Analysis of Recent Downturns in the Georgia's Medicaid Waiver Planning Lists

Executive Summary

Georgia's Home and Community-Based Services ("HCBS") waiver programs are crucial to ensuring individuals with disabilities in Georgia have meaningful opportunities to live independently in the community. Georgia manages access to these programs through a series of waiting lists, or planning lists. State management of these lists has major implications for compliance with the Americans with Disabilities Act ("ADA"). In fact, the U.S. Supreme Court in O*lmstead v. L. C. by Zimring*, 527 U.S. 581, 605-06 (1999), instructs that state planning lists must move at a reasonable rate and serve more than just "keep[ing] [state] institutions fully populated." Now 20 years after *Olmstead*, Georgia's planning lists may not be functioning as required by *Olmstead* and as a result, too many individuals with disabilities in Georgia needlessly remain in segregated settings or remain in their communities where, without the services they need and are entitled to, they become at risk of being placed in a segregated setting.

State agencies recently restructured the way they manage the lists and these changes resulted in stark reductions of the numbers of people on planning lists. For instance, from February to October of 2018, the state removed 30% of individuals from the NOW/COMP planning list. Similarly, the ICWP planning list fell from approximately 67 people in October to zero in December 2018. These reductions do not reflect the scope of need for community services nor do they accurately reflect compliance with the mandates of the ADA.

DBHDD has provided several explanations for the reductions, including that it has expanded access to nonwaiver programs and connected individuals whose needs were not "current or urgent," with "community-based resources." Current data however, shows that DBHDD has drastically cut access to most of these services, leaving only limited temporary services reserved for only those in crisis to fill in the gap.

Such lack in services is exacerbated because access to community-based services in Georgia is much more limited than in states with similar HCBS spending levels or enrollment numbers. Georgia ranks comparatively low in terms of HCBS enrollment but spends a larger share of its Medicaid funding on nursing facilities. This means that Georgia spends more money on nursing facilities than all but six states in the country. In addition, reports show that Georgia fails to effectively implement federal safeguards to ensure that individuals with disabilities are not unlawfully placed in nursing homes for long term care. Georgia consistently ranks among the lowest 15 states in the country in identifying persons who should live in the community and providing them with assistance in locating community-based alternatives to nursing facilities.

This paper discusses these issues in detail. It posits that the waiver planning lists in Georgia do not move at a reasonable speed because of Georgia's persistent failure to provide meaningful access to home and community based services. Finally, it outlines areas for further scrutiny and highlights areas of improvement needed for greater compliance with the ADA.

1. Introduction

The New Options Waiver ("NOW") and Comprehensive ("COMP") Supports Waiver programs are federal Medicaid Home and Community-Based Services ("HCBS") waiver programs authorized in section 1915(c) of the Social Security Act.[1] Both programs are implemented by Georgia's Department of Behavioral Health and Developmental Disabilities ("DBHDD"). The Independent Care Waiver Program ("ICWP") is also a HCBS waiver program.[2] Georgia's Department of Community Health ("DCH") implements this program.

HCBS waivers such as the NOW/COMP and ICWP, provide services and supports to individuals with disabilities so that they can transition to, or remain in, the community instead of living in a more restrictive setting such as a nursing facility or intermediate care facility. These services and supports are individualized and complement or supplement the services available to participants through the Medicaid state plan and other federal, state, and local public programs.[3] Depending on their respective level of need, individuals with an intellectual disability or closely related developmental disabilities[4] can access these services through the COMP waiver (for more intensive services) or the NOW waiver (for less intensive services).[5] Eligible individuals with physical disabilities or traumatic brain injuries receive similar services through the ICWP waiver.[6]

Each waiver program includes a respective planning list for individuals who are clinically eligible under the program but awaiting services. For services through the NOW/COMP waiver, DBHDD intake and evaluation teams determine applicants' level of need and DBHDD provides

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[1] Brian Dowd, *Application for 1915(c) HCBS Waiver: GA.0175.R06.00* (Oct. 1, 2017) (on file with author) [hereinafter NOW/COMP Application]; *see also* Georgia Dept. of Behavioral Health and Disabilities, *Comprehensive Supports Waiver (COMP) Program, Ready Reference Provider Guide*, 3 (2009).

[2] Brian Dowd, *Application for 1915(c) HCBS Waiver: GA.4170.R05.00* (July 1, 2016) (on file with author) [hereinafter, ICWP application].

[3] Georgia Dept. of Community Health, *Policies and Procedures for Comprehensive Supports Waiver Program (COMP) and New Options Waiver Program (NOW), General Manual*, 8 (April 1, 2019) [hereinafter NOW COMP Manual] (one file with author); see also NOW COMP Application.

[4] Note: Eligibility through a "related condition" is defined as having a diagnosis of a condition found to be closely related to an intellectual disability and attributable to: (a) severe forms of cerebral palsy or epilepsy; or (b) any other condition, other than mental illness, found to be closely related to an intellectual disability because this condition results in substantial impairment of general intellectual functioning or adaptive behavior similar to that of persons with an intellectual disability and requires treatment or services similar to those required for these persons; and that meets certain criteria (*i.e.*, onset before the age of 22, ICF/ID level of care, limitations in three or more specified areas of adaptive functioning, and deficits likely to continue indefinitely.) NOW COMP Manual at VII-3.

[5] NOW COMP Manual at 8.

