



**Individuals Who Are Aging with Intellectual
and Developmental Disabilities
and DADS Services**

Department of Aging and Disability Services

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Executive Summary

This report is a preliminary effort to examine and describe the scope of the population of older individuals with intellectual and developmental disabilities (IDD) in Texas, their needs, and issues related to service delivery.

The population of older individuals with IDD is growing.

- DADS serves more than 4,200 older individuals (age 60 and over) with IDD in State Supported Living Centers (SSLCs), community Intermediate Care Facilities (ICFs) and waiver programs. Their numbers have increased substantially over the past ten years.
- If no additional individuals with IDD enrolled in DADS services over the next ten years, the number of older individuals with IDD who receive waiver or institutional services would increase by an estimated 40 percent, to about 5,900.
- Many more individuals who are aging with IDD are likely to seek DADS services in the future. By conservative estimate, 10,000 to 15,000 people who qualify for the DADS priority population (defined on page 4) and who are or soon will be over age 60 are living with family caregivers who are themselves age 60 or older.

Many older individuals with IDD depend on nursing facility services.

- Nursing facilities (NFs) serve about 1,500 individuals who have IDD and are 60 or older.
- Of those, about half have been in a NF for six or more years; one third have been there for nine or more years. Such lengthy stays are unusual for the general NF population.
- Almost half of older individuals in community ICFs and about one third of people in the Home and Community-based Services (HCS) waiver transfer to NFs.
- Once transferred to a NF, individuals seldom return to HCS or ICF.
- Individuals who reside in SSLCs rarely use NFs. Former residents of SSLCs also rarely use NFs.

The limited available information suggests the use of NF services by individuals with IDD is driven by several factors:

- Some individuals meet the eligibility criteria for both ICF and NF services. Increased medical needs or new cognitive impairments may make the NF appear to be a better choice, or make the ICF seem less desirable.
- Community ICFs and HCS providers may have difficulty providing cost-effective service plans that are appropriate to the needs of people who are aging or have health issues. Current reimbursement policies may increase this difficulty.
- Some individuals who had not been using DADS services enter the NF directly when a caregiving arrangement breaks down. In a crisis, the NF may be the most easily available placement option.
- Other factors that have not yet been identified.

To meet the needs of individuals who are aging with IDD in the community, DADS may need to encourage providers to modify services so that, in accordance with policy, services are adequate and appropriate for individuals who:

- have increasingly complex medical needs;
- have dementia; and
- are of retirement age.

For people in crisis who have not been using DADS Medicaid services, DADS may need to consider ways to expand rapid availability of services (as opposed to interest lists) in situations where the existing caregiving arrangement is breaking down.

Some low-cost services could prevent or delay the need for higher-cost services by supporting family caregiving arrangements. Services that may be helpful include:

- Expanded respite services that serve more families, and offer more hours, more flexibility, and quicker response.
- Caregiver support services that offer training, support groups, and resources in addition to respite.
- Planning assistance to families to smooth the transition to other arrangements.

DADS faces significant policy barriers in developing services that will meet the needs of individuals who are aging with IDD.

- The reasons many older residents of community ICFs transfer to NFs are not well documented, but appear to include concerns about cost effective active treatment for individuals with declining health.
- Individuals served by the HCS waiver program are apparently more likely to age in place than residents of community ICFs, but fiscal constraints prevent substantial enrollment expansion.
- Policy and reimbursement issues limit the ability of HCS providers to serve individuals who have developed dementia or serious medical needs.
- Fiscal constraints also limit DADS' ability to expand lower cost programs such as respite, caregiver support, and planning assistance.

In order to reduce dependence upon NFs, the recommendations in this report focus on new ways to approach services and policy modifications that do not require appropriations in the coming biennium.

The following recommendations either have low costs or will require a long time to develop. With more information and specific plans, DADS may be in a position to propose more comprehensive service changes in the future.

- Identify and implement changes to existing services for people with IDD that will allow them to avoid or delay NF placement. Some approaches include:
 - Work with stakeholders and conduct research to identify the factors that cause individuals served in ICFs and HCS to move to NFs.
 - Review practices within SSLCs and within programs in other states to identify strategies that support aging in place for people with IDD.

- Reinforce existing policy through training or other mechanisms to encourage the use of individual plans appropriate for people who are aging.
 - Develop strategies to support people with IDD participating in programs for the general population of people who are over sixty.
 - Identify reimbursement and other changes that will make it easier for individuals with increased health needs or declining cognitive status to remain in ICFs or the HCS program.
- Develop or expand programs to support family caregivers and improve families' long-term planning for the future of individuals with IDD. Some approaches include:
 - Identify funding mechanisms and resources that will permit expansion of existing respite programs.
 - Analyze existing evidence-based caregiver support programs, in Texas and elsewhere, to identify the components of a program aimed specifically at family caregivers of individuals with IDD.
 - Gather information on existing family and sibling support networks and encourage their expansion or replication in Texas.

