



Fact Sheet:

An Analysis of Unmet Service Needs for Washington State's Division of Developmental Disabilities

Department of Social and Health Services

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Purpose

Washington State's service system for people with developmental disabilities is facing many challenges; among them are sharply rising caseloads and tighter budgetary constraints. These two factors have resulted in lengthy waiting lists for services. The Division of Developmental Disabilities (DDD) is concerned about the health and safety of those persons whom it is unable to serve and wishes to reduce risk to those individuals by obtaining resources to provide service to those most in need. As a first step in the process of developing resources, the division needs to fully understand the magnitude of the problem and then work with the Department of Social and Health Services (DSHS) during the budget development process.

In January 1998, DDD contracted with Research and Data Analysis (RDA) to create a quantitative method to assess unmet service needs of their caseload and to guide the budget development process. The goal of the current analysis is to determine the magnitude of the unmet need problem, explore types of needs among the caseload, estimate the associated cost of meeting everyone's needs, help develop short-term goals for addressing the problem during the next biennium and develop an associated budget.

RDA's assessment of unmet service needs involved several tasks:

- ♦ determining the magnitude of the unmet service need problem,
- ♦ exploring types of service needs among the caseload and estimating cost associated with meeting those needs, and
- ♦ projecting future unmet service needs.

This document presents the major findings from the unmet service needs study. A detailed description of the study's methods and other findings is available in RDA report 5.29.

Method

The unmet needs list served as the primary data source for this analysis. The purpose of the unmet needs list is to track information about needed services and supports that have not yet been provided to persons with developmental disabilities. The unmet needs list is intended to represent a cooperative decision between case managers and eligible persons/families. To be included on the list, an eligible person/family must request service. The case manager decides on and enters the most appropriate specific service. For example, a family might request a residential placement; the case manager decides which particular type of residential service (e.g., Intensive Tenant Support, Alternative Living, Group Home) is most appropriate for the particular person. Other services may be entered if the individual or family has other types of service needs. There are four main service need groups on the unmet needs form: residential, therapy, county funded employment/day program, and other service needs (attendant care, family support, nursing services). There is also a section for a need that cannot be classified into the other categories offered on the form. Unmet needs information is to be updated in December of each year, or as a person's circumstances change.

Case managers were directed to update the unmet needs list in December 1997, but complete service information was only available through the end of June 1997 since many service payment systems have a lag time of up to 6 months between when service is received, billing occurs, and a payment is generated. Therefore, we chose FY 1997 (July 1, 1996 through June 30, 1997) as our base year for an analysis of unmet service needs. Our analysis is focused on the set of persons who were on the caseload at some time during FY 1997, the services they received during that year, and their remaining unmet service needs as reported on the unmet needs list as of the time we obtained the list in February 1998.

Since its inception in 1993, the unmet needs list has been criticized on numerous fronts. The validity of DDD's unmet service needs information, the utility of available information, and its ability to be used for accurate unmet service need projections are major concerns. We performed some preliminary analyses that indicate that the form is being used in a reasonable manner and can be used for estimating service needs of the population overall. The types of services one would expect to be requested for certain types of people were consistent with the services actually requested, and the types of services individuals and families reported they would like to receive were reasonably consistent with what was chosen for them by their case manager.

We performed some data cleaning of the unmet needs list. Next, we merged the unmet needs list with the Common Client Database (CCDB)¹ to identify persons on the DDD caseload who do not have unmet service needs, and to obtain demographic and geographic information. We used the Trends and Patterns Database² to identify whether a person had received services. We also performed two surveys to help expand our information about unmet service need. The results from these two surveys were used to estimate additional needs so that we could generate a more comprehensive assessment.

Some people have had little contact with their case manager and have not been receiving services paid or authorized through the division; thus, a case manager may not be familiar with their service needs. Some people may also be receiving services that we cannot track through payment system records because they are being paid through other sources or the services do not generate an individually identifiable payment record. Case managers of a subset of individuals with no needs record and no service records were contacted. If the case manager asserted that he/she knew the circumstances of the individual in question during FY 1997, interviewers completed questionnaires based on information from the case manager. If the case manager did not have significant knowledge about the person, an attempt was made to contact and interview a Significant Other, as listed in DDD's records.

