

Good morning Chairman Di'Girolamo and Subcommittee Chairman Murt. I thank you for the opportunity to testify before you today. My name is Celia Feinstein and I am the Co-Executive Director of the Institute on Disabilities at Temple University. The Institute is one of 67 centers throughout the country, funded by the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000. We are Pennsylvania's University Center for Excellence in Developmental Disabilities Education, Research and Service UCEDD), and although our primary location is on Temple University's main campus in Philadelphia, we are a statewide program and have a satellite office in Wexford, PA.

Our charge through the Developmental Disabilities Act is to provide interdisciplinary pre-service training in order to prepare the next generation of professionals, community training, technical assistance and service, and research and dissemination, all on behalf of people with intellectual and developmental disabilities and their families. We have been Pennsylvania's UCEDD since 1973, celebrating our 43rd anniversary this year.

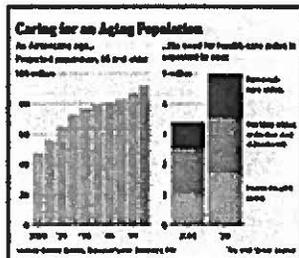
One of the core responsibilities of the UCEDD is to be a resource to the disability community, both in developing information and in interpreting information that exists. It is in this capacity I stand before you today. I have been asked to present data on the issues facing people with disabilities and their families, particularly those individuals graduating from high school and those individuals with aging caregivers. For purposes of this testimony, I will be referring both to national data sources, primarily from the National Association of Directors of Developmental Disabilities Services and from the University of Minnesota, and to the waiting list

information provided through the PA waiting list instrument referred to as the Prioritization of Urgency of Need for Services or PUNS.

From a national perspective there are several assumptions that we must consider:

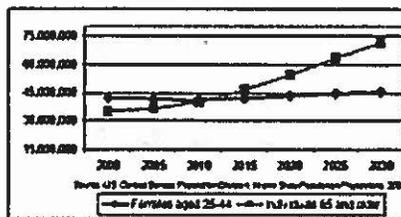
1. Growth in public funding will slow;
2. The workforce will not keep pace with the demand – typically those who provide supports to people with intellectual disabilities are women between the ages of 25 and 44 providing supports, in many cases, to those 65 and older and those with lifelong disabilities

Shortages of Care Givers as America Ages



A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled—just as baby boomers head into old age.

Wall Street Journal
 April 15, 2013



Larson, Edelstein, 2006

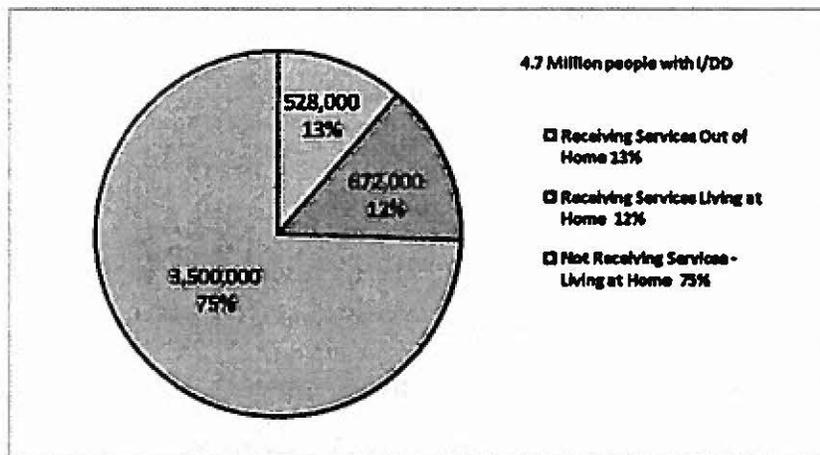
As the chart shows, while the population of individuals aged 65 is on a steady increase, the population of women between the ages of 25 and 44 has flattened. Additionally, the population of individuals with intellectual/developmental disabilities (I/DD) are competing with the aging

community and other communities who utilize the very same population of middle-aged women for support.

