



STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene
201 W. Preston Street • Baltimore, Maryland 21201

Martin O'Malley, Governor – Anthony G. Brown, Lt. Governor – John M. Colmers, Secretary

SEP 02 2009

The Honorable Ulysses Currie
Chairman
Senate Budget and Taxation Committee
3 West Miller Senate Office Building
Annapolis MD 21401-1991

The Honorable Norman H. Conway
Chairman
House Appropriations Committee
121 House Office Building
Annapolis MD 21401-1991

Re: JCR 2009, Page 91, Developmental Disabilities Administration, M00M01.02 -
Community Services - Waiting List

Dear Chairman Currie and Chairman Conway:

Please find enclosed the required report regarding the Department's Developmental Disabilities Administration (DDA) Waiting List. This information is submitted for the 2009 Joint Chairmen's Report, page 91, and it provides the Department an opportunity to update the General Assembly on DDA's activities and the needs of individuals on its Waiting List. This report is contingent upon the release of funds.

If you have any questions regarding the information in this report, please direct your concerns to Anne Hubbard, Director, Office of Governmental Affairs at (410) 767-6481.

Sincerely,



John M. Colmers
Secretary

Enclosures

cc: Audrey Cassidy
Michael Chapman
Renata Henry
Anne Hubbard
James Johnson
Valerie Roddy
Kathleen Wunderlich



Report on DDA Waiting List Priority Access to Service

Introduction

This report, as required by the 2009 Joint Chairman's Report, page 91, provided the Department of Health and Mental Hygiene with an opportunity to update the General Assembly on the activities of the Developmental Disabilities Administration (DDA) to gain a clear understanding of the needs of individuals on the Waiting List. This report specifically addresses the individuals in the Waiting List's highest priority category for service funding, Crisis Resolution. COMAR 10.22.12.07.B.(1) defines Crisis Resolution as a request for service where the applicant meets one or more of the following criteria:

- 1) Homeless or living in temporary housing with clear time-limited ability to continue to live in this setting with no viable non-DDA funded alternative;
- 2) At serious risk of physical harm in the current environment;
- 3) At serious risk of causing physical harm to others in the current environment;
- 4) In danger of losing DDA-funded residential services because of a lack of current day services;
- 5) One who has lost DDA-funded day services; or,
- 6) Living with a caregiver who is unable to provide adequate care due to the caregiver's impaired health, which may place the applicant at risk of serious physical harm.

Over the past several months, DDA staff has systematically reviewed the 4,511 individuals in the Crisis Resolution category. The goal was to validate the actual number of individuals in this category and to describe the type of services requested. This report details the steps taken to achieve this goal and results of DDA's efforts.

Background

The Developmental Disabilities Administration currently maintains one comprehensive waiting list of applicants requesting service funding. This list has grown steadily each year in which data are available. In the years leading up to 1998, it became clear to self-advocates, families, advocates and policy-makers that the waiting list required attention. In 1998, 5,469 individuals were waiting for one or more services offered by the DDA. This demand far exceeded the available resources at that time.

Recognizing the need for more resources, Governor Parris N. Glendening appropriated \$184.5 million of new funding over the next five (5) years to reduce the waiting list, and as a result, the DDA launched the Governor's Waiting List Initiative (WLI) beginning

July 1, 1998. Over the next five (5) years, 8,373 individuals received services. However, during the same period, the waiting list grew to 9,697. This was likely attributable to a public awareness campaign.

In fiscal year 2007, additional WLI funding was allocated to serve additional individuals. By that time the list had grown to over 12,000 people. In subsequent years, the list has grown to where it stands today at nearly 19,000.

DDA's current administration, in an effort to understand the true extent of the waiting list and why it continues to grow, decided to perform a comprehensive review of each person waiting for DDA funding. The following pages provide the current status and preliminary results of DDA's review process and findings.

The waiting list is categorized by priority and eligibility categories. Priority categories are:

- Crisis Resolution
- Crisis Prevention
- Current Request
- Future Need

Eligibility categories are:

- Full Developmental Disability Eligible (DD Eligible) – No Current Service
- Full Developmental Disability Eligible (DD Eligible) – With a Current Service
- Supports Only Eligible (SO Eligible) – No Current Service
- Supports Only Eligible (SO Eligible) – With a Current Service

Attachment A contains the definitions of the priority and eligibility categories as outlined in State regulations and the Annotated Code of Maryland, Health General.

In May 2009, there were 18,928 people on DDA's waiting list. This number represents individuals who are either eligible for full Developmental Disability or Supports Only. Of this number, 4,511 (23.8%) were classified as Crisis Resolution and full Developmental Disability eligible. This group is the current focus of review.

