Medicaid Waiver Programs Interest List Study

As Required by

2020-21 General Appropriations Act, House Bill 1, 86th Legislature, Regular Session, 2019 (Article II, Health and Human Services Commission, Rider 42)

Health and Human Services Commission

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Executive Summary

HHSC submits the *Medicaid Waiver Programs Interest List Study* in compliance with the 2020-21 General Appropriations Act, House Bill 1, 86th Legislature, Regular Session, 2019 (Article II, Health and Human Services Commission [HHSC], Rider 42). Rider 42 requires HHSC to study interest lists and consider:

- Experience of other states in reducing or eliminating interest lists for individuals with an intellectual or developmental disability (IDD)
- Factors affecting waiver program interest lists for the five most recent biennia
- Existing data on persons on waiver program interest lists
- Strategies that HHSC could employ to eliminate waiver program interest lists
- Cost estimates for implementing strategies

Texas uses the term interest list because qualification and eligibility statuses are unknown at the time the individual is placed on a list. However, most reports on other states used the term wait list.

National Trends—Interest Lists

In April 2019, the Kaiser Family Foundation (KFF) published the latest data about state Medicaid home and community-based services (HCBS) waiver waiting lists based on its seventeenth annual survey of these programs. The KFF brief summarized national waiting lists for services, as follows:

- More than three quarters of states reported having an HCBS waiver waiting list for at least one target population in 2017.
- From 2002 to 2017, national interest lists grew from 192,000 individuals to 707,000 individuals.
- Of the 707,000, individuals with IDD make up 67 percent of the individuals on the waiver interest lists. Seniors and adults with physical disabilities make up 28 percent.
- The average waiting period by population ranged from four months for waivers targeting individuals with human immunodeficiency virus, acquired
immunodeficiency syndrome (HIV/AIDS) to 66 months for waivers targeting people with IDD.

Texas like the nation has seen growth in interest lists for HCBS waivers. Nationally, interest lists grew by 65 percent from 2010 to 2017 according to KFF data. Texas’ combined waiver interest lists increased from 78,626 unduplicated individuals in 2010 to 150,364 in 2019 (91.2 percent).

**Experiences of Other States**

HHSC researched nine other states taking actions to address long-standing interest lists for Medicaid waivers for individuals with IDD. Three themes emerged:

1. Prioritizing access to waiver services based on urgency of need, rather than first-come first-serve, using an assessment or screening tool;

2. Enrolling individuals in non-waiver Medicaid state plan HCBS services or less expensive support waivers (often not offering 24-hour residential supports) if these services can meet the individual’s needs;

3. Reassessing individuals at a standard interval (typically one to two years) to ensure the original needs assessment/screening is still valid and the individual has not experienced a change indicating a more urgent need for Medicaid waiver services.

**Texas Economic Indicators from 2010-2019**

HHSC examined trends for key economic indicators over the study period. From 2010 to 2019, the number and percentage of Texans living in poverty declined, the unemployment rate dropped by more than half, and median family income rose about a third. In addition, there was a decline in the number of Texans without health insurance. Based on the data, economic factors do not appear to be associated with the growth of the waiver program interest lists.

**Texas Policies Impacting Interest List Growth**

From 2010 to 2019, the unduplicated number of individuals receiving waiver services grew by 43.8 percent or 31,832 individuals. HHSC has expanded the use of managed care as a delivery system for Medicaid services since the late 1990s. However, managed care delivery of HCBS waiver services did not occur until September 2014 when HHSC integrated the 1915(c) waiver authorizing the Community Based Alternative (CBA) Program into the STAR+PLUS HCBS program.
under the statewide 1115 Healthcare Transformation demonstration waiver. Currently, the majority of individuals are served within a year of expressing interest in STAR+PLUS HCBS services.

In November 2016, Texas moved services for children with disabilities into managed care with the implementation of STAR Kids. This included HCBS waiver services through the Medically Dependent Children Program (MDCP). Currently, individuals on the MDCP interest list are served within one to two years of expressing an interest in MDCP and its interest list has shown a steady decline since implementation of STAR Kids.

**Existing Data on Individuals Expressing an Interest in Services**

As of April 2020, the unduplicated count of individuals on all Texas Medicaid waiver interest lists is 159,419.

- Over 50 percent of individuals on IDD waiver interest lists have been on the list for at least five to seven years.
- Over 50 percent of individuals on all Medicaid interest lists are receiving at least one other Medicaid or non-Medicaid service.
- Over 40 percent of individuals on all interest lists except for STAR+PLUS HCBS are receiving a Medicaid managed care state plan service. Since individuals on the STAR+PLUS HCBS interest list meet Medicaid financial eligibility by receiving waiver services, it is reasonable that these individuals would not be receiving other Medicaid services. Individuals with Supplemental Security Income (SSI) disability are automatically enrolled in STAR+PLUS HCBS if the individual meets functional eligibility for the waiver and needs at least one waiver service.
- HHSC cannot tell from the services data if individuals are receiving all needed services. Individuals may be receiving long-term services and supports (LTSS) through the state plan or solely receiving acute care services and still have a need for LTSS.

**Strategies Texas Could Employ**

The strategies identified in the report are primarily based on how other states reformed their systems for interest list management. Some would require legislative direction and/or funding to implement. Many also incorporate elements
of the Intellectual and Developmental Disability System Redesign Advisory Committee (IDD SRAC) recommendations located in Appendix C.

The strategies fall into three categories:

1. **Addressing gaps in real-time information about the needs of individuals currently on waiver interests lists to better understand and manage timely access to services thereby addressing risks to health and safety or institutionalization.**

2. **Prioritizing certain populations and individuals with the highest level of service needs, similar to what other states have implemented.**

3. **Considering any interest list reduction allocations and targeting additional funding for priority populations.**
1. Introduction

HHSC Rider 42 requires HHSC, in consultation and collaboration with the IDD SRAC established under Sec. 534.053, Government Code, to conduct a study of interest lists or other waiting lists for the following six Medicaid waiver programs:

- Home and Community-based Services (HCBS);
- Community Living Assistance and Support Services (CLASS);
- Deaf-Blind Multiple Disabilities (DBMD);
- Medically Dependent Children Program (MDCP);
- Texas Home Living (TxHmL); and
- STAR+PLUS HCBS.

In conducting the study, HHSC must consider the following:

- Experiences of other states in reducing or eliminating interest lists for services for individuals with an IDD;
- Factors affecting the waiver program interest lists for the five most recent state fiscal biennia, including significant policy changes impacting the interest list;
- Existing data on persons on the waiver program interest lists, including demographics, living arrangement, service preferences, length of time on the interest list, and unmet support needs;
- Strategies that HHSC could employ to eliminate the waiver program interest lists in a manner that results in the provision of person-centered services in the most integrated setting, including strategies employed by other states and opportunities for additional federal funding; and
- Cost estimates to implement strategies for eliminating the interest list for each program.

Regulations Governing Interest Lists

HCBS waiver programs were introduced in the 1980s as an optional Medicaid benefit allowing states to choose to provide LTSS in community-based settings. Throughout the country, the demand for these services often outweighs the
availability. If it is necessary to defer the entrance of individuals to a waiver, the state must have policies that govern the selection of individuals for entrance to the waiver when capacity becomes available.

While the Centers for Medicare and Medicaid Services (CMS) provides states guidance, states have autonomy to manage their waiting or interest lists. Texas uses the term interest list because qualification and eligibility statuses are unknown at the time the individual is placed on a list. However, most reports used the term wait list.

CMS indicates these policies should be based on objective criteria and applied consistently in all geographic areas served. CMS is careful to limit their guidance to the way states establish criteria for selection of entrants into the waiver and does not dictate state strategies for managing a wait list. This flexibility allows states to design an interest list management system targeted for their states unique populations and geographic areas.
2. Texas Interest List Management Process

Texas has four waivers that serve individuals with IDD that waive off the level of care (LOC) required for an intermediate care facility for an individual with an intellectual disability or related condition (ICF/IID):

- Home and Community-based Services Waiver (HCS)
- CLASS
- DBMD
- TxHmL

MDCP and STAR+PLUS HCBS waive off nursing facility level of care. Each of these waivers offer services in the community as an alternative to services in an institution.