3. Families, with whom 87% of individuals with I/DD live nationally, are also continuing to age.

Of the 4.7 million people with I/DD nationally, 13% are receiving services outside the home, 12% are receiving services at home and 75% are not receiving services.

**Of everyone with I/DD in the US
87% of People with I/DD are Supported by Family**

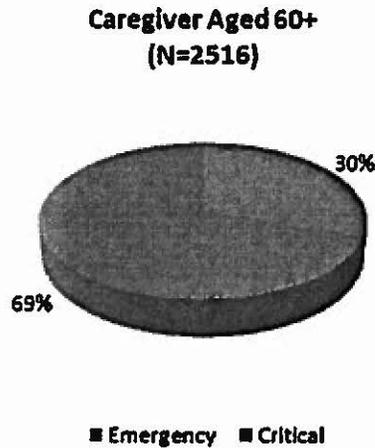


In addition to these national data, we also have data about individuals with I/DD who are waiting for services in PA. Currently the waiting list includes 13,933 people, of whom 35% (approximately 4,876 individuals) are in Emergency need, defined as needing services within the next 6 months. As the PUNS data from January, 2016 show, of the 13,933 people waiting, 2,516 or 18% of the caregivers are over 60. Of these individuals, 744 were

in the emergency category and 1,742 in the critical category (needing services within 2 years).

Aging Caregiver

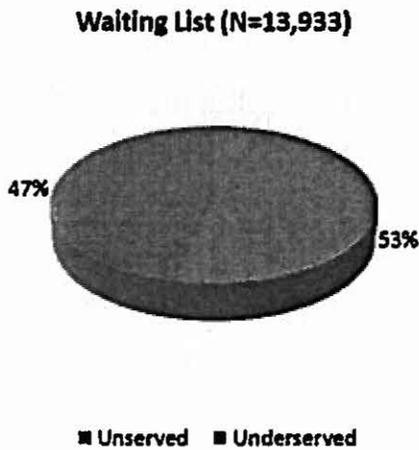
- Of the 13,933 individuals on the Waiting List, there were 2,516 individuals who indicated that the caregiver was aged 60 or older
- Of these, 744 were in the Emergency category and 1,742 were in the Critical category



When you look at whether these individuals are receiving any services, the following slide elucidates the situation. Of those waiting for services, approximately 53% are unserved, 47% underserved. If we add to the mix those individuals who have been authorized or enrolled in the waiver (but are not yet receiving services) there are still 5,658 individuals who are unserved.

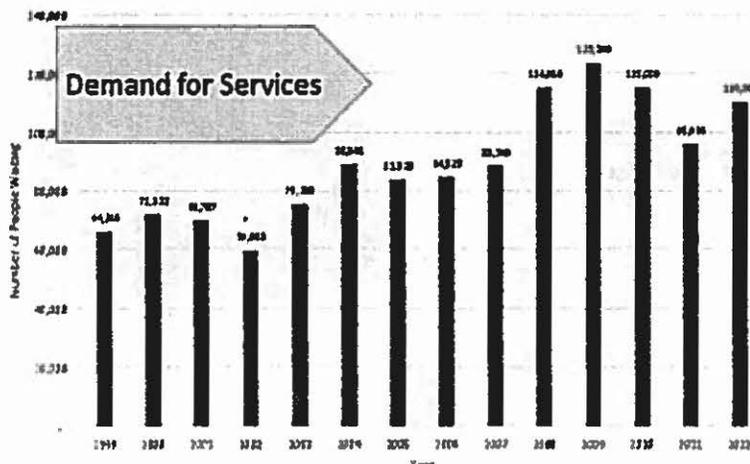
Unreserved

- Of the 13,933 individuals on the Waiting List, 7,424 are unreserved and 6,509 are underserved
- Using comprehensive served status (includes service authorization and waiver/program enrollment), 5,658 are unreserved and 8,275 are underserved



The national data from the University of Minnesota find similar demands for services.

