved waiver programs. These include:

- A. Addition of intensive support coordination through amendment of the COMP Waiver Program. Intensive Support Coordination will provide specialized coordination of waiver services and medical and behavioral support services for participants with exceptional medical and behavioral needs. In addition to the full array of activities included in the standard support coordination service, intensive support coordinators and their clinical supervisors will assist ISC participants by conducting the following activities:
- Identifying and addressing barriers to care;
  - Accessing needed resources and services offered through the waiver and the larger healthcare system;
  - Taking active measures to address complex needs; and
  - Fostering and maintaining family and other informal relationships and supports.

Expectations for holistic care coordination and intensity of oversight will be significantly increased for waiver participants receiving this service.

#### Who will be served?

Approximately 2,000 waiver participants living in all six of DBHDD's geographic service regions meet eligibility criteria for Intensive Support Coordination.

#### How is this service provided?

- Each Intensive Support Coordination team will consist of one ISC clinical supervisor and five ISC coordinators.
  - ISC supervisors must be a registered nurse or a licensed behavioral professional (BCBA, LPC, LCSW, psychologist, or RN) with at least three years of professional experience serving individuals with I/DD.
  - ISC extenders must have a bachelor's degree in a human services field with at least two years of specialized experience with individuals in a healthcare or behavioral health setting and preferred experience with the I/DD population.
  - Each team will serve approximately 100 individuals, with no more than 20 waiver participants on each ISC coordinator's caseload.
- B. Edits to the definitions of behavioral support consultation and therapy services to eliminate barriers to service delivery setting.
- C. Edits to the definition of nursing services to eliminate barriers to service delivery setting.
- D. Participation in the Autism Services Initiative.

- E. Completion of an extensive rate study of residential, respite and in-home services that relied on provider cost data to inform development of a new rate methodology. The rate methodology, (under consideration by the Centers for Medicare and Medicaid Services at the time of this writing), proposes a tiered-rate model consistent with assessed needs and risk levels of individuals served through the COMP Waiver Program.
- F. Addition of behavioral support services through amendment of the COMP Waiver Program
- Behavioral Supports Services are those that assist the participant with significant, intensive challenging behaviors that interfere with activities of daily living, social interaction, work or similar situations through offering direct training and assistance to formal and informal care providers.
  - Positive Behavioral Supports Services complement Positive Behavioral Supports Consultation through the delivery of on-sight training to direct care staff and informal care providers in implementation of the behavior plan, data collection/graphing, monitoring of staff compliance with plan, aversion of risk, and development of crisis plans.
  - Positive Behavioral Supports Services are designed to bridge plan recommendations and implementation for direct care staff and/or family intervention. Positive Behavioral Supports Services may be provided in various settings including the waiver participant’s home, day services setting, and other residential or community setting.

### **Preventive Health Guidelines**

The October 1, 2015 update to COMP Medicaid policy included nursing services as a stand-alone waiver service. As a complement to the nursing services policy, Section 3310 *Annual Health Screening Recommendations* was included for all adults with intellectual/developmental disabilities. The full policy can be found

at: <https://www.mmis.georgia.gov/portal/Portals/0/StaticContent/Public/ALL/HANDBOOKS/Comprehensive%20%20Supports%20Waiver%20Program%20Part%20III%20%20January%202016%2012-01-2016%20195008.pdf>

### **Conclusion & Implications # 3: Lack of Health Professionals with Disability Competency.**

There is a critical lack of primary care, dental and specialty medical personnel to treat the health care needs of individuals with disabilities.<sup>17</sup> The National Council on Disability in its 2009 report noted that, “The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care.”<sup>18</sup> In addition, Medicare and Medicaid reimbursement to providers is significantly below the reimbursement from other health insurance sources, discouraging practitioners from serving

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<sup>17</sup> Persons with Disabilities as an Unrecognized Health Disparity Population, Gloria L. Krahn, PhD, MPH, Deborah Klein Walker, EdD, and Rosaly Correa-De-Araujo, MD, PhD, American Journal of Public Health, April 2015

<sup>18</sup> National Council on Disability. The current state of health care for people with disabilities, 2009. Available at: <http://www.ncd.gov/publications/2009/Sept302009> . Accessed November 13, 2012

the populations such as individuals with developmental disabilities who depend primarily on these government insurance programs.

Despite passage of the ADA more than 20 years ago, health facilities and services often are not fully accessible.<sup>19</sup> National data are not available, but a recent survey of almost 2400 primary care facilities serving Medicaid patients in California noted that fewer than half of facilities were fully architecturally accessible; only 8.4 percent had accessible examination tables, and less than 4 percent had accessible weight scales. Furthermore, there are few resources to help people with disabilities know which medical facilities will accommodate their limitations. As a result, many people with disabilities do not receive complete medical examinations because equipment such as weight scales, examining tables, and mammography equipment do not accommodate their disability.<sup>20</sup>

Problems in accessing community-based, quality, and appropriate health care in a timely way have been lamented for decades;<sup>21</sup> these problems were recently summarized by the National Council on

Disability. Several measures have been developed recently to assess accessibility of health care facilities, but to date, no requirements have called for the systematic collection of data on accessibility of facilities or medical equipment.

### **Recommendations for Specialty Health Care Options for Individuals with Developmental Disabilities**

An understanding of the medical needs of persons with developmental disabilities and the value of providing consistent and quality health care to this population is an important planning step prior to consideration of a managed care model. A study conducted in Florida in 2012 has recommendations that are helpful to improve health care services to persons with developmental disabilities in the existing fee for service health program, as well. These completed recommendations are found in Specialty Health Care Plan for Persons with Developmental Disabilities—2012.<sup>22</sup>

Their recommendations focused on quality recommendations for specialized health care needs and providers

1. Persons with developmental disabilities have more complex medical needs than do the general population and require access to medical care from a network of providers that are knowledgeable in treating persons with developmental disabilities.

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<sup>19</sup> US Access Board. Advancing equal access to diagnostic services: recommendations on standards for the design of medical diagnostic equipment for adults with disabilities. Available at: <http://www.access-board.gov/guidelines-andstandards/health-care/about-this-rulemaking/advisorycommittee> -final-report. Accessed March 10, 2014.

<sup>20</sup> Graham CL, Mann JR, McDermott S. Accessibility of medical offices. Presentation at the Annual Meeting of the American Public Health Association; November 4---8, 2006; Boston, MA. Available at: [https://apha.confex.com/apha/134am/techprogram/paper\\_125494.htm](https://apha.confex.com/apha/134am/techprogram/paper_125494.htm) . Accessed October 21, 2014

<sup>21</sup> 32. National Council on Disability. The current state of health care for people with disabilities, 2009. Available at: <http://www.ncd.gov/publications/2009/Sept302009>.

<sup>22</sup> Specialty Health Care Plan for Persons with Developmental Disabilities—2012. Putnam, Celeste. Georgia Developmental Disability Council.