HHSC maintains separate interest lists for each of these six Texas Medicaid waiver programs. HHSC’s Intellectual and Developmental Disabilities and Behavioral Health Services department manages the HCS and TxHmL waiver interest lists, while Medicaid and CHIP Services manages the CLASS, DBMD, MDCP, and STAR+PLUS HCBS waiver interest lists.

An individual can be on one or up to all six interest lists concurrently. If an individual receives an offer to enroll they may do so and remain on the other interest lists if they choose. Very little information is required to add an individual’s name to the interest list. HHSC does not determine the individual’s eligibility for the waiver program, financial or functional, prior to placing them on an interest list.

Except for the STAR+PLUS HCBS interest list, over 60 percent of individuals on one waiver program interest list were also on another waiver program interest list in the 2018-19 biennium. Since individuals interested in STAR+PLUS HCBS services are generally served less than one year from expressing interest, these individuals do not show up in high numbers on other interest lists.

Because individuals can be on more than one list, it is possible for an individual to reach the top position on more than one interest list within the same year. HHSC attempts to identify and coordinate more than one waiver program offer for the
same individual by providing information on each program, empowering the individual to make an informed decision.¹

HHSC manages enrollment into HCBS waivers using a variety of appropriation or “slot” types:

- Interest list reduction slots are funded to remove individuals from the interest list on a first come, first serve basis. Available appropriations determine availability.
- Diversion slots are funded to assist individuals at risk of entering an institution. Diversion slots are only available in the HCS waiver.
- Promoting Independence (PI) Initiative and Money Follows the Person (MFP) Initiatives fund transition slots for individuals moving from institutions (e.g., nursing facility, ICF/IID) to the community using an HCBS funded waiver slot.

**Standardization of Interest List Management Practices**

Some states manage one waiting list for all waiver programs, while Texas manages separate lists for each waiver program. The history of legacy HHS agencies like the Department of Mental Health and Mental Retardation (MHMR) and the Department of Human Services (DHS) each implementing waiver programs using different processes and systems has added complexity to interest list management as Texas has consolidated HHS agencies over time.²

Today, different policies and processes govern Texas’ interest list management for waiver programs. Local IDD authorities (LIDDAs) contact individuals by phone every two years for HCS and TxHmL. HHSC staff reach out every year by mail to CLASS, DBMD, STAR+PLUS, and MDCP; however, using mail impacts the quality of information obtained during annual contacts. While both groups use the *Questionnaire for LTSS for Waiver Program Interest Lists* for initial placement on an interest list, neither administers it during annual or biannual contacts. Standardizing policies and processes across all interest lists would ensure consistent interest list management across waiver programs.

¹ A person is only assessed for one waiver program at a time.
² MHMR used the Client Assignment and Registration System (CARE) and DHS used the Community Services Interest List (CSIL) system.
Factors Impacting Interest List Management

Availability of slots to reduce waiver program interest lists is dependent upon several factors: legislative appropriations for interest list reduction, the average annual cost of waiver slots by program, the number of slots that become available due to attrition (e.g., a person leaves the waiver) and dedicated resources for ongoing priority PI and MFP initiatives. If the average annual cost of each waiver steadily increases, the number of slots that can be filled with a set appropriation declines. If MFP and PI priority populations increase, and a dedicated number of slots are not available, attrition slots are reprioritized to address priority populations rather than interest list reduction.

Another factor impacting interest list management is known as “take-up rates.” The take-up rate represents the number of slots released that result in waiver enrollment. As Texas allows individuals to be on an interest list without determining eligibility for Medicaid or the waiver programs, it can be challenging to determine how many slots are needed to make a specific reduction to the interest lists.

HHSC assigns a closure reason for every slot released from an interest list. Figure 1 shows the closure reasons for the last five biennia for the IDD waiver interest list slot releases. The combined percentage of slots with a closure reason of declined/withdrawn and no response/unable to locate was between 34 and 49 percent of the slots released. This data demonstrates the importance of real-time information on the status of individuals on the interest list to ensure the most efficient and effective interest list management.
A similar pattern is seen with STAR+PLUS HCBS and MDCP data (Figures 2 and 3). Between 40 and 72 percent of slots released have a closure reason of declined/withdrawn and no response/unable to locate.

In other states, using priority access to waiver services combined with determining financial and functional eligibility for Medicaid and the waiver program when the person is placed on the priority waiting list helped address uncertainty about actual demand for services.
Figure 2 STAR+PLUS HCBS Waiver Enrollment and Slot Releases

Data source: Community Services Interest List (CSIL)
Data Retrieved by: Aging and Disability Data Management, Center for Analytics and Decision Support - 07/2020
Chart Prepared By: Medicaid/CHIP Data Analytics, Center for Analytics and Decision Support, Texas HHSC - 04/2020
Individuals on the Interest Lists with No Contact

Another challenge is maintaining contact with individuals who have expressed an interest in waiver services. Figure 4 shows 34 percent of individuals on the CLASS interest list have been out of contact for two years or more, as of April 2020. Sixteen percent have not had contact in six years. Eighteen percent of individuals on the HCS and TxHmL lists are out of contact for two years or more. Understanding the status of an individual’s need for services is essential to successfully implementing any strategy to reduce the interest list.
Figure 4 Interest List Individuals Out of Contact for 2 Years or More

<table>
<thead>
<tr>
<th>Medicaid Waiver Program</th>
<th>No contact on record</th>
<th>2-5 years</th>
<th>6+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLASS</td>
<td>16%</td>
<td>34%</td>
<td>1%</td>
</tr>
<tr>
<td>DBMD</td>
<td>14%</td>
<td>18%</td>
<td>1%</td>
</tr>
<tr>
<td>HCS</td>
<td>18%</td>
<td>18%</td>
<td>1%</td>
</tr>
<tr>
<td>TxHmL</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>

MDCP and STAR+PLUS are not displayed as 100% of individuals on the interest list have been contacted within one year.
Data source: CSIL
Data Retrieved by: Aging and Disability Data Management, Center for Analytics and Decision Support (CADS)- 04/2020
Chart Prepared by: Medicaid/CHIP Data Analytics, Center for Analytics and Decision Support, Texas HHSC - 07/2020

Accurately Screen the Need for Waiver Services

Researching practices in other states and examining trends for interest list growth over the last five biennia in Texas revealed the need for more information about the needs of individuals currently interested in waiver services. For states that have moved away from a first come, first serve approach, assessing how urgently waiver services are needed is central to the state establishing access to waiver programs. The screening or assessment process is a key part of this strategy.

HHSC currently uses Form 8577, *Questionnaire for LTSS for Waiver Program Interest Lists*. The questionnaire is administered by HHSC and LIDDA staff responsible for interest list management for the respective waivers. The questionnaire is only completed at initial placement on the interest list and the individual requesting interest list placement is not required to answer all 18 questions.

HHSC updated the questionnaire in January 2017 to include questions about needs related to activities of daily living, caregiver situation and what services people are receiving now. It does not ask about immediacy of needs; however, the system used to manage the HCS and TxHmL waivers has fields which request information about when services are needed. The questionnaire also does not address financial or functional eligibility.
As depicted in Figure 5, more than 80 percent of individuals have a questionnaire on file with HHSC. Less than five percent of individuals across the waiver interest lists refuse to complete the questionnaire. Most individuals on each waiver interest list have a questionnaire updated two or more years ago. For example, in CLASS, 80 percent of individuals have a questionnaire that is at least two years old. The same is true for HCS with 84 percent.

**Figure 5 Last Completed 8577 Questionnaire in Years, April 2020**

Numerous questions are left blank on questionnaires in the system for HCS, TxHmL, and CLASS since the questionnaire is not updated at annual or biannual verification checks. For example, whether an individual has a hearing or vision impairment and what type of personal care is needed (e.g., toileting, hygiene, dressing) is not completed in over 70 percent of questionnaires for individuals on the HCS, TxHmL, and CLASS interest lists.

