IV. LONG-TERM SERVICES & SUPPORTS

The Disability Policy Consortium of Texas believes that all Texans with disabilities deserve the right to choose life in their community. Long term services and supports (LTSS) are critical in ensuring Texans with disabilities can live in their own home, work, get to their doctors, and participate in many more daily life activities. Perhaps, most importantly, LTSS helps to shift views away from the disability and onto the person, who wants to be an included, valued, member of society.

The phrasing "long term services" is based on the understanding that daily living is not necessarily an acute or medical need. LTSS provides assistance for eating, bathing, dressing, managing money, socializing, learning independent living and decision-making skills, and much more. These needs continue as long as a disability exists, which for many, means life-long. Individualized supports include things like, personal assistance services/attendant care, transportation, and supported employment. Since private insurance rarely covers LTSS costs, Medicaid is the primary payor of these important services.

Until the 1980s, Medicaid LTSS was only provided in institutions, such as nursing facilities or intermediate care facilities. Over the past couple decades, society has made strides towards more inclusive community-based services for people with disabilities. The creation of Home and Community-Based Services (HCBS) Medicaid waivers (1915(c) of the Social Security Act), The Americans with Disabilities Act (ADA) and the U.S. Supreme Court's Olmstead decision prompted a shift in how and where people with disabilities receive long term services and supports.

Texas continues to have an institutional bias when providing LTSS. Cuts to Medicaid reimbursement rates, changes to the system's infrastructure, and inadequate funding continue to create significant barriers for individuals and their families to receive long-term services and supports in their community. The focus must be on the equality and community inclusion of people with disabilities. To accomplish this, timely access to a flexible array of services that meet the individual's needs must improve.

Areas in need of improvement include responsiveness, accountability, consumer involvement, and quality outcomes. As laws and access to services and supports change, so do people's attitudes and understanding of disability. Despite a continued trend towards individualized, person centered, inclusive, integrated services; policies are struggling to keep up with the shift from outdated congregate, segregated, services and supports. The following recommendations from the DPC will support policy makers to move Texas forward in its treatment and community inclusion of Texans with disabilities by way of robust long-term services and supports.

Key Policies That Impact Long-Term Services & Supports

- Home and Community-Based Services (HCBS) Settings Rule
- The Americans with Disabilities Act (ADA) of 1990
    - The *Olmstead* Integration Mandate of 1999
- The Social Security Act
- Omnibus Budget Reconciliation Act
- Money Follows the Person Rebalancing Demonstration of 2006
- The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act
- The Affordable Care Act (ACA)
- Senate Bill 7 (83R)

COMMUNITY-BASED WAIVERS

Support Texans who choose to live in their community over living in an institution. Embrace the numerous and cost-effective opportunities for promoting independence among Texans with disabilities by adequately investing in community-based waivers.

RECOMMENDATIONS

- Provide funding to reduce the Medicaid Home and Community Based Services (HCBS) waiver interest lists (HCS, TxHmL, MDCP, CLASS, DBMD, and STAR+PLUS Waiver).
- Recommit to Texas' Promoting Independence Plan by enrolling at least 20% each biennium.
- Allow automatic access to individuals on SSI who meet eligibility, in all existing and future managed care models, as done with STAR+PLUS Waiver.
- Adequately fund Promoting Independence waiver initiatives that prevent unnecessary institutionalization through transition and, diversion waivers.
- Expand Promoting Independence initiatives to other waivers (MDCP, CLASS, DBMD, and STAR+PLUS Waiver), so individual's unique needs are met appropriately.
- Provide funding for, and access to, the appropriate waiver when a waiver participant is found to be ineligible for their current waiver (i.e. MDCP to HCS) but meets eligibility for a different waiver.
- Fund and implement, targeted modifications to the HCS program so individuals with high medical, physical, and behavioral support needs can be fully supported in their communities.

BACKGROUND

Medicaid HCBS waivers are a lifeline for Texans with disabilities. Medicaid HCBS waivers provide cost-effective long-term services and supports such as, personal attendant services, nursing, and employment support. Private insurance does not cover these critical services. When individuals are provided the appropriate waiver services, the state achieves positive outcomes. Outcomes such as decreased hospitalization, increased employment, and overall higher quality of life among HCBS waiver recipients makes waivers the most efficient service option for the state and the most desired by Texans with intellectual and developmental disabilities (IDD) and their families. Texas provides two methods for individuals to access critical LTSS services: Promoting Independence and interest list sign up.