2. All practitioners providing services must have experience or receive training in providing services to persons with developmental disabilities.
3. Services should be provided through a multi-disciplinary team approach with the medical home, led by the primary care physician, providing the coordination.
4. The primary care providers should operate within a person- and family-centered medical home model.
5. Providers should receive enhanced rates for providing services to persons with developmental disabilities. If providers render services through a prepaid mechanism, then their payment should be risk-adjusted based upon the complexity of the patients that they are seeing.

### **Conclusion & Implications # 4: Transitions in Health Needs.**

Transitions from pediatric to adult health care are difficult, at best, and when done inadequately may negatively affect health outcomes. At the other end of the spectrum, the aging of Georgia's individuals with disabilities and their caregivers adds a further transition to this challenge, one that has received little attention from health care providers. The current services available for these individuals are information and referral through the Aging and Disability Resource Connection (ADRC).

#### **Georgia's Aging and Disability Resource Connection (ADRC)**

A partnership program with the Georgia Division of Aging Services provides resources and assistance for older adults as caregivers and aging individuals with intellectual/developmental disabilities. Georgia's Division of Aging Services (DAS) maintains a network of service providers located throughout the state. Information about Aging and Disability Services is available from the local Area Agency on Aging (AAA) by telephone or the statewide hotline at 866-552-4464. Each region has a developmental disabilities resource specialist who meets with staff at least monthly, and is available for consultation on requests that are complex. Referrals are made to the developmental disabilities program when a caller is in need of those services.

The Georgia developmental disabilities program within the DBHDD agency is the disability partner that offers a coordinated system of partnering organizations dedicated to:

- Providing accurate information about publicly and privately financed long-term supports and services.
- Offering a consumer-oriented approach to learning about the availability of services in the home and community.
- Alleviating the need for multiple calls and/or visits to receive services.
- Supporting individuals and family members who are aging or living with a disability.

The developmental disability program office provides support for persons seeking to submit an application for services, but does not operate a telephone information and referral program. The number of individuals requesting new applications for NOW/COMP applications statewide for the 12



months from April 1, 2015-March 31, 2016 was 2,150. Their staff are cross-trained to refer callers who need other services to the ADRC local partner.

The statewide data from the ADRC for 2012 to 2015 is found below. It demonstrates a significant increase in use of the ARDC resources over the four-year period. Between 2014 and 2015 usage more than doubled.

**Table 7: Individuals Contacting ADRC for Assistance**

State Fiscal Year	Distinct Clients	Total Contacts
SFY 2012	8,899	14,419
SFY 2013	9,891	16,381
SFY 2014	10,989	19,010
SFY 2015	23,704	44,326
Grand Total	47,533	76,764

**Table 8: Requests for Assistance by Individuals with Various Disabilities**

State Fiscal Year	MR/DD /ID	Physical	Mental Illness	Traumatic Brain Injury	Multiple Disabilities	No Disability	Unknown	Refused to provide	Grand Total
SFY 2012		230	1	1	65	7	8,595		8,899
SFY 2013	1	320	2		81	7	9,479	1	9,891
SFY 2014	1	502	2	1	136	12	10,334	1	10,989
SFY 2015	68	7,785	119	88	2,189	584	12,858	14	23,704
Grand Total	68	7,865	119	88	2,207	585	36,588	14	47,533

**Table 9: Requests by Age**

State Fiscal Year	Over 60	Under 60	Age Unknown	Grand Total
SFY 2012	7680	1216	3	8899
SFY 2013	8388	1493	10	9891
SFY 2014	9051	1934	4	10989
SFY 2015	18358	3730	1616	23704
Grand Total	38188	7713	1632	47533

## Barriers and Obstacles

While many people encounter difficulty in finding affordable, high quality health care, individuals with developmental disabilities (IDD) face additional barriers, sometimes life-threatening, when attempting

to access timely, appropriate health services in their communities.<sup>23</sup> These barriers, as described by The Arc, include:

- *Access* - Underinvestment in public health and wellness targeted to people with I/DD results in preventable health care disparities and poorer health outcomes. Inadequate training, lack of coordinated care, and inadequate levels of reimbursement are some of the factors that create programmatic barriers while inaccessible clinical settings and diagnostic and medical equipment, along with translation and interpretation challenges, create physical barriers.
- *Discrimination* - Health care providers sometimes provide inadequate or inappropriate interventions and treatments or deny appropriate care for people with I/DD because of professional ignorance as well as personal and/or societal bias. State statutory liability damage limits discriminate against people with severe and/or life-long disabilities because they fail to provide sufficient compensation.
- *Affordability* - People with I/DD are more likely to live in poverty and cannot afford cost-sharing. For cost containment purposes, many public and private health care plans limit access to specialists and critical services. Even when services are available in a community, many people with I/DD lack adequate public or private insurance to pay for them.
- *Communication and personal decision making* - People with I/DD may have difficulties communicating their needs and making health care decisions without support. Their decisions may not be respected and implemented by health care providers and, where applicable, surrogate decision makers.<sup>2</sup> People have not been ensured access to all necessary supports and information required to understand a health care decision and communicate their choices.

### **Financing and Access to Health Insurance Coverage**

The first and perhaps most complex obstacle to health for individuals with developmental disabilities is obtaining access either to federal/state funded programs that include health insurance, or locating private health insurers who will cover individuals with developmental disabilities. Health reform, through the Affordable Care Act (ACA), holds special importance for people with disabilities through a number of key provisions. Denial of coverage because of preexisting conditions is no longer be allowed (ACA §1101 and §2704). Protection through a new patient's bill of rights no longer allows a lifetime cap on benefits that leave people with disabilities without the care they need when they need it most (ACA §2711). Expansion of the Medicaid program was intended to allow many Americans with disabilities who did not previously qualify for coverage to be insured and stay healthy (ACA §2001). Georgia has opted not to participate in Medicaid expansion.

Medicaid is the state and federal partnership that provides health coverage for selected categories of people with low incomes. Its purpose is to improve the health of people who might otherwise go without medical care for themselves and their children.<sup>24</sup> Eligibility for Medicaid is determined by the following agencies:

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<sup>23</sup> <http://www.thearc.org/who-we-are/position-statements/life-in-the-community/health-care>

<sup>24</sup> <http://www.georgialegalaid.org/organization/disability-law-and-policy-center-of-georgia-i?ref=JTNbG>

- The Social Security Administration (SSA) determines eligibility for Supplemental Security Income (SSI) which includes Medicaid health insurance, and Social Security Disability Income (SSDI) which includes Medicare health insurance.
- The Georgia Department of Families and Children (DFCS) determines eligibility for low-income children and families, aged persons, disabled persons, and persons seeking institutional care.