Introduction

This report is a preliminary effort to describe the scope of the population of older individuals with IDD in Texas, their needs, and issues related to service delivery. Historically, people with IDD were generally not expected to live to an old age. Programs and services were not necessarily designed for older individuals, and their medical and social needs were not examined. However, data indicates that people with IDD are living past age 60 in increasing numbers. This report also responds to the mandate of RP-42, the Governor's Executive Order establishing the Aging Texas Well initiative.

Definitions

Older: For purposes of this report "older" refers to people aged 60 and over. This is consistent with the Older Americans Act and with the Aging Texas Well initiative. The population 50-59 is also discussed, as an indicator of the future size of the 60+ population.

Priority Population: This report is concerned with the "priority population for mental retardation services" as defined in law and policy. The law still uses the term "mental retardation", which is not otherwise used in this report. The priority population includes individuals who would qualify for services in:

- An Intermediate Care Facility (ICF)
- A Medicaid waiver program related to ICF
- General revenue services provided by local authorities

DADS estimates that 0.5 percent of Texans, or five out of every thousand, are in the priority population, totaling about 126,000 individuals in 2010. Many more individuals have IQs below 70 but have little functional impairment and are not part of the priority population.

The priority population includes many individuals who are not served by DADS in the three categories of service above. Many people live in the community without DADS services; others live in privately funded facilities or in NFs.

Data Sources

Information about individuals and the DADS services they use comes primarily from the Quality Assurance and Improvement (QAI) Datamart, which contains data from all DADS Medicaid waiver and institutional programs. Information in the Datamart comes from service authorization and payment data which is not identical to data used for financial purposes. The Datamart does not include data about people served by local authorities with non-Medicaid funds.

Data on the general population of Texas and its changes over time are from the 2000 and 2010 U.S. Census Demographic Profiles for Texas and from the State Data Center's population projections, Scenario 3.

Current Population

DADS currently serves about 4,200 older individuals (age 60 and over) with IDD in institutional and waiver programs. This includes individuals in the SSLCs, community ICFs, waivers related

to ICF, and individuals who are in NFs whose records indicate they have an intellectual disability, a developmental disability, or both.¹ Waiver programs related to ICF include:

- Community Living and Support Services (CLASS), which serves individuals with conditions related to intellectual disabilities;
- Deaf Blind and Multiple Disabilities (DBMD), which services individuals with who have both sensory impairments and at least one other disability;
- Home and Community Based Services (HCS), a full-service waiver for people with IDD; and
- Texas Home Living (TxHmL), which provides selected essential waiver and supports people with IDD.

Data in Table 1, below, are from March 2010, and include all individuals receiving paid services in that month. Some individuals who did not receive services in March are excluded, even if they were enrolled.

Table 1: Individuals with IDD by Age and DADS Service Program for 2010

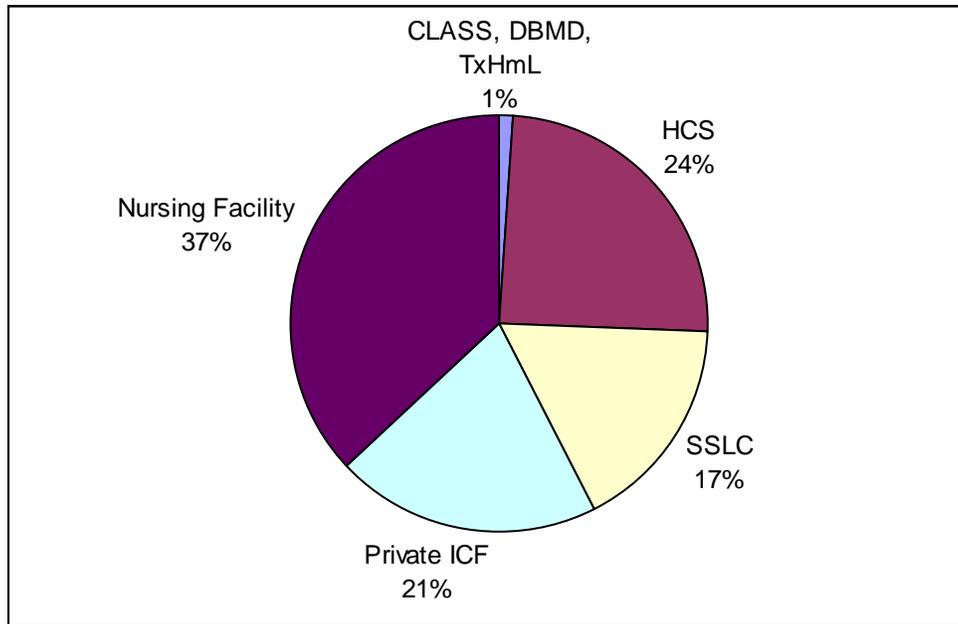
	Total	Under 50	Percent within Program	50-59	Percent within Program	60+	Percent within Program
CLASS	4,113	3,959	96%	108	3%	46	1%
DBMD	153	142	93%	8	5%	3	2%
HCS	16,523	13,307	81%	2,189	13%	1,027	6%
SSLC	4,254	2,342	55%	1,197	28%	712	17%
Community ICF	6,067	3,915	65%	1,281	21%	871	14%
TxHmL	911	818	90%	78	9%	15	2%
Nursing Facility	2,783	606	22%	624	22%	1,553	56%
Total	34,801	25,089	72%	5,485	16%	4,227	12%

In the general Texas population in 2010, about 15 percent of Texans were age 60 and up, 12 percent were 50-59, and about 73 percent were under 50. Compared to the general population, people with IDD who are served by DADS are more likely to be in their 50s and less likely to be 60 or older.

