

# Assessment Findings for Persons with Developmental Disabilities Served in Residential Habilitation Centers and Community Settings

Barbara A. Lucenko, PhD and Lijian He, PhD

In collaboration with DSHS Aging and Disability Services Administration Division of Developmental Disabilities, Linda Rolfe, Director and Lisa A. Weber, PhD

The Division of Developmental Disabilities (DDD) of the Washington State Department of Social and Health Services serves clients in a variety of community and institutional settings. The level of support needed by DDD clients to assist them in their daily lives and to help them participate in the community varies greatly across individuals. The purpose of this report is to examine the similarity of support needs among DDD clients living in the following three settings: 1) Residential Habilitation Centers (long-term residents of RHCs with recent full assessments of need), 2) community residential, and 3) DDD clients supported in other community-based settings.

The assessments of support needs are from: 1) the Supports Intensity Scale (SIS), a measure of support needs specifically designed for individuals with developmental or similar disabilities, and 2) acuity scales based on the DDD Support Assessment that are designed to measure level of risk or urgency of need for care. Results of these analyses will be used in the next steps of developing an algorithm for identifying immediacy of need for institutional placement and a cost study of DDD clients in different levels of care.

This report expands upon analyses conducted with more limited assessment data published in early 2010. The earlier analyses found that DDD clients served in institutions and community residential programs have more severe behavioral and other support needs than individuals supported in other community-based settings, that there is considerable overlap in the range of support needs across residential settings and that some clients supported in the community had exceptionally high support needs. As part of the implementation of ESSB 6444 PL Sec 129, full assessments were conducted by DDD with long-term Residential Habilitation Center (RHC) residents. The current report updates the earlier findings using more complete assessment data that has since become available for RHC clients.

### **Key Findings**

- Support needs are higher in most general life tasks, such as daily and community living activities, for DDD clients served in RHCs and community residential settings than for those supported in other community-based settings.
- DDD clients served in RHCs and community residential programs have more intensive behavioral and medical support needs compared to individuals supported in other community-based settings.
- Although those in RHCs had higher support needs on average in most general living, behavioral, and health-related domains than individuals living in the community, some clients supported in the community had SIS scores that were equivalent or higher to those of RHC clients.
- The majority of persons with intensive support needs reside in community based settings, such as their family home.



#### **MEASURES**

The Washington State Department of Social and Health Services (DSHS) Division of Developmental Disabilities (DDD) administers assessments annually to clients receiving services in non-institutional settings to identify and measure support needs. The DDD full assessment is a set of measures currently used to develop individual support plans.

As part of this comprehensive assessment process, DDD implemented the use of the Supports Intensity Scale (SIS) in state fiscal year 2007 to provide information on the supports needed by DDD clients who are age 16 or older. DDD has also developed a full range of acuity measures that, in combination with clinical judgment, provide information on client service needs.

The DDD assessment items are administered in interview format by a DDD case manager or social worker. Respondents are typically clients, caregivers, or residential facility staff members who are familiar with the individual. Summary data and comparisons are presented by residence type on the following sets of measures:

- Supports Intensity Scale (SIS), Section 1, Support Needs (standardized scales)
- Supports Intensity Scale (SIS), Section 3, Exceptional Medical and Behavioral Support Needs
- · DDD Acuity Scales

#### **RHC ASSESSMENT PROCESS**

DDD assessment items are not routinely administered to DDD clients in institutions. As part of the implementation of ESSB 6444 PL Sec 129, assessments were required to be administered to all residents of Residential Habilitation Centers (RHCs) "... to determine the optimum setting for these individuals..." As directed, full assessments were conducted by DDD with all current long-term RHC clients who did not have recent full assessments on file. These assessments were completed by Case Managers and Joint Requirements Planning staff between July and September 2010. Because of this, more complete assessment data are now available for the current population of long-term RHC clients. A list of these long-term RHC clients with completed assessments was provided by DDD to RDA. All clients in the group referred to as "RHC" in this report were drawn from the DDD client list. In cases where there were multiple assessments available for one person, we used the most recent assessment date.

#### **RESIDENCE TYPES**

For this project, assessment data, including SIS and acuity scale scores, were extracted from the Case Management Information System (CMIS) and analyzed for clients who were served by DDD during state fiscal year 2008 through September 30, 2010, which encompasses the RHC assessment project period and the timeframe for our prior study. Data are summarized according to the client's residence type: Residential Habilitation Centers (RHCs), Community Residential, or Other Community-based.

In our prior report, RHC client assessments were combined with those residing in community-based Immediate Care Facilities for the Mentally Retarded (ICF/MRs) in order to compensate for the limited assessment data available for RHC clients. Because the current report focus is on RHC long-term residents, clients residing in ICF/MRs have been excluded from the comparisons.

Statistical comparisons are presented for differences among the three groups of DDD clients:

- Residential Habilitation Centers,
- Community Residential, and
- Other Community-Based.

### **Context**

The Washington State Department of Social and Health Services (DSHS) Division of Developmental Disabilities (DDD), within the Aging and Disability Services Administration (ADSA) is working towards developing an algorithm to inform placement decisions, including immediacy of need for admission to a Residential Habilitation Center (RHC) or other institutional facility for people with developmental disabilities who otherwise qualify for such levels of care. The analyses of client support needs served in different levels of care contained in this report will be used to inform the development of the algorithm.

In 2009, DDD asked the DSHS Research and Data Analysis (RDA) division to analyze the assessed needs of individuals currently being served in institutional and community settings. In particular, DDD requested comprehensive descriptive analyses of assessment findings and, specifically, the Supports Intensity Scale (SIS), a measure of support needs designed for individuals with developmental or similar disabilities. This study was completed in early 2010 and found that DDD clients served in institutions who had been assessed (primarily recent admissions) had more severe behavioral support needs compared to individuals served in the community, based on both the SIS and DDD acuity scale scores. The study also found that support needs were higher in most general life tasks for DDD clients served in institutions and community residential settings than for those receiving other community-based services.