Families with a child with a developmental disability may include their child in an employers' group health insurance until the child is age 26. Based on family income and the parent's work history, the child may also be eligible for SSI or SSDI. Navigating this eligibility and application process is complex, but it is an essential safety net for the individuals with developmental disabilities for his/her lifetime. The parent's private health insurance may provide coverage that is more expansive than Medicaid. Employer health insurance also pays providers at a much higher rate than Medicare and Medicaid, so this may open doors to providers who limit the number of Medicaid patients they serve.

The low reimbursement of health care providers is a major barrier to health care for individuals with developmental disabilities who depend upon Medicare and Medicaid.

Georgia funds mental health and substance abuse services through the Department Behavioral Health and Developmental Disabilities. Services for children and youth in state programs through child welfare, adoption assistance and juvenile justice programs have mental health and substance abuse services funded jointly by the responsible state agency and Georgia Families 360©, the Medicaid MCO.

### **Transition from Pediatric to Adult Health Care**

Nationally, the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Grant #90DD0595, Administration on Developmental Disabilities, ACF, HHS) has developed a website -- [Health Care for Adults with Intellectual and Developmental Disabilities](#)--with extensive tools for use by individuals, their caregivers, health professionals and community coalitions.

An editorial in the September 2014 issue of the Journal of Adolescent Health "The Promise and Potential of Adolescent Engagement in Health" by Margaret McManus, M.H.S., reflected that adolescents' engagement even in direct care has been limited. In fact, past research has shown that most adolescents' ages 12–17 years do not have time alone with their providers.<sup>25</sup> Clearly, this significantly impedes the development of health literacy and, ultimately, engagement. Adolescent involvement in providing input to improve the delivery of care to their peers and to formulate health care policies is unusual but often found in practices specializing in the care of adolescents.<sup>26</sup>

The authors note that incorporating transition readiness might be appropriate as a next step for improving the measurement of adolescent engagement. Recently, a new transition readiness assessment tool was developed by Got Transition, the federally funded program operated by The National Alliance to Advance Adolescent Health, as part of the "Six Core Elements of Health Care

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<sup>25</sup> Irwin, C.E., Adams, S.H., Park, M.J., and Newacheck, P.W. Preventive care for adolescents: Few get visits and fewer get services. *Pediatrics*. 2009; 123: e565–e572

<sup>26</sup> <http://www.jahonline.org/article/S1054-139X%2814%2900270-5/fulltext>

Transition (2.0).”<sup>27</sup> This self-care assessment tool asks youth to rank transition importance and confidence and includes a set of 23 questions about knowledge and skills related to health needs and using health care. It is intended for use at age 14 and can be repeated annually until the youth or parent and/or caregiver (in the case of youth with significant intellectual disabilities) achieves a level of self-efficacy appropriate to manage an adult approach to care. This new self-care assessment tool has not yet been validated.

Recognizing that the adolescent period is a critical stage when health behaviors are established, when chronic conditions increase dramatically, and when service utilization declines precipitously, it is critical for health plans and practices to discover effective approaches for engaging adolescents and improving their experience with care. Involving adolescents in the development and application of new patient engagement tools will be key.

### **Pending Litigation**

Georgia is currently in litigation on two issues that affect individuals with developmental disabilities, and other due process issues are percolating.

#### **United States of America v. The State of Georgia**

The most critical one is the settlement agreement between the US Department of Justice and Georgia related to ending the use of state operated facilities for people with behavioral health needs and developmental disabilities.

From the perspective of the Georgia Advocacy Office, the key question is how to improve transition process. Challenge is right-sizing and building out a community-based system for people coming out of hospitals and on the short-term waiting list, which has a distinct group of people at high risk of imminent institutionalization. The most serious group needing different and improved community care are persons with severe needs, including the medically fragile. They need to be connected to the community.

A fundamental problem with the system as currently structured is that the housing stock is under the control/responsibility of the care provider, not the consumer living there. If there is any problem with the provider; the consumer is displaced. People with developmental disabilities on waiver programs need access to additional HUD housing vouchers, which are currently focused on the settlement’s targeted population and the development of supported housing. Georgia created its own housing vouchers because the HUD-funded vouchers were inadequate, but almost all have been utilized for the seriously mentally ill consumers.

#### **M.H. vs Reese**

This is a class complaint; GAO is looking to certify the class later in 2016. It is focused on the lack of implementation of EPSDT, particularly as it relates to Medicaid payment for the treatment of identified needs. Children with complex needs not getting the treatment they need. Personal supports are

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<sup>27</sup> <http://www.gottransition.org/resourceGet.cfm?id=331>

currently only available through the waivers, which have long waiting lists, but are not funded through basic Medicaid after EPSDT screening as federal law prescribes.

### **Other Due Process Issues**

Katie Beckett Program—Children are eligible if they need the traditional ICF or nursing care level of care. Recent changes require documentation that the child needs skilled intervention 5X weekly and is already getting it 5X a week. Substantially fewer children are qualifying under the new procedure. They no longer have access to Medicaid funding for their complex needs.

NOW or COMP waiver participants currently have no due process if services are reduced. After the provider and support coordinator agree on services, central office can approve something less, without an appeal process, particularly for exceptional rate. Regular Medicaid rules say they must explain and provide due process.

## **Underserved Populations**

### **Health Disparities**

An important study of health disparities was published in April 2015 in the American Journal of Public Health. “Persons with Disabilities as an Unrecognized Health Disparity Population”, Gloria L. Krahn, PhD, MPH, Deborah Klein Walker, EdD, and Rosaly Correa-De-Araujo, MD, PhD.<sup>28</sup> For the first time the data is analyzed in one concise document. This issue of health disparities is an important issue for future attention.

Disability has been defined differently across federal agencies, national data systems, and international frameworks. Definitions that determine eligibility for services and supports, such as Social Security Disability Insurance and Supplemental Security Income, are understandably restrictive to limit the number of beneficiaries, whereas others that guarantee protection of rights, such as in the Americans with Disabilities Act, are deliberately inclusive to provide anti-discriminatory protection to a broad group of people.

The first disability objective in Healthy People 2010 called for use of a standardized set of questions to identify people with disabilities in surveys.<sup>29</sup> These standard questions across the life span ask about:

1. Deafness or serious difficulty in hearing (all ages);
2. Blindness or serious difficulty in seeing (all ages);
3. Serious difficulty in concentrating, remembering, or making decisions because of a physical, mental, or emotional condition (5 years or older);
4. Serious difficulty walking or climbing stairs (5 years or older);
5. Difficulty dressing or bathing (5 years or older); and

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<sup>28</sup> <http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2014.302182>

<sup>29</sup> [US Department of Health and Human Services. Healthy People 2010. Available at: http://www.healthypeople.gov/2010/Publications. Accessed April 16, 2013.](http://www.healthypeople.gov/2010/Publications)

6. Difficulty doing errands alone (e.g., visiting a doctor’s office or shopping) because of a physical, mental, or emotional condition (15 years or older).