¹ Individuals served in the Consolidated Waiver Program were not included, since the available records do not distinguish individuals with IDD from others. A small number of individuals with IDD receive services in Community Based Alternatives, and STAR+PLUS, but as they cannot be distinguished in the available data they were also excluded.

Most older individuals with IDD are served in HCS, SSLCs, community ICFs or NFs. The other IDD waivers serve very few people over age 60.

Figure 1: Distribution of Older Individuals with IDD across Programs, 2010



Includes all individuals age 60 or older with an IDD diagnosis.

The largest group of older individuals with IDD receive services in NFs, which serve 37 percent of the total IDD population receiving Medicaid Services. Although only 6 percent of individuals enrolled in HCS are over 60, they constitute nearly a quarter of all the older people with IDD who are enrolled in DADS programs.

Growth of the Population

Adults with IDD receiving DADS services

In order to determine how much the older population with IDD services grew between 2001 and 2010, staff compared the age distribution of individuals enrolled in large DADS programs in 2001 and 2010.²

² A comparable analysis could not be made for nursing facility services due to lack of nursing facility data from 2001.

Table 2: Percent Change by Age and Program 2001-2010

% change	CLASS	HCS	SSLC	Community ICF	Total
Under 50	185%	410%	- 40%	- 28%	74%
51-59	185%	438%	36%	9%	91%
60+	360%	330%	14%	24%	69%
Total	186%	407%	- 23%	- 18%	76%

Program growth in the past ten years was dominated by the expansion of the CLASS and HCS waivers, while the numbers of individuals residing in SSLCs and community ICFs declined largely due to the Promoting Independence initiative and the Money Follows the Person Demonstration. Relatively few individuals over age 60 enrolled in CLASS and HCS, but the number of people over 60 increased more than three-fold in those programs between 2001 and 2010. This increase includes new enrollments and the aging of individuals already in the programs. In SSLCs and community ICFs, the number of individuals over 60 increased despite overall program decrease.

Table 2 also shows increases in the number of individuals aged 51-59. In 2010, this group consisted entirely of members of the Baby Boom cohort (people born between 1946 and 1964); over the next 13 years, even the youngest of these individuals will all have moved into their 60s. Thus, the number of individuals with IDD who are aging and are served in DADS programs is likely to increase sharply by 2020.

Not everyone who is over 50 and currently receiving DADS services will still be receiving services in 2020. To better understand the likely survival rate, staff tracked service use by individuals with IDD who were 50 or older in 2001 and discovered the majority were still receiving services in 2010. This analysis includes people receiving HCS, community ICF, or SSLCs services in 2001, and tracks their use of any DADS waiver or institutional service, including NF.

Based on this information, it is possible to estimate roughly the number of people who:

- are currently receiving DADS services;
- have IDD;
- will be over age 60 in 2020; and
- will still be receiving DADS services in 2020.

As Table 3 shows, about 70 percent of people in their 50s, and 49 percent of people over 60 were still receiving services after ten years. Assuming that survival rates remain the same for the next ten years, about 5,900 individuals will be over 60 and still receiving DADS services. This is an increase of more than 50 percent, and does not include any new individuals enrolling in DADS services.

Table 3: Individuals with IDD Still Receiving DADS Services after 10 Years

Age Group	Still Receiving Services after 10 Years	Number in 2010	Estimated Number in 2020
50-59	70%	5,485	3,800
60+	49%	4,227	2,100
Total 60+ in 2020			5,900

Adults with IDD in the community

Many individuals who meet the requirements for the DADS priority population for IDD services are living in the community without DADS Medicaid services. As noted in Table 1, DADS provides Medicaid services to about 35,000 individuals with IDD. The estimated size of the total priority population in Texas is about 126,000 individuals in 2010. Of those living without DADS Medicaid services, many are or will be over 60 within the next ten years. Unfortunately, there is too little data currently available to estimate their numbers with any precision.

DADS estimates 0.5 percent of Texans, or five of every thousand people in Texas, have IDD and would qualify for DADS services. Among people over 60, it is likely that fewer than five per thousand would qualify for DADS IDD services. While life expectancies for people with IDD generally are improving, individuals with severe impairments are still less likely to live to advanced ages.