Promoting Independence initiatives provide HCS waivers 1) to allow individuals in institutions to access the services needed to move back into the community, and 2) to prevent individuals from going into an institution who are in crisis or at imminent risk of entering an institution. Currently, Promoting Independence funding is only for HCS waivers even though some individual's needs could be more appropriately met through one of the other HCBS waiver options. Promoting Independence initiatives also fund services through reducing the number of Texans on the interest list for an HCBS waiver.

Zero appropriations were provided to reduce the interest list during the 2018-2019 biennium. The "interest list" refers to the list Texans with IDD can choose to put their names on when demand for Medicaid HCBS waivers outweighs available resources. Interest list applicants are placed on a first-come, first-serve basis and are contacted once services become available. Most will wait over 10 years before they get comprehensive waiver services; some will wait over 13 years. Service availability is dependent on legislative appropriations to include more individuals in a waiver or when an existing waiver recipient vacates services.

Over
140,000
unduplicated Texans are waiting for a HCBS waiver. Some will wait up to
13 years
before receiving comprehensive Medicaid waiver services.

CONCLUSION

The longer individuals wait for services, the more likely they are to experience negative health outcomes, crisis, and institutionalization. With over 140,000 Texans currently seeking HCBS waivers, the state should align with the choice of the majority of Texans with disabilities and prioritize investing in home and community-based services.

CONTACT

- Ginger Mayeaux | The Arc of Texas | (512) 454-6694 | gmayeaux@thearcoftexas.org
- Susan Murphree | Disability Rights Texas | (512) 407-2754 | smuprhree@disabilityrightstexas.org

DAY HABILITATION COMPLIANCE

Fully implement a robust set of modifications to programs and services in order to comply with Home and Community Based Services (HCBS) settings, person centered planning, and service rules and guidelines from Centers for Medicare and Medicaid Services (CMS) to transition into fully integrated day habilitation services.

RECOMMENDATIONS

The following recommendations align with the Texas Health and Human Services (HHSC) LAR Exceptional Item Request - Comply with Federal Requirements for Community Integration. Support Texas to a transition into fully integrated day habilitation services by:

- Prioritizing funding for Community Integration (CI) and Community Integration Support (CIS) services for all waivers so that Texas can transition effectively and fully into compliance with theHCBS settings rule.
- Providing funding to include additional transportation costs that includes everyone in activities regardless of level of support needs, appropriate additional staffing (reduced ratios), and additional supports for individuals with complex medical and behavioral needs.
- Developing a process for registration to ensure day habilitation services are regulated and monitored to provide appropriate quality services. Fully implement a robust set of modifications to programs and services in order to comply with the HCBS settings rule, person centered planning, and services rules and guidelines from CMS.
- Ensuring provider capacity and choice of provider as required by state and federal law inall community-based services and programs.

BACKGROUND

Texas needs to significantly improve services to individuals with disabilities to fully comply with HCBS settings and ensure that individuals with disabilities have access to the general community. Without appropriate funding, compliance will be limited, and the number of day habilitation providers will dramatically decrease, reducing choice and negatively impacting individuals in the program. Currently, it is common that not all participants are included in integrated community activities due to the lack of appropriate transportation, staffing, or behavioral supports.

The new services of Community Integration (CI) and Community Integration Support (CIS) are critical components for state compliance with federal HCBS regulations. Currently, day habilitation programs in Texas are facility-based and not directly regulated for program accessibility or inspected for physical accessibility or physical environment. Sheltered workshops which only offer segregated employment are often co-located at the day habilitation facility.[xviii] The 2014 Final Rule, CMS 2249-F and CMS 2296-F, or

Community-Based Settings Rule, also creates the expectation that Medicaid-funded services will support competitive, integrated employment and other community life engagement activities, and that agencies will shift away from service settings that isolate or segregate people with disabilities from the general population (CMS, 2014).[xix]

CONCLUSION

Texas needs to significantly improve services to individuals with disabilities to fully comply with HCBS settings and ensure that individuals with disabilities have access to the general community. Without appropriate funding and regulations, compliance will be limited and individuals will not have adequate supports to fully access the community for meaningful day activities.

CONTACT

- Kyle Piccola | The Arc of Texas | (512) 454-6694 | kpiccola@thearcoftexas.org
- Jeff Miller | Disability Rights Texas | (512) 454-4816 | jmiller@disabilityrightstx.org
- Brooke Hohfeld | Texas Advocates | (940) 704-9116 | bhohfeld@gmail.com

DENTAL CARE FOR ADULTS

Fund preventative dental care for all adult Texans with a disability receiving Medicaid.