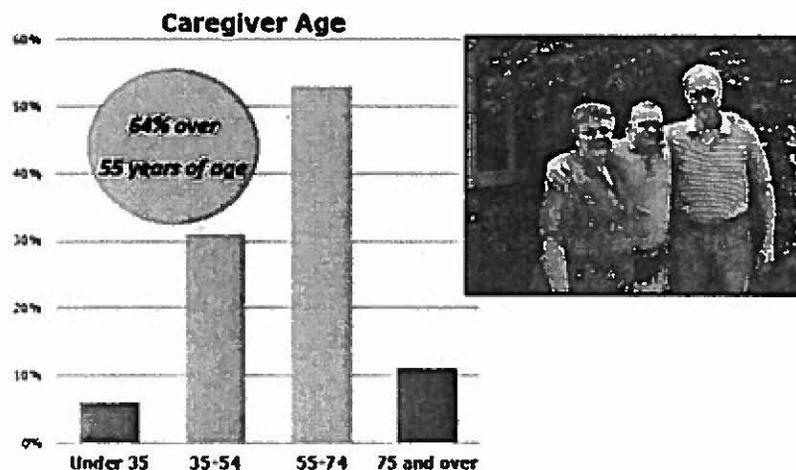
Figure 1.3 Change in People with IDD on a Waiting List For, But Not Receiving Residential Services 1999 through 2012



The National Core Indicators NCI, is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the program, which began in 1997, is to support state developmental disabilities agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks. Pennsylvania has participated in NCI since its inception. Currently 46 states and the District of Columbia participate in NCI efforts.

As the NCI data show, 64% of aging caregivers are over 55 years of age. This is inclusive of the 11% who are 75 years of age or older.

The Majority of Care Givers Today are Older



www.NationalCoreIndicators.org

In PA, as the next chart shows, of the individuals with I/DD receiving

services, 57% of them are living with family members. The PA percentage is similar to the national average.

Persons with I/DD Receiving Services While Living with Family Members as a Percentage of All Persons with I/DD Receiving Services

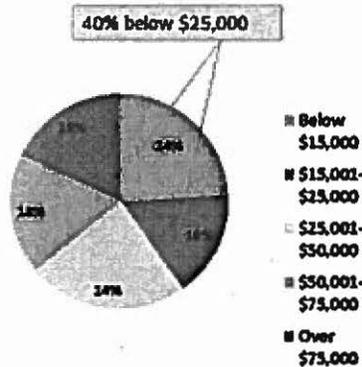
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State	2011		State	2011	State	2011
AL	48.8%		LA	67.20%	OK	44.1%
AK	23.8%		ME	8.60%	OR	60.6%
AZ	86.4%	1	MD	22.1%	PA	57.0%
AR	34.5%		MA	DNF	RI	28.4%
CA	70.7%	3	MI	53.6%	SC	DNF
CO	51.4%		MN	50.3%	SD	31.4%
CT	53.6%		MS	DNF	TN	32.2%
DE	68.9%		MO	50.8%	TX	DNF
DC	33.4%		MT	56.1%	UT	34.3%
FL	69.9%		NE	22.3%	VT	50.8%
GA	52.4%		NV	66.9%	VA	18.8%
HI	68%		NH	25.8%	WA	65.7%
ID	DNF		NJ	71.3%	WV	DNF
IL	29.1%		NM	15.8%	WI	37.6%
IN	46.4%		NY	62.0%	WY	42.4%
IA	36.8%		NC	DNF	Reported	56.5%
KS	34.4%		ND	30.0%	US Total	
KY	25.6%		OH	69.0%		

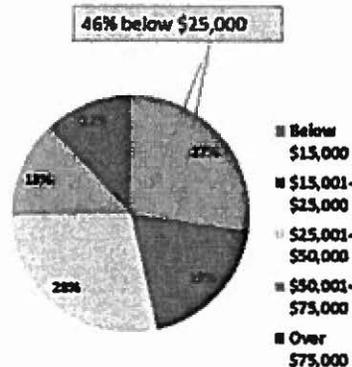
Another issue that must be considered in making to decisions about how to support people with disabilities and their families, is to look at the situation that finds so many families in poverty. From the 2011 NCI data, as the slide shows, 46% of the people interviewed in the adult family survey are living in poverty, defined as below \$25,000 (HHS poverty guidelines for a family of four in 2011 was \$22,350).