For DBMD and MDCP, a higher percentage of individuals are on the interest list for less than two years, so the questionnaires for these individuals tend to be more complete. For example, only 30 percent of questionnaires for DBMD and 13 percent of questionnaires for MDCP have blank responses for questions added in 2017.
STAR+PLUS HCBS is the only waiver program that does not require completion of the questionnaire, because the Community Services Interest List (CSIL) system excludes this function for the program.

For states that restructured interest list management by prioritizing individual’s access to waiting lists based on service needs within one year or less, administering accurate and up to date screening or assessment tools for all individuals on the waiting lists was a first step in the transition process. Considering the size of Texas’ current interest lists and current data available on an individual’s needs, this approach would require additional resources and time for HHSC to gather information necessary to identify individuals with an urgent need for waiver services.
3. Research on Other States Interest List Reductions

In April 2019, KFF published the latest data about state Medicaid HCBS waiver waiting lists based on its seventeenth annual survey of these programs. The KFF brief summarized national waiting lists for services, as follows:

- More than three quarters of states reported having an HCBS waiver waiting list for at least one target population in 2017.

- From 2002 to 2017, national interest lists grew from 192,000 individuals to 707,000 individuals.

- Of the 707,000, individuals with IDD make up 67 percent of the individuals on the waiver interest lists. Seniors and adults with physical disabilities make up 28 percent.

- The average waiting period by population ranged from four months for waivers targeting individuals with HIV/AIDS to 66 months for waivers targeting people with IDD.

The brief highlighted that 39 of 40 states with waiting lists prioritize individuals with certain characteristics to receive services when waiver slots become available:

- 23 states prioritize individuals who meet specific crisis or emergency criteria.

- 22 states prioritize people moving out of institutions into the community.

- 19 states prioritize individuals at risk of entering an institution without waiver services.

- 9 states prioritize based on assessed level of need and 6 states prioritize based on age.

- 22 states have more than one priority group.

In addition to reviewing the KFF report, HHSC researched nine states that implemented an interest list reduction strategy. Research reports from Alaska, California, Colorado, Louisiana, Minnesota, Nebraska, Ohio, New York, and Utah are summarized in this section. Appendix C contains more detailed information on some states.
**Alaska**

Alaska Department of Health and Social Services released the Developmental Disabilities (DD) Waiting List Report (2005-2006) describing how Alaska updated its waiting list process for LTSS. The DD Waiting List is referred to as The DD Registry. The DD Registry has information on people who have been determined eligible for developmental disability services and is used to select people for enrollment in services when resources are available. Alaska state statute requires an annual report to the Governor and specified legislative committees when there is not adequate funding to meet the needs of individuals with DD.

Alaska uses the Developmental Disabilities Registration and Review (DDRR) as a screening/assessment tool. The DDRR provides the state and other stakeholders information on the current needs and preferences of the individuals and families waiting for expanded supports services. Once a DDRR form is received it is scored by a Qualified Intellectual Disability Professional (QIDP). At least annually, the Division contacts those on the DD Registry to update personal information about changes in their condition or family circumstances. The DD Registry assists the Division of Senior and Disability Services in planning for the future needs of people with a developmental disability.

By incorporating strategies as described above, Alaska has cut its waiting list in half over the past 10 years by providing policy makers current and targeted information about the immediate demand for services.

**California**

In 2018, The Department of Developmental Services (DDS) in California published an HCBS report. California’s HCBS waiver services are available to regional center consumers who are Medicaid eligible and meet the level-of-care requirements for an intermediate care facility serving individuals with developmental disabilities. DDS reports all individuals who express an interest and are eligible are enrolled in the DD waiver.

California will submit necessary DD waiver amendments to CMS to accommodate all individuals who are eligible for and express an interest in participating in the DD Waiver if the approved DD waiver capacity is insufficient to accommodate all interested persons. The HCBS waiver gives California the flexibility to develop and implement creative, community alternatives to institutions.
Colorado

Colorado maintains a waiting list for the Home and Community Based Services for Persons with Developmental Disabilities (HCBS-DD) waiver. Eligibility for the HCBS-DD waiver is limited to individuals who have DD, are eighteen years of age or older, require access to services and supports 24 hours a day, meet the level of care for an ICF/IID, and meet Medicaid financial eligibility. Community Centered Board personnel, which are entities like the LIDDAs in Texas, make the determination of need for access to services and supports 24 hours a day. Many individuals who seek enrollment in the HCBS-DD waiver are already receiving services in the Home and Community Based Services-Supported Living Services (HCBS-SLS) Waiver or the Home and Community Based Services Children’s Exceptional Support Waiver. The HCBS-DD waiver provides for access to 24-hour supports and services provided in or out of the home of the individual or family home with higher number of hours or dollar limits than the HCBS-SLS which only provides services in the individual own home or family home.

Colorado uses three interest list statuses:

- As Soon as Available—individual requests enrollment as soon as possible.
- Date Specific—the individual does not need services at this time but has requested enrollment at a future date.
- Safety Net—the individual does not need or want services currently, but requests to be on the waiting list in case a need arises later.

In April 2017, Colorado reported 2,680 people registered as waiting for enrollment into the HCBS-DD waiver with a timeline of “As Soon as Available.”

Louisiana

The Louisiana Department of Health (LDH) and the Office for Citizens with DD (OCDD) began the IDD services system redesign in 2012. Redesign consisted of significant stakeholder engagement from various workgroups over several years. Louisiana transformed from first come, first served interest list management to an approach based on urgency of need determined through an assessment tool. Through the redesign, Louisiana created a tiered waiver system wherein each person receives the lowest waiver tier appropriate to meet identified needs. This involves face-to-face contact, screening, and assessment of every individual on a registry.
The state’s phased approach to transformation included the combination of IDD waiver waiting lists into a single registry and prioritization of the waiting list tool, called the Screening for Urgency of Need (SUN). Scores on the SUN determine if a person moves from the “registry” to the “waiting list.” A score of 4 on the SUN means a need for services in 90 days and a score of 3 means needing services within 1 year. Louisiana offered the entire waiting list a slot into the HCBS waivers using appropriation, attrition, and surplus funding.

All other individuals who were identified as having future needs or no current unmet needs were considered “requestors” of services but not considered “waiting” for services. By serving all individuals with emergent or urgent needs and shifting the status of those without immediate needs to requestors, LDH, OCDD, and advocacy groups described this initiative as elimination of the waiting lists.

OCDD team conducts re-screening at the following intervals:

- 3-Urgent: every year
- 2-Critical: every two years
- 1-Planning: every three years
- 0-No Unmet Needs: every five years

**Minnesota**

The Minnesota Department of Human Services (MDHS) began implementation of reforms to the management of the DD waiver waiting list as of December 1, 2015. Minnesota’s Olmstead Plan, which established waiting list goals in May 2014, and existing Minnesota statutory waiver priorities informed these efforts. Waiting lists also decreased as county agencies verified and prioritized urgency of need for DD waiver services.

The changes made to the waiting list for people with DD include two related components: immediate need and institutional exit. Those with needs determined in the future are not included on the wait list and are placed on a registry to be reassessed for needs later.

For each of the need definitions below, a slot is targeted for release 45 days from determination an individual met the criteria. The future need category does not have a standard because it is not included as part of the waiting list.
• Institutional exit: People in this category currently reside in an institutional setting, have indicated they would like to leave that setting and prefer to receive HCBS.

• Immediate need: People in this category meet prioritization criteria based on the following:
  o Unstable living situation due to the age, incapacity, or sudden loss of the primary caregivers.
  o Experience a sudden closure of their current residence.
  o Require protection from confirmed abuse, neglect, or exploitation.
  o Experience a sudden change in need that no longer can be met through state plan or other funding sources.

• Defined need: People in this category have an assessed need for waiver services within one year of the date of assessment.

• Future need: People in this category do not have a current need for waiver.

**Nebraska**

The Nebraska Department of Health and Human Services (DHHS) and the DHHS-DD Division of Developmental Disabilities make the initial determination of IDD for individuals interested in waiver services. Nebraska uses six priorities to assess individuals on a wait list. The priority mirrors reserved capacity slots.

