

The Wait List for the Agency for Persons with Disabilities (APD) Waiver Program in 2008

Background

According to the 2011 American Community Survey (ACS), more than 2.4 million Floridians are living with a disability. The Agency for Persons with Disabilities (APD) serves a segment of this population as outlined in Florida Statutes Chapter 393; specifically, individuals with a diagnosis of:

- Intellectual disability, autism, cerebral palsy, spina bifida, Prader-Willi syndrome, or other high-risk individuals.

APD's 14 area offices across the state provide a comprehensive range of services to eligible individuals and their families through waiver programs. The purpose of the waiver is to promote, maintain and restore the health of eligible recipients with developmental disabilities; minimize the effects of illness and disabilities through the provision of needed supports and services; and prevent institutionalization.

Currently, approximately **22,000** Floridians eligible to receive waiver-funded services through the Agency for Persons with Disabilities (APD) are on a wait list for these services.

APD, the Florida Legislature, and other organizations like the Florida Developmental Disabilities Council (FDDC) are interested in understanding the immediate and long-term needs of the clients on the wait list and developing and implementing a tool for annual and multi-year planning. The Florida Office on Disability and Health surveyed individuals and caregivers of individuals on the APD wait list who are living in their own home in order to gain a better understanding of their needs.

Key Findings

The results for the 985 complete and eligible respondents are as follows, comparing responses between individuals on the wait list under age 21 and those 21 and older.

Employment

The majority of self-respondents were unemployed.

- 30.0% under 21 and 38.8% 21 and older were employed

Employment was higher among caregivers.

- 60.5% under 21 and 46.1% 21 and older were employed.

Most self-respondents reported they would like to be employed if given appropriate supports.

- 90.9% of self-respondents under 21 would like to be employed
- 70.3% of self-respondents 21 and older would like to be employed

Employed self-respondents were less likely than employed caregivers to report they needed additional supports in order to maintain their employment.

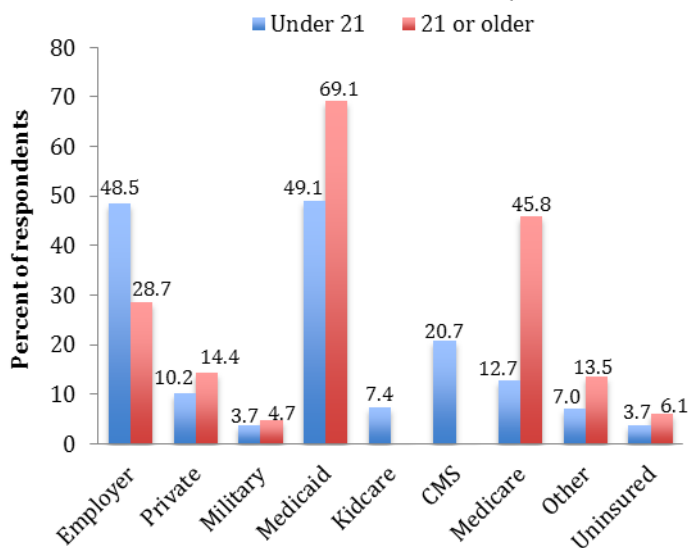
Insurance Coverage

Medicaid was the most common source of insurance for individuals on the wait list regardless of age, followed by Medicare, and insurance through an employer (either self or family member's employer).¹

In this sample of individuals on the wait list,

- 3.7% of individuals under 21 and 6.1% of individuals 21 and older reported not having any health insurance coverage.

Sources of health insurance for individuals on the wait list, 2008



Caregiving and Caregiver Experience

Almost all individuals on the wait list had a caregiver, and most caregivers were the parent or foster parent of the individual on the wait list (92.7% under 21; 79.3% 21 and older).

- Half of the individuals in the older age group had an alternative caregiver if their primary caregiver was sick or could not provide care.
- More than 60% of individuals in the younger age group had an alternative caregiver.

Caregivers provided assistance with a broad range of medical needs for the individuals on the wait list. More than 90% of caregivers assisted with medical care, regardless of the age of the individual on the wait list. For the younger age group, caregivers provided the most help with:

- Self-care (57.3%)
- Learning, remembering, or confusion (46.6%)

For the older age group, caregivers provided the most help with:

- Learning, remembering, or confusion (32.2%)
- Communicating with others (29.0%).

Respondents also were asked what other areas they needed more information or additional help with.

- Caregivers most often said they needed help planning for long-term care and making more time for themselves.
- Self-respondents said they needed help finding transportation to a variety of places (work, school, medical appointments, shopping, and social events).
- Employed caregivers reported they needed additional services for the client in order to maintain their own employment.
 - The most commonly reported services were respite care (70.8%) and in-home supports (70.8%).

Services

Respondents were asked about the services they received at the time of the survey.