The second survey obtained further information about the category of "other needs not covered by other categories" on the unmet needs form. While there is space on the unmet needs form to write a text description of the need, the description is not entered into the computerized unmet needs list. We selected a subset of persons with an "other need" for follow-up. Case managers of these persons were contacted and asked to provide clarification of the "other need." Where this "other need" could be met by one of the options on the unmet needs form, we added a new item to the person's unmet needs profile. Since the Family Support program is so flexible, many needs were recoded to this service.

¹ The CCDB is the data system that tracks persons enrolled with the Division of Developmental Disabilities.

² The Trends and Patterns Database includes all DDD services, all Division of Vocational Rehabilitation services, all Aging and Adult Services Administration services, and Children's Administration services that are tracked through SSPS. TPD does not include Children's Administration services tracked through CAMIS.

Results

How many people are getting services relative to number of persons with needs?

Some persons seek eligibility for the Division of Developmental Disabilities although they have no need for services at the present time (“No Services Requested”); they seek eligibility to increase the speed at which services could be received in an emergent situation. Others seek eligibility from the division because they currently have a need for services.

DDD does not have enough resources available to meet the needs of all these persons, so needs remain totally unmet for some people and partially unmet for others. Persons for whom DDD and associated divisions are providing services of some type, but not the type desired or who have other needs still to be met, are referred to as the “Underserved.”³ Persons for whom DDD and associated divisions are not providing any services, but who have an identified unmet service need, are referred to as the “Unserved.”

The following 2 x 2 table (Table 1) presents a frequency distribution for the FY 1997 caseload of need by services received. “Need” is defined as having one or more service needs indicated on a person’s unmet needs record (after our cleaning procedures). “Services is defined as having received one or more services through the Division of Developmental Disabilities or associated divisions at some point during FY 1997 (according to the TPD services file).

This table shows that

- DDD and their associated divisions are fully meeting the needs of 62% of the DDD caseload,
- partially meeting the needs of 16% of their caseload,
- and not meeting any needs for 11% of their caseload.

³ The division often refers to persons who need more of the service currently being received as also being “underserved.” The unmet needs list, however, cannot distinguish these persons from persons whose request was not removed from the unmet needs list after receiving services. Therefore, the true count of persons who are “underserved” is higher than the numbers we are presenting.

TABLE 1
 Unmet Need – by Services Received during FY97
 Those Identified as Having an Unmet Need
 (With Survey Adjustments)
 December '97, January '98

	No Unmet Need	Unmet Need
Receiving Services*	16,207 62% Served	4,063 16% Underserved
Receiving No	2,899 11% No Services Requested	2,956 11% Unservd

* Receiving DDD, AASA, DCFS, DVR Services (Fiscal '97)

Caseload = 26,125

Persons for whom the Division is providing no services and who have no service needs are presumed to be persons who are capable of meeting all their own needs, or whose needs are being met through other DSHS divisions not included in our assessment, through personal or community resources.

What types of services do people need and what are the associated costs?

Because the number of services on the unmet needs form is large and because several of the services (e.g., day programs and therapies) have similar rates, we created three categories of services: Residential, Day Program, and Family Support. The Residential and Day Program groups match the corresponding sections on the unmet needs form. The Family Support group expands beyond the family support program to include family support, attendant care, communications therapy, and occupational/physical therapy.

Because the unmet needs form gives no indication of the level of support a person requires, we used the nursing services, counseling/behavior management, and mental health therapy items as a proxy. Our assumption is that these persons, in general, are more likely to require higher supervision or care, and thus the cost for providing services is likely to be greater than for those who do not have these requirements. By combining logical

combinations of these three service groups with level of support, we obtained 10 needs categories.⁴

Estimated costs to provide services are based on typical costs for similar services during FY 1997, plus a 3% rate increase that occurred as of July 1, 1997. Rates were further increased to reflect projected vendor rate adjustments required to reduce excessive provider staff turnover in the service system. For the Underserved, we subtracted out savings from DDD services currently received that will no longer be needed once a need has been met (i.e., someone who receives a residential placement will no longer receive family support funds.) The costs presented in Table 2, below, are therefore additional dollars required to meet service needs, above and beyond dollars currently available.