[6] Georgia Dept. of Community Health, *Policies and Procedures for Independent Care Waiver Services,* 1 (Jan. 1, 2019) [hereinafter ICWP Manual] (one file with author).

funding to those most in need as it becomes available.[7] Until then, eligible applicants remain on the NOW/COMP planning list. Individuals eligible for the ICWP must complete a series a screenings and face-to-face assessments, after which, they are prioritized for placement into the program on a "first come, first served" basis.[8] If an applicant is eligible for services and there are no openings, they are placed on a waiting list.[9] Applicants remain in the ICWP planning list until additional funding becomes available or other beneficiaries are discharged from the program.[10]

These planning lists have been highly scrutinized components of Georgia's HCBS provision system for decades. The Supreme Court decided the principal case on states' responsibilities under the Americans with Disabilities Act ("ADA") to provide community-based care in a Georgia case from 1999, *Olmstead v. L.C. ex rel. Zimring*.[11] *Olmstead* found that the ADA prohibited the unnecessary institutionalization of a person with a disability. The *Olmstead* court criticized Georgia's lack of a "comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated."[12] The Court did not define exactly what an "effectively working plan" was or what pace would be reasonable for a state's waiting list to move; so, the nations' courts continue to grapple with this definition.[13] Nonetheless, *Olmstead* makes clear that states must look to more than their budgets when managing individuals' access to community-based care.

Georgia agreed to expand its HCBS waiver programs after *Olmstead.* However, by FY 2010, the state had only accepted the applications of 46% percent of the total number of NOW waivers (then called the "MRWP" waiver) it agreed to provide and 21% of the ICWP waivers.[14] The remaining thousands lingered on waiting lists and the number of individuals on these waiting lists continued to grow from year to year.[15]

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[7] Georgia Dept. of Behavioral Health and Disabilities, Planning Lists for Developmental Disability Services for Individuals Living in the Community, 02-101, PolicyStat ID: 3943407 (Aug. 18, 2019).

[8] Georgia Dept. of Community Health, Policies and Procedures for Independent Care Waiver Services, 28-30 (Jan. 1, 2019) [hereinafter ICWP Manual] (one file with author).

[9] *Id*. at 31.

[10] *Id.*

[11] *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

[12] *Id.* at 606.

[13] *See i.e., Sanchez v. Johnson and Arc of Washington State, Inc. v. Braddock,* 427 F.3d 615, 620–22 (9th Cir. 2005) and *Frederick L. v. Dep't of Public Welfare,* 422 F.3d 151, 156 (3d Cir. 2005).

[14] Amy Tidwell, *Deinstitutionalization: Georgia's Progress in Developing and Implementing an "Effectively Working Plan" As Required By Olmstead v. L.C. Ex Rel*, 25, Tables 1 and 2, Ga. St. U. L. Rev. (2009).

[15] *Id*. at 28-29.

Georgia's implementation of these lists has major implications for policy makers and individuals with disabilities, alike. Georgia's management of these lists has a dramatic impact on the daily experiences of people with disabilities throughout the state. Simply put, it determines who these individuals live with, where they live, and most significantly, whether they retain any connection to their families and communities.

2. Recent Reductions in the Planning List

In the fall of 2018, the state reported that the number of individuals on the NOW/COMP planning lists suddenly dropped, with the planning list for ICWP dropping to zero. This demonstrated a major departure from historic levels of people on the planning lists. While a reduction in the planning list should evidence an increase in the people receiving supports to live in the community, evidence does not support this conclusion.

Data obtained from DBHDD and DCH about the numbers of individuals on the planning lists, confirmed that the agencies removed a significant number of individuals from the lists in the latter half of 2018.

a. Reductions in the NOW/COMP planning list

Prior to 2018, the numbers of individuals receiving services through the NOW/COMP waiver, as well as those on the planning list, increased at the same gradual rate from month to month. Data showed that from April 2016 to January 2018, the total number of individuals receiving services grew from 11,662 to 12,066 at a rate on average, of less than 1% a month.[16] This mirrors the number of individuals on the planning list, which ranged from 8,457 in April 2016 to 8,915 in July of 2017. [17] During this time, the trajectories remained steady for both sets of numbers.

The data shows a marked change for the months after January 2018. Some 2,332 people were removed from the planning list from February to October of 2018, an overall reduction of almost 30%. The data shows that afterward, the total number of individuals on the planning list remained at around 5,980. In contrast, the total number of individuals served through the waiver during the same period increased by less than 4%, from 12,076 in February 2018 to 12,513 in

[16] Response from Young Tae, DBHDD Privacy Officer, to the Georgia Advocacy Office, *Re: Open Records Request received April 10, 2019* (May 6, 2019) (on file with author); *see also* Department of Behavioral Health and Developmental Disabilities*, Planning List Report: Muliyear Plan*, 1 (Dec. 2017) [*hereinafter*, DBHDD Multiyear Plan].

[17] Response from Young Tae, DBHDD Privacy Officer, to the Georgia Advocacy Office, *Re: Open Records Request received April 10, 2019* (May 6, 2019) (on file with author).