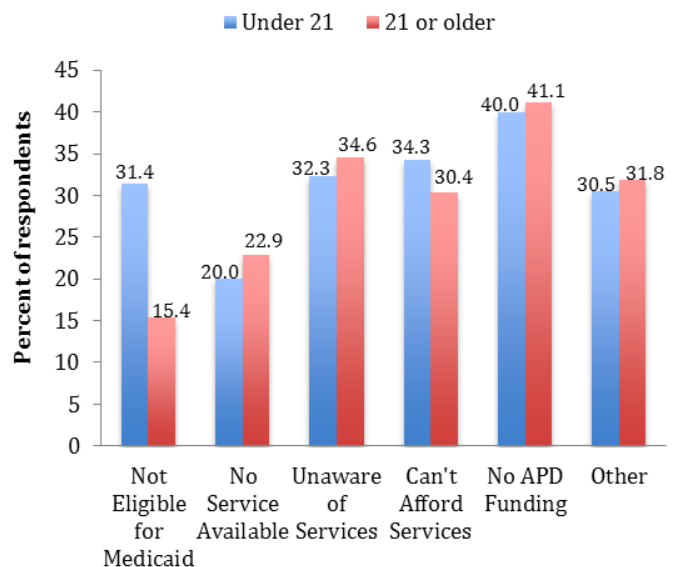
- Individuals on the wait list under age 21 most often received services through their school (70.3%). These individuals will lose their school-based services if they drop out of school or when they reach age 22 and are no longer eligible.
- Medicaid was the most common provider for older individuals (26.4%).

Almost half of individuals over 21 (48.2%) received no services at all, compared to 19.3% of individuals under 21.

The reasons most commonly cited for not receiving services were:¹

- Lack of APD funding (40.0% under 21; 41.1% 21 and older)
- Cost (34.3% under 21; 30.4% 21 and older)
- Not knowing that services were available (32.3% under 21; 34.6% 21 and older)

Reasons individuals on the wait list report receiving no services, 2008



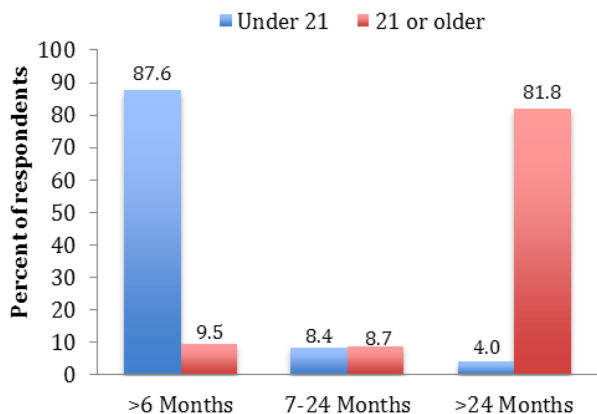
The most frequently needed services also differed by the age of the individual on the wait list.

- Behavioral analysis (44.7%), speech therapy (41.4%), and occupational therapy (38.3%) were the most needed services for younger individuals.
- Transportation (46.0%), in-home supports (36.3%), and speech therapy (29.5%) were most needed for older individuals.

Living Arrangements

More than 80% of all respondents expected the individual on the wait list to remain in their current living situations for more than two years, though this proportion was considerably lower among self-respondents (68.5% of self-respondents expect to remain in their current home for more than 2 years).

Time the individual on the wait list expects to remain in current living situation, 2008



6.4% of individuals were expected to leave their current living situation within the next six months, and 14.9% were expected to move within the next two years. Respondents said they would consider a variety of potential living situations with roughly 20-30% of respondents saying yes to each option:

- Moving to own home
- Moving in with family/friends
- Moving into home with assisted living services
- Moving to group home/residential facility

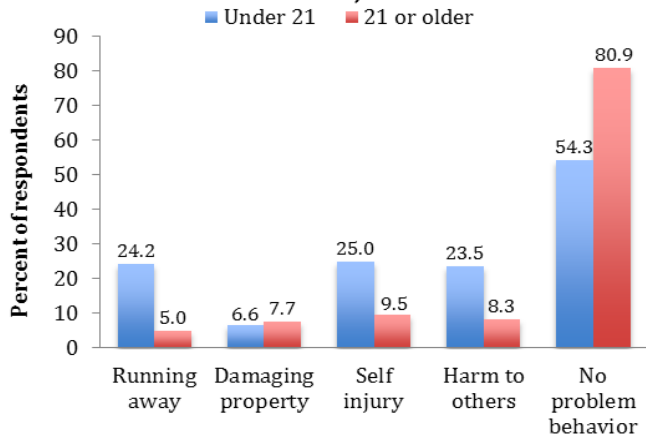
Self-respondents were more likely to say they planned to move into their own home.

Potential Risk Factors

Individuals on the wait list under age 21 were more likely to have a behavioral problem (45.7% under 21; 19.1% 21 and older). However, more than half of individuals in both age groups needed additional services to help manage behaviors (68.9% under 21; 53.0% 21 and older).

- Around 15% of respondents in both age groups reported experiencing a family crisis, such as a divorce or death, in the past six months.

Problem behaviors in individuals on the wait list, 2008



Among individuals in the younger age group, 12.2% had graduated or left high school in the past five years, and 32.5% were currently enrolled in high school.