Many families we are serving are living in poverty

Child Family Survey



Adult Family Survey***



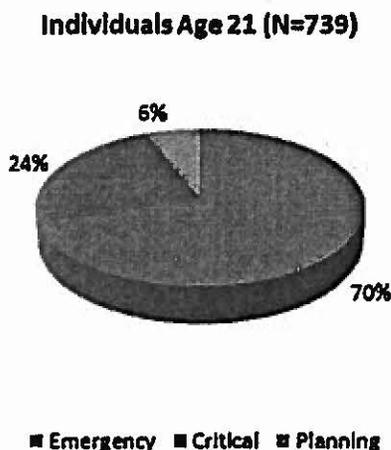
2011 HHS Poverty Guidelines for a Family of Four: \$22,350

***www.nationalcoreindicators.org

Another area of need identified in PA is the need for supports for those transitioning from high school to adult life. ODP, the Bureau of Special Education in the PA Department of Education and the Office of Vocational Rehabilitation in the Department of Labor and Industry have made tremendous strides in supports to students with I/DD so that when students reach the age of 21 it is no longer like falling off a cliff into an abyss for many students. However, despite the strides made, more needs to be done on behalf of students, both while they are still in school to prepare them for life after high school and once they graduate from high school. Whether a student chooses to continue their education through a post-secondary option of some kind, or begin life in the world of work, supports should be available as needed. The PUNS data reflect the following:

Individuals Age 21 Leaving School

- There were 739 individuals on the Waiting List who are 21 and must leave the education system
- Of these, 518 were in the Emergency category, 176 were in the Critical category, and 45 were in the Planning category
- Of the 739, most are waiting for Adult Day Supports, Community Employment, Habilitation, or Pre-Vocational Supports



As the data show, there were 739 individuals who are 21 and leaving the education system, according to PUNS (January, 2016). Of those individuals, 518 were in the Emergency Category and 176 in the Critical Category. These individuals are waiting for employment and other pre-vocational supports.

The two groups of people I have spoken about today represent among the most critically needy individuals on the waiting list. However, others wait as well. I have not talked about the families who struggle to make it every day, yet still need support. They may only be in their 40's or 50's, but if one of the two parents becomes ill, if the parents divorce, or if like so many of us, they are sandwiched by taking care of children and parents at the same time, they are minutes from disaster on a daily basis. It is our greatest hope that families will be kept together with just a little support from the

system when needed. It is our sincere hope that resources will be made available to support everyone on the waiting list who needs support.

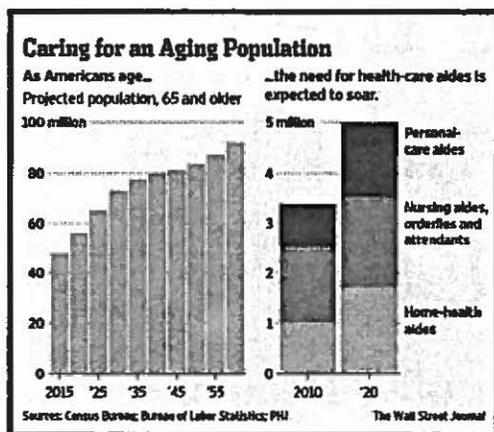
If you have any questions, please don't hesitate to contact me. I can be reached at 215-204-6561 or shoes100@temple.edu.