RECOMMENDATIONS

- Cover regular cleanings, simple restorations, and other dental procedures in all Texas Medicaid programs for adults with disabilities.
- Include general anesthesia coverage in adult dental care Medicaid services.
- Prevent unnecessary emergency room visits for dental care that could be provided in a dental office.

BACKGROUND

Currently there are 250,000 to 300,000 adults with disabilities in Medicaid who receive little to no dental services. Dental care ends on the 21st birthday of adults in Medicaid. While preventive dentistry is partially covered in some Medicaid programs, it is not covered in many.

Oral infection can begin with surface caries, but it can be prevented and corrected with simple fillings. Left unchecked, a minor infection can be catastrophic and lead to additional health issues. Many individuals can only receive dental care through emergency room visits, which often fail to address the root cause. Ultimately, inadequate dental coverage can lead to the state to incurring higher costs.

Data from the Texas Health Institute suggests that the lapse in preventative dental coverage among adults at age 21 results in a spike in emergency room visits (rate of 299 for Medicaid enrollees 19 and under compared to 1821 for enrollees 20 and older, per 100,000 of Medicaid enrolled population).[xx]

People with disabilities face additional barriers to oral health, including inaccessible dentist offices or reliance on another person to perform daily hygiene.

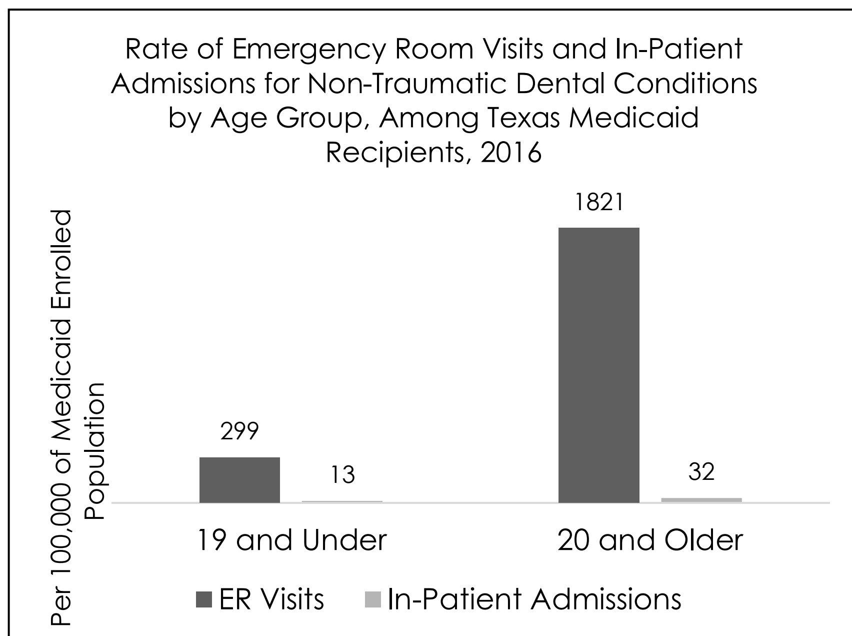


Figure 12: Rate of Emergency Room Visits and In-Patient Admissions for Non-Traumatic Dental Conditions by Age Group, Among Texas Medicaid Recipients, 2016

CONCLUSION

Texans with disabilities cannot maintain a healthy body with if there is poor oral health. A dental benefit would be cost-effective by reducing emergency room and hospital visits, reducing acute care needs for heart disease, diabetes, stroke, and other conditions co-indicated with poor oral health. Furthermore, adequate dental care can ensure adults maintain a healthy, balanced diet and do not have a need to be prescribed opioids.

CONTACT

- Dennis Borel | Coalition of Texas with Disabilities | (512) 478-3366 | dborel@txdisabilities.org
- Linda Litzinger | Texas Parent to Parent | (512) 922 3810 | linda.litzinger@txp2p.org

MEDICAID MANAGED CARE

Increase transparency and improve consumer experience and protections for Texans with disabilities in Texas Medicaid Managed Care.