Table 2 presents the number of persons with service needs and associated costs to meet their needs, assuming that the waiting list as of FY 1997 is eliminated during the next biennium. These numbers include survey adjustments.

TABLE 2
Biennial Cost to Serve FY 1997 Unmet Need

Needs Categories	Persons	Biennial Cost
1. Residential Only	1,522	\$ 55,633,806
2. Residential Only - High Cost	173	\$ 29,382,781
3. Residential/Day Program	728	\$ 36,973,096
4. Residential/Day Program - High Cost	112	\$ 21,813,687
5. Day Program Only	1,240	\$ 11,556,406
6. Day Program Only - High Cost	116	\$ 2,217,215
7. Day Program/Family Support	172	\$ 2,409,600
8. Day Program/Family Support - High Cost	50	\$ 2,389,905
9. Family Support Only	1,848	\$ 6,005,475
10. Family Support Only - High Cost	1,066	\$ 20,060,270
Total Persons	7,027	
Total Biennial Cost		\$ 188,442,241

⁴ A few modifications to the basic categorization scheme were made to ensure that all persons with service needs were classified into a category and that persons were not classified as high when their support level was likely not severe. For instance, if a person has a need for counseling/behavior management or mental health services but only requires a residential service with low supervision (AFH, AL, CCF, TS), he/she is classified as low rather than high, unless nursing services are also needed. Persons with nursing service needs are never classified as low, but they are classified as having a high cost family support need rather than a residential need if a residential service has not been requested. Our assumption is that these requests indicate a need for in home care rather than a full-time nursing home placement. Our classification scheme gives precedence to the residential need when both family support and a residential service have been requested for the same person.

As of the end of FY 1997, the Division of Developmental Disabilities is in need of:

- 2,535 new residential slots or changes in placements,
- 2,418 day program slots or changes in day program placements,
- 3,136 family support, attendant care, or therapy slots.

The projected cost to meet all needs of these **7,027 persons** is in excess of **\$188 million**⁵.

As a person's service needs are met, their unmet needs record includes only remaining service needs and no longer provides a complete picture of that individual's support requirements. The number of persons in a category in Table 2 represents only the type of needs that remain to be met. For example, a person who requires both a typical residential placement and a day program will appear in category 3 before receiving services, but once a day program is received, the same person will appear in category 1. Number of persons per category is therefore not comparable to the analysis presented below, although total overall need and cost can be compared.

How many persons are expected to be on the unmet needs list as of the end of the next biennium (FY 2001) and what are the associated costs?

The unmet needs list contains only persons whose needs have been identified at the present time. For budget development purposes, we need to know how many persons will have needs by the end of the next biennium. This requires a projection of the number of persons expected to be on the caseload by the end of the next biennium and what their service needs will be. We also need to assess the ability of the service system to meet those needs through existing services, planned expansion, and service turnover. Projected need is the difference between the anticipated service requirements of the caseload and the anticipated ability of the service system to meet those needs. Once the service deficit is known, we can estimate cost associated with the projected need.

To estimate the number of persons expected to be on the caseload by the end of the next biennium, we performed an age-adjusted linear caseload projection based on the average growth in number of persons on the caseload between FY 1993 and FY 1997. These projections provide an estimated caseload size through FY 2001 (see Table 3).

⁵ Costs include direct costs for providing care, resource development and start-up costs to place a person into a service, ongoing case management and associated staff, county administrative costs, and costs associated with staff training.

TABLE 3
Age Adjusted Caseload Projections*

Age Group	FY 98	FY 99	FY00	FY01
Age 0-2	2,075	2,132	2,191	2,251
Age 3-17	10,448	11,805	13,341	15,082
Age 18-21	1,998	2,160	2,335	2,525
Age 22-39	7,761	7,982	8,210	8,445
Age 40-49	3,093	3,315	3,553	3,808
Age 50-59	1,683	1,864	2,064	2,286
Age 60+	<u>1,116</u>	<u>1,180</u>	<u>1,248</u>	<u>1,319</u>
Total	28,176	30,439	32,943	35,717

*Fiscal Year Counts include total persons expected to be on the caseload at any time in the fiscal year.