Testimony before the Human Services Committee PA House

Celia S. Feinstein, Co-Executive Director
Institute on Disabilities, Temple University

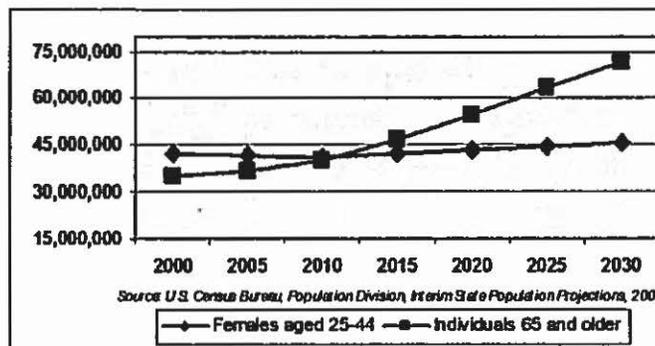
March 21, 2016

Shortages of Care Givers as America Ages



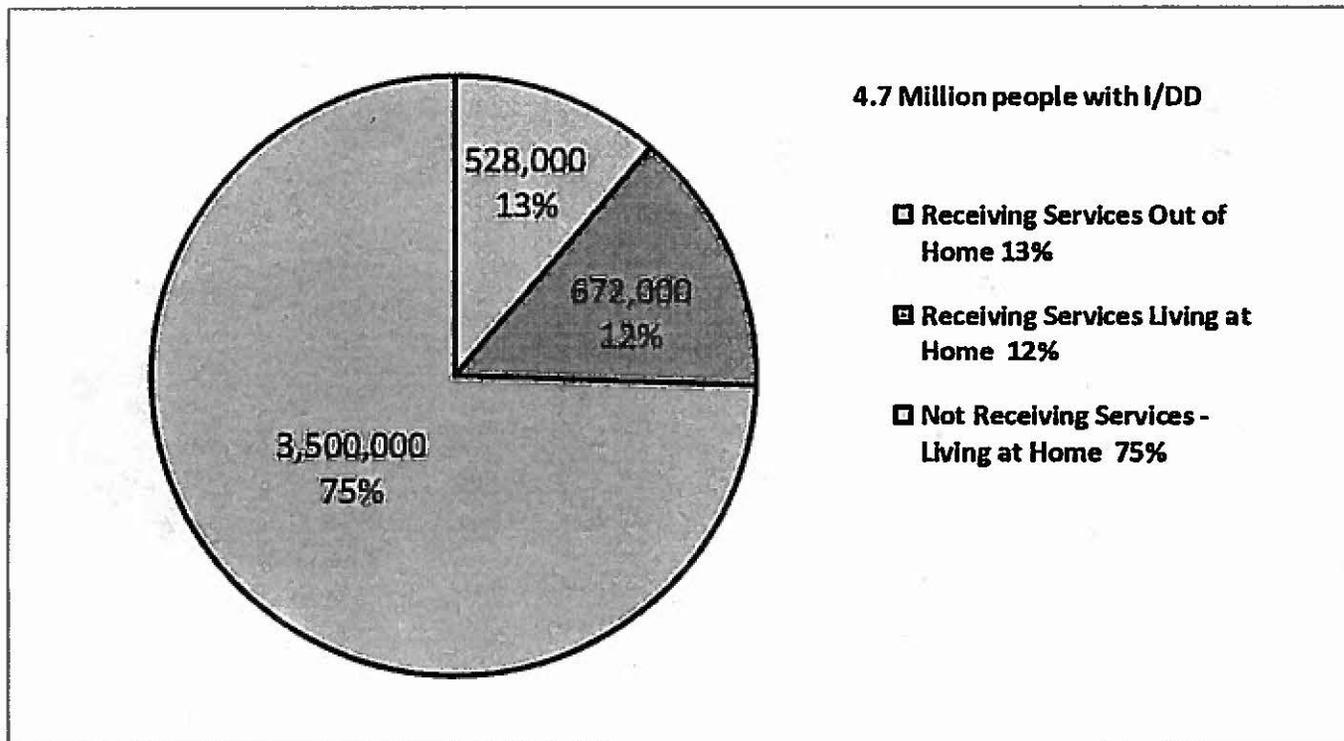
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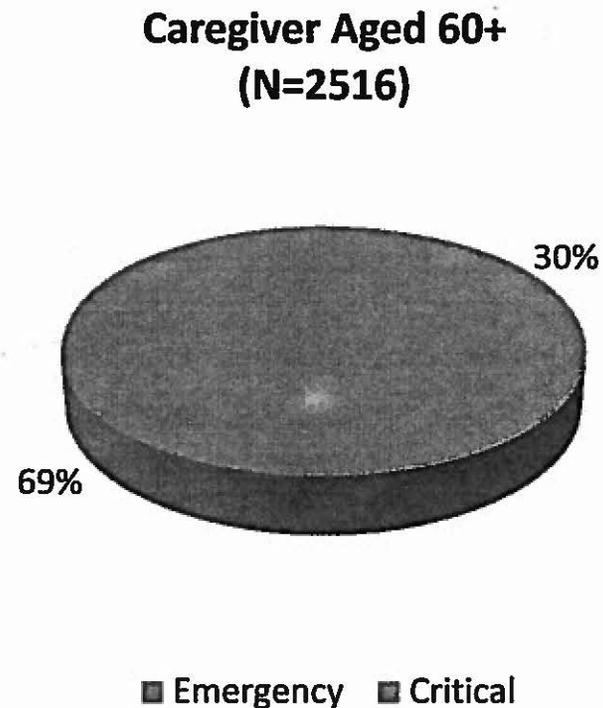