February 2019, or just 437 individuals. That number has declined since, to 11,773 in March of 2019. (See chart 1, below).[18]

DBHDD has attempted to manage and reduce the size of the planning list. According to the Department's "Multiyear Plan," DBHDD planned on reducing the size of the planning list by increasing the number of new waiver recipients by 3,500 by 2023, expanding other nonwaiver programs, and improving planning lists processes and operations.[19] This included adjusting several of the processes it uses to manage the planning list so that it is "accurate and fair" and does not included people whose needs were not "current or urgent."[20] DBHDD also stated that it would identify "additional resources" beyond the NOW/COMP waiver and that new "Planning List Navigators" will connect individuals with "community-based resources."[21]

However, evidence illustrates that DBHDD has not achieved these outcomes, undermining any conclusion that the reduction in planning list totals was caused by any of the efforts described above. First, the total number of NOW/COMP waiver recipients has *decreased* from 12,053 in December 2017 to 11,773 in March 2019,[22] contrary to DBHDD's announcement that it would add 3,500 recipients. Second, DBHDD significantly reduced the number of state-funded non-waiver ("SF/NW") services since announcing that it would expand these services. DBHDD decreased the number of services available through eight of the nine SF/NW services areas from FY 2016 to FY 2020.[23,24] For instance, DBHDD cut the number of "community access group" allocations from 889 in FY 2016 to 698 in FY 2020. It cut supported employment allocations from 677 to 392 and individual community access services from 49 to 30.

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[18] Please note that Chart 1 does not include data for the number of individuals on the planning lists for the months of June and July of 2018 or the numbers of individuals served for the month of March 2019. DBHDD did not provide these totals and accordingly, they are not depicted on Chart 1.

[19] Multiyear Plan at 8.

[20] Cobb County & Douglas County Community Services Board, *DBHDD Makes Changes to the I/DD Planning list Process* (March 6, 2018) (on file with author).

[21] *Id*.

[22] Response from Young Tae, DBHDD Privacy Officer, to the Georgia Advocacy Office, *Re: Open Records Request received April 10, 2019* (May 6, 2019) (on file with author).

[23] Response from Young Tae, DBHDD Privacy Officer, to the Georgia Advocacy Office, *Re: Open Records Request dated December 13, 2019* (Jan. 10, 2020) (on file with author).

[24] "State funded DD services," or "non-waiver" services, include Community Access Group Services (CAG), Community Access Individual Services (CAI), Prevocational Services, Supported Employment Services, Community Living Support Services (CLS), Community Residential Alternative Services (CRA), Respite Services, Behavioral Supports Consultation Services, and Community-Based Crisis Services. Georgia Dept. of Behavioral Health & Developmental Disabilities, *Provider Manual for Community Developmental Disability Providers of State-Funded Developmental Disability Services* (Posted November 27, 2019, effective January 1, 2020).

What's more, data show that DBHDD consistently fails to spend down significant portions of the money budgeted for these services, leaving behind millions of dollars in services each year. In FY 2017, DBHDD failed to spend $6.3 million in allocated SF/NW services. This number grew to $10.4 million in FY 2019. (See Chart 2, below). This means that DBHDD failed to spend down as much as 36% of the funds intended for SF/NW services. Accordingly, data shows a clear reduction in both the absolute number of individuals receiving SF/NW services and the total amount of money DBHDD budgeted for these services during and after the time that DBHDD announced plans to expand these services.

The ninth category of SF/NW services is "community-based crisis expenses." These services include assistance implementing established behavioral intervention strategies, safety plans, or behavioral support plans; the provision of one-to-one, incident specific supports; assistance with simple environmental adaptations; placement in a "crisis support home"; and case management services, among some others.[25] However, these services are "measure[s] of last resort and provided on a time-limited basis to ameliorate the presenting crisis."[26] Contrary to the other eight categories, DBHDD consistently spends around $22 million on these services annually.[27]

These figures raise considerable concerns about the feasibility of DBHDD's explanation of the reductions in the planning lists. Georgia is now well into DBHDD's five-year plan to provide an additional 3,500 individuals with services through the NOW/COMP waiver. However, less individuals are receiving NOW/COMP services now than in 2017, when DBHDD announced this expansion in services. DBHDD's data indicates that SF/NW services cannot have had a meaningful impact on the size of the NOW/COMP planning list. With few and only minor exceptions, DBHDD has consistently allocated fewer and fewer services in terms of individual services and specific individuals served. The only exception to this is DBHDD's provision of "community-based crisis expenses." This might suggest that DBHDD is providing individuals with "community-based crisis" services as a means of managing the planning list. However, expended amounts in this category has remained consistent—within 2%—in the past three fiscal years. This suggests that there has not been a significant uptick in DBHDD's provision of these services, even after announcing its plans to manage the NOW/COMP planning list through increased access to non-waiver community-based services. And given the limited and temporary nature of these services, these services would be an altogether inadequate substitute for the services available through the NOW/COMP waiver, even on a temporary basis.

b. Reductions in the ICWP planning list

[25] *Id.* at 27-28.
[26] *Id.*
[27] Response from Young Tae, DBHDD Privacy Officer, to the Georgia Advocacy Office, *Re: Open Records Request dated December 13, 2019* (Jan. 10, 2020) (on file with author).

DCH's monthly totals show that the ICWP planning list also fell precipitously in the fall of 2018. Since April 2016, a monthly average of 77 people remained or continued on the planning list. That number fell to three in November, 2018 and then to zero the following month.

DCH internal documents show that it "cleared"[28] the planning list in October 2018, after the Centers for Medicare and Medicaid Services ("CMS") approved DCH's latest ICWP renewal application.[29]

3. Remaining Limitations to Waiver Program Accessibility

Despite these explanations of the recent drop in planning list totals, access to community-based services through Georgia's waiver programs remains comparatively low. Georgia allocates a disproportionate amount of federal dollars for nursing facilities at the expense of waiver programs like ICWP and NOW/COMP. Georgia spends a comparatively low amount of its Medicaid dollars on individual care. And despite laws meant to ensure that individuals in hospitals and nursing homes are given a meaningful choice to receive long-term care in their own communities, Georgia has not ensured that these laws are being followed. All together, these distinctions work against applicants in Georgia and make the planning list totals for these programs artificially low.

a. Georgia's Medicaid spending on LTSS: Institutional versus HCBS spending.