An affirmative response to any of these questions is considered a disability. Among people who report serious limitations, 46 percent report mobility disability, 39 percent report problem-solving or concentration limitations, 26 percent report hearing, and 21 percent report vision, with 43 percent reporting more than 1 limitation.<sup>30</sup>

As a group, people with disabilities fare far worse than their nondisabled counterparts across a broad range of health indicators and social determinants of health. Adults with disabilities are 2.5 times more likely to report skipping or delaying health care because of cost.

This issue is gaining traction at the national policy level. The Office of the Surgeon General issued a report in 2002 that outlined a blueprint for action to improve the health of people with intellectual disabilities. The National Council on Disability report of 2009<sup>31</sup> summarized the shortcomings of health care access for people with disabilities. The Healthy People 2020 objectives in disability and health are distributed across 4 areas: systems and policies, barriers to health care, environment, and activities and participation. Without action on these objectives, health disparities can be expected to continue and possibly increase for people with disabilities. Health expenditures associated with disabilities, including medical care and long-term services, have been estimated at \$400 billion annually, with 70 percent of these costs covered through public programs. This represents a significant national expenditure that still results in preventable health gaps.

Every major report addressing the poor health of people with disabilities has called for improvements in training of health care providers about adults with disabilities. The National Council on Disability in its 2009 report noted that, “The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care.”<sup>32</sup> The Institute of Medicine<sup>33</sup> reported that health professionals are poorly prepared to meet the complex medical and psychosocial needs of people with disabilities. However, disability competency is not currently a core curriculum requirement for medical school accreditation or for receipt of federal funding. Furthermore, a 2000 survey of US graduate schools of public health showed that only 13 percent of programs had a graduate track in disabilities. Healthy People 2020 includes a disability and health objective that calls for increasing the number of public health programs with a course on disability.

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<sup>30</sup> Centers for Disease Control and Prevention. CDC grand rounds: public health practices to include persons with disabilities. *MMWR Morb Mortal Wkly Rep.* 2013;62(34):697---701.

<sup>31</sup> National Council on Disability. The current state of health care for people with disabilities, 2009. Available at: <http://www.ncd.gov/publications/2009/> Sept302009. Accessed November 13, 2012.

<sup>32</sup> Ibid.

<sup>33</sup> Institute of Medicine. *The Future of Disability in America*. Washington, DC: National Academies Press; 2007

## **Autism Spectrum Disorders (ASD) Initiative**

The Autism Services Initiative for Adults is a partnership of the Georgia Department of Behavioral Health and Developmental Disabilities and Emory Autism Center. The following summary and data were provided by Catherine Grey of the DBHDD. The goals of the initiative are as follows:

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

Although originally projected for the gap analysis to be completed by March 31, 2016, the DBHDD contract recently was approved for an extension until September 30, 2016. Because of how much has been undertaken for the initiative, the deliverable requirements will take more time to complete.

The decision to conduct an initiative focused on adults receiving or eligible for DBHDD services resulted from:

- Hearing from Georgia families that it is hard to find high-quality developmental disability care for adults living with autism
- Recognizing that the lack of high-quality developmental disability care for adults with ASD often results in costly and inefficient use of emergency services
- Knowing that the number of adults with ASD is expected to grow rapidly in the upcoming years
- Being aware of national data supporting poorer life outcomes for adults with ASD than for adults with other developmental disabilities

The Autism Advisory Committee consists of diverse partners, including self-advocates, family members, providers, advocates, and others involved in the system of care for adults with ASD; a representative of the Georgia Council on Developmental Disabilities serves on the Autism Advisory Committee. This committee:

- Ensures that the initiative is relevant and informs the state's understanding of the comprehensive needs of the target population
- Serves as our eyes and ears in the community by providing their suggestions and perspective, and disseminating information about the initiative
- Meets as a committee every two months and participates in subcommittee work

The gap analysis of DBHDD services for adults with ASD includes the following actions:

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

The target population for the gap analysis is:

- Adults with a primary or secondary diagnosis of Autism Spectrum Disorder who were at a point in time in 2015:
- Receiving state or waiver funded services from DBHDD
- Waiting for waiver services

The conducting of focus groups also is in process. The Emory Team has completed some initial focus group meetings of parents. The participants were invited to talk about such topics as their experience taking care of their family member, the role that DBHDD played in the individual's care, provider competency/availability and suggestions for training providers of services for individuals with ASD. The first round of focus groups has yielded good information, and certain trends appear to be emerging from the information. The following broad trends about training emerged from the focus group sessions:

- The direct contact staff does not have the skills to deal with the individual with ASD.
- Staff is not given autism-specific training.
- Help with behavioral supports is a real need. Parents request expertise here.
- In most cases, the parents are the experts at dealing with their adult children.
- Parents/families need training in how to deal with the service delivery system; peer to peer, networking is suggested.
- Try tapping into families to provide training. It will help with sustainability.
- There should be co-learning between service provider and the parent, working together to create a good environment and making them a "unit."

The next step for the focus group effort is to strive for more diversity in the participant base and go into the outlying regions of the state. The conducting of focus groups of self-advocates and individuals involved in the system of care for adults with ASD is planned.

Table #9 describes the demographic characteristics for the cohort of adults with adults with ASD. This table provides demographic characteristics of the cohort of adults with ASD by those on the waiver, receiving state funded services, or on the planning list (short term or long term). Demographic characteristics include age, gender, race, marital status, ethnicity, and DBHDD region. Also attached are additional tables on the demographic characteristics of the cohort of adults with ASD.

The demographic information is the first look at information on the cohort of adults with ASD. Other data analysis currently is in process. The cohort of adults with Autism Spectrum Disorder are adults with a primary or secondary diagnosis of Autism Spectrum Disorder who were receiving from the Georgia Department of Behavioral Health and Developmental Disabilities state or waiver funded services or waiting for waiver services at a point in time in 2015.



