

## COMMONWEALTH of VIRGINIA

JACK BARBER, M.D. INTERIM COMMISSIONER

# DEPARTMENT OF BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES

Post Office Box 1797 Richmond, Virginia 23218-1797 Telephone (804) 786-3921 Fax (804) 371-6638 www.dbhds.virginia.gov

October 15, 2017

The Honorable Thomas K. Norment, Jr., Co-chair The Honorable Emmett W. Hanger, Jr., Co-chair Senate Finance Committee 14th Floor, Pocahontas Building, 900 East Main Street, Richmond, VA 23219

Dear Senator Norment and Senator Hanger:

Item 313.W. of the 2017 Appropriation Act required the Department of Behavioral Health and Developmental Services to "provide a report on the management and characteristics of individuals on the waiting list for services through the Developmentally Disabled Waiver programs".

Please find enclosed the report in accordance with Item 313.W. Staff at the department are available should you wish to discuss this request.

Sincerely,

Jachn Berberm

Jack Barber, M.D.

Enc.

Cc: William A. Hazel, Jr., M.D.

Joe Flores

Susan E. Massart Mike Tweedy



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The Honorable S. Chris Jones, Chair House Appropriations Committee 900 East Main Street Pocahontas Building, 13th Floor Richmond, Virginia 23219

Dear Delegate Jones:

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# DD Waiver Program Waiting List (Item 313.W.)

October 15, 2017

DBHDS Vision: A Life of Possibilities for All Virginians

# **DD** Waiver Program Waiting List

#### **Preface**

This report is submitted in response to Item 313.W. of the 2016 Appropriation Act to report on individuals on the Developmentally Disabled Waiver waiting list.

W. The Department of Behavioral Health and Developmental Services shall provide a report on the management and characteristics of individuals on the waiting list for services through the Developmentally Disabled Waiver programs. The report shall include (i) the age of individuals on the waiting list, and (ii) the number of individuals designated as Priority 1, 2 and 3 on the waiting list. The department shall submit this report by October 15, 2017 to the Chairmen of the House Appropriations and Senate Finance Committees."

# **DD Program Waiting List**

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#### **Executive Summary**

The three waivers for individuals with developmental disabilities (DD) were redesigned in 2016. One of the elements of the redesigned waivers is a single waiting list for the three waivers known as the Community Living, Family and Individual Supports and Building Independence waivers.

The Department of Behavioral Health and Developmental Services (DBHDS) manages the DD waivers waiting list. As of July 14, 2017, the waiting list totaled 11,786 individuals. On that date, 46 percent of these individuals were 15 years or younger and 81 percent were 26 years or younger, attesting to a predominantly young waiting list composition.

The statewide waiting list is divided into three priority categories. Those in Priority One are identified as needing services in less than a year and are eligible to be assigned a DD waiver slot according to urgency of need at the time a slot comes available. Individuals in Priority Two are identified as needing a slot in one to five years and Priority Three in over five years. Individuals in Priorities Two and Three may receive slots when all Priority One individuals have been offered slots; although, they may move into Priority One as their needs change. The largest percentage of individuals on the statewide DD waivers waiting list are in the Priority Two category (42 percent or 3,044 individuals) followed by Priority Three (32 percent or 3,819 individuals). Those in Priority One, who will need services in less than one year, while still over 3,000 individuals, represent the smallest percentage (26 percent).

### **Description of DD Waivers Waitlist Priorities**

The DD waivers waiting list is divided into three priority categories that are defined by needs-based criteria, as well as the length of time before the individual will require services. This means of managing the waiting list was part of the 2016 waiver redesign. Prior to that, the former Intellectual Disability waiver waiting list was divided into "urgent" and "non-urgent" categories, while the former Developmental Disabilities waiver waiting list was chronological. Under the present system, individuals are assigned to slots based on the urgency of their needs at the time slots become available, with Priority One individuals accessing slots before those in the other categories.