Georgia has one of the largest populations of Medicaid beneficiaries in the country with a total of 1.6 million individuals enrolled.[30] This makes Georgia's Medicaid enrollment the eighth highest in the nation.[31] In terms of spending for Long Term Services and Supports[32] ("LTSS"), Georgia

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[28] Email response from Clarence Lord, DCH Open Records Officer, Re: Open Records Request # 35163, attachment *DCH ORR_ICWP_5.9.19.xlsx*, (May 10, 2019) (on file with author).

[29] *Id.*, attachment JP-DCH Leadership Meeting re ICWP Changes - Nov 26 2018.docx (on file with author).

[30] Medicaid.gov, *June 2019 Medicaid & CHIP Enrollment Data Highlights*, https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html (last visited Sept. 23, 2019).

[31] Medicaid.gov, *2019 01 Preliminary applications, eligibility determinations, and enrollment data*, https://data.medicaid.gov/Enrollment/2019-01-Preliminary-applications-eligibility-deter/dxp8-r8wr, (last visited June 27, 2019).

[32] LTSS "refer to a broad range of supportive services needed by people who have limitations in their capacity for self-care because of a physical, cognitive, or mental disability or condition." LTSS includes both institutional services, such as nursing facility care, and home and community-based services (HCBS), such as section 1915(c) waiver services. Steve Eiken *et al*., Medicaid Innovation Accelerator Program (IAP), *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*, i (May 2018) *citing* C. O'Shaughnessy and Eiken.

ranks in the top twenty in the nation.[33] This is significant because HCBS funding—the funding that individuals with disabilities need and use to live independently—is a portion of LTSS funding. How much LTSS funds go to HCBS services varies from state to state.

A deeper look at these numbers shows that Georgia spends a disproportionate amount of its LTSS dollars on institutions rather than community-based care options. The amount of LTSS funds that Georgia spends on community-based services is among the lowest in the country.[34] In fact, Georgia ranks 30th in the nation in terms of HCBS enrollment.[35] Instead, Georgia spends a larger share of its LTSS funding on nursing facilities. On average, states spend 34% of their respective LTSS budgets on nursing facilities. In contrast, Georgia, spends over 50% on nursing facilities. This means that Georgia spends more money on nursing facilities than all but six states in the country (Alabama, Hawaii, Michigan, Florida, Indiana, and Mississippi).[36] What's more, Georgia spends less money than the vast majority of states on care for actual individuals, whether they are in a nursing facility or receiving services in the community.[37]

Georgia's disproportionate reliance on nursing homes is a long-standing issue. Georgia's Department of Audits and Accounts scrutinized this very problem in 2012. The 2012 audit pointed out that from 2008 to 2011, Georgia's HCBS spending grew 4% to $337 million but that this amount paled when compared to the $1 billion the state spent on nursing facilities.[38] It also included a discussion on what other states have done to "rebalance" HCBS spending and noted that one of Georgia's challenges in taking similar measures was a lack of information about the effectiveness of HCBS spending on specific subcategories of waiver participants, specifically the elderly and those with developmental disabilities.[39] Three years later in a follow up report, the Department noted that Georgia had not developed useful performance information that allows the state's decision-makers to assess whether elderly and disabled populations were using HCBS

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[33] Steve Eiken *et al*., Medicaid Innovation Accelerator Program (IAP), *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*, Table C (May 2018).

[34] *Id*. at 7.

[35] MaryBeth Musumeci *et al*., Kaiser Family Foundation/Watts Health Policy Consulting, *Medicaid Home and Community-Based Services Enrollment and Spending*, -- (April 2019).

[36] Steve Eiken *et al*., Medicaid Innovation Accelerator Program (IAP), *Medicaid Expenditures for Long-Term Services and Supports in FY 2016,* Table C (May 2018).

[37] *Id*. at Table AO (Per resident spending on total HCBS for FY 2016 was 48th in the nation and less than half the national average. That is, Georgia spent $119.68 per resident whereas the national average was $291.92. (Table J). Per resident spending for nursing facilities was 39th in the nation (table E); per resident spending on 1915(c) waivers for FY 2016 was 36th in the nation (Table K); and per resident total medical expenditures was 49th in the nation.)

[38] Russell Hinton and Leslie McGuire, Georgia Department of Audits and Accounts Performance Audit Division, *Home and Community Based Services for Elderly and Physically Disabled,* 9 (June 2012) (on file with author).

[39] *Id* at 10.

services instead of going into nursing homes.[40] The Department's specific concern was that DCH did not track data for specific groups who may be served in a community setting (*e.g.*, ID, DD). And aggregate information could not be used to determine if the state's efforts to fund and promote HCBS had been successful.[41]

b. Failures of Federal Safeguards

Georgia's planning lists do not present an accurate picture of *Olmstead* compliance. The reduction in list size evidences an inefficient rather than a successful implementation of the HCBS rule. *First*, Georgians admitted to nursing facilities are often unaware of HCBS options due to improper implementation of the Pre-Admission Screening and Resident Review (PASRR).[42] *Second*, nursing staff do not dependably and reliably revisit this issue during residents' stay as required by federal law.[43]

i. PASRR Level 1 Screening

Federal regulation requires that states operate a preadmission screening and annual resident review program to determine whether an individual requires the level of services provided by a nursing facility and whether specialized services are needed for individuals with a mental illness an intellectual disability.[44] States fulfill their obligations under the regulation by ensuring that nursing facilities administer the PASRR to individuals prior to admitting them into long-term care. This review is intended to achieve the following:

1. Prevent individuals with mental illness, developmental disabilities, intellectual disabilities, or related conditions from being inappropriately placed in nursing homes for long term care;
2. Ensure individuals with these disabilities and/or conditions receive specialized services; and
3. Ensure that these individuals have the opportunity to live in the least restrictive setting that best meets their needs.