**Table 10: Demographic Characteristics for a Cohort of Adults with Autism Spectrum Disorder**

<b>Demographic Characteristic</b>	<b>Long Term Planning List (N=218)</b>	<b>Short Term Planning List (N=281)</b>	<b>State Funded Services (N=121)</b>	<b>Waiver (N=884)</b>
Age, mean (SD), years	22.85 (5.97)	24.12 (6.00)	27.17 (7.34)	29.05 (9.29)
Gender, N (%)				
Male	171 (78.4)	219 (77.9)	95 (78.5)	686 (77.6)
Female	44 (20.2)	61 (21.7)	25 (20.7)	198 (22.4)
Missing Information	3 (1.4)	1 (0.4)	1 (0.8)	0 (0.0)
Race, N (%)				
White	92 (42.2)	112 (39.9)	64 (52.9)	437 (49.4)
Black/African American	72 (33.0)	115 (40.9)	52 (43.0)	392 (44.3)
Asian	4 (1.8)	10 (3.6)	2 (1.6)	12 (1.4)
Pacific Islander	1 (0.5)	0 (0.0)	0 (0.0)	5 (0.6)
American Indian or Alaska Native	0 (0.0)	1 (0.4)	0 (0.0)	0 (0.0)
Two or more races	2 (0.9)	6 (2.1)	1 (0.8)	6 (0.7)
Other	8 (3.7)	12 (4.3)	1 (0.8)	27 (3.1)
Unsure	39 (17.9)	25 (8.9)	1 (0.8)	5 (0.6)
Marital Status, N (%)				
Single	205 (94.0)	263 (93.6)	121 (100.0)	882 (99.8)
Married	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Divorced/Widowed	1 (0.5)	0 (0.0)	0 (0.0)	0 (0.0)
Missing Information	12 (5.5)	18 (6.4)	0 (0.0)	2 (0.2)
<b>Demographic Characteristic</b>	<b>Long Term Planning List (N=218)</b>	<b>Short Term Planning List (N=281)</b>	<b>State Funded Services (N=121)</b>	<b>Waiver (N=884)</b>
Ethnicity, N (%)				
Hispanic	6 (2.8)	11 (3.9)	2 (1.7)	31 (3.5)
Non-Hispanic	121 (55.5)	225 (80.1)	115 (95.0)	745 (84.3)
Unsure	91 (41.7)	45 (16.0)	4 (3.3)	108 (12.2)
DBHDD Region, N (%)				
Region 1	61 (28.0)	59 (21.0)	39 (32.2)	200 (22.6)
Region 2	30 (13.8)	57 (20.3)	17 (14.0)	149 (16.9)
Region 3	43 (19.7)	104 (37.0)	20 (16.5)	297 (33.6)
Region 4	9 (4.1)	14 (5.0)	10 (8.3)	55 (6.2)
Region 5	31 (14.2)	28 (10.0)	14 (11.6)	88 (9.9)
Region 6	44 (20.2)	19 (6.7)	21 (17.4)	95 (10.8)

**Table 11: Waiver and Planning List Information for Cohort of Adults with Autism Spectrum Disorder in Georgia**

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

**Table 12: Population-Based\* Rates for Cohort of Adults with Autism Spectrum Disorder in Georgia**

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

**Table 13: Median Age for Cohort of Adults with Autism Spectrum Disorder in Georgia**

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

**Table 14: Planning List Information by Age for Cohort of Adults with Autism Spectrum Disorder in Georgia**

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

**Dual Diagnoses**

Nationally, it is estimated that 30 -to- 35 percent of all people with a developmental disability also have a mental health diagnosis.

Families find difficulty navigating between different agencies for treatment and support services. Few of the available mental health services have adaptations required for those who have more complex behavioral and mental health needs. Individuals and families need a continuum of care that specializes in the needs of those with both developmental disabilities and mental health diagnosis.

Individuals with developmental disabilities and/or their families can access mental health services through a variety of methods. The most frequent method is through their local community/behavioral health provider (CSB).

DBHDD does not require its CSBs to develop specific services for individuals with developmental disabilities who are dually diagnosed; but they are required to create local systems of care based on Identified local needs.

## Data

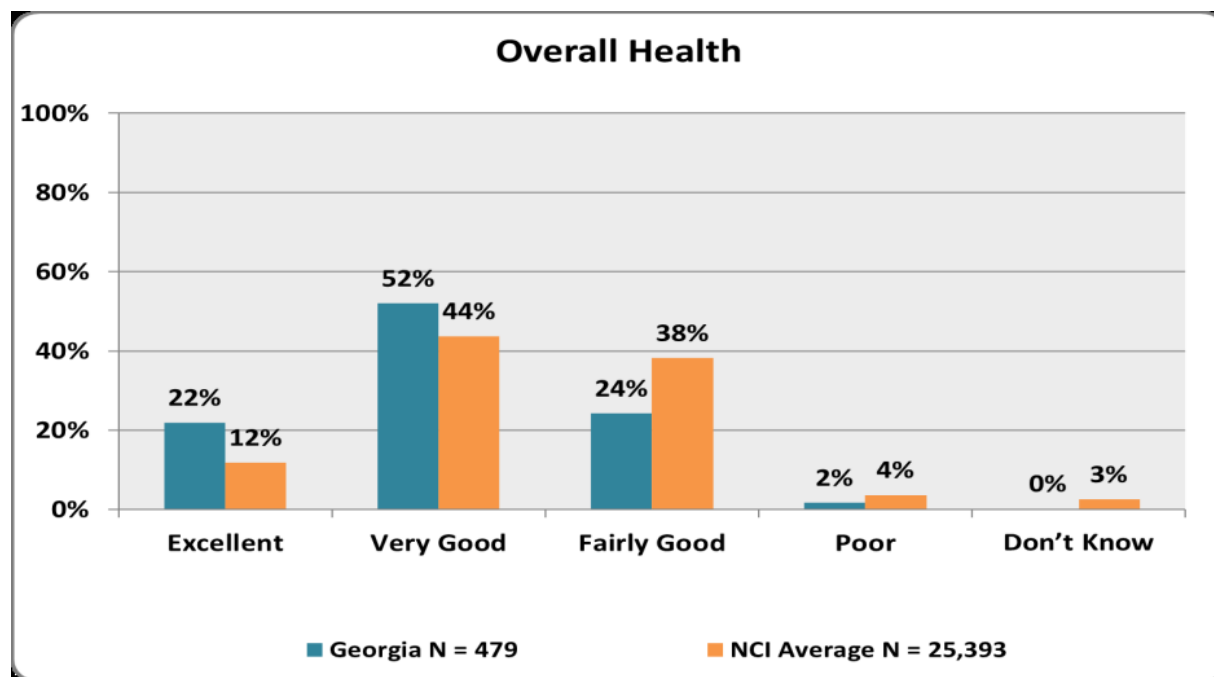
### National Core Indicators-- Georgia

Data about the experience of individuals with developmental disabilities who participate in Georgia Medicaid services is developed by Delmarva, under contract to the Department of Community Health. Reviewers utilize an extensive Health Summary tool to help determine the individual's health status in various areas. That data is also submitted by Georgia to The National Core Indicators (NCI) program. This is a voluntary effort by agencies to track and measure their own performance and to pool knowledge and resources to create a nationally validated set of performance measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI). NCI is one of the first successful efforts to identify indicators that measure impact on the lives of the individuals served, not just the process to providing services. These indicators focus on areas such as: employment, rights, service planning, community inclusion, choice, health, and safety.

The following graphs are from the new indicators for 2014-15.