According to Census data, the general population of Texans aged 60-75 increased by 44 percent in the past ten years. According to the State Data Center, it is projected to increase an additional 48 percent over the next ten years. It is reasonable to assume, therefore, that the number of individuals in this age group with IDD who qualify for DADS services will increase by a substantial amount. An exact estimate is not possible with the available data.

Many individuals with IDD in the community are living with family caregivers. A recent survey of Texans 18 and over³ found that about 363,000 were providing care for someone with IDD. Definite numbers are difficult to obtain because there is no formal assessment of the individual receiving care and there is no way to know how many people are providing care for the same individual. Some caregivers are providing care to people who also receive DADS services. The survey does give strong evidence, however, that far more people with IDD are being cared for by family or friends than are receiving DADS services.

Over time family caregivers will be lost to age, declining health, and death. Some individuals with disabilities will be cared for by siblings after the loss of parental care, but others will seek services from DADS. Using the limited data available, staff estimate that between 10,000 and 15,000 individuals with IDD are currently living with caregivers aged 60 or older. Details of the estimate are in Appendix 1.

³ Behavioral Risk Factor Surveillance Survey for Texas, 2010, unpublished data.

People who are over 60 and caring for a person with IDD are at significant risk of becoming unable to continue providing care. Because of these breakdowns in caregiver supports, more individuals with IDD may be in need of DADS services in the next ten years. Many of those will be age 60 and over.

Overall, it is likely that the new requests for DADS services for support of individuals with IDD over age 60 will increase by at least 50 percent in the next ten years, and may increase even further.

Patterns of Service Use

Staff tracked movement among DADS waiver and institutional services by individuals who were age 50 or over in 2001, and enrolled in HCS, community ICF, or SSLCs services. About 70 percent of these individuals used only one program during the ten years (2001-2010), but there were important differences between age groups and services. Tables detailing these differences are in Appendix 3. A description of the differences is presented below.

State Supported Living Centers

- Residents at SSLCs were least likely to change programs, with 89 percent of those over 60, and 84 percent of those in their 50s, remaining in SSLCs.
- Those who left SSLCs usually moved to HCS; three to four percent used NFs and one percent or less used community ICFs.
- Over 80 percent of those who left SSLCs for another program remained in the new program through 2010.

Community ICFs

- Older individuals living in community ICFs were the most likely to use another program, with 59 percent of those over 60 and 37 percent of those in their 50s moving to another program.
- Those who left community ICFs most often went to NFs; nearly one-half of those over 60 and about 30 percent of those in their 50s moved to a NF.
- Among older former residents of community ICFs who moved to NFs, a large majority (84-87 percent) remained in the NF for the remainder of the tracking period.
- After NFs, HCS was the second most common program for older individuals with IDD moving out of community ICFs.

HCS

- Older individuals enrolled in the HCS program used other programs fairly often. About 40 percent of those over 60, and 30 percent of those in their 50s, used at least one other program.
- The most common other program used by older individuals in HCS was NF. More than a third of those over 60, and about a quarter of those in their 50s, used a NF at some time.

- When older individuals enrolled in HCS moved to NFs, a majority remained in the NF. Among those over 60, almost 80 percent remained in the NF; among those in their 50s, almost 70 percent remained.
- About five percent of people receiving HCS services moved to community ICFs, SSLCs or other waivers.

Nursing Facilities

In the case of individuals with IDD in NFs, only retrospective data is available. Rather than describing the experience of those enrolled in 2001, staff looked at the experiences of those enrolled in the spring of 2010, looking backward to 2001. This approach gives information about individuals with IDD who spend long periods in NFs, but probably conceals some of the experiences of those who have only short stays in the NF.

Among people with IDD over age 50 who were in a NF in 2010, just over two thirds had used no other DADS Medicaid program since 2001. There is no information on their use of General Revenue services. There was little difference between those in their 50s and those over 60 in their use of other programs.

- About 15 percent had been previously enrolled in community ICFs.
- A similar number had been previously enrolled in other waivers, most often CBA.
- In each age group, four to five percent had been enrolled in HCS while one to two percent had been SSLC residents.

Individuals with IDD in NF often have very long stays. Staff examined the length of time in a NF for a sample of all people using Medicaid NF services in March of 2010, and found that such long stays are unusual among NF residents in general.

- Among NF residents of in general, the majority (just over one half) had been in a facility for less than three years. In contrast, among NF residents with IDD, the majority had been residents for longer than three years. Less than a quarter of those in their 50s and less than a third of those over 60 had stays of less than three years.
- About one third of residents of NFs with IDD over age 60 had been in a nursing facility for nine or more years; about one quarter of those with IDD in their 50s had similar stays. In the general NF population, only eight percent had been NF residents over nine years.

There is little data about the reasons that individuals with IDD enter NFs. The following factors may be involved.

- Some anecdotal reports indicate families may not make plans for the long-term care of a family member with a disability. Thus, when a parental care arrangement breaks down, relatives typically know little about available options and have little time to make decisions.
- When a family caregiving relationship breaks down because of the death or illness of the caregiver, the NF is often the easiest arrangement the family can make. Nursing facilities in Texas usually have a high vacancy rate and there is no interest list. An individual may be admitted to a NF without any prior involvement by DADS or any agency.