For the 2010 report, the group of clients in "institutions" was made up of recent RHC (short-term, long-term, and respite stays) and community-based ICF/MR admissions and other residents who had assessments completed due to behavioral or other difficulties. However, there were limitations and cautions presented with the findings due to the fact that assessments are not required for clients living in institutions and therefore very limited assessment data were available for this population.

As part of the budget issued for SFY 2011, Governor Gregoire directed DDD to complete assessments for all RHC clients as part of a consultation on needs of those clients currently living in institutions to determine optimum settings [ESSB 6444.PL Sec. 129). To address this, DDD completed full assessments of need for all current long-term RHC clients who did not have assessments within the previous year. This process was completed by DDD in September 2010, making it possible to update the 2010 analysis with more complete and representative assessment information for the full population of RHC clients.

### **Background**

In 1999, the United States Supreme Court found that a state's unjustified institutionalization of a person with disabilities violates the Americans with Disabilities Act of 1990 (ADA)<sup>4</sup> and is a form of discrimination:

For the reasons stated, we conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities....<sup>5</sup>

The provision of community-based services for clients with developmental disabilities who need long-term care is a priority for state programs. In Washington State, DDD has requested a series of analyses to continue supporting progress towards providing the most appropriate and least restrictive placements possible for individuals with developmental disabilities (DD) receiving state services. Priority is also based on legislative declarations of policy in RCW 71A.10.015 and 71A.12.020 that DSHS deliver services to individuals with developmental disabilities in the least restrictive living environment that is appropriate and able to meet the person's needs.

## **Division of Developmental Disabilities**

DDD provides support services for persons with lifelong disabilities resulting from mental retardation, epilepsy, cerebral palsy, autism, or similar neurological conditions that originated before adulthood. Clients receive services along a continuum of care based on support needs and acuity determinations, subject to available funding.

Persons with developmental disabilities often need support in a number of activities to assist them in their daily lives, to help them participate in the community and to ensure their health and well-being. The level of support needed varies from one individual to another depending on each person's abilities, natural supports and unique competencies.

### **Residential Habilitation Centers (RHCs)**

RHCs are state-operated residential settings that provide habilitation training, 24-hour supervision, and medical/nursing services for clients who meet Medicaid eligibility and need active treatment services. RHCs may be ICF/MR-certified and/or licensed nursing facilities. In addition, respite and other specialized services may be available to clients living in the community, however only residents with long-term status and those with no viable community placement option at the time of assessment are included in this category for this analysis. There are five RHCs in Washington State, currently serving approximately 900 clients. Additionally, a small number of persons reside in privately operated ICF/MRs or nursing homes in the community, but persons residing in private programs have been excluded from the analyses contained in this report.

### **Community Residential**

Community Residential programs provide instruction and support in a variety of settings. In some settings, the client owns or rents the home and staff come to assist the person with everyday activities, routines, and relationships common to most citizens. In other programs, the provider owns the home, and room, meals, laundry, supervision and assistance are provided to the resident by that provider. Some programs serve only one or two persons at a time, while others are congregate settings serving up to six persons living in the same home (a couple of programs are larger). Instruction and support services are based on the client's assessed needs and vary from a few hours of support per month to 24-hour daily support. Persons in community residential programs may also receive other services outside the home; such as, support to obtain or maintain a job, specialized equipment or professional therapies. Approximately 6,300 individuals currently receive community residential services.

## **Other Community Based**

Persons residing in Other Community Based settings typically live in a family-style home with parents or relatives, or they may live independently. Some persons included in this category may live in non-DDD funded settings such as boarding homes, foster care, or mental health diversion placements. Persons residing in Other Community Based settings may receive supports from family, friends, or others. They may also be receiving DDD funded supports; such as, personal care assistance, respite, support to obtain or maintain a job, specialized equipment or professional therapies. Of the approximately 32,000 clients residing in other community-based settings, about 11,000 have received the DDD assessment.

### **Purpose of This Report**

Since Olmstead (1999), the provision of appropriate services in the least restrictive placements possible for clients with developmental disabilities has become a priority in Washington State. To this end, this report updates our prior work, comparing service needs for DDD clients in three residential settings, Residential Habilitation Centers (RHCs), community residential, and those supported in other community-based settings. We have provided statistical comparisons of support needs for clients served in these three settings.

## The Supports Intensity Scale

The Supports Intensity Scale (SIS) is a valid and reliable standardized measure that has six scales measuring support needs for daily activities. <sup>1,6</sup> Need for support is rated for each item in terms of frequency (such as less than monthly to hourly or more), daily support time (such as less than 30 minutes to 4 hours or more), and type of support (such as monitoring to full physical assistance). The six scales in the Support Needs section that comprise the Support Needs Scale measure need for assistance in six life areas: Home Living Activities, Community Living Activities, Lifelong Learning Activities, Employment Activities, Health and Safety Activities, and Social Activities. Scales and sample items are presented in Table 1.

In addition to a total raw support needs score, standardized scale scores are available for each of the six support need scales in Section I and a total Support Needs Index. The normative sample for the SIS standardized scores was made up of 1,306 people with developmental disabilities from 33 states. The SIS normalized standard scale scores have means of 10 and standard deviations of 3, and the composite score is standardized with a mean of 100 and standard deviation of 15.<sup>1</sup>

TABLE 1
Supports Intensity Scales: Section I

SIS SCALE	SAMPLE ACTIVITY ITEMS	SIS Section
Home Living Activities	Using the toilet, eating food, dressing	1A
Community Living Activities	Transportation, using public services in the community (such as banking), shopping and purchasing goods and services	1B
Lifelong Learning Activities	Interacting with others in learning activities (participate in school), learning and using problem solving strategies, learning self-management strategies	1C
Employment Activities	Learning and using specific job skills, completing work-related tasks with acceptable quality, interacting with co-workers	1D
Health and Safety Activities	Taking medications, avoiding health and safety hazards, learning how to access emergency services	1E
Social Activities	Participating in recreation/leisure activities, making and keeping friends, using appropriate social skills	1F

# Supports Intensity Scale: Exceptional Medical and Behavioral Support Needs

The Supports Intensity Scale (SIS) has a separate section on Exceptional Medical and Behavioral Support needs. Need for support is rated for each item on a scale of 0-2, indicating none, some monitoring, or extensive support needed to manage the condition or behavior. Total raw scores and presence of any extensive support need can be used for planning purposes. Scales and sample items are presented in Table 2.