DDA's Review Methodology

In November 2008, the DDA initiated a comprehensive review of the 4,511 individuals in the Crisis Resolution priority category. To determine the accuracy of the needs of those in this group, DDA staff did the following:

1. Developed a survey to validate the priority category. The survey includes demographic information, information regarding the individual's needs and, the name and signature of the person responding to the survey. If the individual could not complete the survey, the relationship to that

- individual is also indicated.
2. The survey was mailed to every person waiting for a service in that category.
 3. The survey was mailed a second time to those who did not respond.
 4. Phone calls were then made to those who did not respond to either mailing of the survey.
 5. All known contact information was used in this process.
 6. The results of the surveys that were completed were verified by each DDA regional office (see Attachments B – F).

Results

Summary of the findings to date of the 4,511 individuals reviewed in the Crisis Resolution are detailed in the chart below.

Final Results - Crisis Resolution					
	Crisis Resolution	Crisis Prevention	Current Request	Future Need	To Be Made Inactive or Request Withdrawn
DD Eligible – No Current Service	365	40	556	268	1,564*
DD Eligible – With Current Service	165	44	250	113	1,146*
TOTAL	530	84	806	381	2,710*

*Includes those who had indicated no need for services, no response to mailings/phone calls or were deceased.

As noted above, of the initial 4,511 individuals identified in the Crisis Resolution category, DDA has verified that 530 meet this category of need based on the survey/personal phone calls results. The results further indicate that 1,271 individuals are in a priority category other than Crisis Resolution. Finally, the results show that 2,710 either did not respond or responded that no services were needed.

Of the 530 individuals identified as being the highest priority to receive service, 1,318 service requests have been made. The following tables indicate the services they have requested. Some individuals have requested more than one service.

No Current Service		
Day	Requests	340
	Individuals	333
Residential	Requests	337
	Individuals	333
Supports	Requests	361
	Individuals	347
All Services	Requests	1,038
	Individuals	365

With Current Service		
Day	Requests	46
	Individuals	44
Residential	Requests	138
	Individuals	134
Supports	Requests	96
	Individuals	94
All Services	Requests	280
	Individuals	165

NOTE: There are over 14,000 people in lower priority categories (Crisis Prevention, Current Request, Future Need) who DDA will contact as part of this project. The numbers are fluid and as we begin to review the other categories, it is likely some individuals will meet the criteria to be placed in Crisis Resolution.

Plan to keep the Waiting List up-to-date

The DDA is committed to maintaining an accurate waiting list. Accurate data is essential to our ability to manage the waiting list and to plan for future services. To keep the waiting list current, DDA Headquarters will:

- Implement a statewide process to ensure the consistent application of standardized criteria to determine a person’s eligibility, their needs and the appropriate prioritization of the waiting list category;
- Direct the regional directors to annually verify the accuracy of each person’s status on the waiting list; and
- Revise resource coordination contracts to ensure regular, meaningful contacts with every individual on the waiting list to locate appropriate generic community supports/referrals to address the needs of the person/family.

Recommendations

DDA recommends:

- Restructuring the Waiting List to consist of those individuals who are not receiving any services and who meet the requirements for Crisis Resolution or Crisis Prevention;
- Removing those individuals from the Waiting List who are receiving waiver services. A process exists currently that allows these to substantiate the need for additional services, therefore eliminating the need for this waiting list category.
- Creating a separate registry for:
 - Individuals who are not receiving services in the waiver and who do not meet the requirements for Crisis Resolution or Crisis Prevention
 - Individuals who are receiving non-waiver services and are requesting additional services
- Seeking input from the Waiting List Advisory Council on the appropriate implementation of the above stated recommendations.

ATTACHMENT A

Each person on the waiting list has been found eligible for services in one of two eligibility categories and is assigned to one of four priority categories for each of their service requests.

Definition of Eligibility Type

- **“Developmental Disability (DD) Eligible”** (as defined in Annotated Code of Maryland, Health General §7-101(e))

means a person has been found eligible for services funded by the Developmental Disabilities Administration by virtue of having a developmental disability which is severe, chronic and :

- (a) Is attributable to a physical or mental impairment other than the sole diagnosis of mental illness, or to a combination of mental and physical impairments;
- (b) Is manifested before the individual becomes 22 years old;
- (c) Is likely to continue indefinitely;
- (d) Results in an inability to live independently without external support or continuing and regular assistance; and
- (e) Reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are individually planned and coordinated for the individual.