- By contrast, there is a long wait for HCS or CLASS services, community ICFs have very low vacancy rates, and families need to involve the local authority before admission.
- Regulations require that individuals living in ICFs have an Individual Program Plan and participate in "active treatment." Often those plans involve day habilitation or employment activities. Providers may encounter difficulties designing affordable service plans for individuals who are no longer willing or able to participate in such activities.
- The staffing and reimbursement structures for community ICFs and HCS group homes present challenges in meeting the needs of individuals whose medical needs are increasing with age. When medical needs appear to be greater than the ICF or HCS group home can accommodate, the individual may be transferred to a NF.

While the federal PreAdmission Screening and Resident Review (PASRR) requirements are intended to prevent inappropriate placements of people with IDD in NFs, they do allow an NF placement if it is an appropriate placement. Given the limitations on other services, the NF is sometimes the only available placement.

Policy Considerations

Over the next few years, DADS can expect a substantial increase in the number of individuals who are aging with IDD and need DADS services. There are significant challenges in providing adequate and appropriate services at a time of serious fiscal constraint. Ideally, services for this population would have the following characteristics:

- Rapid availability for individuals in crisis (at risk of institutionalization) (as opposed to interest lists) where the existing caregiving arrangement is breaking down.
- Individual service plans that respond to changing needs and encourage community participation comparable to the experience of an older individual without disability.
- Avoidance of unnecessary or premature NF placement.
- Appropriate housing for individuals who do not live with family.

Existing regulations clearly support aging in place and avoidance of nursing home placement, but the widespread use of NFs indicates there are difficulties in implementation.

While a system with highly flexible waiver services available without interest lists would be ideal, there are a number of directions DADS could pursue to improve flexibility within existing constraints. Even when changes cannot be made in the coming biennium, it may be possible to research and develop new program models for implementation in the future.

Service Plans for Retirement and Increased Medical Need

One approach to creating more appropriate services would be to work with stakeholders to encourage treatment and service plans more suitable for older people with IDD. In both ICF and waiver services, individuals have personalized plans of service, called an Individual Program Plan (IPP) in ICFs and an Individual Service Plan (ISP) in waiver services. Additional emphasis may be needed on the following existing requirements:

- acquisition of skills appropriate to an active retirement;

- participation in age-appropriate community activities, including senior center programs developed for the general aging population; or
- medical and therapeutic interventions to prevent or delay regression because of changes in health or cognitive status.

New approaches to service planning do not require new programs; they may be facilitated by some change in policies. Some issues would need to be addressed before such changes are made.

- While there are many anecdotes about the reasons individuals leave ICFs or HCS services for a NF, there is little or no systematically collected data. At a minimum, focus groups or stakeholder surveys would be needed to inform any new policies.
- Service planning that includes daytime leisure and enhanced medical and therapeutic services will affect the cost of delivering services. This may result in changes to the rate-setting methodology, utilization review activities, and staffing expectations.
- People who participate in senior center programs may be uncomfortable with people who have IDD joining them. Specific strategies would be needed to ease the transition.

The development and testing of new approaches to IDD services for older individuals would probably require one year or more, especially if resources are very limited.

Meeting the Needs of Individuals Living with Family Caregivers

As noted earlier, the majority of individuals with IDD in NFs have no prior use of DADS Medicaid services. It will be especially challenging to develop policies to prevent or delay the use of NFs by people leaving family caregiving situations.

Many individuals in their 50s and 60s with IDD are living with family caregivers, often parents. These caregiving arrangements are inherently fragile, becoming more so as both the individual with IDD and the caregiver age. The death of a caregiver or the caregiver's partner, or the declining health of anyone in the household can create a crisis that may force the individual with disabilities into a new residential setting, often a NF.

Several types of low-cost services could extend the life of family caregiving arrangements. In some cases, it will be necessary to adapt interventions developed for other caregiving situations. Possible services are listed below.

Respite care is a well-recognized intervention available on a limited basis in Texas. Both state and federal initiatives have supported respite care. In Texas, The Texas Lifespan Respite Care Program created by the 81st Legislature, Regular Session, 2009, works to implement a state-wide respite care system, and enhance and expand the coordination and availability of respite services. State and federal funds are used to build a foundation for community-based systems, build capacity and increase knowledge about and access to respite care options.

While useful on its own, respite care may also be used as part of a comprehensive caregiver support program.

Caregiver support can take many forms. The Rosalyn Carter Institute (RCI) has identified characteristics of effective caregiver support programs, including long-term involvement, use of structured protocols, and use of multiple modes of interaction with the caregiver. One of the most successful programs, the New York University Caregiver Intervention (NYUCI), delayed NF admission for people with dementia by 18 months. While there is less information available about supporting caregivers of people with IDD, the success of programs like NYUCI suggests well-designed programs could extend family caregiving relationships.