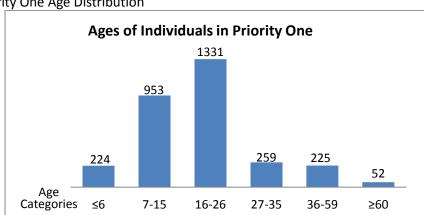
#### **Definition of Priority One**

It is anticipated that the individual will need waiver services *within one year* and the individual meets one of the following criteria:

- An immediate jeopardy exists to the health and safety of the individual due to the unpaid primary caregiver having a chronic or long-term physical or psychiatric condition or conditions that significantly limit the ability of the primary caregiver or caregivers to care for the individual; there are no other unpaid caregivers available to provide supports; or
- There is immediate risk to the health or safety of the individual, primary caregiver, or other person living in the home due to either of the following conditions:

- The individual's behavior or behaviors, presenting a risk to himself or others, cannot be effectively managed by the primary caregiver or unpaid provider even with support coordinator/case manager-arranged generic or specialized supports; or
- O There are physical care needs or medical needs that cannot be managed by the primary caregiver even with support coordinator/case manager-arranged generic or specialized supports; or
- The individual lives in an institutional setting and has a viable discharge plan; or
- The individual is a young adult who is no longer eligible for IDEA services and is transitioning to independent living. After individuals attain 27 years of age, this criterion shall no longer apply.

As seen in Diagram 1 below, the greatest number of individuals in the Priority One category are "transition age" youth and young adults (those between the ages of 16 and 26), followed by school age children. While there are lower numbers of adults in the Priority One category, those who are 36 years and older are likely to have caregivers who are 60 years of age or older. These aging caregivers will likely not be able to sustain caregiving responsibilities for much longer.



**Diagram 1**: Priority One Age Distribution

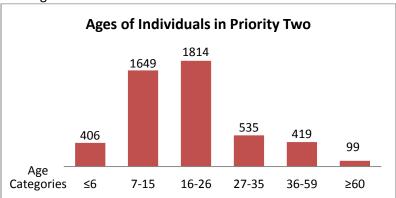
#### **Definition of Priority Two**

In Priority Two, it is anticipated that the individual may require waiver services *in one to five years* and the individual meets one of the following criteria:

- The health and safety of the individual is likely to be in future jeopardy due to
  - the unpaid primary caregiver or caregivers having a declining chronic or longterm physical or psychiatric condition or conditions that significantly limit his ability to care for the individual;
  - o There are no other unpaid caregivers available to provide supports; and
  - o The individual's skills are declining as a result of lack of supports; or
- The individual is at risk of losing employment supports; or

- The individual is at risk of losing current housing due to a lack of adequate supports and services; or
- The individual has needs or desired outcomes that with adequate supports will result in a significantly improved quality of life.

Diagram 2: Priority Two Age Distribution



Once again, though by a narrower margin, the transition age youth (16-26 years of age) represent the largest number in this category, followed by school age children between 7-15 years of age, as shown below in Diagram 2. While the members of these two groups are not likely to need services in the immediate future, those adults (36 years and older) could move into the Priority One category at any time, due to the declining health/abilities of their aging caregivers. This age group represents 10.5 percent of the members of the Priority Two portion of the waiting list.

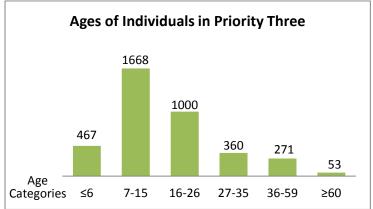
#### **Definition of Priority Three**

Priority Three is assigned to individuals who meet one of the following criteria and will need a waiver slot in *five or more years*, as long as the current supports and services remain:

- The individual is receiving a service through another funding source that meets current needs; or
- The individual is not currently receiving a service but is likely to need a service in five or more years or
- The individual has needs or desired outcomes that with adequate supports will result in a significantly improved quality of life.

The largest number of individuals in the Priority Three category are children, who are currently being served by the school system, followed by transition age youth and young adults aged 16 - 26 years, as shown in Diagram 3, below. Those adults over 36 years and above, who likely have aging caregivers, may present in the near future as a Priority One individuals. This group represents 8 percent of the current Priority Three individuals.

Diagram 2: Priority 3 Age Distribution



#### **DD** Waiver Waiting List by Age and Priority

As of July 14, 2017, the total number of individuals on the DD waivers waiting list was 11,786. Those individuals needing services in less than one year (Priority One) represented 26 percent (3,044 persons) of the total waiting list. Those needing services in one to five years (Priority Two) made up 42 percent (4,922 persons) of the list. Finally, those who may require services in five or more years (Priority Three) comprised 32 percent (3,819 persons) of the overall list (*Tables 1 and 2 and Diagrams 4 and 5*).