Once the PASRR Level 1 screen identifies that an individual experiences one of the identified disabilities, nursing staff perform a Level 2 screen to determine an appropriate placement and corresponding course of action.

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[40] Greg S. Griffin and Leslie McGuire, Georgia Department of Audits and Accounts Performance Audit Division, Follow-Up Review Home and Community Based Services for the Elderly and Disabled, 4 (May 2015).

[41] *Id.*

[42] *See infra* fn 41-42.

[43] *See infra* section 3(b)(ii).

[44] 42 C.F.R. § 483.106.

Despite this safe guard, Georgians in acute care hospitals transition into nursing facilities too often. As pointed out by Georgia's own Department of Audits and Reports, staff at nursing facilities have little incentive to discuss HCBS options with incoming patients or conduct pre-admission screenings of potential clients. The same report points out that nursing homes may not be asking residents if they would like HCBS options counseling from the Area Agencies on Aging ("AAA"),[45] as required by Medicaid. They point out further that "nearly one-third of nursing homes made no referrals for HCBS options counseling during a six-month period in 2014."[46]

ii. MDS Section Q Screening

The core safeguard geared toward transition from nursing facilities to community-based services is Section Q of the Minimum Data Set ("MDS"). Federal law requires that nursing homes utilize this assessment tool upon patient admission and periodically thereafter.[47] Beginning in 2010, the assessment was expanded to specifically identify individuals who wished to learn about home and community service options and to require referrals for information and assistance in locating community-based alternatives to nursing facilities.[48]

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[45] The Area Agencies on Aging (AAAs) were established under the Older Americans Act (OAA) in 1973 to respond to the needs of Americans 60 and older in every community in the country. The National Association of Area Agencies on Aging (n4a), *Annual Report 2017-18*, *available at* https://www.n4a.org/Files/20172018%20AR_ final_web.pdf.

[46] Greg S. Griffin and Leslie McGuire, Georgia Department of Audits and Accounts Performance Audit Division, *Follow-Up Review Home and Community Based Services for the Elderly and Disabled*, 4 (May 2015).

[47] The MDS section Q assesses individual's willingness to receive community-based services by posing a series of questions to them. For instance, section Q includes questions about the individual's expectations and whether they expect to be discharged into the community or to remain in the nursing facility. Other questions document whether the nursing facility has developed a discharge plan for the individual and whether the individual was involved in developing the discharge plan. *See* Centers for Medicare & Medicaid Services, *Long-Term Care Facility Resident Assessment Instrument 3.0 User's Manual - Version 1.16*, Ch. 3 (October 2018) *available at* https://downloads. cms.gov/files/1-MDS-30-RAI-Manual-v1-16-October-1-2018.pdf (last visited June 27, 2019).

[48] In the pilot test summary, the goal of Section Q is described as "an opportunity to improve the identification of individuals in nursing facilities who want to get information about available alternative options and supports for community living and to support individual choice." The intent was further explained as an effort "to enhance the identification of candidates and strengthen the referral and transition process. Individuals identified for transition to community services in the Section Q process would be referred to local contact agencies to receive information about community choices and for assistance in transitioning to community living situations." The questions have been designed, in response to requests "from both consumer advocates and states," to "reinforce states' efforts to comply with the Americans with Disabilities Act and the United States Supreme Court decision in *Olmstead vs. L.C.*" This focus was described as "part of broader systemic efforts by CMS to support an individual's right to choose the services and settings in which they receive those services. This right became law under the ADA (1990) and with further interpretation by the U.S. Supreme Court in the *Olmstead vs. LC* decision in 1999. The anticipated trigger was the question: "do you want to talk to someone about the possibility of returning to the community?" Dann Milne, *MDS 3.0 Section Q Pilot Test*, 1,4-5 (March 2010) (on file with author).

Patient responses to these questions show that Georgia is not taking adequate measures to implement this critical safeguard measure. In national MDS data from 2018, Georgia consistently ranked among the lowest 15 states in the country. Most notably, Georgia ranked 39th in the percentage of residents who actually participated in the MDS Q survey and ranked among the lowest 15 states for residents having an active discharge plan. Only nine other states reported fewer residents per capita who could possibly return to the community.[49]

A review of a small but representative sample of MDS surveys highlight this point.[50] Only 7% of the sample indicated that the resident "would you like to learn about community alternatives," a number that seems conspicuously low. The surveys also show that none of those who requested additional information about community alternatives were actually referred to the local contact agency.[51]

Interviews of individuals involved in the MDS Section Q information and referral process, revealed that the survey is not effective in identifying people who could live in more integrated settings. In fact, this aspect of the survey seems to have become lost in what appears to be perfunctory administration of the lengthy document. It is unclear as to whether the ineffectiveness of this portion of the MDS results from concern for the resident, lack of training, lack of alternative services, or frustration with the referral process. Regardless of the cause however, it is evident that the MDS does not provide sufficient protection from unnecessary segregation resulting from wrongful placement in nursing facilities.