- Among those who expected to graduate within two years, most (81.8%) said they need help finding a job or in home supports (58.5%).
 - Nearly one-quarter (23.6%) would need a new place to live.

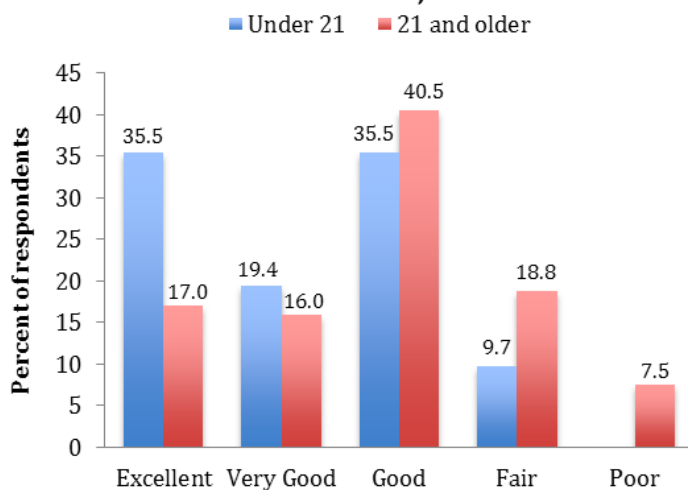
Almost half of individuals in the older age group had recently graduated or left high school (45.5%), and only 4.3% were currently enrolled.

- Among those who expected to graduate within two years, more than half (57.1%) would need help finding a job, and fewer expected to need in-home supports (38.1%) or a new place to live (19.0%).

Finally, respondents were asked about their current health. The general health of both self-respondents and caregivers was better if the client was under age 21.

- Among clients, 9.7% of individuals under age 21 reported fair health (none rated their health as poor), while 26.3% of individuals age 21 and older said their health was fair or poor.
- Fourteen percent of caregivers for younger clients rated their own health as fair or poor, compared to 26.9% of caregivers for clients age 21 and older.

General health status of individuals on the wait list, 2008



A similar trend can be seen when comparing the prevalence of activity limitations and the need for special equipment between the two groups.

- Twenty-eight percent of younger clients reported an activity limitation and 13.0% reported using special equipment, compared to 54.3% and 31.2% of older clients.

- Sixteen percent of caregivers of individuals under age 21 said their own activities were limited, and 4.0% used special equipment versus 26.5% and 9.6% reported by caregivers of individuals age 21 and older.

Methods

A random sample of individuals was taken from the full APD wait list as of February 1, 2008 and given a telephone survey to complete. Two versions of the survey were created:

- One for people on the wait list who respond for themselves (clients)
- One for a caregiver (i.e., a parent, guardian, or other caregiver) to respond for the person on the wait list

Respondents of any age who lived in their own home or a family home were eligible to complete the survey. Individuals who lived in a group home or residential setting were excluded. Only adults age 18 or older could complete the survey. One thousand surveys were completed representing 500 clients on the wait list under age 21 and 500 clients age 21 and older.

Demographics

For survey respondents under 21, the majority of surveys –94.1% – were completed by a parent, guardian, or other caregiver. Among the 21 and older age group, more individuals self-responded (24.5%). Self-respondents in both age groups were equally divided between genders. Regardless of the age of the individual, roughly 86% of caregiver respondents were women. In both age groups, the most commonly reported income level was less than \$15,000 per year for both self-respondents and caregivers. The majority of respondents reported their race as white or African-American.

- 66.2% reported white
- 18.4% reported African-American/black
- 20.0% reported Hispanic ethnicity

Nearly 90% of respondents spoke English as their primary language at home, and approximately 10% spoke primarily Spanish at home.

Policy Solutions

States often have more eligible individuals in need of waiver services than funding is available to support. Many states use waiting lists when waiver programs are at capacity or when state legislatures decrease funding. States continue to prioritize cost effective alternatives that decrease the number of individuals

on waiting lists for long-term services and supports. Programs aimed at developing and expanding home and community based alternatives to institutional care include the Money Follows the Person (MFP) demonstration and Community First Choice (CFC).

- MFP is a federal grant program designed to reduce reliance on institutional services and increase options for community-based long-term services and support.
 - States are offered enhanced federal matching funds for 12 months for each beneficiary who transitions from an institution to a home or community-based setting.
 - Over 25,000 individuals have transitioned to the community nationwide.
 - Currently, Florida is participating in the demonstration but the program is not yet operational.
- CFC provides states choosing to participate in this option a six percentage point increase in federal Medicaid matching funds for providing community-based attendant services and supports to individuals who would otherwise be confined to a nursing home or other institution.
 - Currently, Florida is not participating in the Medicaid state plan option.

In May of 2013, Governor Rick Scott approved \$36 million in funding for the APD waiver waiting list in Florida. The funds helped more than 750 people with the most critical needs to enroll in the APD Home and Community-Based Services Medicaid waiver and receive services in their communities.

¹ Percentages will not add up to 100 because respondents were given the option to select more than one response option

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