As seen in Tables 1 and 2 and Diagrams 4 and 5, the highest number/percentage of individuals on the waiting list by age grouping is those between the ages of seven and 26 (8,415 persons or 71.4 percent). While most of these individuals are currently receiving school-based services and living with their families, their need for waiver services to prevent skills decline and to relieve their family caregivers, as well as to help the individuals themselves maximize their independence as they age, will grow in the coming years. It is important to note that, of the 204 individuals who are 60 years and older, 41 of these individuals are receiving services on the EDCD (Elderly or Disabled with Consumer Direction) waiver.

Table 1: Numbers of Individuals on the Waiting List by Age and Priority Level

DD Waiver Program Waiting List (as of July 14, 2017)					
Age Category	Priority 1	Priority 2	Priority 3	Unknown	<b>Grand Total</b>
≤6	224	406	467		1097
7-15	953	1649	1668		4270
16-26	1331	1814	1000		4145
27-35	259	535	360	1	1155
36-59	225	419	271		915
≥60	52	99	53		204
<b>Grand Total</b>	3044	4922	3819	<b>1</b> <sup>1</sup>	11786

<sup>&</sup>lt;sup>1</sup> At the time of report, the individual was in the prioritization process.

**Table 2**: Percentages of Individuals on the Waiting List by Age and Priority Level

DD Waiver Program Waiting List (as of July 14, 2017)					
Age Category	Priority 1	Priority 2	Priority 3	Unknown	<b>Grand Total</b>
≤6	1.90%	3.44%	3.96%	0.00%	9.31%
7-15	8.09%	13.99%	14.15%	0.00%	36.23%
16-26	11.29%	15.39%	8.48%	0.00%	35.17%
27-35	2.20%	4.54%	3.05%	0.01%	9.80%
36-59	1.91%	3.56%	2.30%	0.00%	7.76%
≥60	0.44%	0.84%	0.45%	0.00%	1.73%
<b>Grand Total</b>	25.83%	41.76%	32.40%	<b>0.01%</b> <sup>1</sup>	100.00%

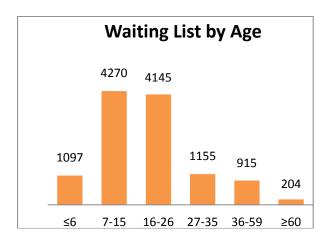
**Diagram 3**: Waiting List by Priority

Priority
3
32%

Priority
1
26%

Priority
2
42%

Diagram 4: Waiting List by Age



## **Waiting List Growth Trends**

As of September 1, 2016, there were 10,599 individuals on the combined DD waiting list. As of July 13, 2017, the list had grown to 11,786. During the evaluated time frame (315 days), 3.8 individuals were added to the wait list per calendar day. Table 3 below details the waiting list growth.

Table 3: Waiting List Growth Detail

Date	# of Ind. on Active Waitlist	Description
9/1/2016	10,599	Begin study period
	2,755	Added to active waitlist
	-1,568	Removed from active waitlist*
7/13/2017	11,786	Waitlist as of 7/13/2017

\*Individuals are removed from the waitlist for numerous reasons. A ten percent sample (of removals) was studied in order to better understand the reason for removals. The results of the sample are displayed below in Table 4.

Table 4: Reasons Individuals were Removed from the Waiting List

Reason	Percentage
Enrolled in a DD waiver	60.8%
Unable to Contact, Moved out of State, Declined, etc.	27.7%
Movement Between Waivers	6.3%
Did not meet VIDES (Virginia Individual Developmental	4.7%
Disabilities Eligibility Survey)	
Deceased	4.1%
Other	2.7%

#### Conclusion

As waiver slots are authorized and funded by the General Assembly, they are allocated to the various Community Services Boards (CSBs). This distribution is based on overall population in the CSB catchment area, the number of "Medicaid lives" in that area, and the number of individuals in the area who are on the Priority One portion of the DD waiver waiting list. The statewide waiting list is divided into three categories representing length of time an individual may be able to wait for services and the gravity of his needs. Those with the most imminent needs make up 26 percent of the waiting list and a full 81 percent of those on the overall waiting list are 26 years of age or younger. This means that the need for DD waiver services will continue to grow as these youth and their caregivers' age. DBHDS will continue to work with the General Assembly and the Department of Medical Assistance Services to address the needs of the individuals on the waiting list.