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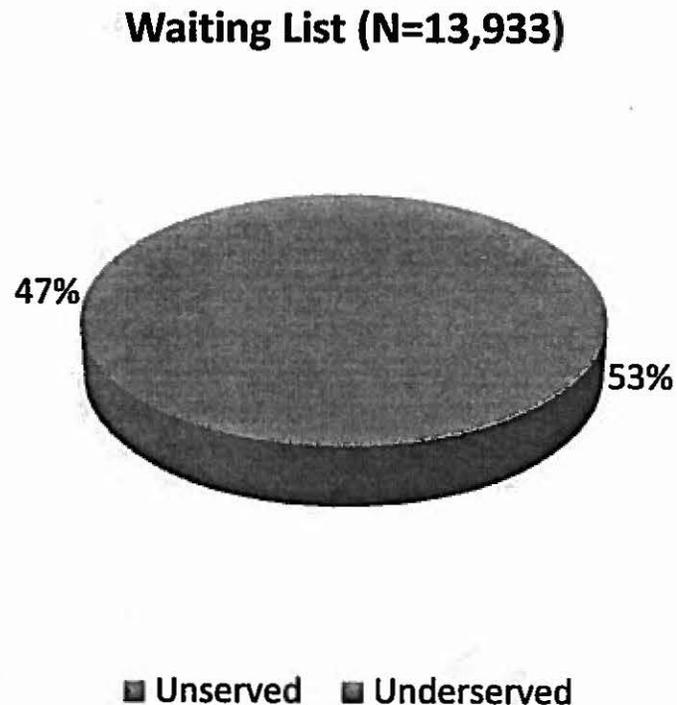
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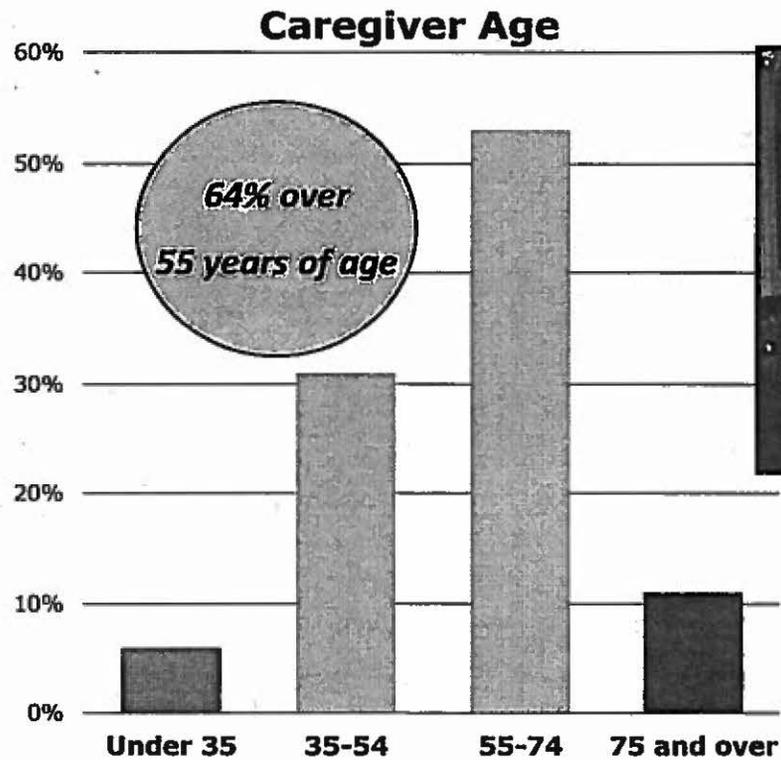
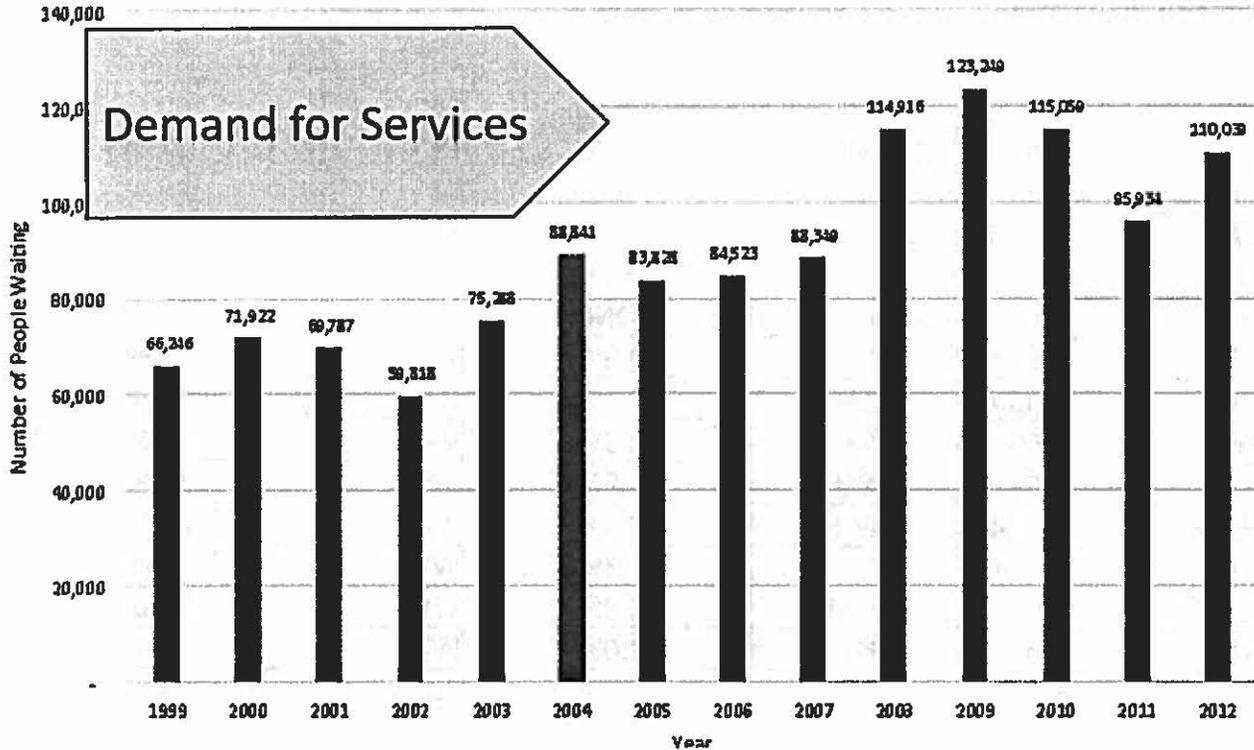