Information from the Aging and Disability Resource Center[52] ("ADRC") illustrates similar outcomes. According to this data, nursing facilities made only 70 referrals to options counselors through the MDS process from February 1, 2017 to July 31, 2017. Local referral agencies reported making only 11 referrals in Savannah region, none in Coastal Georgia region, two in

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[49] *See* CMS.gov, *MDS 3.0 Frequency Report/First Quarter 2019*, *available at* https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report.html (last accessed June 27, 2019).

[50] This report includes information gathered and analyzed by Sue Jamieson through her work with the Alliance to Nursing Facility Alternatives ("ANFA"). ANFA seeks to create a framework for changing the way Georgia provides disability services to persons segregated, or at risk of being segregated, in nursing facilities.

[51] The MDS 3.0 Section Q requires that state departments of health designate Local Contact Agencies ("LCA") that will receive requests for information about community-based long-term services and supports ("LTSS") from residents in nursing facilities.

[52] The Aging and Disability Resource Connection (ADRC) is a coordinated system of partnering organizations dedicated to (1) providing accurate information about publicly and privately financed long-term supports and services; (2) offering a consumer-oriented approach to learning about the availability of services in the home and community; (3) alleviating the need for multiple calls and/or visits to receive services; and (4) supporting individuals and family members who are aging or living with a disability. Aging and Disability Resource Connection, *Welcome to Georgia's Aging and Disability Resource Connection*, https://www.georgiaadrc.com/site/1/home.aspx (last visited June 27, 2019).

Georgia Mountain region, one in Heart of Georgia region, 55 in Middle Georgia region, and one in the Northeast Georgia region.

iii. Explanations

Both of these safeguard systems—the PASRR 1 and the MDS Q—are intended to divert would-be residents from being admitted to nursing facilities or to facilitate their transition out of nursing facilities. However, they both rely exclusively on nursing facility staff as the triggering mechanisms for transition. This is a clear flaw in Georgia's model. As the Department of Auditing and Accounts documented in 2015, nursing facility staff are responsible for conducting the PASRR 1 despite having a diminished incentive to inform resident of HCBS options.[53] In addition, current [processes] do not require nursing facilities to provide residents with options counseling until after these patients become entrenched in the nursing facility.

Other state agencies such as the ADRC may align better with the needs and interests of nursing home residents and thus, may be better suited to regularly perform these screens. Unfortunately, there are also impediments to this approach. Upon admission, nursing homes must provide information to residents about HCBS, not ADRC options counseling. Only later, after residents have been admitted and have remained in the facility for months, are nursing facilities required to provide residents with an opportunity to receive options counseling from the ADRC.

Even so, nursing home referrals to the ADRC are dismally low. In July 2011, nursing facilities became responsible for referring certain residents to ADRCs for options counselling; but, as of January 2012, 27% of nursing homes had not referred a single resident.[54] Similarly, reports show that on average over a 5 year period (2013-2017), ADRC referrals amounted to only 7.8 per year per nursing home.[55] And according to the options counselors who oversee referrals and others familiar with the process, *even this small number is not likely to be generated through the MDS process* but, rather, through outreach by advocates, and referrals by nursing facility social workers.

5. Conclusion and Position Points

[53] Greg S. Griffin and Leslie McGuire, Georgia Department of Audits and Accounts Performance Audit Division, *Follow-Up Review Home and Community Based Services for the Elderly and Disabled*, 1 (May 2015).

[54] Russell Hinton and Leslie McGuire, Georgia Department of Audits and Accounts Performance Audit Division, *Home and Community Based Services for Elderly and Physically Disabled,* Executive Summary (June 2012) (on file with author).

[55] Georgia Dept. of Human Services, Dept. of Aging Services, *State Fiscal Year 2017 – Just the Facts,* 20 (date unknown) (on file with author).

Now 20 years after the *Olmstead* decision, the case has not resulted in significant changes for everyone in Georgia, especially those with disabilities in nursing facilities. Not surprisingly, the planning lists remain a focal point in the debate surrounding the unnecessary institutionalization of these individuals. What's more, *Olmstead* contemplates the factors that might slow the pace at which a state's planning lists move and whether those factors would be legitimate under the ADA.[56]

This research fleshes out these concerns. It shows that Georgia reduced the numbers of people on the planning lists by providing nonwaiver services and changing aspects of its management of the lists. However, these factors affect a relatively small number of people on the lists. The majority of the people remain on the lists, especially the NOW/COMP list, due to factors that the state has not addressed, namely: the state's preference in spending LTSS funds on nursing facilities over HCBS, poor implementation of the PASRR 1, and poor implementation of the MDS Q. Yet, it is unclear whether these reasons, individually or collectively, would provide legitimate reasons for delay in the planning list, as contemplated in *Olmstead*. Accordingly, more information is needed about Georgia's LTSS spending preferences, the causes of those preferences, and the state's efforts to ensure the implementation of the PASRR 1 and the MDS Q.

Regardless, research supports that there is cause for continued concern. These takeaways best frame the issues identified thus far:

- The number of individuals removed from the NOW/COMP planning list in 2018 is not proportional to the increase in individuals receiving services through the waiver. A portion of the individuals DBHDD removed from the list will receive "nonwaiver" service. It is unclear what these services entail, how long recipients might receive them, or how receiving these services will affect these individuals' ability to access the services through the NOW/COMP waiver should they need them.
- The ICWP waiver is most impacted by PASRR 1 and MDS Section Q implementation.
- The number of individuals on the waiting lists does not accurately reflect the total need for waiver services in Georgia.
- Georgia's use of LTSS funding for spending on nursing facilities is needlessly out of step with national trends. Georgia spends far less than the national average on community-based support and spends more on nursing homes than all but six other states.
- Georgia's preference towards nursing home spending is inefficient. It spends less money per dollar on individual care than almost every other state in the nation.