These priorities are listed below:

- Priority 1: Based on the length of time on the wait list, may include those that are homeless or experience the death of caregiver.
- Priority 2: Individuals that move to an ICF/IID setting.
- Priority 3: Children exiting child welfare and need permanency.
- Priority 4: Students that turn 21 that exit the public education system and that qualify for day waiver.

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3 Reserving waiver capacity means that some waiver openings (a.k.a “slots”) are set aside for persons who will be admitted to the waiver on a priority basis if they meet the criteria specified in the reserve capacity.
• Priority 5: Military families.

• Priority 6: Everyone else is based on the date of application.

If an individual meets waiver eligibility and one of the priority groups, waiver services are provided. If the individual does not meet one of the six priorities, they remain on the waiting list until funding is available. The approximate wait time for services is 6-7 years.

**New York**

The New York State Department of Health governs the Office of People with Developmental Disabilities (OPWDD) and this office relies on its local partners to manage the waiver services by county, like the LIDDAs in Texas. Individuals can go to the local county office or they can call an information line to begin the process to apply. New York offers what they call *The Front Door Experience*. With *The Front Door Experience*, the first step to receiving assistance is to determine if a person is eligible to receive services and supports. Once a person is determined eligible they begin the planning process.

There is no waiting list for Medicaid waiver services in New York. However, many people in New York report they are receiving minimal supports. There is a waiting list for 24/7 residential opportunities for people with developmental disabilities. OPWDD has limited funding to develop new homes with 24/7 supports.⁴

**Ohio**

Before Ohio⁵ made reforms, anyone could be on a waiting list for any reason – regardless of whether they needed a waiver – and could be on waiting lists in multiple Ohio counties, even if they did not live there. A person could also be on multiple waiting lists for different waivers, even if the waiver they were requesting would not meet their needs.

The “Fix the List Coalition” [Coalition] worked for two years to develop a new waiting list process that is easier to understand and can meet the needs of those waiting for services. The Coalition’s work resulted in a standardized waiting list assessment tool used to determine if someone needs to be placed on the statewide HCBS waiting list or if their needs can be met through community-based alternatives to waiver enrollment. The Coalition’s work also resulted in the creation

⁴ [http://medicaidwaiver.org/state/new_york.html](http://medicaidwaiver.org/state/new_york.html), 2019

⁵ The Ohio Department of Developmental Disabilities (DODD) published the Medicaid Services Updates report in October of 2019
of the Transitional Waiting List, which pulled everyone who was on a waiting list in any county onto a single list for the entire state. The Ohio county boards are currently contacting every person on the Transitional Waiting List to evaluate their current situation and administer the Waiting List Assessment, as appropriate. Once everyone has been contacted by December 31, 2020, the Transitional Waiting List will no longer be needed.

Utah

In response to legislative direction in 2018, the Division of Services for People with Disabilities (DSPD) conducted a study on effective waiting list management. To provide the right scope of services for everyone, DSPD developed a strategy to implement two additional 1915(c) Medicaid waivers—Level 1 and Level 2 limited support waivers. Stakeholder input was obtained through initial focus groups, final public webinar presentation, and survey follow-up.

Level 1 limited support waiver for all ages is designed to help individuals who need minimal supports to remain in their own home or family home. Foundational services focus on case management and family training (training limited to $1,800). The case management and family training does not count against the waiver cost cap and families can use $16,400 to purchase services such as: respite, behavior consultation, employment services, day programs, transportation, environmental adaptations, and community integrated programs (after school/summer/senior programs). Individuals who need enhanced services can request a one-time increase of $10,600 for a total budget of $28,800. Personal care services, supported living services, and residential habilitation are not included in this option.

Level 2 targets individuals 18 and older and includes personal care services and supported living services designed to assist with activities of daily living. When possible, the waiver seeks technology solutions in place of direct support professionals. Maximum spending is $48,200 with a one-time enhanced spending option of $10,600 for a total of $60,600 based on additional needs. The waiver does not provide residential habilitation services.

At the time Utah reported on its study, many decisions were not final, and the newly proposed waivers had not been approved by Utah’s Legislature. The report identifies processes and approvals still needed to ensure appropriate system redesign, including how individuals would gain access to the new waivers (first come/first serve, needs based criteria), which waivers individuals would receive based on their needs, and the criteria for access to one-time enhanced need funding.
4. External Factors Impacting Texas Waiver Interest Lists

Between 2010 and 2019, the unduplicated number of people on any waiver program interest list increased 91.2 percent, from 78,626 in 2010 to 150,364 in 2019 (change of 71,738). During the same period, the number of persons enrolled in a waiver program increased by 43.8 percent, from 72,717 in 2010 to 104,549 in 2019 (change of 31,832).

In 2010, there were 108 persons on an interest list for every 100 enrolled in a waiver program. Whereas in 2019, there were close to 144 persons on an interest list for every 100 enrolled in a waiver program. This raises the question of whether current trends for key demographic and socio-economic factors could explain or be associated with the accelerated growth rate of waiver programs’ interest lists during the last decade.

Population and Service Delivery Trends—2010-2019

Between 2010 and 2019, the Texas population grew by 3.9 million people which is a growth rate of 15.8 percent. As demonstrated by Figure 6, during the same period, the number of individuals residing outside of an institution that reported living with a disability grew by 437,000, a growth rate of 15.4 percent. Within this group, the number of individuals with incomes at or below 222 percent of the Federal Poverty Level (FPL) grew by 33,000, a growth rate of 2.1 percent. It is important to focus on growth patterns for individuals with disabilities at or below 222 percent of FPL as this is the group who may need Medicaid LTSS now or in the future.
The data shown in Figure 7 reflects a 44 percent growth rate of the non-institutional population age 65 and older with and without disabilities between 2010 and 2019. The growth significantly outpaced the 15.8 percent growth rate of the state’s total non-institutional population. The growth rate of the non-institutional population age 65 and older with a disability was 29 percent as compared to 15.4 percent growth rate of the non-institutional population with disabilities. The non-institutional population 65 and older with a disability and an income at or below 222 percent of the FPL grew at 14 percent as compared to a 2.1 percent growth rate for the non-institutionalized population with disabilities (any age) and an income at or below 222 percent of FPL.

While these growth patterns have not impacted the STAR+PLUS HCBS interest list to date, it is important to consider whether changes to how Texas manages interest
lists will be needed to ensure future resources are available for individuals who urgently need waiver services to avoid institutionalization.

**Figure 7 Cumulative Percent Change in Non-Institutional Population 65 & Older**

During the last decade, the waiver programs have served less than 7 percent of the population that may benefit from them as demonstrated in Figure 6 and 7. In 2010, there were 1,544,000 Texans with a disability with income at or below 222 percent of FPL, of which 72,717 or 4.7 percent were enrolled in a waiver program. In 2019, there were 1,577,000 Texans with a disability with income at or below 222 percent of FPL, of which 104,549 or 6.6 percent were enrolled in a waiver program. While the reach of the waiver programs expanded significantly between 2010 and 2019, that expansion resulted in a slight increase in the percent of income-eligible Texans with a disability served by these programs.

**Socio-Economic Trends-2010-2019**

HHSC examined the trends for 2010-2019 to explore whether socio-economic factors were associated with waiver interest list growth. The analysis of the data
reveals, key socio-economic factors that have historically impacted the demand for safety net health and human services programs, especially for means-tested entitlement programs such as, the Medicaid and Supplemental Nutrition Assistance Program, experienced an improvement between 2010 and 2019.

As Figure 8 demonstrates, there was a 17 percent reduction in Texas households/families living with incomes below the poverty level. The unemployment rate dropped from 8.1 in 2010 to 4.6 in Calendar Year 2019, which is a 57 percent decrease. The number of individuals without health insurance dropped by 842,000 or 14 percent.

**Figure 8 Cumulative Percent Change in Economic Indicators from 2010**


Chart Prepared By: Medicaid/CHIP Data Analytics Program, Centers for Analytics and Decision Support, Texas Health and Human Services Commission. 7/20/2020 * Among population for whom poverty income status is determined (civilian, non-institutional)

** CLASS, DBMD, HCS, TXHML, MDCP, STAR + (Figure are as of month of August)
Because of more people being employed and a tighter labor market more favorable to workers, wages went up as well. This had a positive impact on another key indicator: median family income. Not adjusted for inflation, the median family income in Texas increased by almost one-third between 2010 and 2019, increasing from $56,600 to $74,200.