Since the unmet needs list does not give a complete picture of a person's service requirements once needs begin to be met (only remaining service need is reflected), we combined each person's unmet needs record with his/her service payment records for FY 1997 to create a profile of the types of supports required for that particular person. We summarized and categorized this information into 10 categories, similar to those used for the FY 1997 unmet needs analysis, but the categories now reflect support requirements rather than just needs that remain to be met. Table 4 presents the number of persons on the FY 1997 caseload by the type of supports they require. These numbers include survey adjustments.

TABLE 4
Current (FY97) Support Requirements

Support Categories	Frequency	Percent
1. Residential Only	2,916	11%
2. Residential Only - High Cost	432	2%
3. Residential/Day Program	4,311	17%
4. Residential/Day Program - High Cost	1,694	6%
5. Day Program Only	2,141	8%
6. Day Program Only - High Cost	125	0%
7. Day Program/Family Support	261	1%
8. Day Program/Family Support - High Cost	273	1%
9. Family Support Only	3,281	13%
10. Family Support Only - High Cost	3,923	15%
Total Caseload	26,125	

We made the assumption that support requirements for the FY 2001 caseload will be reasonably similar to those of the FY 1997 caseload. While we are aware that the nature of the caseload is changing, we do not anticipate dramatic changes over the short time frame of four years. We calculated the percentage of persons within an age group for each of the 10 support categories and applied the same percentages to the projected FY 2001 caseload. Projected support requirements by fiscal year are displayed in Table 5.

Table 5⁶

Projected Support Requirements

Support Categories	FY98	FY99	FY00	FY01
1. Residential Only	3,118	3,339	3,579	3,842
2. Residential Only - High Cost	469	509	553	602
3. Residential/Day Program	4,531	4,767	5,018	5,286
4. Residential/Day Program - High Cost	1,792	1,897	2,010	2,132
5. Day Program Only	2,239	2,343	2,453	2,571
6. Day Program Only - High Cost	131	138	144	152
7. Day Program/Family Support	274	287	301	316
8. Day Program/Family Support - High Cost	284	296	308	321
9. Family Support Only	3,653	4,074	4,549	5,084
10. Family Support Only - High Cost	4,318	4,762	5,259	5,818
Total Persons Requiring Support	20,809	22,412	24,174	26,124

From here, we subtracted the number of services currently available to DDD caseload members and service development anticipated throughout the 97-99 Biennium based on DDD's administrative plans and supplemental funding for Fiscal Year 1998. We also subtracted the number of additional slots anticipated to be available through turnover. The result is the number of additional services required to meet everyone's needs as of the end of the 99-01 Biennium. We calculated costs for providing these services using techniques similar to our FY 1997 unmet needs analysis. Table 6 displays the number of persons expected to be on the unmet needs list as of FY 2001 and the costs associated with meeting their needs. These costs are in addition to extensive planned service development during the 97-99 Biennium and FY 1998 supplemental funding.

⁶ The application of percentages in Table 4 to the projected caseload will not exactly equal the numbers presented in Table 5 because projections were based on support needs within an age group.

Table 6
Biennial Cost to Serve FY 2001 Unmet Need

Needs Categories	Persons	Biennial Cost
1. Residential Only	1,595	\$ 64,229,389
2. Residential Only - High Cost	130	\$ 18,454,884
3. Residential/Day Program	2,391	\$ 78,824,580
4. Residential/Day Program - High Cost	389	\$ 60,678,682
5. Day Program Only	405	\$ 3,050,600
6. Day Program Only - High Cost	90	\$ 1,308,270
7. Day Program/Family Support	50	\$ 226,648
8. Day Program/Family Support - High Cost	196	\$ 8,565,147
9. Family Support Only	1,454	\$ 3,752,804
10. Family Support Only - High Cost	2,272	\$ 47,860,512
Total Persons	8,972	
Total Biennial Cost		\$ 286,951,516

If the Division of Developmental Disabilities receives no additional funding to expand services during the next biennium, waiting lists⁷ are anticipated to be:

- 4,504 residential placements,
- 2,927 day program placements, and
- 3,964 family support, attendant care, or therapy placements.