TABLE 2
Supports Intensity Scales: Exceptional Medical and Behavioral Scales

SIS SCALE	SAMPLE ACTIVITY ITEMS	SIS Section
Exceptional Medical Support	Inhalation or oxygen therapy, suctioning, tube feeding, turning or positioning, seizure management	3A
Exceptional Behavioral Support	Prevention of assaults or injuries to others, prevention of property destruction, prevention of self-injury, prevention of pica (eating non-food items), prevention of sexual aggression or inappropriate sexual behavior, prevention of wandering	3B

## **Supports Intensity Standard Scale Score Group Comparisons**

Clients in RHCs had significantly higher support needs indicated for all SIS scales than clients in community residential programs and those supported in other community-based settings. DDD clients in community residential programs scored higher than those in other community-based programs on all support needs except Employment Activities. There were statistically significant differences between each of the residence types on the measure of average overall support need: individuals in RHCs scored highest, followed by community residential, and those supported in other community-based settings had the lowest average Support Needs Index score.

TABLE 3
Supports Intensity Scales: Mean SIS Scale Scores by Residence Type

Supports Intensity Scale								
Mean SIS Standard Scale Scores by Residence Types								
N = 18,338	Residential Center		Community n = 6		Otl Commun n = 13	ity Based		
	a	1	t	)	(	С		
	MEAN	SD	MEAN	SD	MEAN	SD	Significant at p<.05	
SIS Scale Scores								
A. Home Living Activities	12.02	1.54	10.28	2.42	9.76	2.7	a>b a>c b>c	
B. Community Living Activities	10.09	1.26	9.00	1.65	8.67	2.06	a>b a>c b>c	
C. Lifelong Learning Activities	11.06	1.35	9.91	1.36	9.71	1.9	a>b a>c b>c	
D. Employment Activities	10.23	1.48	9.08	1.44	9.09	1.75	a>b a>c	
E. Health and Safety Activities	11.16	1.37	9.75	1.66	8.97	2.2	a>b a>c b>c	
F. Social Activities	10.62	1.08	9.40	1.56	8.79	1.96	a>b a>c b>c	
Support Needs Index	105.9	7.52	97.00	9.83	94.21	12.64	a>b a>c b>c	

NOTES. One-way analyses of variance (ANOVA) were conducted to assess for differences in means on each of the SIS scale scores and the Support Needs Index standard score among the three groups: RHC, Community Residential, and other Community Based. One-way ANOVAs were used to test for differences in means among groups for each scale, with pairwise comparisons (t-tests) conducted to test for differences between pairs of groups when the overall ANOVA was statistically significant. For example, an overall difference was detected for Home Living Activities, so individual comparisons were done between groups as follows: (a to b) RHCs compared to Community Residential; (b to c) Community Residential to Other Community Based; and (a to c) RHCs to Other Community Based. The RHC group had an average higher scale score on Home Living Activities than Community Residential and Other Community Based, and the Community Residential group had an average standard score on Home Living Activities support need that was higher than the mean score for those supported in Other Community Based settings; all of these comparisons on Home Living Activities were statistically significant (a>b, b>c, a>c).

# **Supports Intensity Scale: Medical and Behavioral Group Comparisons**

Clients in RHCs had significantly higher Behavioral Support and Medical Support need scores than clients in community residential programs and those receiving other community-based services. Average medical support needs were similar for clients in community residential and other community-based settings. Clients residing in community residential settings also had significantly higher behavioral support need scores than those in other community-based services.

TABLE 4
Medical and Behavioral Supports Intensity Scales: Mean Scores by Residence Type

		Supports	Intensity Sca	ale				
Mean SIS Scale Raw Scores by Residence Types								
N = 18,338	Residential Center	(RHC)		Residential 5,294	Otl Commun n = 1:	ity Based		
	а		В		с			
	MEAN	SD	MEAN	SD	MEAN	SD	Significant at p<.05	
SIS Scale Scores								
3a. Medical Supports Needs	4.58	4.18	2.88	3.02	2.79	3.63	a>b a>c	
3b. Behavioral Supports Needs	5.44	4.46	4.44	4.13	3.34	3.8	a>b a>c b>c	

**NOTES.** One-way analyses of variance (ANOVA) were conducted to assess for differences in means on each of the SIS exceptional needs raw scale scores among the three groups: RHCs, Community Residential, and other Community Based. One-way ANOVAs were used to assess for differences in means among groups, with pairwise comparisons (t-tests) conducted to assess for differences between pairs of groups when the overall ANOVA was statistically significant. For example, an overall difference was detected for Behavioral Support Needs, so individual comparisons were done between groups as follows: (a to b) RHCs compared to Community Residential; (b to c) Community Residential to Other Community Based; and (a to c) RHCs to Other Community Based. All three comparisons were statistically significant, indicating that clients in RHCs have higher behavioral support needs on average than those in both Community Residential and Other Community Based services, and that clients in Community Residential programs have higher average behavioral support needs than those served in the community.

## Supports Intensity Scale: Likelihood of Exceptional Medical Support Needs

In addition to analyses of differences in average need scores, we conducted a set of analyses to examine differences in the proportions of clients in each group who met criteria for exceptional medical support need and the number of clients meeting criteria who reside in RHCs, Community Residential, and Other Community-Based settings. According to the SIS manual, the accepted criteria for determining exceptional need are: a total score on a support needs scale greater than 5 or at least one item with a response of "extensive support needed" (scored as "2"). Statistical tests revealed significant differences between the three client groups in the proportions meeting both criteria for exceptional need for medical support. Among DDD clients assessed, the majority with exceptional medical support needs reside in Community Residential and Other Community-Based settings.