#### GRAPH #12: Overall Health

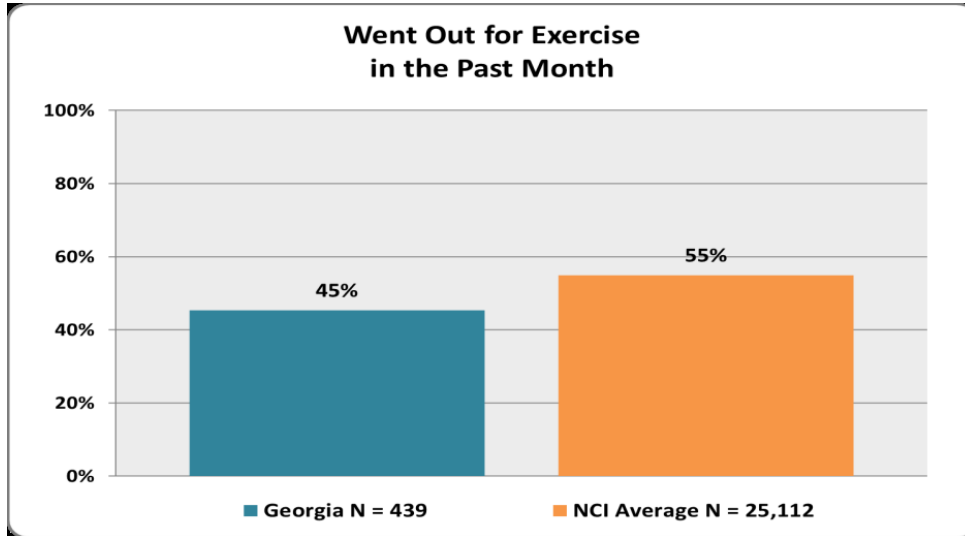
This graph indicates that Georgia's respondents are doing well on overall health.



#### Indicators that need recognition

**GRAPH 38. Went Out for Exercise in The Past Month**

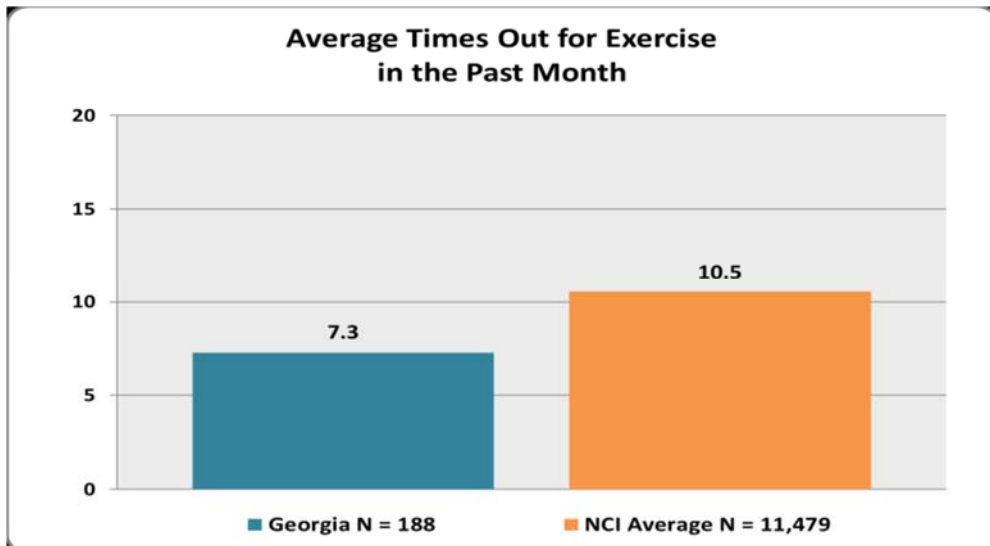
This graph illustrates that 45% of respondents from Georgia and 55% across NCI states reported that they went out for exercise in the past month. States ranged from 22% to 83%.



**Needs Improvement**

**GRAPH 39. Average Times Went Out for Exercise in The Past Month**

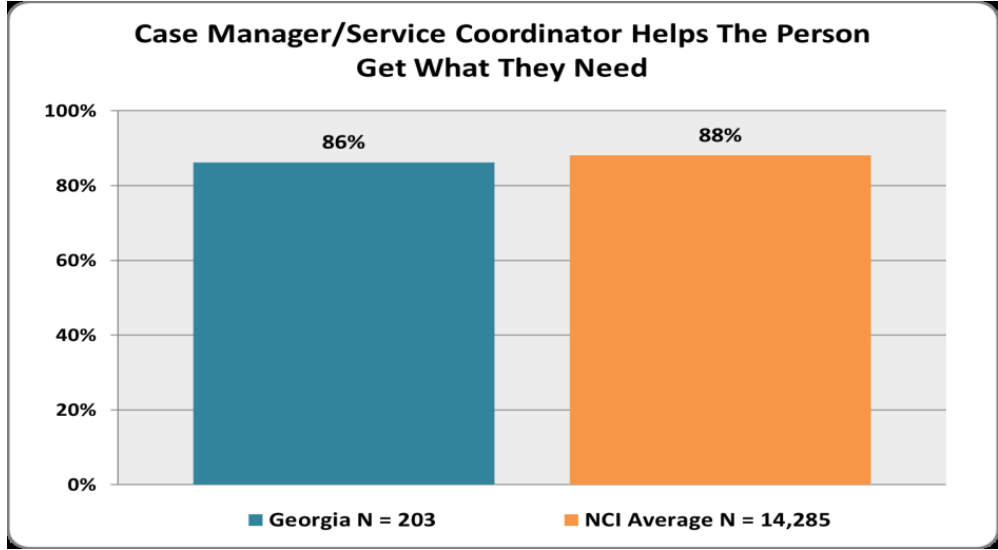
This graph illustrates that respondents from Georgia went out for exercise an average of 7.3 times in the past month, and respondents across NCI states went an average of 10.5 times. States ranged from 5.1 to 14.5 times.



**Needs Improvement**

**GRAPH 72. Case Manager/Service Coordinator Helps Get What Person Needs**

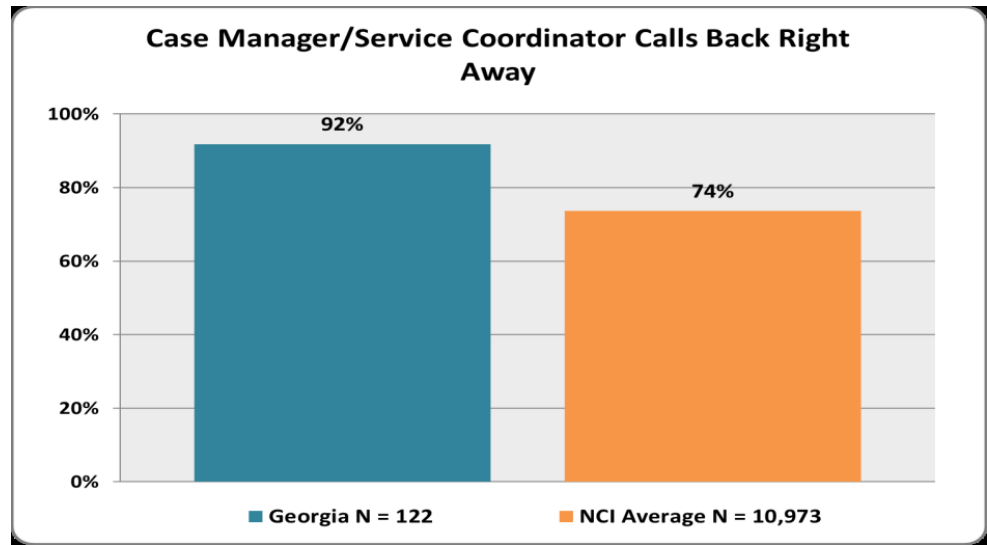
This graph illustrates that 86% of respondents from Georgia and 88% across NCI states reported their case manager/service coordinator helps them get what they need. States ranged from 77% to 97%.