From this data, it is difficult to conclude that trends in socio-economic factors are associated with the growth seen in waiver programs interest lists.

**Federal and State Policies Impacting Medicaid**

The Balanced Budget Act of 1997 (BBA) is federal legislation that created the Children’s Health Insurance Program (CHIP) and changed Medicaid and Medicare rules and regulations. Under the BBA, new Medicaid eligibility groups, relevant to this topic, were allowed:

- Medicaid Buy-In: allows states to offer individuals with disabilities and income below 250 percent of the FPL an opportunity to buy in to the Medicaid program.
- Medicaid Buy-In for Children: allows states to offer children age 18 and younger with disabilities an opportunity to buy in to the Medicaid program.

Texas Medicaid instituted the Medicaid Buy-In for Children (MBIC) in October 2010. Children with family countable income at or below 300 percent of FPL may qualify for the program. MBIC families make monthly payments according to a sliding scale that is based on family income; households at or below 10 percent of FPL will not pay a premium. MBIC is a Medicaid designation that is not allowable for waiver services; however, children with this Medicaid type may receive Medicaid state plan services.

The 2010-11 General Appropriations Act, Senate Bill 1, 81st Legislature, Regular Session, 2009 (Article II, Special Provisions Relating to All Health and Human Services Agencies, Section 46) required HHSC to implement the most cost-effective, integrated managed care model for clients who are age 65 and older and those with disabilities in the Dallas and Tarrant service areas. At that time, the CBA waiver delivered HCBS to this population of adults using a fee-for-service delivery model. After analyzing current managed care models, HHSC determined STAR+PLUS was the most appropriate cost-effective model to meet the legislative mandate. HHSC expanded STAR+PLUS to the Dallas and Tarrant service areas in February 2011. Individuals in these areas receiving CBA transitioned to STAR+PLUS HCBS.
Effective September 1, 2011, Primary Care Case Management (PCCM) Medicaid clients in 28 of the counties contiguous to existing STAR and STAR+PLUS service areas were transitioned from PCCM to the STAR or STAR+PLUS Medicaid managed care program. In March 2012, HHSC entered new contracts with Medicaid managed care organizations (MCOs) in 11 service areas and eliminated PCCM from 174 counties. Other changes implemented included delivering pharmacy benefits via the managed care model, including in-patient hospital services as a capitated benefit in STAR+PLUS, and implementing dental services in a managed care model for children.

During the 2010-11 biennium, HHSC began enrolling individuals under 18 in the DBMD waiver. Accepting children into the DBMD waiver resulted in a 48 percent growth rate in the interest list between the 2010-11 biennium and the 2012-13 biennium. The interest list continued to grow by 26 percent from the 2012-13 biennium to the 2014-15 biennium; however, the 83rd Legislature increased appropriations for interest list reduction for DBMD, which allowed HHSC to reduce the interest list by 34 percent between the 2014-15 biennium and 2016-17 biennium. As compared to other IDD waiver interest lists, the DBMD list remains very small.

On September 1, 2014, STAR+PLUS expanded to the Medicaid Rural Service Areas (MRSA), providing acute care and long-term services and supports to those age 65 and older and those with disabilities. The CBA program transitioned to STAR+PLUS HCBS and any individuals on the CBA interest list with SSI Medicaid were immediately eligible to be assessed for services. Adults with IDD being served through a 1915(c) IDD waiver and those receiving services in a community-based ICF/IID also began receiving their acute care services through STAR+PLUS on this date. On March 1, 2015, HHSC began delivering nursing facility benefits for most adults ages 21 and older through the STAR+PLUS managed care model.

In June 2015, HHSC implemented Community First Choice (CFC), a federal Medicaid state plan option allowing states to provide personal assistance services and habilitation to individuals who qualify for an institutional level of care in a nursing facility, ICF/IID, hospital, or institution for mental disease. Individuals can receive CFC services and maintain their position on an interest list or continue to receive services in a waiver program. CFC services must be provided in community-based settings. In addition to habilitation and personal assistance services, CFC in Texas offers emergency response services and support consultation.

In November 2016, as required by Senate Bill 7, 83rd Legislature, Regular Session, 2013, HHSC implemented the STAR Kids program, which provides a wide array of Medicaid managed care state plan and MDCP waiver services to children with
disabilities. MDCP transitioned from fee-for-service to managed care with the implementation of STAR Kids and is also available for individuals in STAR Health. Unlike when the CBA waiver transitioned to managed care through the 2014 expansion of STAR+PLUS HCBS, individuals with SSI Medicaid were not automatically enrolled in the MDCP waiver program with the implementation of STAR Kids.

**Figure 9 Interest List Growth by Program and Biennia Fiscal Years (FYs) 2010-19**

![Interest List Growth by Program and Biennia](chart)

Data source: Community Services Interest List (CSIL)
Data Retrieved By: Aging and Disability Data Management, Center for Analytics and Decision Support -04/2020
Chart Prepared By: Medicaid/CHIP Data Analytics, Center for Analytics and Decision Support, - 07/2020

**Summary of Key Policies and Potential Impact**

Examining the changes in interest list growth rates by program during major policy initiatives, as illustrated in Figure 9, yielded some relationships between policy changes and subsequent impacts on program interest lists. The ongoing expansion of STAR+PLUS and the transition of the CBA waiver to managed care resulted in an
18 percent growth rate in the STAR+PLUS HCBS interest list between the 2012-13 biennium and the 2014-15 biennium, which is much lower than the 51 percent increase between 2010-11 biennium and 2012-013 biennium; however, the interest list grew by 47 percent between the 2014-15 biennium and the 2016-17 biennium. The growth rate was zero between the 2016-17 biennium and the 2018-19 biennium, demonstrating a leveling of growth four years into managed care delivery of HCBS services to individuals 65 and older and adults with physical disabilities. It is important to note the growth rate of individuals age 65 and over between 2010 and 2019 far exceeds the population growth in Texas of individuals under 65, 44.3 percent as compared to 15.8 percent. This could present challenges for maintaining the time an individual is on an interest list for STAR+PLUS HCBS, which currently is a year or less.

Implementation of CFC has not shown an impact on IDD waiver interest list growth rates. Between the 2014-15 biennium and the 2016-17 biennium, the TxHmL interest list grew by 8 percent. Between the 2016-17 biennium and 2018-19 biennium, the TxHmL interest list grew by 20 percent compared to 13 percent for HCS and 14 percent for CLASS.

The growth rate of the MDCP interest list was impacted by the implementation of CFC and STAR Kids. CFC implemented in June of 2015 and the MDCP interest list rate decreased by 24 percent between the 2014-15 biennium and the 2016-17 biennium. STAR Kids implemented in November 2016 and the rate continued to decline by 10 percent between the 2016-17 biennium and the 2018-19 biennium.
5. Data on Individuals Currently on Waiver Interest Lists

General Demographics

Figures 10 and 11 illustrate age and gender breakdowns for individuals on interest lists. In all waivers except STAR+PLUS HCBS, most individuals are 30 or younger and the majority are male. The STAR+PLUS HCBS interest list is 58 percent female.

Figure 10 Medicaid Waiver Interest List by Age Group, April 2020

Data Source: Community Services Interest List, CSIL
Data Retrieved by: Aging and Disability Data Management, Center for Analytics and Decision Support (CADS), 4/2020
Chart Prepared by: Medicaid and CHIP Data Analytics Program (MCDA), Center for Analytics and Decision Support
Figure 11 Medicaid Waiver Interest List by Gender, April 2020

Living Arrangements

As Figure 12, outlines, 79 percent or more of individuals on CLASS, DBMD, and MDCP program interest lists live with family or friends. The next largest category for living arrangement in these programs is personal residence which is the largest percentage for STAR+PLUS HCBS at 38 percent. Personal residence and family/friends are combined for purposes of simplification.