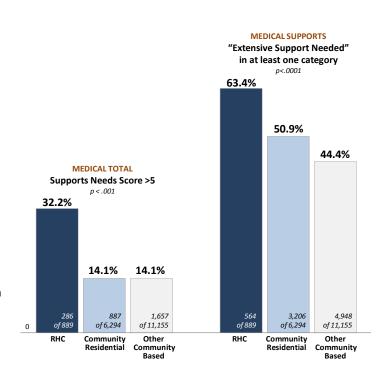
## Proportion of Clients in Each Residence Type with Exceptional Medical Support Needs

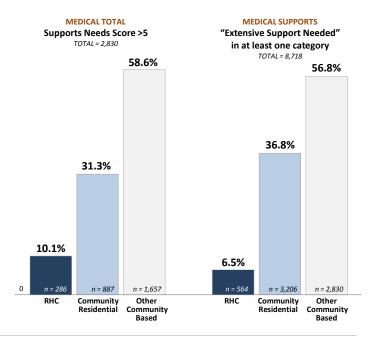
Clients in RHCs were significantly more likely than clients receiving community residential or other community-based services to have medical support needs scores greater than 5 (p values < .0001). Clients in RHCs were also significantly more likely to have extensive medical support needs in at least one category than those living in community residential settings and those receiving other community-based services (p values < .0001).

In addition, clients living in community residential settings were more likely to have extensive medical support needs in at least one category than those receiving other community-based services (p < .0001), but the two community groups did not differ on the proportion of persons with medical support needs scores greater than 5.

## Where DDD Clients with Exceptional Medical Support Needs Live

Although clients in RHCs are proportionally more likely to have exceptional medical needs, there are many more total individuals residing in community settings with extensive medical support needs. For example, among those assessed, there are five times as many Community Residential and 8 times as many Other Community-Based clients as RHC clients who need extensive medical support in at least one category.





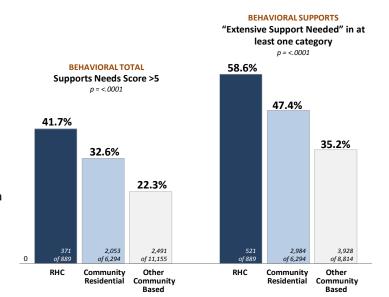
# Supports Intensity Scale: Likelihood of Exceptional Behavioral Support Needs

In addition to analyses of differences in average need scores, we conducted a set of analyses to examine differences in the proportions of clients in each group who met criteria for exceptional behavioral support need and the number of clients meeting criteria who reside in RHCs, Community Residential, and Other Community-Based settings. According to the SIS manual, the accepted criteria for determining exceptional need are: a total score on a support needs scale greater than 5 or at least one item with a response of "extensive support needed" (scored as "2"). Statistical tests revealed significant differences between the three client groups in the proportions meeting both criteria for exceptional behavioral support need. Among DDD clients assessed, the majority with exceptional behavioral support needs reside in Community Residential and Other Community-Based settings.

# Behavioral Support Needs by Residence Type

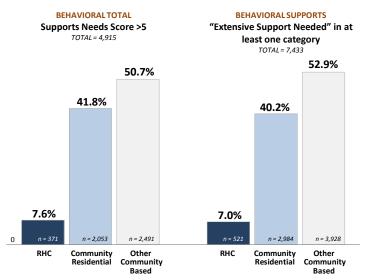
Clients in RHCs were significantly more likely to meet both extensive behavioral support criteria than clients in either community residential settings or those receiving other community-based services (p values < .0001).

Clients in community residential programs were also more likely to meet both SIS behavioral support need criteria than those receiving other community-based services (p values < .0001).



# Where DDD Clients with Exceptional Behavioral Support Needs Live

Although clients in RHCs are proportionally more likely to have exceptional behavioral needs, there are many more total individuals residing in community settings with extensive behavioral support needs. For example, among those assessed, there are five times as many Community Residential and 8 times as many Other Community-Based clients as RHC clients who need extensive behavioral support in at least one category.

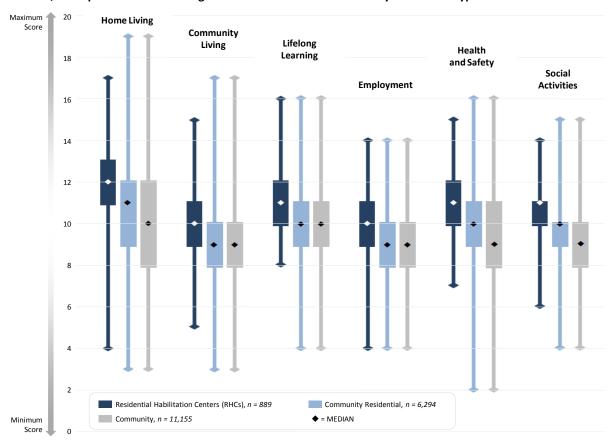


## Range of Support Needs for Basic Living Activities

Despite the differences in means between the three client groups, much overlap exists in the distribution of clients on the six SIS scales (Home Living, Community Living, Lifelong Learning, Employment, Health and Safety, and Social Activities). Employment was the only SIS scale where variability was similar for all three groups. For all other scales, there is more variability in support needs scores among clients served in non-institutional settings (community residential and other community-based programs) than in RHCs, as shown by the full range of scores for each group (bottom arrow to top arrow on each bar in the graph below). Community residential and other community-based clients had similar variability in scores on each of the SIS scales. The clients with the most extreme support needs for Home Living, Community Living, Health and Safety, or Social Activities lived in non-institutional settings, and clients with the highest support needs for Lifelong Learning and Employment were found in all three residence types, indicating that it is possible to support persons with the most extreme support needs outside of an institutional setting.

Based on the interquartile ranges (25th-75th percentile, where half of each group's scores lie), represented as a rectangle on each line in the chart below, and the medians (the midpoint of the distribution of scores, represented by the diamond shape inside each rectangle), support needs for RHC clients are typically higher on all scales, and clients residing in community-based settings have more diverse support needs for home living, health and safety, and social activity than clients in RHCs or community residential settings. Individuals in community residential settings tended to have higher scores on Home Living, Health and Safety, and Social Activities than those in other community-based settings. Persons with support needs similar to those in community residential settings were not unusual in other community-based settings, such as family homes (indicated by the top of the rectangle being identical for these two residence types).