Figure 1.3 Change in People with IDD on a Waiting List For, But Not Receiving Residential Services 1999 through 2012



Persons with I/DD Receiving Services While Living with Family Members as a Percentage of All Persons with I/DD Receiving Services

Data Downloaded: 10/14/14 RISP-UMINN

State	2011
AL	48.8%
AK	23.8%
AZ	86.4%
AR	34.5%
CA	70.7%
CO	51.4%
CT	53.6%
DE	68.9%
DC	33.4%
FL	69.9%
GA	52.4%
HI	68%
ID	DNF
IL	29.1%
IN	46.4%
IA	36.8%
KS	34.4%
KY	25.6%

1
3

State	2011
LA	67.20%
ME	8.60%
MD	22.1%
MA	DNF
MI	53.6%
MN	50.3%
MS	DNF
MO	50.8%
MT	56.1%
NE	22.3%
NV	66.9%
NH	25.8%
NJ	71.3%
NM	15.8%
NY	62.0%
NC	DNF
ND	30.0%
OH	69.0%

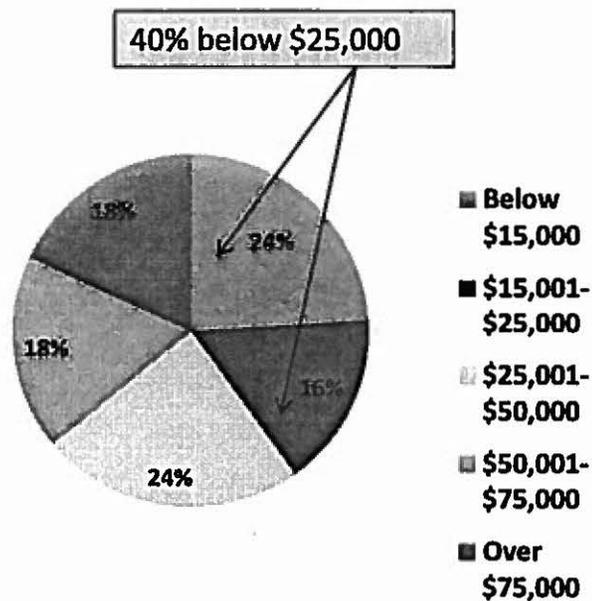
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State	2011
OK	44.1%
OR	60.6%
PA	57.0%
RI	28.4%
SC	DNF
SD	31.4%
TN	32.2%
TX	DNF
UT	34.3%
VT	50.8%
VA	18.8%
WA	65.7%
WV	DNF
WI	37.6%
WY	42.4%
Reported	56.5%
US Total	

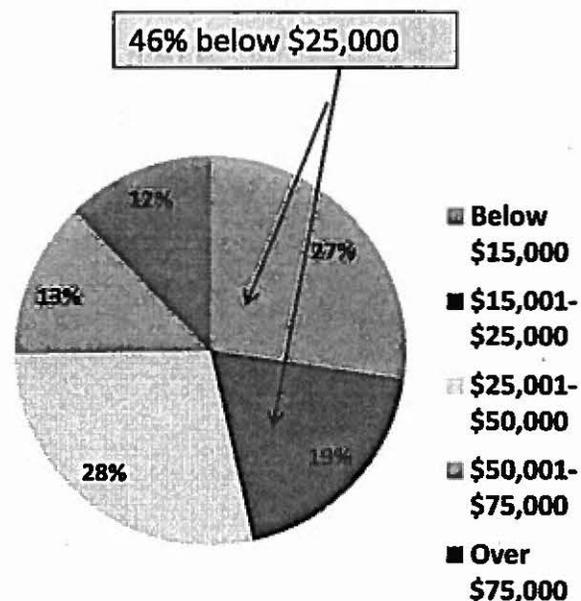
DNF—Did not furnish

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