HCS and TxHmL show 33 percent and 32 percent, respectively, live with family or friends; unfortunately, the data available in the system for both waivers shows 66 percent and 67 percent, respectively, as no response for these two programs. STAR+PLUS HCBS also shows 47 percent as non-responsive for living arrangement.
Individuals on Interest Lists Receiving Services

Except for STAR+PLUS HCBS, more than 50 percent of individuals on all Medicaid interest lists are receiving at least one other Medicaid or non-Medicaid service. As indicated in Figure 13, more than 40 percent of individuals on all interest lists except STAR+PLUS HCBS are receiving a Medicaid managed care state plan service. Individuals on STAR+PLUS interest list are not financially eligible for Medicaid without the higher income limits associated with waiver eligibility, which explains the lack of individuals on the STAR+PLUS interest list receiving Medicaid services.

The percentage of individuals already receiving waiver services while still listed on a waiver interest list varies significantly by programs. For CLASS the total is 19
percent, but for MDCP it is 2 percent. The number of individuals receiving institutional services while on a waiver interest list also varies across programs with HCS at 3 percent; CLASS, DBMD and STAR+PLUS HCBS at 1 percent; and MDCP less than one percent\(^6\).

**Figure 13 Percentage of Individuals on Medicaid Waiver Interest List and Enrolled in other Programs**

![Percentage of Individuals on Medicaid Waiver Interest List Programs Simultaneously Enrolled in Other Programs/Services](chart)

Data Source: CSIL; Service Authorization System, Client Assignment Registration and Enrollment, Premium Payables System, Acute care claims data from TMHP Vision 21 AHQP Universe; Mental Retardation and Behavioral Outpatient Warehouse

Data Retrieved by: Aging and Disability Data Management, Center for Analytics and Decision Support (CADS) - 04/2020

Chart Prepared by: Medicaid and CHIP Data Analytics Program (MCDA), Center for Analytics and Decision Support (CADS)

**Geographic Location**

As depicted in Appendix A, most of the individuals on the interest list live in counties with a metro designation (50,000 or more) with the next largest percentage residing in rural counties rather than micro counties (10,000 but less

\(^6\) These percentages may be low due to state initiatives designed to move people from institutional settings into the community.
Individuals on the DBMD and CLASS programs mostly reside in Dallas or Houston, making up 47.1 percent of individuals expressing an interest in CLASS and 51.1 percent expressing an interest in DBMD. If San Antonio and Austin regions are added, CLASS is 71.3 percent and DBMD is 75 percent.

Individuals on the HCS and TxHmL interest lists are designated by LIDDA. Most individuals on the interest list for both HCS and TxHmL reside in the Harris County LIDDA service area which is more than double any other LIDDA. The next largest is Alamo in San Antonio, MHMR of Tarrant County, and Metrocare in Dallas, all with 7 percent.

MDCP shows a similar geographic trend for individuals on the interest lists by service delivery area (SDA). MDCP has 61 percent of individuals in four major SDAs: Harris, Hidalgo, Tarrant, and Dallas. STAR+PLUS HCBS has 47 percent in Hidalgo, Dallas, and MRSA Northeast; however, STAR+PLUS is more diversified with several SDAs having 5-8 percent, with some of these areas less populated like Jefferson, Nueces, and MRSA West.

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6. Strategies Texas Could Employ and Costs

The identified strategies are primarily based on how other states reformed their systems for interest list management. Some strategies would require legislative direction and/or new appropriations to implement.

The strategies outlined below fall into three categories:

1. Addressing gaps in real-time information about the needs of individuals currently on waiver interests lists to better understand and manage timely access to services thereby addressing risks to health and safety or institutionalization.

2. Prioritizing certain populations and individuals with the highest level of service needs, similar to what other states have implemented.

3. Considering any interest list reduction allocations and targeting additional funding for priority populations.

HHSC consulted with the IDD SRAC and recommendations developed and approved by the full committee are included in Appendix C. The members supported the need for more information about individuals on the interest lists and using statutory and rule changes to expand the availability of services in a person-centered and cost-effective manner, which is the foundation for many of the committee’s recommendations. The IDD SRAC also recommended sustaining the state’s first-come, first-served approach and many members expressed concern about moving away from this model for interest list management.

**Strategy 1: Address gaps in and accuracy of information about individuals currently on waiver interest lists.**

The following are actions HHSC could implement to align with this strategy:

❖ Develop a revised Questionnaire for LTSS Waiver Program Interest Lists to capture information necessary to determine what types of services individual needs, and when the services are needed to ensure an individual’s health and safety in the least restrictive setting. HHSC would work with appropriate external stakeholders, including the IDD SRAC, to obtain input on the revision.

➢ **Cost Impact:** Revising the current questionnaire would require changes to the CSIL system. HHSC estimates 1,200 hours of development time at $100 per hour for a total estimated cost of approximately $120,000.
Administer the revised *Questionnaire for LTSS Waiver Program Interest Lists* to all individuals currently on a waiver interest list.

- **Cost Impact:** HHSC estimates additional resources would be needed to implement this strategy. Using existing biannual contacts for the HCS and TxHmL waivers performed by the LIDDAs would be possible within existing resources. Performing an in-person contact for all the other waiver programs would require four full-time-equivalent positions at an estimated cost of approximately $174,844 per year in All Funds.

Explore expanding the use of available technology to create a “no wrong door” approach allowing individuals access to an online portal for requesting interest list placement and providing current interest list questionnaire information. This could allow real-time access to interest list status, inform priority for access to services and potentially reduce the need for staff resources dedicated to interest list management.

- **Cost Impact:** Exploring available options for the use of technology would not have a cost impact; however, there would likely be costs for HHSC to develop and deploy an online portal.

Remove individuals from the interest list who have been out of contact with HHSC for four years or more. Individuals’ names and information and original interest list request dates would be maintained as inactive, but these individuals would no longer be listed as interested in services. HHSC would continue to outreach by mail these individuals every two years.

- **Cost Impact:** No fiscal impact to implement.

**Strategy 2: Prioritize certain populations and/or individuals with the highest level of service needs.**

HHSC could implement policies to align with this strategy while maintaining the first come, first served interest list management process:

- Establish priorities for waiver services with rules prioritizing access to more costly waiver programs and by determining which programs (state plan LTSS or waiver programs) best address the individual’s assessed need.

  - **Cost Impact:** Costs would depend upon which services individuals are eligible for given their needs.

- Fund staffing for annual administration of the Questionnaire for LTSS Waiver Program Interest Lists for everyone on the HCS and TxHmL interest list. Ensure
completion of planned 2021 Client Assignment and Registration System (CARE) interest list data migration to CSIL for HCS and TxHmL. Administration of the interest lists will improve if all information is in one data system.

➢ **Cost Impact:** For the additional time to complete the assessments and administrative activities, LIDDAs would require 56 additional full-time equivalents, or an additional (estimated) $3,047,856. Funding for the CARE migration to CSIL is already appropriated.

**Strategy 3: Targeting any interest list reduction allocation for certain populations.**

The following are examples of actions Texas could implement to align with this strategy:

❖ Increase access to TxHmL as a lower cost support waiver by changing the income limit to include individuals earning 300 percent of SSI and add related conditions as an eligibility criterion. With additional appropriations for TxHmL slots, HHSC could offer individuals on appropriate waiver interest lists access to TxHmL.

➢ **Cost Impact:** Fiscal impact would depend on new appropriations for TxHmL to remove individuals from the interest list. As of June 2020, the average cost per person per month in TxHmL was $2,066.45 with an average annual cost per person of $24,797.

❖ Allow individuals with SSI on the MDCP interest list to receive automatic assessment for waiver eligibility. The monthly average individuals served, shown below, represents the new enrollees who would be removed from the interest list because they have SSI eligibility.

➢ **Cost Impact:**

<table>
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7. Conclusion

Many states like Texas are facing growing demand for HCBS with a finite amount of resources. A key component of restructuring any process for interest list management is understanding the needs of individuals who have expressed an interest in services. Gathering information on current needs for assistance, living arrangements, status of caregiving resources, and basic diagnostic information can assist in planning for future resource needs.