The projected cost to meet all of the anticipated service needs for the **8,972 persons** on the FY 2001 caseload who are expected to have unmet service needs is in excess of **\$286 million**⁸.

Several assumptions underlying our methodology suggest that our estimate of need should be interpreted as a minimum. Because additional needs or the extent of need can be unidentified or underestimated, the total amount of need should be considered to be at least as high as the amounts indicated in our analysis. Also, our analysis does not take into account those who need something more or different than what the division routinely provides.

There may be others whom the division should serve despite an expressed desire for services (e.g., persons with community protection issues or living in an inadequate situation). The above numbers include early childhood services and transition services to the extent that persons have actually sought out and received those services. Ideally, all persons of these ages should be offered these services, but historically only half of transition age students approach the division for services.

⁷ A sum of the appropriate categories in Table 6 will exceed waiting list totals because some persons will be “Underserved.” That is, their needs may be partially met.

⁸ Costs include direct costs for providing care, resource development and start-up costs to place a person into a service, ongoing case management and associated staff, county administrative costs, and costs associated with staff training.

Discussion

Our results provide an estimate of the number of persons expected to have unmet service needs by the end of the 99-01 Biennium and the associated cost for fulfilling those needs, given anticipated expenditures for those services during the next biennium. These numbers are merely a reflection of services likely to be requested under the constraints of the current service system. If the service system or social environment changes, or if individuals and families are given new service options or their perceptions of existing services change, the number of persons requesting particular service types and the associated cost could potentially change.

The results of this study should not be interpreted as a recommended method for allocating resources, but merely a forecast of service need assuming that the current service system continues. The current service system may or may not be the most efficient and effective method for allocating resources. This study did not attempt to evaluate the current service system in terms of these dimensions.

Our analysis also does not address whether services currently being provided are of sufficient quality or quantity. Feedback from case managers and families, however, does indicate that many individuals need something more or different than what they are currently receiving. The division's history of limited resources has required that some persons be placed in less than adequate situations when some service is better than no service at all. Our analysis assumes that the services caseload members do receive are appropriate and adequate. The division likely could use additional funds, above and beyond our estimates, to improve the services some caseload members are currently receiving, or to move them into a more appropriate type of service.

Aside from the type or quality of service, failure to obtain additional funding for the 99-01 Biennium would mean that the gap in number of available services as of the close of the Biennium would be even greater than it was as of the 95-97 Biennium when the division was in crisis. Substantial service development during the current Biennium and FY 1998 supplemental funding are insufficient to counteract anticipated caseload growth.

Clearly, the existing service system cannot accommodate all persons with unmet service needs by the close of the next biennium. Likewise, the division cannot submit a budget proposal that requests a 70% increase in funding for the next biennium. Even if funding were to be approved, a major restructuring of the service system, to accommodate a greater capacity for expansion, cannot be completed within two years. A more appropriate goal for the division is to reduce, rather than eradicate, waiting lists by the close of the next biennium.

The magnitude of unmet service need for the Division of Developmental Disabilities is extensive, and clearly exceeds any errors that may have been introduced due to methodological limitations or the quality of the unmet needs list. The division will likely experience a significant service deficit for many years into the future. Alternative sources of support, other than State funds, need to be explored in order to attenuate a significant crisis. Prevention and a revision of the service system to handle more extensive and rapid expansion are also worthy of consideration.

Particularly troublesome for the division is the rate of growth among caseload members having unmet needs for residential services. The unmet needs list for residential services is growing at such a large rate because the number of persons requiring services exceeds the number vacating these services plus the number of slots typically developed in a year. The current residential system is clearly inadequate for the division. Prevention efforts will be vital in the short term. The division's emphasis on eliminating the Family Support waiting list and raising the maximum allotment under this program during the next biennium may reduce the need for residential placements. As families become more capable of caring for family members at home, residential placements may be requested less frequently. The sheer magnitude of the residential crisis seems to suggest that this measure alone will not be fully adequate. Efforts will need to be expended to redesign the residential system into one that can handle far greater expansion. Residential need should be carefully examined during future unmet service need analyses.