Planning assistance can help families prepare for changes in long-term caregiving arrangements. In some respects, this would be an expansion of General Revenue services now provided by local authorities. Many families delay or avoid considering alternative care for a person with a disability until a crisis occurs. Supporting families with information, planning tools, outreach and social networking can encourage family members to prepare proactively for the time a parent can no longer be a caregiver. Sibling networks and sibling outreach programs like the Sibling Support Project could be used as models.

A significant challenge will be offering support to families of people who do not participate in Medicaid waiver programs. However, the savings from such low cost programs could be significant. A brief list of related resources is presented in Appendix 3.

Conclusion

- The number of individuals within the DADS priority population for IDD services who will be 60 or older will increase significantly over the next ten years.
- The number of older individuals with IDD seeking DADS services will increase as family caregivers are lost to age, illness, and death.
- Some aspects of the current service delivery system tend to encourage the long-term use of NF services by individuals with IDD.
- New programs or changes in practice may be needed to meet the needs of older people with IDD in the future.

Recommendations

DADS faces complex challenges meeting the needs of people over 60 who have IDD. The number of individuals using or seeking services is expected to grow, but fiscal constraints limit the actions DADS can take in response. The following recommendations either have low costs or will require a long time to develop. With more information and specific plans, DADS may be in a position to propose more comprehensive service changes in the future.

- Identify and implement changes to existing services for people with IDD that will allow them to avoid or delay NF placement. Some approaches include:
 - Work with stakeholders and conduct research to identify the factors that cause individuals served in ICFs and HCS to move to NFs.
 - Review practices within SSLCs and within programs in other states to identify strategies that support aging in place for people with IDD.

- Reinforce existing policy through training or other mechanisms to encourage the use of individual plans appropriate for people who are aging.
- Develop strategies to support people with IDD participating in programs for the general population of people who are over sixty.
- Identify reimbursement and other changes that will make it easier for individuals with increased health needs or declining cognitive status to remain in ICFs or the HCS program.
- Develop or expand programs to support family caregivers and improve families' long-term planning for the future of individuals with IDD. Some approaches include:
 - Identify funding mechanisms and resources that will permit expansion of existing respite programs.
 - Analyze existing evidence-based caregiver support programs, in Texas and elsewhere, to identify the components of a program aimed specifically at family caregivers of individuals with IDD.
 - Gather information on existing family and sibling support networks and encourage their expansion or replication in Texas.

Appendix 1. Number of people with IDD living in the community with caregivers aged 60+

In *State of the States in Developmental Disabilities, 7th Edition* (aaid, 2008, David Braddock, Richard E. Hemp, Mary C. Rizzolo) the authors estimate that 47,035 Texans with IDD are living with caregivers aged 60+ (Table 19, page 62). For purpose of this paper, the Braddock number is substantially reduced. Because:

1. The Braddock estimate is based on an estimate that 1.58 percent of the total population has intellectual disability, cerebral palsy, epilepsy or any of several other early-onset conditions (pp. 60-61). This estimate is much larger than the estimate of 0.5 percent used for the DADS priority population.
2. The DADS priority population estimate represents only individuals with significant deficits in Adaptive Behavioral Level (ABL). Individuals with mild or moderate intellectual disability, few ABL deficits, few physical impairments and little or no mental illness constitute the majority of people in the 1.58 percent estimate. Such individuals are not included in the DADS priority population.
3. Research cited by Braddock on page 62 found that people with mild IDD have life expectancies similar to the general population. Those with severe and profound impairment had life expectancies 19 percent to 35 percent shorter than the general population. We can assume, therefore, that the DADS priority population would have a shorter life expectancy than the general population. This is consistent with the number of individuals no longer receiving DADS services after nine years.
4. Given the number of uncertainties and the lack of reliable, current, and US-based information, it is only possible to estimate the number of individuals with IDD living with aging caregivers very broadly, hence the estimate of 10,000 to 15,000 individuals.

Appendix 2. Detailed Tables

The following tables and figures provide additional detail on information in the main report.

Demographic Details

Table 4: Gender and Ethnicity of Older Consumers with IDD, 2010

	Female	Male	Anglo	African-American	Hispanic	Other/Unknown
HCS	48%	52%	61%	16%	20%	3%
SSLC	48%	52%	76%	9%	13%	2%
Community ICF	46%	54%	75%	12%	10%	3%
Nursing Facility	59%	41%	68%	14%	15%	3%
Other Waivers	49%	51%	67%	13%	21%	0%
Total	52%	48%	69%	13%	15%	3%

Includes all individuals 60 or older with an IDD diagnosis.