RECOMMENDATIONS

- Texas must hold contractors accountable in their role in service delivery.
  - Disallow or discontinue purchasing practices that result in reduced, delayed or restricted access to care and ensure choice of providers and suppliers.
  - Ensure individuals have access to and are provided high quality services and supports in the most appropriate, least restrictive setting,
  - Provide person-centered services based on a comprehensive assessment by qualified assessors that identifies unique individual preferences, strengths, and needs.
  - Provide guidance to improve access to medically necessary services for children and adults, such as therapy, private duty nursing, durable medical equipment and community attendant services and prohibit MCOs from using State Supported Living Centers to provide benefits covered through managed care contracts.
  - Improve and standardize prior authorization processes.
  - Provide additional standardization, guidance and training to health plans, members and care coordinators, about internal appeals and fair hearings, including federal law regarding continuation of services pending when timely (within 10 days) requested.
  - Require a higher level of training for care coordinators who need more skills to perform their functions effectively, review care coordination and pay for quality and ensure an appropriate caseload for complex care coordination. Require MCOs to develop service coordinator retention plans.
  - Create more efficient service delivery areas and ease of access to specialists, clinics and hospitals that are out of network or in a different service delivery area.
- Require MCOs to expand provider networks to allow greater access to care closer to home.
  - Develop, track, and publically report data and address performance measures for community long term supports and services (LTSS), such as timely, continuing access to and satisfaction with high quality, well trained attendant/direct support staff and services authorized and utilized per MCO and contract area.
  - Ensure appointment availability and transportation assistance, when needed, to emergency, routine and specialty care, regardless of type or intensity of disability and in accordance with the provider's treatment plan.
  - Determine and publically report type, frequency and cost of potentially preventable events related to lack of access to attendant/direct support staff and related community supports and services.
  - Require contracting, indefinitely and not just three years, with significant traditional providers that meet standards of care.

- Set attendant recruitment and retention standards and ensure rates that support an adequate workforce for acute and LTSS services.
- Improve information about and access to consumer directed/self-directed services with required targets for utilization of consumer directed services.

- Increase transparency and respond quickly, accurately and completely to issues generated through inquiries, complaints, conducting investigations, inspections and other contract compliance regulatory actions.
  - Consolidate and streamline the complaints process and increase public awareness and outreach to MCO members about where to go for help and how to make a complaint. Require state agencies and MCOs to track all instances of access to care issues as a complaint.
  - Improve timely access to qualified, conflict free service coordination/case management that assists with removing barriers to care and coordinates with other care coordinators and providers across programs and settings. Incentivize care coordination at the physician or clinic practice rather than the payor level.
  - Require Ombudsman and Consumer Rights Services to keep individuals informed of agency action and findings about complaints regarding programs and services and elevate systemic issues with recommendations for improvement to HHSC leadership and the legislature.
  - Improve data integration and transparency by providing online information available to the public across systems relating to inquiries, complaints, informal MCO appeals, Medicaid Fair Hearings, and MCO plans of correction.
  - Improve and coordinate MCO informal appeals and HHSC Fair Hearings, by providing consumer information that explains and assists with both processes and meets all state and federal due process requirements, such as proper notices and packets with complete and relevant information used to deny, suspend, or reduce services.
  - Delay inclusion of additional LTSS services into managed care unless and until related evaluations are completed and access to and quality of care are resolved in current managed care programs and operational systems and providers are in place for a successful transition.
  - Consistent with 42 C.F.R. 438.56 (d) (2), facilitate information about and assistance with disenrollment of managed care members experiencing access to and quality of care barriers impacting health, safety and quality of life.
  - Provide an opt-in or opt-out mechanism for MDCP Star Kids and Star Health members rather than mandatory enrollment. Create an alternative MDCP fee for service (FSS) option and/or transition to a different waiver program including HCS, CLASS or DBMD.

BACKGROUND

Over the past 20 years, Texas Medicaid has shifted gradually from a fully Fee for Service (FFS) model that pays providers for each service delivered to an extensive managed care service delivery model that pays a fixed fee per member per month, called capitation. Texas managed care includes CHIP, STAR, STAR+PLUS, STAR Kids, STAR Health, Dual Eligible Integrated Care Demonstration and dental for children and youth. HHSC develops and oversees Medicaid managed care contracts.

Texans with disabilities need reliable access to person-centered, high quality health and Long Term Supports and Services (LTSS) services in the most integrated setting, but are experiencing barriers to remain safe,

healthy, and independent in their communities. While we encourage implementing crucial improvements, such as improving network adequacy, enhancing care coordination, oversight, grievances, appeals and transparency, some individuals may not be successful in a managed care model and may require other options when warranted. Currently, Managed Care Organization (MCO) members are not made aware of the disenrollment option and are not assisted in pursuing disenrollment for cause, including for poor quality of care, lack of access to services, lack of access to providers experienced in serving certain populations or meeting members complex care needs.