- **“Supports Only (SO) Eligible”** (as defined in Annotated Code of Maryland, Health General §7-403(c))

means a person has been found eligible for support services only by virtue of having a severe chronic disability that is:

- (a) Attributable to a physical or mental impairment other than the sole diagnosis of mental illness, or to a combination of mental and physical impairments; and
- (b) Likely to continue indefinitely.

Definition of Priority Categories (as defined in Code of Maryland Regulations 10.22.12.07B (1)-(3))

- **Crisis Resolution**

(a) To qualify for this category, the applicant shall meet one or more of the following criteria. The applicant shall be:

- (i) Homeless or living in temporary housing with clear time-limited ability to continue to live in this setting with no viable non-DDA-funded alternative;
- (ii) At serious risk of physical harm in the current environment;
- (iii) At serious risk of causing physical harm to others in the current environment;
- (iv) In danger of losing DDA-funded residential services because of a lack of current day services;
- (v) One who has lost DDA-funded day services; or
- (vi) Living with a caregiver who is unable to provide adequate care due to the caregiver's impaired health, which may place the applicant at risk of serious physical harm.

(b) To qualify for Category I under §B(1)(a)(ii), evidence such as the following shall be necessary. The applicant:

- (i) Has recently received severe injuries due to the behavior of others in the home or community;
- (ii) Has recently been the victim of sexual abuse;
- (iii) Has been neglected to the extent that the individual is at serious risk of sustaining injuries which are life threatening or which substantially impair functioning;
- (iv) Engages in self-injurious behavior which puts the individual at serious risk of sustaining injuries which are life threatening or which substantially impair functioning; or
- (v) Is at serious risk of sustaining injuries which are life threatening or which substantially impair functioning due to the physical surroundings.

(c) If the applicant qualifies for Category I under §B(1)(a)(v), the individual shall qualify for day services only.

(d) If the applicant is living in a situation where the applicant is the caregiver, §B(1)(a)(vi) shall apply to the applicant.

(e) Individuals who qualify for services under this category shall, at a minimum, remain in this category until they have been provided with those services required to resolve the situation.

(f) Individuals become eligible to receive services as the need occurs.

- **Crisis Prevention**

(a) To qualify for this priority category, the applicant:

(i) Shall have been determined by the DDA to have an urgent need for services;

(ii) May not qualify for services based on the criteria for Category I; and

(iii) Shall be at substantial risk for meeting one or more of the criteria in §B(1)(a) within 1 year, or have a caregiver who is 65 years old or more.

(b) Individuals who qualify for services under this category shall, at a minimum, remain in this category until they have been provided with those services required to resolve the situation.

(c) Individuals become eligible to receive services from the date of approval of priority status, except when eligibility is determined by the age of the caregiver. In this case, priority is determined by the caregiver's date of birth so that individuals with caregivers born at an earlier date have priority over individuals with caregivers born at a later date.

- **Current Request**

(a) To qualify for this priority category, the applicant shall indicate at least a current need for services.

(b) Prioritization of Services.

(i) Applicants shall be prioritized for services based on the number of fiscal years they have been on the waiting list, except as provided for in §B(3)(b)(iv) of this regulation.

(ii) Applicants on the waiting list for the longest period of time shall receive services before those who have been on the list for fewer years, except as provided for in §B(3)(b)(iv) of this regulation.

(iii) Applicants whose applications are received by the DDA access unit within a given fiscal year shall be ranked by the fiscal year of application, and the month and day of birth. Those applicants born at the beginning of the fiscal year have priority over those born later in the year.

(iv) For day programs only, the period of time that shall be counted toward prioritizing an individual shall begin with the year of departure from school or the year of application, whichever is later.

- **Future Need**

To qualify for this priority category, the applicant shall indicate an anticipated need for services at least 2 years in the future.

ATTACHMENT B

**SUMMARY OF WAITING LIST VERIFICATION EFFORTS FOR
INDIVIDUALS IN CRISIS RESOLUTION PRIORITY STATUS (ALL)**

**4,511 people categorized by DDA as DD Eligible, Crisis Resolution Priority Status, waiting for a service
as of May 2009**

2,793 No current service

1,428 were successfully reached

365 were found Crisis Resolution
40 were found Crisis Prevention
556 were found Current Request
268 were found Future Need
194 were found to have no need for services
5 were deceased

1,365 did not respond to either survey and were unreachable by phone

1,718 Currently receiving a service

763 were successfully reached

629 are enrolled in the waiver

141 were found Crisis Resolution
33 were found Crisis Prevention
207 were found Current Request
91 were found Future Need
157 were found to have no need for services