HHSC has outlined strategies Texas could implement aimed at filling gaps in information and targeted reduction of current interest lists. HHSC will continue its collaboration with stakeholders and the IDD SRAC on planning and implementation strategies to improve interest list management and ensure state and federal funding is maximized to effectively support individuals with disabilities living in the community.
### List of Acronyms

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<th>Acronym</th>
<th>Full Name</th>
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<td>Balanced Budget Act</td>
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<tr>
<td>CARE</td>
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<td>Children’s Health Insurance Program</td>
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<td>Community Living and Assistance Support Services Waiver</td>
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<td>Community Services Interest List</td>
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<td>Abbreviation</td>
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Appendix A. **LIDDA Mappings by County**

Data Source: Community Services Interest List, CSV; Service Authorization System, SAS; Client Assignment Registration and Enrollment, CARE; Premium Payables System, PPS; Acute care claims data from TMHP Vision: 31 AMHP Universe, Mental Retardation and Behavioral Outpatient Warehouse (MRBW)

Data Retrieved by: Aging and Disability Data Management, Center for Analytics and Decision Support (CADS), Texas HHSC - 07/2020

Chart Prepared by: Medicaid and CHIP Data Analytics Program (MCDA), Center for Analytics and Decision Support (CADS), Texas HHSC
Data Source: Community Services Interest List, CSA; Service Authorization System, SAS; Client Assignment Registration and Enrollment, CARE; Premium Payables System, PPS; Acute care claims data from TMRP Vision 21 AMQP Universe; Mental Retardation and Behavioral Outpatient Warehouse (MBOW)

Data Retrieved by: Aging and Disability Data Management, Center for Analytics and Decision Support (CADS), Texas HSC - 07/2020

Chart Prepared by: Medicaid and CHIP Data Analytics Program (MCDA), Center for Analytics and Decision Support (CADS), Texas HSC
Appendix B. Other States Research

Alaska

Alaska utilizes the Developmental Disabilities Registration and Review Tool (DDRR). The DDRR is traditionally used as a waitlist tool. The DDRR provides the State and other stakeholders information on the current needs and preferences of the individuals and families waiting for expanded supports services. The DDRR is available to be completed online, by emailing completed forms, or submitting completed paper copies to Senior and Disabilities Services (SDS). Once a DDRR form is received it is scored by a Qualified Intellectual Disability Professional (QIDP). For an individual to be included on the DDRR, they must complete an Eligibility Determination application. Additionally, SDS attempts to update participant’s eligibility status as identified in their original DD eligibility determination letter. If a participant does not reapply for services or is determined ineligible they are removed from the list. Alaska reports zero institutions for persons with I/DD.

Their current statute dictates these seven data elements are reported to the legislature each year:

1. Purpose of Wait Lists;
2. Process, ranking criteria, and management of the wait list;
3. Basic demographic information;
4. Level of need services and supports required;
5. Individuals removed from the wait list during the past year by number along with reason for removal and length of wait;
6. Number of persons waiting for more than 90 days; and
7. Number of people with I/DD graduated, dropping out or turning 22 without a high school diploma.

Colorado

Colorado hired the LNUSS Group (private consulting group led by Laura Nuss\(^8\)) who published a report in June of 2017, Report to the Colorado Department of Health

\(^8\) Former President of the Board of Directors for the National Association of State Directors of Developmental Disabilities Services. Over 30 years of experience in private and public-
Care Policy and Financing: A Review of National I/DD Medicaid Home and Community-based Services 1915(c) Waiver Waiting List Management Practices and Analysis of Colorado’s Home and Community Based Services-Developmental Disability Waiver Waiting List Statute, Policies and Procedures. Colorado’s study was very informative because of the national research previously done by the LNUSS group in conjunction with the National Association of State Directors of Developmental Disabilities on behalf of the Ohio Department of Developmental Disabilities. LNUSS reported on IDD waiting list practices in 21 states and summarized their findings in the Colorado report.

LNUSS found that 21 states reported or included in state policies or rules that prior to placement on a waiting list, the person is first determined to be eligible for state IDD services. Nine states further determine Medicaid eligibility, 9 states determine eligibility for HCBS waiver and one additional state determines potential eligibility for HCBS waiver prior to placement on a waiting list for HCBS enrollment. Colorado determines eligibility for the HCBS waivers serving individuals with IDD and confirms Medicaid eligibility when enrollment in the waiver is requested or placement on a waiting list is required by policy.

LNUSS also found that eight states limited placement on a waiting list to a time-period within which services are expected to be needed. One state limited placement on the waiting list to persons who require services within 12 months; two states limit placement on the waiting list to those persons who will need services in 24 months; one state limits placement to target groups (e.g. emergency, transitioning youth and “current need”) and three states limit placement to those who will need services within 6 months to five years.

LNUSS also found that 19 states explicitly provide for an “emergency” category or definition to supersede any other order of enrollment. In 15 states, what would constitute an emergency is in effect the first priority group to gain entrance to the waiver programs and two states, Missouri, and Massachusetts, only allow individuals found to be in an emergency are able to enroll in the state’s comprehensive waiver (e.g. waiver that provides out-of-home and extensive supports). LNUSS reported common factors considered to constitute an emergency for people on a waiting list include:

- Incapacitation or impairment of a caregiver places a person at serious risk of physical harm;
• Loss of caregiver;
• Individual is subject to abuse, neglect, or exploitation;
• Individual is homeless or living in inappropriate housing;
• Individual is currently in or at eminent risk of entering an institution;
• Individual presents a significant danger of physical harm to self or others;
• Prevent out of home placement of a child; and
• Need for services exceeding current HCBS waiver.

Based on extensive research of other states, LNUSS reported that beyond emergency, priority for enrollment varies across the states. All states researched included more than one priority categorization group to organize those persons who are waiting for services and to determine order of enrollment. LNUSS reported that states determination of when services are needed follows a guided interview process or assessment tool process completed by the government entity responsible for entering individuals on the waiting list. The results of the LNUSS research align with a report done in 2002 report prepared by the Research and Training Center on Community Living Institute on Community Integration/University Centers for Excellence in Developmental Disabilities (UCEDDs), University of Minnesota on waiting list policies and resources. In the report, 47 states responded to a survey regarding the relative importance of factors used to determine access to services and supports among persons on waiting lists. The authors concluded from those findings that “the factors of immediate crisis, emergencies, substantial concern for loss of present services were more important that length of time of waiting, age of caregiver or severity of disability.”

LNUSS further reported that the review also indicates that states when defining what constitutes an emergency are using health and safety considerations specifically and not the more generic term of health and welfare. There is also clear emphasis on the terms immediate or imminent risk to describe urgency of the situation and the use of the terms significant or serious to describe the severity of the situation. Where an emergency is predicated specifically on the status of the caregiver, all states are specific that the caregiver has been lost (e.g. death, admitted to a nursing facility), the caregiver has a life threatening or serious persistent illness and the situation of the caregiver places the individual at serious physical harm or the needs of the individual cannot be met because of the change in the caregiver’s status. LNUSS points out that states with waiting lists using additional criteria to reflect the intent of the legislature and/or resource
management strategies of the state it is critical to tightly define what will rise to a level of emergency to supersede the policy strategies and priorities to ensure both transparency and equity in the administration of the state waiting list.

Research of the 21 states revealed that in states that offer more than one waiver program, the state or local authority determine which waiver programs is offered. The determination is based on the identified need(s) of the person, caregiver situation, and/or where the person lives and whether the waiver program can meet the health and safety needs accordingly. The determination of need is based on either a developed service plan or a formal assessment of the individual’s needs and in most cases the caregiver situational factors.

Ohio

The county board determines level of need on a case by case basis. If there is critical need, they may not have to wait for waiver services. However, because the waiting lists for the waiver programs are so large in certain counties, if a person does not meet emergency status criteria they may have to wait many years before receiving waiver services.