[56] Justice Ginsburg in *Olmstead*, discussed the significance of waiting lists to states' plans for placing qualified individuals with disabilities in less restrictive settings. She noted that a "waiting list that move[s] at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated" would meet the ADA's reasonable-modifications standard. O*lmstead v. L. C. by Zimring*, 527 U.S. 581, 605-06 (1999).

- Georgia's failure to increase community-based care options may have legal implications under the *Olmstead* decision and subsequent settlements.
- Despite multiple safeguards (*e.g.*, PASRR 1 and MDS Section Q), Georgians in acute care hospitals are wrongly transitioned into nursing facilities too often.

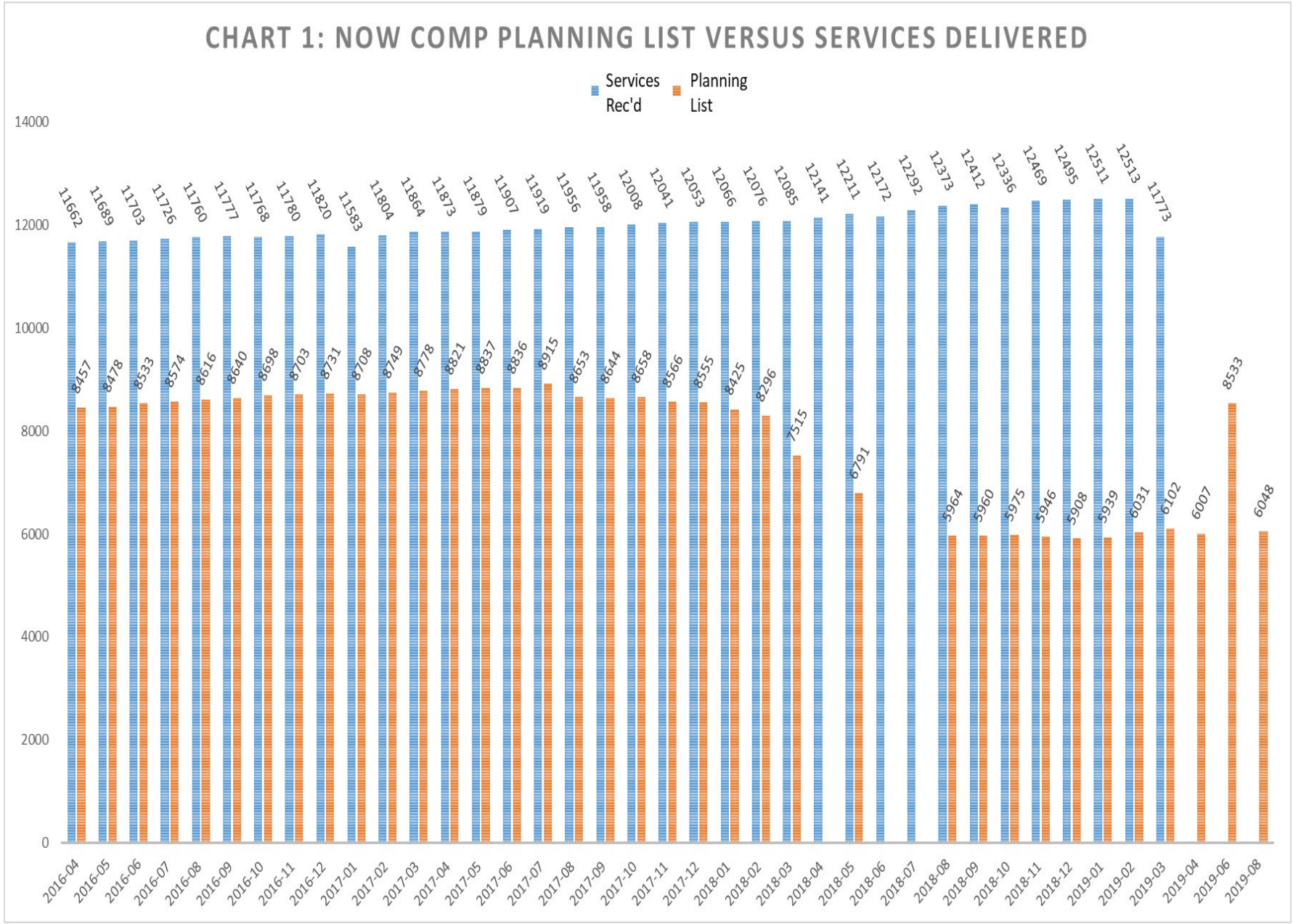
CHART 1: NOW COMP PLANNING LIST VERSUS SERVICES DELIVERED
Services Rec'd
Planning List
14000
12000
10000
8000
6000
4000
2000
0
11662
11689
11703
11726
11760
11777
11768
11780
11820
11583
11804
11864
11873
11879
11907
11919
11956
11958
12008
12041
12053
12066
12076
12085
12141
12211
12172
12292
12373
12412
12336
12469
12495
12511
12513
11773
8457
8478
8533
8574
8616
8640
8698
8703
8731
8708
8749
8778
8821
8837
8836