According to data from the National Healthcare Quality and Disparities Report by the U.S. Department of Health and Human Services, there are many Medicaid Managed Care healthcare quality benchmarks that Texas is far from meeting compared to other top-performing states.[xxi] The table below details selected quality measures in Texas Medicaid Managed Care that are far away from achievable benchmarks.

Medicaid Managed Care Measures	Distance to Benchmark
Adults who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never explained things in a way they could understand	244%
Adults who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never showed respect for what they had to say	208%
Adults who needed care right away for an illness, injury, or condition in the last 12 months who sometimes or never got care as soon as wanted	201%
Adults who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never spent enough time with them	172%
Adults who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never listened carefully to them	150%
Adults who had a doctor's office or clinic visit in the last 12 months and needed care, tests, or treatment who sometimes or never found it easy to get the care, tests, or treatment	109%

Figure 13: Quality Measures Compared to Achievable Benchmarks, FFY 2016

CONCLUSION

Without sufficient health care access, improved care/service coordination and community supports, individuals with disabilities are at risk of costly hospitalizations, poor health or long term, unnecessary institutionalization.

CONTACT

- Kyle Piccola | The Arc of Texas | (512) 454-6694 | kpiccola@thearcoftexas.org
- Susan Murphree | Disability Rights Texas | (512) 407-2754 | smuprhree@disabilityrightstexas.org
- Chis Masey | Coalition of Texans with Disabilities | 512-478-3366 | cmasey@txdisabilities.org
- Bob Kafka | ADAPT of Texas | (512) 442- 0252 | bkafka@sbcglobal.net

RELOCATION SERVICES TO COMMUNITY

Improve Medicaid relocation services for people with disabilities moving from institutions to the community.

RECOMMENDATIONS

Require a comprehensive, third-party review of the managed care Medicaid relocation services. This review should:

- Determine whether resources for relocation are adequate and effectively providing desired outcomes.
- Determine the adequacy of funding established through managed care organizations to support relocation personnel and transition assistance services and the solvency of a strong and high-performing consumer-centered long-term care system.
- Survey relocation contractors, consumers, and other stakeholders in the managed care process to identify barriers to consumer relocation or avoidance of institutionalization, as well as creative uses of partnerships and leveraged opportunities.

BACKGROUND

In Texas, relocation from institutions to the community is cost-effective and preferred by individuals with disabilities. In previous years, fee-for-service contracts between community-based organizations and the Texas Health and Human Services Commission (HHSC) formed a highly successful model recognized nationwide to provide assistance for individuals eligible for Medicaid to leave nursing facilities. However, since September 1, 2017, the model changed from a community-based model to Texas' Medicaid Managed Care program.

CONCLUSION

Texas should ensure that steps are taken to implement appropriate measures that will achieve preferred person-centered relocation and transition assistance services and supports.

CONTACT

- Judy Telge | Coastal Bend Center for Independent Living | judyt@cbcil.org
- Dennis Borel | Coalition of Texas with Disabilities | (512) 478-3366 | dborel@txdisabilities.org

STATE SUPPORTED LIVING CENTERS

Long community-based services wait lists and inadequate funding for some community supports leave some individuals and families with no viable alternative except institutional care. It is time for Texas to rebalance the way it prioritizes Medicaid services and allocate taxpayer dollars more efficiently.

RECOMMENDATIONS

- Set the expectation of fewer institutions while also bringing services up to accepted professional standards of care for those remaining in state supported living centers (SSLCs). Consider implementing a moratorium on SSLC admissions, with sufficient, high-quality, community capacity.
- Develop and implement an SSLC peer support program for individuals with intellectual and developmental disabilities (IDD) to foster supported decision-making, informed choice, and encourage self-determination.
- Expand access and quality of Medicaid home and community-based services (HCBS) waivers to address the increased demands for services in our state. Prevent individuals from being unnecessarily segregated in an institution due to inadequate funding.