For HCBS waivers, if the resources are available, the law requires a County Board to offer enrollment in this order:

- 1st Emergencies
- 2nd Priorities
- Last- Everyone else

The waiting list processes vary by each county. Except “your date of request” remains the same even if they move to another county in Ohio. Their position on the waiting list varies if they are in a priority category or if their situation meets emergency status criteria. If their priority score is low, they can expect to wait many years before receiving waiver services in Ohio. The county board puts persons on the Long-Term Service Planning Registry. It is not a waiting list, and a person will not be automatically transferred to the waiting list. Waiver inquiries are managed through a call line. From there, they can refer to the County Board of Developmental Disabilities. To enroll for services, persons need to contact the local County Board of Developmental Disabilities. (Ohio has 88 counties in all, and 88 county boards). When persons call, ask to speak to the person who handles “Intake.” Potential outcomes of the Waiting List Assessment are; Immediate Need, Current Need or No unmet, immediate, or current needs.
Utah

The Utah Department of Health (UDOH) is designated as the Single State Agency for the Utah Medicaid program. In its coverage of HCBS waivers, UDOH must maintain final administrative oversight of all HCBS waivers, but has discretion to designate a separate state agency, known as an “Operating Agency,” to perform day-to-day waiver administration and operations.

Utah saw no measurable growth between 2005 and 2015; a sharp contrast to the 16.3 percent average annual growth between 2015 and 2018.

- Utah removes people from their IL if they are notified that the person moved out of state, passed away
- Do not respond to repeated attempts at contact
- No longer interested in DSPD supports.
- DSPD currently administers the Needs Assessment Questionnaire (NAQ) to all individuals applying for waiver services.

In 2018, DSPD conducted a legislatively mandated study on effective waiting list management. Resulted in a finding that 27,206 people with disabilities (79% children) would need DSPD services by 2030. DSPD structure at that time warranted a cost of $628,820. Utah conducted focus groups with individuals, families, self-advocates, support coordinators, providers, and advocates to identify obstacles and barriers to living as independently as possible. Utah wanted to understand why families and individuals did or did not choose to join the waiting list.

Four themes were identified:

- lengthy and complicated eligibility process;
- individuals entering the system tended to be in crisis or have higher needs; individuals with lower needs did not feel they should apply and take up a slot. The system is not set up to intervene earlier in a person’s life to avoid a crisis;
- existence of a waiting list discourages individual’s from applying; and
- lack of awareness about services.
Note: Because of this study, UDOH and DSPD decided not to pursue the following funding strategies to wait list reduction: 1915(i) State Plan, or 1915(k) CFC, or 1115 Demonstration, or combining waiver authorities-managed LTSS.
[Appendix C] Intellectual and Developmental Disability System Redesign Advisory Committee (IDD SRAC) Systems Adequacy Subcommittee Recommendations

Background:

Rider 42 requires HHSC to consider “existing data on persons on the IL for each waiver program, including demographics, living arrangements, service preferences, length of time on the interest list, and unmet support need.” HHSC reported that data on unmet support need is not available, and the IDD SRAC Systems Adequacy Subcommittee (SA S/C) requested other available data to better inform the S/C recommendations for strategies to reduce or eliminate the Interest List (IL). The SA S/C made recommendations on how to obtain data on unmet service needs in the future.

Recommendations:

Interest List Study to include a description of Texas Interest List information in a format that facilitates a comparison between Texas and other states.

Process to Assess Unmet Needs

1. **HHSC to standardize Interest List data collection forms and process for individuals across all Interest Lists:**

   A. Consistent processes to gather demographic data on unmet needs to include housing and residential needs.

   B. Consistent processes to gather data on those who support an individual in the community to assess risks and future needs.

   C. Modernized processes, utilizing technology for online access, text alert options for updates, text notifications and online updates to annual contacts.

   D. Data processes that allow for the extraction of any information that is gathered on the interest list.

   E. In the selection of a standardized assessment, consider adoption of an assessment, or screening, tool that identifies current needs and imminent risks of individuals on Interest Lists. Practical options are to modify Form 8577, develop an assessment tool, adopt a fully vetted IDD assessment tool, and/or incorporate existing health and risk assessments used by MCOs.
F. Consistent processes to assist individuals on the Interest Lists to receive information about alternate community resources during the routine Interest List contacts. Process should include training requirements for entities responsible for completing the Interest List contacts. In addition, process should require the provision of written information about critical resources, to include Medicaid Eligibility, Community First Choice, Texas Home Living, Money Follows the Person, diversion for at risk individuals, and local community resources.

**Strategies to Reduce or Eliminate the Interest List**

**HHSC to sustain current processes that are effective in meeting individual needs:**

A. Sustain the first come, first serve principles of the current IL process. Fund supports to assist individuals to access enrollment in a timely manner.

B. Continue availability of Diversion slots for behavioral, medical and crisis situations.

C. Continue availability of Transition slots from institutions to the community.

D. Continue policy to allow Interest List slot recipient, who is determined ineligible for the allocated waiver slot, to ‘bridge’ to an appropriate waiver Interest list with the original date of the Interest List waiver for which they have been determined ineligible.

E. Ensure implementation of ‘no interest list’ policy for MDCP SSI recipients (STAR Kids and STAR Health managed care programs).

**HHSC to improve existing processes and programs to better meet the needs of individuals on waiver Interest Lists:**

A. Improve and strengthen the Community First Choice (CFC) program.

   A. Set sustainable CFC rates that allow for hiring and retention of Direct Service Workers (DSW) with experience in habilitation.

   B. Enhance CFC service array with the addition of transportation and respite.

   C. Assess feasibility to revise CFC assessment to offer alternate services for individuals on waiver Interest Lists who do not meet institutional
level of care.

D. Increase awareness through a concerted, statewide outreach effort to include publication of an HHSC CFC brochure and website enhancements. Materials should offer guidance to recipients regarding differences in CFC when offered as a stand-alone service or when offered in conjunction with a waiver.

E. Establish consistent practice by MCOs, LIDDAs, and Local Mental Health Authorities (LMHAs) to screen for eligibility and interest in CFC benefits.

F. Develop electronic reporting to track from the date of CFC request, to CFC assessment date, to date of service delivery or to date of service denial.

G. Develop reporting to track timeframes for exchanges between MCOs and the LIDDAs.

H. Fund current LIDDA processes for eligibility, ID/RC, CFC Assessment, or develop and implement streamlined processes.

I. Enhance training to MCOs, LIDDAs, and LMHAs on CFC benefits and reporting requirements.

J. Re-examine HCS/TxHmL policy that prohibits persons/family members residing in the home to provide CFC services.

B. Improve Medicaid STAR and STAR Kids processes for individuals to access minor home modifications and adaptive aids that support community living.

A. Create a mechanism for children to access minor home modifications and/or van lifts (short-term need).

B. Ensure an individual’s right to appeal a needs assessment finding that limits access.

C. Examine opportunities to expand Money Follows the Person (MFP) programs to meet unmet residential needs of individuals on a waiver Interest List.

HHSC to develop and implement new processes to better manage the waiver Interest List process:
A. Develop and implement a “No wrong door” process for placement on a waiver Interest List: one call, right list(s). Individuals should receive adequate information and education to request placement on the most appropriate list(s).

B. Attain funding to maintain and improve waiver Interest Lists processes.

Strategies to Address the Cost of Reducing or Eliminating the Interest List:

A. HHSC to develop processes to accurately forecast the costs to reduce and eliminate the waiver Interest Lists, to include contacting individuals, assessing needs, providing follow up information on community resources, and reporting data.

B. HHSC to identify mechanisms to meet the growing population and needs of Texans, consistent with the most integrated setting mandate of the ADA and 1999 Olmstead Decision. Specific strategies to consider include the following:

a. Continue to request legislative funding for all waivers.

b. Utilize the same financial eligibility criteria for TxHmL as other waivers, to include not deeming parental income and allowing for 300% of the SSI FBR (Federal Benefit Rate). Consider increasing the TxHmL cap to $25,000.

c. Explore offering a Katie Beckett/TEFRA (Tax Equity and Fiscal Responsibility Act) waiver. This waiver, administered in 21 other States, offers Medicaid coverage to children with severe disabilities under 19.

d. Develop and implement processes to ensure adequate safety-net, adequate provider capacity and availability of a stable attendant workforce to support the needs of persons enrolled in waivers.

e. Ensure HCBS Settings Requirements are met for continuation of waiver funding.

f. Expand eligibility for Medicaid Buy-In to the federally allowed limits.