Table 5: Enrollment by Age and Program for 2001 and 2010

2001					
	CLASS	HCS	SSLCs	Community ICF	Sum
Under 50	1,393	2,680	4,124	5,651	13,848
51-59	33	365	792	1,035	2,225
60+	10	240	623	703	1,576
Total	1,436	3,285	5,539	7,389	17,649
2010					
Under 50	3,970	13,655	2,461	4,047	24,133
51-59	94	1,962	1,077	1,127	4,260
60+	46	1,031	712	870	2,659
Total	4,110	16,648	4,250	6,044	31,052

Details of Movement among Programs

In the following tables, HCS, TxHmL and two similar but discontinued programs (known as MRLA and HCS-O) are treated as a single “program”, since all serve a similar population with similar services. “Other” programs include CBA, CLASS, and DBMD

Each table describes the use of DADS programs over the period 2001-2010. In Table 3 for example, of 425 individuals enrolled in HCS in 2001, 21 had used SSLC services by the end of 2010.

Table 6: People Age 50-59: Additional Programs Used During 2001-2010

	HCS		Community ICF		SSLC		Total	
Number of enrollees, 2001	425		1,167		912		2,504	
Other programs used later	Number	%	Number	%	Number	%	Number	%
Only used original program	299	70%	730	63%	765	84%	1,794	72%
Also used HCS			164	14%	125	14%	289	14%
Also used Community ICF	3	1%			8	1%	11	1%
Also used SSLC	21	5%	18	2%			39	2%
Also used NF	110	26%	345	30%	26	3%	481	19%
Also used other program(s)	3	1%	9	1%	0	0%	12	0%

Table 7: People 60 and up in 2001: Additional Programs Used

	HCS		Community ICF		SSLC		Total	
Number of enrollees, 2001	248		691		616		1,487	
Other programs used later	Number	%	Number	%	Number	%	Number	%
Only used original program	151	61%	282	41%	545	89%	1059	68%
Also used HCS			91	13%	56	9%	129	9%
Also used Community ICF	3	1%			1	0%	4	0%
Also used SSLC	6	2%	7	1%			13	1%
Also used NF	89	36%	336	49%	22	4%	447	30%
Also used other program(s)	4	2%	3	0%	1	0%	8	1%

Table 8: People 50-59 in 2001: Last Program Used

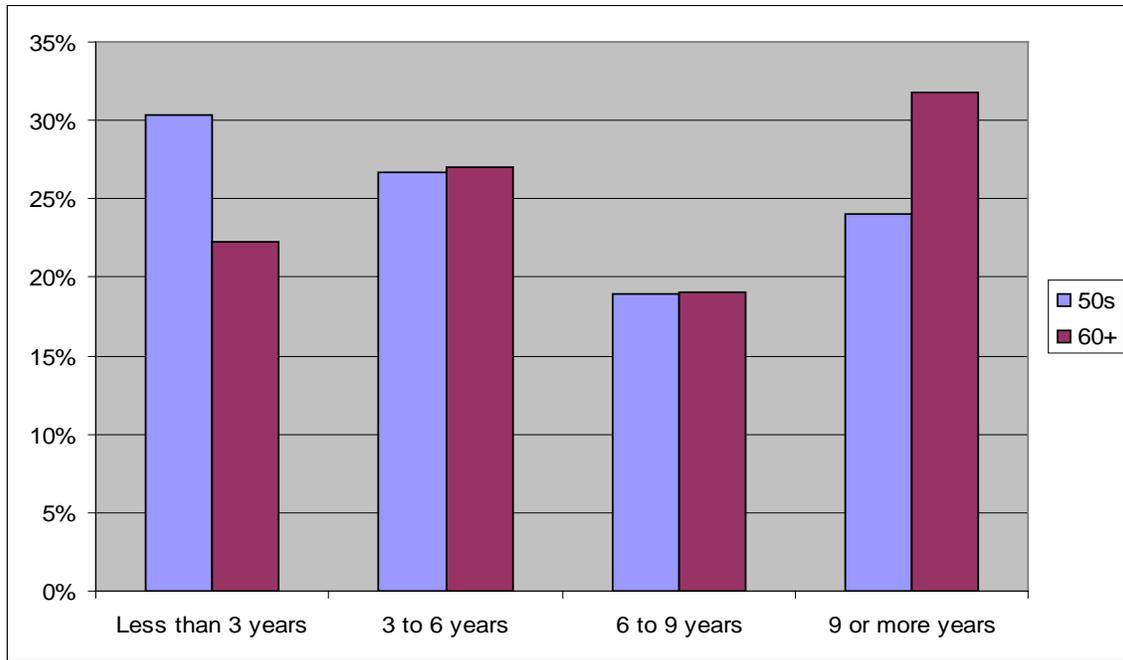
	HCS		Community ICF		SSLC		Total	
Number of enrollees, 2001	425		1,167		912		2,504	
	Number	%	Number	%	Number	%	Number	%
Last in HCS	330	78%	148	13%	115	13%	593	24%
Last in Community ICF	0	0%	699	60%	4	0%	703	28%
Last in SSLC	14	3%	17	1%	777	85%	808	32%
Last in NF	78	18%	304	26%	17	2%	399	16%
Last in Other	2	0%	1	0%	0	0%	3	0%