**Excellent Performance**

**GRAPH 73. Case Manager/Service Coordinator Calls Person Back Right Away**

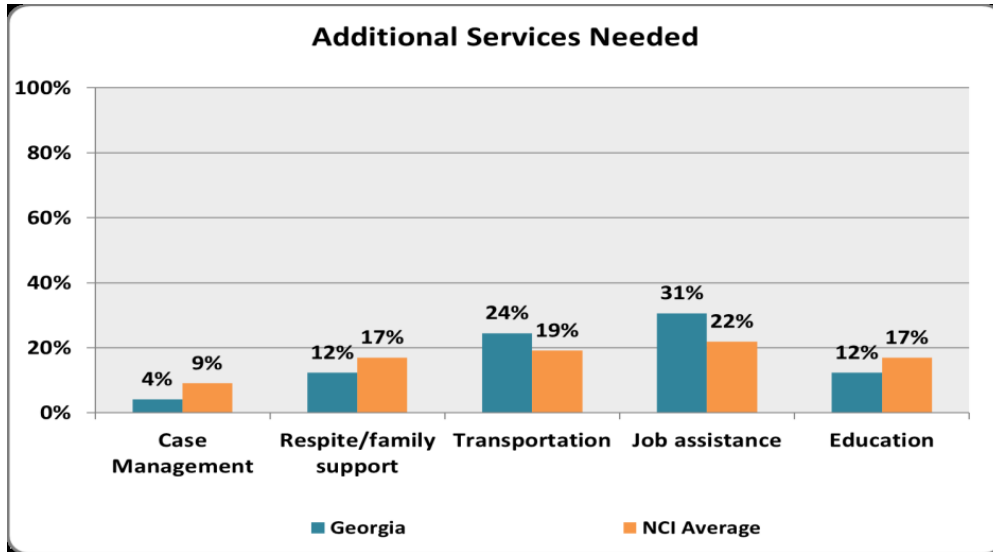
This graph illustrates that 92% of respondents from Georgia and 74% across NCI states reported that if they leave a message, their case manager/service coordinator calls them back right away.



**EXCELLENT PERFORMANCE**

**GRAPH 80. Additional Services Needed (1 Of 3)**

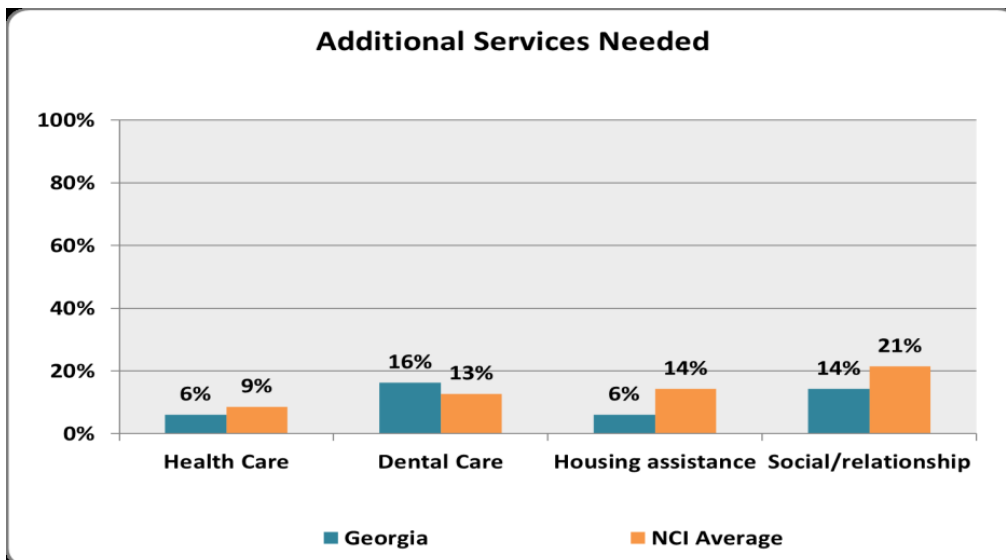
This chart illustrates the proportion of respondents from Georgia and across NCI states need the following services: and case management; and respite or family support, and transportation; and job assistance, and education. States ranged from 0% to 48% for case management; 2% to 35% for respite or family support, 0% to 35% for transportation; 0% to 56% for job assistance, 0% to 38% for education.



**More Transportation Needed**

**GRAPH 81. ADDITIONAL SERVICES NEEDED (2 OF 3)**

This chart illustrates the proportion of respondents from Georgia and across NCI states need the following services: 6% and 9% health care; 16% and 13% dental care; 6% and 14% housing assistance; 14% and 21% social or relationships. States ranged from 2% to 26% for health care; 0% to 31% for dental care; 3% to 51% for housing assistance; 3% to 47% for social or relationships.



**Dental Care Needed**

## Background on Managed Care as a Solution to Rising Medicaid Costs

MLTSS grew significantly between 2004 and 2012. State use of managed long-term services and supports (MLTSS) is not widespread; MLTSS accounted for only 5 percent of Medicaid's total LTSS expenditures in Federal Fiscal Year 2009. Sixteen states currently offer MLTSS programs: Arizona, California, Delaware, Florida, Hawaii, Massachusetts, Michigan, Minnesota, New Mexico, New York, North Carolina, Pennsylvania, Tennessee, Texas, Washington and Wisconsin. At least 9 of these states have several years of experience operating MLTSS programs and will be discussed further as case studies. Among states with MLTSS programs, 7 of 16 have programs that operate statewide, but some of these statewide programs only serve specific populations. For example, Michigan, North Carolina and Pennsylvania only use MLTSS to serve beneficiaries with developmental disabilities or severe mental illnesses<sup>34</sup>. The development of the MLTSS market was initially hampered by a very limited supply of organizations that had both the experience and ability to accept risk for LTSS. However, the supply of organizations that have decided to develop this product line has increased greatly since 2004, giving most States a larger selection of organizations with which to contract.<sup>35</sup>

CMS recently launched the Medicare-Medicaid Financial Alignment Initiative, often referred to as the "duals integration demonstration."<sup>36</sup> The Initiative enables states to use a capitated managed care model or an enhanced fee for-service model, or both, to make significant changes to the way that acute care and LTSS services for Medicare-Medicaid dual eligibles are funded. Under a capitated model (payment is a fixed per person, per month payment), states will contract with managed care organizations (MCOs) that will be authorized to manage both the acute care benefits covered under Medicare and Medicaid-financed LTSS. Both Medicare and Medicaid capitated payments will be made to the MCOs.