134 are not enrolled in the waiver

24 were found Crisis Resolution
11 were found Crisis Prevention
43 were found Current Request
22 were found Future Need
34 were found to have no need for services

955 did not respond to either survey (DDA is currently calling these individuals)

770 are enrolled in the waiver
185 are not enrolled in the waiver

ATTACHMENT C

SUMMARY OF WAITING LIST VERIFICATION EFFORTS FOR INDIVIDUALS IN CRISIS RESOLUTION PRIORITY STATUS (CMRO)

1,891 people categorized by DDA as DD Eligible, Crisis Resolution Priority Status, waiting for a service
as of May 2009

956 No current service

524 were successfully reached

181 were found Crisis Resolution
12 were found Crisis Prevention
207 were found Current Request
81 were found Future Need
40 were found to have no need for services
3 were deceased

432 did not respond to either survey and were unreachable by phone

935 Currently receiving a service

380 were successfully reached

327 are enrolled in the waiver

97 were found Crisis Resolution
5 were found Crisis Prevention
94 were found Current Request
48 were found Future Need
83 were found to have no need for services

53 are not enrolled in the waiver

13 were found Crisis Resolution
1 were found Crisis Prevention
16 were found Current Request
7 were found Future Need
16 were found to have no need for services

555 did not respond to either survey (DDA is currently calling these individuals)

470 are enrolled in the waiver
85 are not enrolled in the waiver

ATTACHMENT D

SUMMARY OF WAITING LIST VERIFICATION EFFORTS FOR INDIVIDUALS IN CRISIS RESOLUTION PRIORITY STATUS (SMRO)

2,504 people categorized by DDA as DD Eligible, Crisis Resolution Priority Status, waiting for a service
as of May 2009

1,797 No current service

882 were successfully reached

177 were found Crisis Resolution
26 were found Crisis Prevention
344 were found Current Request
185 were found Future Need
148 were found to have no need for services
2 were deceased

915 did not respond to either survey and were unreachable by phone

707 Currently receiving a service

338 were successfully reached

265 are enrolled in the waiver

36 were found Crisis Resolution
28 were found Crisis Prevention
113 were found Current Request
40 were found Future Need
48 were found to have no need for services

73 are not enrolled in the waiver

10 were found Crisis Resolution
9 were found Crisis Prevention
25 were found Current Request
15 were found Future Need
14 were found to have no need for services

369 did not respond to either survey (DDA is currently calling these individuals)

276 are enrolled in the waiver
93 are not enrolled in the waiver

ATTACHMENT E

SUMMARY OF WAITING LIST VERIFICATION EFFORTS FOR INDIVIDUALS IN CRISIS RESOLUTION PRIORITY STATUS (ESRO)

88 people categorized by DDA as DD Eligible, Crisis Resolution Priority Status, waiting for a service
as of May 2009

30 No current service

12 were successfully reached

3 were found Crisis Resolution
0 were found Crisis Prevention
5 were found Current Request
2 were found Future Need
2 were found to have no need for services
0 were deceased

18 did not respond to either survey and were unreachable by phone

58 Currently receiving a service

28 were successfully reached

23 are enrolled in the waiver

5 were found Crisis Resolution
0 were found Crisis Prevention
0 were found Current Request
3 were found Future Need
15 were found to have no need for services

5 are not enrolled in the waiver

1 were found Crisis Resolution
0 were found Crisis Prevention
1 were found Current Request
0 were found Future Need
3 were found to have no need for services

30 did not respond to either survey (DDA is currently calling these individuals)

23 are enrolled in the waiver

7 are not enrolled in the waiver

ATTACHMENT F

SUMMARY OF WAITING LIST VERIFICATION EFFORTS FOR INDIVIDUALS IN CRISIS RESOLUTION PRIORITY STATUS (WMRO)

28 people categorized by DDA as DD Eligible, Crisis Resolution Priority Status, waiting for a service
as of May 2009

10 No current service

10 were successfully reached

4 were found Crisis Resolution
2 were found Crisis Prevention
0 were found Current Request
0 were found Future Need
4 were found to have no need for services
0 were deceased

0 did not respond to either survey and were unreachable by phone

18 Currently receiving a service

17 were successfully reached

14 are enrolled in the waiver

3 were found Crisis Resolution
0 were found Crisis Prevention
0 were found Current Request
0 were found Future Need
11 were found to have no need for services

3 are not enrolled in the waiver

0 were found Crisis Resolution
1 were found Crisis Prevention
1 were found Current Request
0 were found Future Need
1 were found to have no need for services

1 did not respond to either survey (DDA is currently calling this individual)

1 is enrolled in the waiver
0 are not enrolled in the waiver