### Medians, Interquartile and Full Ranges of SIS Standard Scale Scores by Residence Type

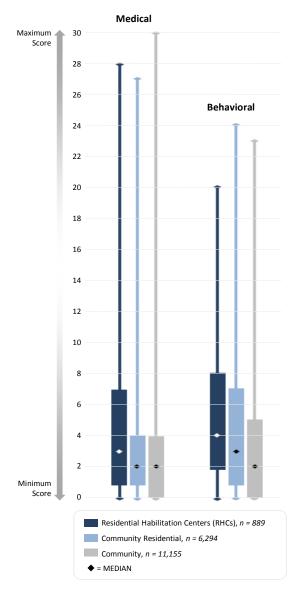


# Range of Exceptional Medical and Behavioral Support Needs

# Medians, Interquartile and Full Ranges of Exceptional Medical and Behavioral Support Need Raw Scores by Residence Type

The three client groups overlap considerably in the range of scores on the Exceptional Medical Support Scale for the half of the clients falling between the 25th and the 75th percentile (interquartile range), represented as a rectangle on each line. The maximum score, the upward pointing arrow on each line, representing exceptional medical support needs, is actually highest for clients receiving other community-based services than for those residing in RHCs or community residential settings.

There is a bit less overlap between the three groups in their Exceptional Behavioral Support Needs based on the interquartile range of scores on this scale, the rectangles on each line in the chart. This is primarily due to the fact that clients served in RHCs tend to have a higher interquartile range than clients in the other two groups. In contrast, at least some of the clients supported in community residential and other community-based settings appear to have higher behavioral support needs than those in RHCs based on the highest scores, as represented by the upward pointing arrow on each line.



## **DDD Assessment Acuity Scales**

Additional analyses were conducted to describe the acuity levels of DDD clients by setting. Washington State's DDD acuity scales are summary indicators of levels of support needs in specific categories such as activities of daily living, interpersonal support (communication and social skills), medical support, mobility, behavioral assistance, protective supervision (for example, line of sight, periodic monitoring), and seizures. Acuity levels of none, low, medium, and high represent the urgency and severity of needed assistance for a particular client. An acuity scale of "high" indicates that the client's needs in this area have been assessed to be relatively severe or urgent.

For these analyses, we looked at differences in proportions of clients with high levels of acuity across the three client groups. Some scales include items drawn from SIS scales. Scoring and use of the responses, however, is quite different from the prior analyses. For example, the ADL acuity scale consists of four items from the SIS Home Living scale and two from the SIS Health and Safety scale, and these items are combined into a single scale score to describe support needed for personal care activities that people typically do on a daily basis. For the Medical Acuity scale, the SIS Exceptional Medical Support Needs items are used with a slightly different scoring algorithm to describe critical care needs, rather than intensity of support needs for a variety of medical conditions, some of which do not require critical care. For the Behavior Acuity scale, a list of problem behaviors is obtained from the SIS Exceptional Behavior Support Need scale plus other behavior items, and DDD staff then gather details on frequency, severity, and assistance provided for the most prominent problem behavior. This scale is intended to measure intensity of support needed for a single, most prominent behavior, rather than support across a variety of behaviors.

TABLE 5

DDD Assessment Acuity Scales and Sample Items

DDD ACUITY SCALE <sup>*</sup>	SAMPLE ITEMS	SAMPLE CRITERIA FOR "HIGH" ACUITY
ADL Acuity	Using the toilet, eating food, ambulating and moving about	Score > 15 or one item = 4
Interpersonal Support Acuity	Interacting with community members, interacting with supervisors/coaches	Score ≥ 56
Medical Acuity	Inhalation or oxygen therapy, suctioning, dialysis	Any item requires extensive support or total score ≥ 8
Mobility Acuity	Ambulating or moving about (SIS item E4)	Type of Support = full physical, or frequency is ≥ hourly
Behavior Acuity	Based on frequency, severity, and assistance provided for most prominent problem behavior (for example, self-injury, sexual aggression, wandering)	Physical assistance required AND behavior dangerous/life threatening
Protective Supervision	Level of monitoring required during awake hours	Onsite or line of site, within earshot
Seizure Acuity	Existence of seizures, type, severity, and support needs	≥2 ER visits in past year or seizure duration > 5 minutes

<sup>\*</sup> Caregiver and Backup Caregiver scales reported in the RDA, 2010 report were not administered to RHC clients and so were not used in analyses for the current report.

## **Acuity Scale Scores Group Comparisons**

Clients in RHCs were more likely than those in community residential programs or clients receiving other community-based services to have high scores on all the DDD acuity scales presented below, except for seizure acuity. An extremely large percentage of clients living in RHCs have high acuity levels (and therefore elevated or urgent need) for protective supervision (95.3 percent) and interpersonal support (86.3 percent), and almost three fourths have high acuity levels for activities of daily living (73.6 percent). RHC and community residential clients were also more likely than those in other community-based programs to score high on interpersonal support and protective supervision, indicating that they are more likely to need help interacting with others and require intense supervision (line of sight or on site). Over two-thirds of community residential clients scored high on protective supervision.

Clients in RHCs were more likely than those in community residential or other community-based programs to have high acuity levels noted for behavior problems. Over one third have high behavioral acuity scores (40.6 percent). High behavioral acuity scores indicate that the most prominent problem behaviors for these clients are potentially dangerous or life threatening. Clients in RHCs were also more likely to have high medical and mobility acuity than those in the other two residence types, with over one third in RHCs having high medical acuity and one fourth of those in RHCs having high mobility acuity.

In addition to differences in interpersonal support and protective supervision, clients in RHCs and community residential settings were more likely to have high acuity scale scores on measures of ADL than those receiving other community-based services, meaning that they need additional assistance with activities of daily living, such as using the toilet, eating, and moving about. There were no statistically significant differences in proportions of clients in community residential programs and those living in other community based settings who had high medical, mobility, or behavioral acuity.