Twenty states have developed draft proposals for participation in the Financial Alignment Initiative under the capitated model, and ten have officially submitted capitated model proposals to CMS. Another 6 states have drafted managed FFS proposals, and one state has submitted an official MFFS proposal. A number of states have withdrawn their proposals including AZ, HI, OR, MN, NM, and TN. With the exception of OR, all of these states have extensive experience with MLTSS and/or integrated care.

From the consumer perspective, the National Disability Leadership Alliance<sup>37</sup> has developed principles regarding the implementation of managed care and urges that they be applied fully by individual state Medicaid programs as they examine ways to broaden the application of managed care to beneficiaries with significant disabilities in the interest of containing spiraling health care costs. The National

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<sup>34</sup> Medicaid Long Term Services and Supports: A Review of Available Evidence. American Health Care Association. 2014. p.3. [https://www.ahcancal.org/facility\\_operations/medicaid/Documents/MLTSS\\_Analysis.pdf](https://www.ahcancal.org/facility_operations/medicaid/Documents/MLTSS_Analysis.pdf)

<sup>35</sup> The Growth of Managed Long-Term Services and Prepared for the Centers for Medicare & Medicaid Services (CMS), Disabled and Elderly Health Programs Group under Contract #: HHSM-500-2005-000251, Task Order No. 0002 Supports (MLTSS) Programs: A 2012 Update

<sup>36</sup> Medicaid Long Term Services and Supports: A Review of Available Evidence. American Health Care Association, 2014. p. 7. [https://www.ahcancal.org/facility\\_operations/medicaid/Documents/MLTSS\\_Analysis.pdf](https://www.ahcancal.org/facility_operations/medicaid/Documents/MLTSS_Analysis.pdf)

<sup>37</sup> National Disability Alliance principles.

<http://www.disabilityleadership.net/files/NDLA%20PRINCIPLES%20FOR%20MEDICAID%20MANAGED%20CARE%20%28March%202012%29%20--%20%20FINAL.PDF>



Disability Leadership Alliance (NDLA) “is a national cross-disability coalition, led by disability groups run by persons with disabilities, with support from allies...representing the authentic voice of people with disabilities”.

This rush to MCO has not been smooth for consumers. In 2014, The New York Times, in “Pitfalls Seen in a State’s Turn to Privately Run Long Term Care”<sup>38</sup> by Nina Bernstein, wrote that a closer look at Tennessee, widely cited as a model, reveals hidden pitfalls as the system of caring for the frail comes under the twin pressures of cost containment and profit motive. In many cases, care was denied after needs grew costlier — including care that people would have received under the old system. Tennessee has chosen to be as cost-effective as possible, and that has allowed the state to eliminate waiting lists for community-based services, which now serve nearly 13,000 people, up from 5,000, while keeping the number of nursing home residents flat at 19,200. Patti Killingsworth, director of long-term services and supports in Tennessee, pointed out that the state was serving a quarter more people with inexpensive home and community services. A TennCare spokeswoman, added that in any long-term care program, “difficult public policy decisions must be made, including whether to provide an unlimited array of benefits to a few, or a reasonable package of benefits sufficient to safely serve individuals in the community to many.”

The experience of states with long-running managed care for acute services shows that beneficiary access to needed providers and services is commonly problematic. In a recent survey by the Kaiser Family Foundation, over two-thirds of states with Medicaid managed care programs reported that beneficiaries enrolled in MCOs sometimes experience access problems; difficulties seeing specialists and behavioral health providers are among the problems frequently cited. Given that individuals receiving long-term care are heavy users of these services, MLTSS programs will need to be especially vigilant in facilitating beneficiary access. Many states do report that their MLTSS programs have increased access to care, especially for home- and community based services (HCBS), which are largely non-medical services such as home care and homemaker services<sup>39</sup>.

MCO Utilization of LTSS Participant-Directed Services: The Department of Health and Human Services defines participant-direction as a way to allow beneficiaries and their families to control what services are received, who provides them, and how and when those services are delivered. Participant direction has been shown to improve beneficiary outcomes and increase access to care. A recent inventory of MLTSS found that 12 of 16 states offer participant-directed options in their programs. Eight of these offer only employer authority, allowing beneficiaries to hire, supervise, and fire care workers, and the remaining four states also offer budgetary authority, giving beneficiaries a flexible budget for the purchase of goods and services related to LTSS needs. In order to ensure beneficiary access to participant-directed services, these states generally require MCOs to discuss the availability of such services with all members during the initial needs assessment and at regular reassessment intervals. Beyond contractually requiring MCOs to offer participant-directed services, states can use monitoring tools to ensure proper administration.<sup>40</sup>

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<sup>38</sup> Pitfalls Seen in a State's Turn to Privately Run Long-Term Care, New York Times, March 7, 2014.

<sup>39</sup> Medicaid Long Term Services and Supports: A Review of Available Evidence. American Health Care Association, 2014. P 15. [https://www.ahcancal.org/facility\\_operations/medicaid/Documents/MLTSS\\_Analysis.pdf](https://www.ahcancal.org/facility_operations/medicaid/Documents/MLTSS_Analysis.pdf)

<sup>40</sup> Ibid. P. 17. [https://www.ahcancal.org/facility\\_operations/medicaid/Documents/MLTSS\\_Analysis.pdf](https://www.ahcancal.org/facility_operations/medicaid/Documents/MLTSS_Analysis.pdf)

The Center for Health Care Strategies (CHCS) <sup>41</sup> is a helpful resource to states and advocates working to ensure that Medicare-Medicaid enrollees have access to seamless, high-quality, and cost-effective care. It supports activities at the state and federal level to integrate medical and behavioral health care and long-term services and supports. CHCS also supports states in rebalancing long-term services and supports toward more person-centered, home- and community-based options to help people remain living in their communities. A comprehensive communications work plan can help ensure that MLTSS programs meet the diverse needs of these individuals.<sup>42</sup> CHCS has a number of useful research documents available.

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<sup>41</sup> <http://www.chcs.org/topics/managed-long-term-services-and-supports/>

<sup>42</sup> [http://www.chcs.org/media/Communications\\_Workplan\\_Tool\\_Final.pdf](http://www.chcs.org/media/Communications_Workplan_Tool_Final.pdf)