Table 9: People 60 and Over in 2001: Last Program Used

	HCS		Community ICF		SSLC		Total	
Number of enrollees, 2001	251		691		618		1,561	
	Number	%	Number	%	Number	%	Number	%
Last in HCS	165	66%	62	9%	49	8%	276	18%
Last in Community ICF	2	1%	314	45%	1	0%	317	20%
Last in SSLC	4	2%	5	1%	549	89%	558	36%
Last in NF	78	31%	309	45%	19	3%	406	26%
Last in Other	2	1%	2	0%	0	0%	4	0%

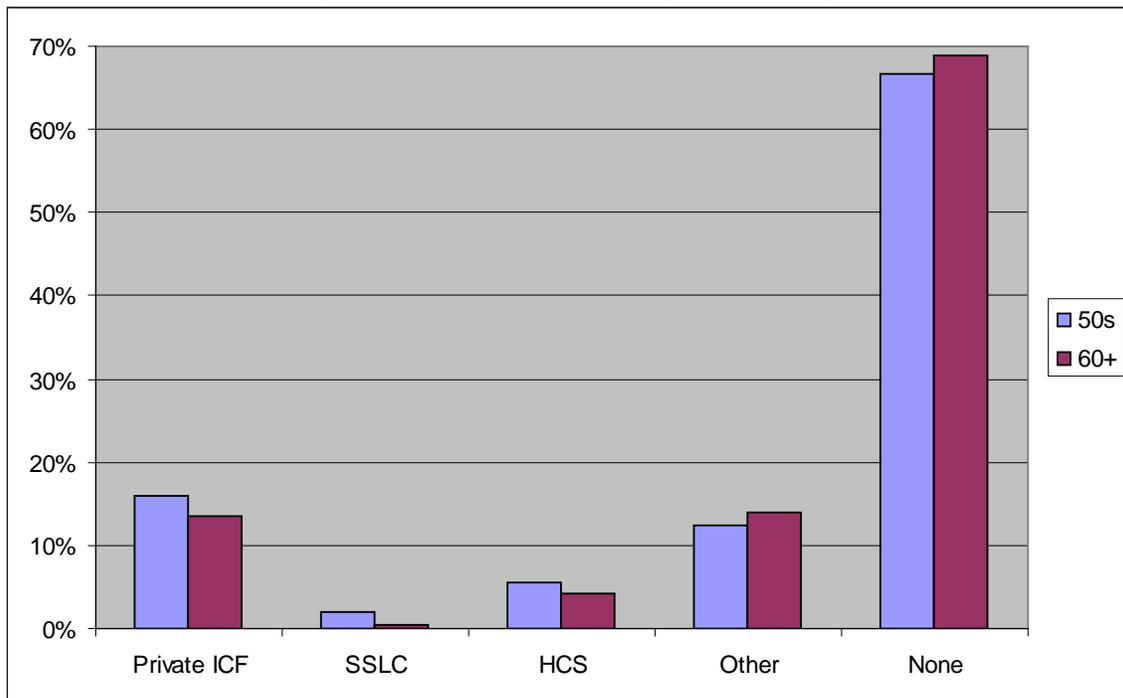
Details of Nursing Facility Use

Figure 2: Length of Stay in Nursing Facility by Age



Includes all individuals 50 or older with an IDD diagnosis.

Figure 3: Use of Other Programs by Age



Includes all NF residents 50 or older with an IDD diagnosis.

Appendix 3. Resources

Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities: Lifespan Health and Function.

Department of Disability and Human Development (DHD)

College of Applied Health Sciences (CAHS)

University of Illinois at Chicago (UIC)

<http://www.rrtcadd.org/>

The GRACE Project

Manual for Aging Adults with Developmental Disabilities

<http://www.clearbrook.org/page.aspx?pid=516>

Special Edition of IMPACT from

<http://ici.umn.edu/products/impact/231/>

This publication contains numerous additional resources, including information about projects for siblings, guidelines for long-term planning, and examples of programs emphasizing community inclusion for people aging with IDD.

Examples of programs to consider

The GRACE Project

Manual for Aging Adults with Developmental Disabilities

<http://www.clearbrook.org/page.aspx?pid=516>

Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities: Lifespan Health and Function.

Department of Disability and Human Development (DHD)

College of Applied Health Sciences (CAHS)

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<http://www.rrtcadd.org/>

<http://ici.umn.edu/products/impact/231/>

For more information about the Sibling Support Project visit its Web site at www.siblingsupport.org or call 206/297-6368.

For more information visit <http://sibleadership.blogspot.com> or contact network leaders Katie Arnold at kkeiling@uic.edu or 312/996-1002; and John Kramer at john.kramer@sibleadership.com or 312/436-1839.

For more information about “The Future is Now” curriculum manual and train-the-trainer workshops, contact the RRTCADD at rrtcadd@uic.edu or call 800/996-8845.

• **RRTCADD Clearinghouse on Aging and Developmental Disabilities** (<http://www.rrtcadd.org/Resource/Home.html>)