TABLE 6 **DDD Clients Acuity Scale Scores** 

		Assessm	ent Scale Sc	ores			
	Numb	er and Percent	t of Clients at I	mmediate or I	High Acuity Lev	/el (%)	
N = 18,338	Residential Habilitation Center (RHC) n = 889 a		Community Residential n = 6,294 b		Other Community Based n = 11,155		p-value Significant
						C	at p<.05
Acuity Scales	NUMBER	PERCENT	NUMBER	PERCENT	NUMBER	PERCENT	
ADL Acuity	654	73.57%	2,630	41.79%	3,996	35.82%	a>b a>c b>c
Interpersonal Support Acuity	767	86.28%	2,895	46.0%	4,108	36.83%	a>b a>c b>c
Medical Acuity	334	37.57%	1,234	19.61%	2,115	18.96%	a>b a>c
Mobility Acuity	221	24.86%	478	7.59%	820	7.35%	a>b a>c
Behavior Acuity	361	40.61%	1,124	17.86%	1,841	16.5%	a>b a>c
Protective Supervision	847	95.28%	4,388	69.72%	4,704	42.17%	a>b a>c b>c
Seizure Acuity	30	3.37%	156	2.48%	320	2.87%	ns

**NOTES.** The likelihood ratio chi-square test of proportional differences was used to test for differences between groups. When significant group differences were detected, pairwise comparisons were conducted. For example, an overall test of significance detected group differences on ADL acuity. Pairwise chi-square comparisons indicated that community residential clients were proportionally more likely to score "high" on this acuity measure than clients in Other Community Based settings.

# The majority of persons with intensive support needs reside in community based settings, such as their family home.

Although clients in RHCs are proportionally more likely to have acuity levels in the immediate or high range, there are more total individuals supported in other community-based settings who have a high acuity level than in the other settings. For example, although RHC clients are much more likely to have a high or immediate ADL acuity, indicating urgent or severe need for help with activities of daily living (using the toilet, eating, etc.), there are four times as many clients in community residential (n = 2,630) and six times as many clients supported in other community-based settings (n = 3,996) with the same level of need. Because of the large number of clients served in the community with wide ranges of need, this is true for all measure of acuity.

Table 7 demonstrates the number of clients with high acuity on each scale as a percentage of the total number of clients with high acuity. It is clear that a great deal of clients with high acuity are being supported in the community.

TABLE 7

Number and Percent of High Acuity DDD Clients by Residence Type

		Assessm	nent Scale Sc	ores			
Numbe	r and Percent o	of Clients at Im	mediate or Hi	gh Acuity Level	(%)		
N = 18,338	Center	Habilitation (RHC) 889	Community Resi		' Commun		
		9		b		С	
Acuity Scales	NUMBER WITH HIGH ACUITY	PERCENT OF ALL HIGH ACUITY CLIENTS	NUMBER WITH HIGH ACUITY	PERCENT OF ALL HIGH ACUITY CLIENTS	NUMBER WITH HIGH ACUITY	PERCENT OF ALL HIGH ACUITY CLIENTS	TOTAL IN THREE RESIDENCE TYPES WITH HIGH ACUITY
ADL Acuity	654	8.98%	2,630	36.13%	3,996	54.89%	7,280
Interpersonal Support Acuity	767	9.87%	2,895	37.26%	4,108	52.87%	7,770
Medical Acuity	334	9.07%	1,234	33.51%	2,115	57.43%	3,683
Mobility Acuity	221	14.55%	478	31.47%	820	53.98%	1,519
Behavior Acuity	361	10.85%	1,124	33.79%	1,841	55.35%	3,326
Protective Supervision	847	8.52%	4,388	44.15%	4,704	47.33%	9,939
Seizure Acuity	30	5.93%	156	30.83%	320	63.24%	506

**NOTES.** The percentages here represent a percent of the total number of clients with high or immediate acuity levels on each scale, as presented in Table 7. For example, the 654 RHC clients with high or immediate ADL acuity make up 8.98% of all the DDD clients with high or immediate ADL acuity supported in RHCs, community residential and other-community-based settings.

## **ICF/MR Admissions Referrals**

For our 2010 report, we examined all case files reviewed by the DDD ICF/MR Admissions Committee during calendar year 2008 to further understand the support needs of clients referred for admission. These files contain information on referral for ICF/MR placement, including individual support plans, diagnoses, medications, medical and behavioral problems, and in some cases, stated concerns from guardians, facility staff or case managers. The file review indicated that the presence of challenging behaviors, safety risk to self or others, and assaultive behavior were common for individuals referred for ICF/MR admission. For example, in one calendar year 84 percent of those referred had indicated "severity of challenging behaviors." Safety risk was also indicated for most (84 percent), as were physical assault towards others (81 percent) and psychiatric diagnoses (71 percent).

TABLE 8
Extract from 2010 report: CF/MR Admissions Review Team File Review

DDD Clients CY 2008 ICF/MR Admissions Review Team		
N = 31		
File Review Themes	NUMBER	PERCENT
Severity of challenging behaviors	26	84%
Safety risk	26	84%
Physical assault	25	81%
Psychiatric diagnosis	22	71%
Client/guardian refusal of community placement	17	55%
Self-harm	16	52%
Community placement failure or no provider	14	45%
Autism	11	35%
Many current medications (>=10)	11	35%
Requires 1+:1 staffing or single-household	10	32%
Fleeing/bolting	10	32%
Need for stabilization (medical, psychiatric, behavioral)	8	26%
Inappropriate sexual behavior (includes disrobing)	8	26%
Prader-Willi/Other severe eating disturbance (includes Pica)	6	19%

**SOURCE:** Lucenko B, He L, Mancuso D. Assessment Findings for Persons with Developmental Disabilities Served in Institutional and Community Settings. Olympia, WA: WA State Dept. of Social and Health Services, Research and Data Analysis Division; 2010. 5.35.