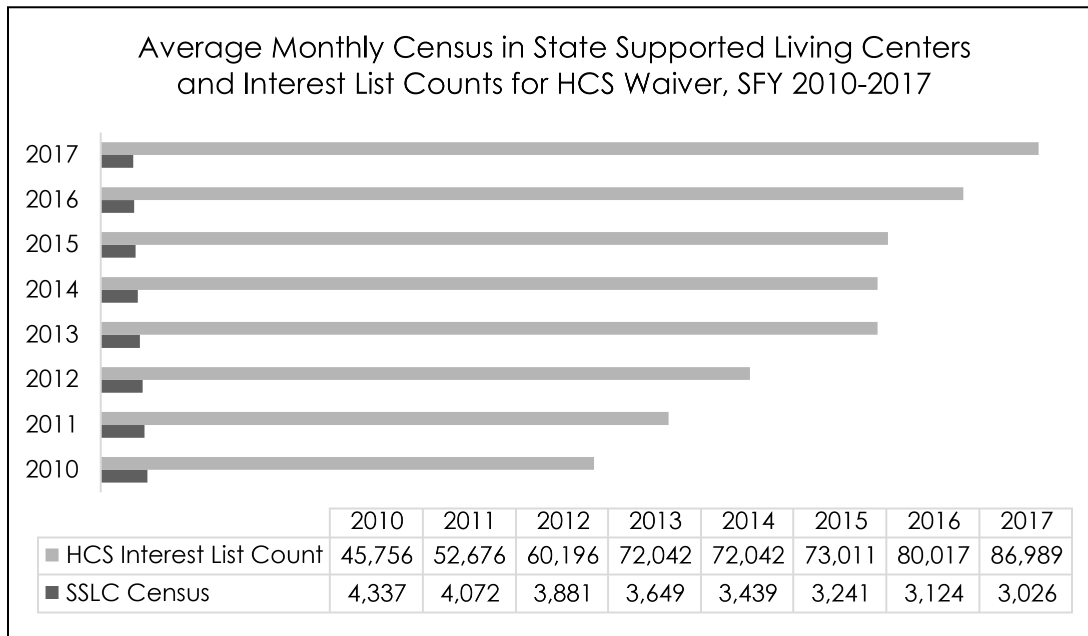
BACKGROUND

Despite a national trend to reduce institutionalization and expand community options for individuals with IDD, Texas continues to have the highest institutionalized population of individuals with IDD in the nation. HCBS waivers are not only the preferred choice of most Texans with IDD but are often the less expensive option, yet 50% of the state budget for individuals with IDD went to SSLCs this past biennium. Most people with IDD live safer, healthier, happier lives when more fully integrated into the community, living among family and friends. Texas prioritizes institutional funding for 13 SSLCs, undermining access to community living. SSLCs are state run residential institutions for about 3,000 Texans with IDD. These expensive institutions are currently under a U.S. Department of Justice (DOJ) settlement agreement as a result of systemic abuse, neglect, and exploitation.

In 2015, the Texas Senate approved a Sunset Advisory Commission recommendation to close Austin SSLC and establish a closure commission to decide if five more SSLCs should also close. The measure failed to be passed by the Texas House of Representatives, thus no progress was made. The number of people in SSLCs continues to decline, but funding for SSLCs continues to rise, by about 25% per biennium. Meanwhile, the number of Texans with IDD waiting for community-based services, which are considerably less expensive, continues to grow.[xxii]

There is no wait for SSLCs, but Texans who prefer low-cost, community-based living sometimes must wait at least 13 years for services. While waiting for these necessary supports, thousands of Texans with IDD are at increased risk for negative health outcomes, crisis, and unnecessary institutionalization.

Despite common misconceptions, people with the most complex needs can be and are supported in the community. There are 10 times as many people with the highest level of need supported with waiver services in the community than there are in SSLCs.



	2010	2011	2012	2013	2014	2015	2016	2017
HCS Interest List Count	45,756	52,676	60,196	72,042	72,042	73,011	80,017	86,989
SSLC Census	4,337	4,072	3,881	3,649	3,439	3,241	3,124	3,026

Figure 14: Average Monthly Census in State Supported Living Centers and Interest List Counts for HCS Waiver, SFY 2010-2017

CONCLUSION

The over 140,000 Texans waiting for HCBS services proves the demand for community is higher than for institutional care. In addition, many SSLC residents have made their preferences known, choosing community-based options over institutions. Yet, SSLC residents face unnecessary barriers to community living before being released, perpetuating the Texas system of institutional care. Investing in the already established and preferred option of HCBS waivers for Texans, improves the lives of thousands in and out of institutions. The legislature should take the opportunity to reduce institutional bias and more efficiently allocate taxpayer dollars.

CONTACT

- Ginger Mayeaux | The Arc of Texas | (512) 454-6694 | gmayeaux@thearcoftexas.org
- Dennis Borel | Coalition of Texas with Disabilities | (512) 478-3366 | dborel@txdisabilities.org