8915
8653
8644
8658
8566
8555
8425
8296
7515
8791
5964
5960
5975
5946
5908
5939
6031
6102
6007
8533
6048
2016-04
2016-05
2016-06
2016-07
2016-08
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2016-10
2016-11
2016-12
2017-01
2017-02
2017-03
2017-04
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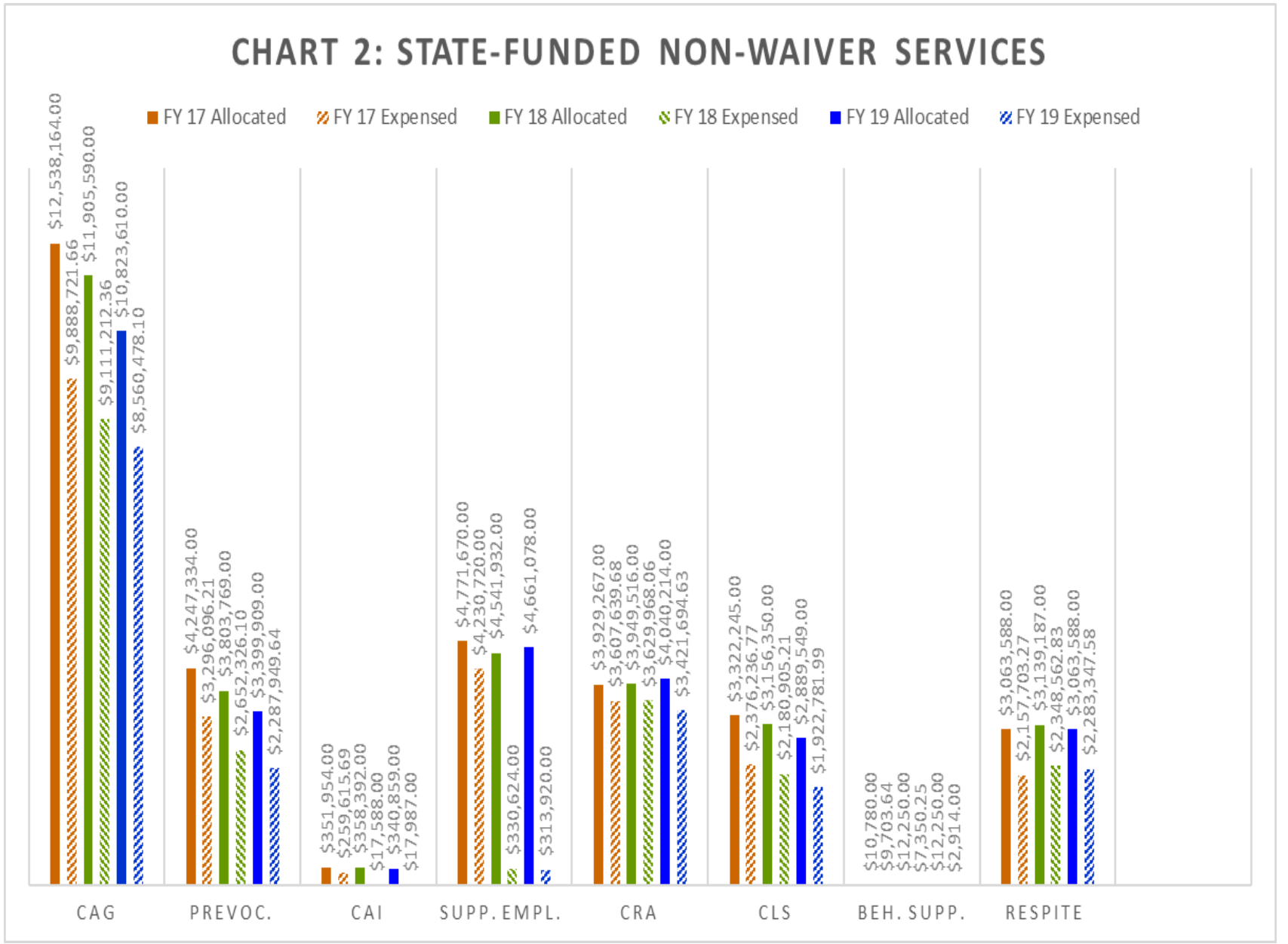
CHART 2: STATE-FUNDED NON-WAIVER SERVICES
FY 17 Allocated
FY 17 Expensed
FY 18 Allocated
FY 18 Expensed
FY 19 Allocated
FY 19 Expensed
$12,538,164.00
$9,888,721.66
$11,905,590.00
$9,111,212.36
$10,823,610.00
$8,560,478.10
$4,247,334.00
$3,296,096.21
$3,803,769.00
$2,652,326.10
$3,399,909.00
$2,287,949.64
$351,954.00
$259,615.69
$358,392.00
$17,588.00
$340,859.00
$17,987.00
$4,771,670.00
$4,230,720.00
$4,541,932.00
$330,624.00
$4,661,078.00
$313,920.00
$3,929,267.00
$3,607,639.68
$3,949,516.00
$3,629,968.06
$4,040,214.00
$3,421,694.63
$3,322,245.00
$2,376,236.77
$3,156,350.00
$2,180,905.21
$2,889,549.00
$1,922,781.99
$10,780.00
$9,703.64
$12,250.00
$7,350.25
$12,250.00
$2,914.00
$3,063,588.00
$2,157,703.27
$3,139,187.00
$2,348,562.83
$3,063,588.00
$2,283,347.58
CAG
PREVOC.
CAI
SUPP. EMPL.
CRA
CLS
BEH. SUPP.
RESPITE