### **Conclusions and Recommendations**

Individuals with developmental disabilities have a range of competencies and challenges, along with associated medical, social, and behavioral support needs. Assessing and determining levels of care for individuals with varying needs and environmental supports is a major challenge for state programs providing services. The SIS analyses presented in this report indicate that there is a great deal of overlap in support needs for individuals across residential settings, however, there are some clear differences. Overall, individuals in other community-based programs had lower average measured support needs than those in more restrictive settings. Differences between these groups on specific acuity scale scores supports these findings. However, the majority of clients with high acuity live in community settings, such as their family home.

# Support needs are higher in most general life tasks for DDD clients served in RHCs and community residential settings than for those supported in other community-based settings.

As a group, clients residing in both RHCs and community residential programs had higher overall support needs than those residing in other community-based settings as indicated by their significantly higher Support Needs Index scores. It is important to note, however that there are more total individuals living in other community-based settings who have high level of acuity than in the other settings.

Clients residing in RHCs had significantly higher support needs than clients in community residential programs who, in turn, had higher needs than those residing in other community-based settings for activities in the following life areas: Home Living, Community Living, Lifelong Learning, Health and Safety, and Social Activities. Also, clients in RHCs had higher support needs, on average, than those in other community-based settings in Employment Activities, but employment support needs did not differ for persons supported in community residential settings versus other community-based settings.

Clients in RHCs and community residential programs were more likely than those in other community-based settings to be categorized as "high acuity" based on their DDD acuity scale scores in terms of activities of daily living, interpersonal support and protective supervision needs. RHC clients were also more likely to have high acuity scores on medical, mobility and behavioral measures than those supported in the community, but the difference in scores on these three acuity scales between those supported in community residential settings versus other community-based settings was not statistically significant.

# DDD clients served in RHCs and community residential programs have more intensive behavioral support needs compared to individuals supported in other community-based settings.

Our 2010 report noted that behavioral problems and support needs appeared to be a greater concern for DDD clients living in institutions or community residential programs as compared to those residing in other community-based settings. This finding was supported with our updated data for RHC clients, including group comparisons on the SIS Exceptional Behavioral Support Needs scale and the DDD Assessment Problem Behavior acuity scale. Behavioral support needs were significantly higher for RHC clients than for those in community residential and those in other community-based settings. This finding was clear regardless of the measure or criteria used. Persons in community residential programs scored higher on the SIS Exceptional Behavior Support Needs scale than did those residing in other communitybased settings, but the difference between these two groups was not statistically significant for the DDD Problem Behavior Acuity Scale which may indicate that, although overall behavioral support needs for these two residential settings may be similar, persons with potentially dangerous or life threatening behaviors are proportionally more likely to live in community residential or RHC settings. Additionally, a qualitative file review completed for the 2010 study indicated that the presence of challenging behaviors, safety risk to self or others, and assaultive behavior were common for individuals referred for ICF/MR admission. Although the RHC and community residential groups have proportionally more clients with intensive behavioral support needs, the majority of persons with intensive behavioral support needs reside in other community-based settings.

### The more restrictive the setting, the greater the likelihood of having high medical support needs.

In our 2010 report, there were no differences in average SIS extensive medical support needs between the three client groups examined. However, as noted, the assessment data available for RHC clients in

2010 was primarily for those clients who were recently admitted. Our current findings suggest very clear differences in medical support needs, with those in RHCs being more likely to have high medical support needs than those in community residential programs, and those in community residential programs being more likely to have high medical support needs than those in other community-based settings. Specifically, clients served in RHC's were more likely to have an exceptional medical support need than those in either of the community settings, and clients in community residential settings were more likely to have one than those in other community-based settings.

However, individuals in community residential settings and other community-based settings did not differ on their total SIS Medical score or their DDD Medical Acuity Scale scores, indicating that extensive support needs for a particular medical condition are associated with living in an RHC or community residential setting, and that persons with medical conditions that require critical care are more likely to be found among the RHC residential grouping than in non-institutional settings.

The other criterion for identifying an exceptional medical support need was having an overall score on the Exceptional Medical Support scale greater than five. In our 2010 report, roughly 12 to 13 percent of clients in the three groups met this criterion. With updated data for long-term RHC residents, there is now a clear difference; with those in RHCs more likely to have a medical support needs score greater than five than those in community residential or other community-based settings. It is important to note that, despite these proportional differences, more than half of the clients with extensive support need scores are living in other community-based settings.

Our analysis of the number of persons with exceptional medical needs indicates that more than half of those with critical care needs are living in other community-based settings. This finding is consistent across both SIS exceptional medical need indicators and the DDD medical acuity scale.

Although those in RHCs had higher support needs on average in most general living, behavioral, and health-related domains than individuals living in the community, some clients supported in the community had SIS scores that were equivalent or higher to those of RHC clients.

There were clients with very high support need scores who were supported in community residential and other community-based settings. Despite differences in average support need scores between the three client groups, there was much overlap between these groups in the level of support needed in areas of basic living (e.g., home living, community living, health and safety) and exceptional behavioral and medical support needs. Although the average scores are higher in institutional settings, those DDD clients with the highest support needs scores live in community settings. This may indicate that a capacity issue exists in community residential settings that support individuals with high behavioral and medical needs. This was also supported by the analysis of admission review files whereby admission was pending the availability or establishment of an appropriate community residential placement. It also may indicate that it is possible to support individuals with high acuity and even the highest support needs in non-institutional or family home settings.

# The findings from this report will be used in developing an algorithm for informing placement decisions and in completing a cost comparison study.

This report provides empirical information about the level of assessed support needs among DDD clients residing in RHCs, community residential, and other community-based settings. This is a preliminary step toward developing an algorithm to assist professionals when making level of care decisions based on standardized and objective measures of client support needs.

In reviewing the demographics of the three groups (see technical appendix), it is obvious that RHCs are serving an older population than other community-based settings. Factors such as age will be important to take into account in developing the algorithm. Specifically, the scale scores found to be associated with group status, and other risk and protective factors such as past RHC residence, referrals for ICF/MR admission, and receipt of intensive community-based services will be entered into multivariate risk models to predict placement. These findings will also serve as first steps towards comparing costs across the three groups.

#### REFERENCES

- Thompson JR, American Association on Mental R. Supports Intensity Scale: users manual. Washington, D.C. (444
   N. Capitol St., NW, Suite 846, Washington 20001): American Association on Mental Retardation; 2004.
- 2. Lucenko B, He L, Mancuso D. Assessment Findings for Persons with Developmental Disabilities Served in Institutional and Community Settings. Olympia, WA: WA State Dept. of Social and Health Services, Research and Data Analysis Division; 2010. 5.35.
- 3. Developmental disabilities clients: A look at client participation using DSHS's Client Services Database. Washington State Department of Social and Health Services, Research and Data Analysis; 2008. <a href="http://publications.rda.dshs.wa.gov/1366/">http://publications.rda.dshs.wa.gov/1366/</a>. Updated Last Updated Date.
- 4. United States. Congress (101st 2nd session: 1990). Americans with Disabilities Act of 1990: (to accompany S. 933), conference report (H. Rept 101-558). Washington, D.C.: U.S. G.P.O.: For sale by the Supt. of Docs., U.S. G.P.O.; 1990.
- 5. Olmstead v L.C. In: Court S, ed. Vol 212187. United States; 1999.
- Weiss JA, Lunsky Y, Tasse MJ, Durbin J. Support for the construct validity of the Supports Intensity Scale based on clinician rankings of need. Res Dev Disabil. Sep-Oct 2009;30(5):933-941.

#### **TECHNICAL NOTES**

### **Data Notes**

CMIS, the DDD information system, was the primary data source for this study. Client information extracted directly from CMIS included client's most recent assessment, demographic, service dates, and residence details for clients served by DDD and assessed during the timeframe July 2007 through September 2010. For clients served in the community, assessments are administered annually. The most recent complete assessment data were used for each client in these analyses.

### **Statistical Comparisons**

One-way analyses of variance (ANOVA) were conducted to assess for differences in means on each of the SIS scale scores and the Support Needs Index standard score among the three groups: RHCs, Community Residential, and Other Community Based. One-way ANOVAs were used to assess for differences in means among groups on continuous variables, with pairwise comparisons (t-tests) conducted to assess for differences between pairs of groups when the overall ANOVA was statistically significant. Similarly, the likelihood ratio chi-square test of proportional differences was used to assess for differences between groups on categorical variables. When significant group differences were detected, pairwise comparisons were conducted. Missing values (nonresponses) on these scales may represent a combination of differences in policy, regarding mandatory assessment questions by service type, and client needs in differing DDD residences.

#### **Qualitative Review**

One calendar year of ICF/MR admissions review team files was examined and coded for themes relevant to support needs. This qualitative review was conducted for all DDD clients referred for ICF/MR admission during calendar year 2008 for our report completed in 2010.

## **Demographics**

Demographics and disability diagnoses by residence type are presented in the following table. Disability diagnosis is based on the latest DDD determination through September 30, 2010. Multiple disability codes are included when present and so total numbers are greater than 100 percent for this category in the demographics table.

ABLE 9	DDD Clients by Residence Type							
DEMOGRAPHICS	Cente	Habilitation r (RHC) 889		/ Residential 5,294	Other Community Based n = 11,155			
	Age							
	Number	Percent	Number	Percent	Number	Percent		
16 to 24 years	37	4%	596	9%	4,444	40%		
25 to 34 years	56	6%	1,126	18%	3,320	30%		
35 to 44	124	14%	1,279	20%	1,710	15%		
45 to 54	299	34%	1,629	26%	1,072	10%		
55 to 64 years	252	28%	1,094	17%	449	4%		
65 and over	121	14%	570	9%	160	1%		
			Ge	nder				
Female	353	40%	2,739	44%	4,822	43%		
Male	535	60%	3,555	56%	6,333	57%		
		Race   Ethnicity						
Hispanic	7	1%	157	2%	896	8%		
American or Alaska Native	7	1%	144	2%	270	2%		
Asian	5	1%	122	2%	553	5%		
Black or African American	17	2%	254	4%	647	6%		
Native Hawaiian/Pacific Islander	5	1%	26	0%	99	1%		
White	841	95%	5,542	88%	8,518	76%		
Multiple Race	3	0%	41	1%	140	1%		
Unknown	4	0%	8	0%	32	0%		
		D	isability (CCDB E	ligibility) Diagno	sis			
Autism	51	6%	216	3%	698	6%		
Cerebral Palsy	6	1%	383	6%	1,043	9%		
Developmental Delay	0	0%	1	0%	2	0%		
Epilepsy	3	0%	136	2%	314	3%		
Medically Intensive	0	0%	0	0%	2	0%		
Mental Retardation	827	93%	5,137	82%	7,658	69%		
Another Neurological Condition	2	0%	49	1%	170	2%		
Other Condition	4	0%	421	7%	1,548	14%		

### **TECHNICAL TABLES**

TABLE 10

### **Detail on Residential Categories**

Residence type was determined for those in Community Residential and Other Community-based settings as the residence at the time of assessment. For those two groups, residence type was defined based on client residence type codes recorded in CMIS: (residence type based CLRS\_TYPECODE). For the RHC group, residence was established as RHC based on the list provided by DDD.

### RHC

Residential Habilitation Center, current and recent residents with assessment, from DDD list 9/2010

### **Community Residential**

Adult Family Home

Own Home (Alternative Living)

Congregate Care Facility

**Group Home DDD** 

Own Home (Supported Living)

**Intensive Tenant Support** 

State Operated Living Alternatives (SOLA)

Child Foster Home

Own Home (Companion Home)

Child Licensed Staff Residential

Adult Residential Care (ARC)

Child Group Care

Child Foster Home/Group Care

### **Other Community Based**

Own Home

Parents Home

**Relatives Home** 

Boarding Home (non-ARC)

Child Foster Home/DCFS

Child Care Agency

Homeless

Own Home (with Spouse/Partner)

Own Home (Alone)

Mental Health Diversion



Copies of this report may be obtained from the Research and Data Analysis Division: http://www.dshs.wa.gov/rda/.