DSHS | **Clients with Developmental Disabilities**

REPORT 5.35 | **Report for the Division of Developmental Disabilities**

Assessment Findings for Persons with Developmental Disabilities Served in Institutional and Community Settings

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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 and unique competencies. The Department of Social and Health Services (DSHS) is committed to serving individuals with developmental disabilities in the least restrictive living environment possible. Therefore, the department has prioritized the development of a data-based algorithm based on the types of support needed by each person designed to determine immediacy of need for admission to different types of care settings.

This report presents analyses pertaining to the support needs of clients served by the DSHS Division of Developmental Disabilities (DDD) designed to inform the development of a level of care algorithm. Measures include assessment findings from: 1) the Supports Intensity Scale (SIS), a measure of support needs specifically designed for individuals with developmental or similar disabilities,[1] and 2) acuity scales based on the DDD Support Assessment that are designed to measure level of risk or urgency of need for care.

Comparisons are presented for DDD clients served in three types of settings: 1) institutions (primarily recent admissions to Residential Habilitation Centers and Community Intermediate Care Facilities for the Mentally Retarded), 2) community residential, and 3) other community-based programs. A qualitative review of files for DDD clients referred for admission to an Intermediate Care Facility for the Mentally Retarded (ICF/MR) is also presented.

Key Findings

DDD clients served in institutions (primarily recent admissions) and community residential programs have more severe behavioral support needs compared to individuals receiving other community-based services.

- Extensive behavioral support needs in at least one SIS category (such as prevention of assaults, self-injury, or property destruction) were indicated for 72 percent of DDD clients served in institutions, 46 percent in community residential, and 33 percent in other community-based services.
- Assessments of behavioral acuity levels that indicate dangerous or life-threatening behavior were more likely to occur for clients in institutions (37 percent) than for those in community residential (20 percent) or community-based (16 percent) programs.
- A qualitative review of records for individuals referred for ICF/MR admission in calendar year 2008 revealed several common concerns, including the severity of challenging behaviors (84 percent), safety risk to self or others (84 percent), and assaultive behavior (81 percent).

Support needs are higher in most general life tasks for DDD clients served in institutions (primarily recent admissions) and community residential settings than for those receiving other community-based services.

- Clients residing in both institutions and community residential programs had significantly higher scores on the SIS Support Needs Index and several scales indicating more support needs for general life tasks than clients in other community-based services.

Overlap exists in support needs for all DDD clients and some clients served in the community had extremely high support needs.

- There were clients with very high support need scores who were served 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).
- There is much less apparent overlap in the level of behavioral support needs for clients served in the three settings (institutions, community residential and other community-based), although clients with very high behavioral support needs were present in all three groups.
- There were no statistically significant differences in assessment scores between clients in Institutions and those in Community Residential programs, except for the Behavior scale and some medical scale scores. However, the clients who were assessed with the highest behavioral and medical scale scores were residing in the community rather than in institutions. This may indicate that a capacity issue exists in community residential settings that support individuals with high behavioral and medical needs.

Broadening the DDD full assessment requirement and further analyses are recommended next steps in developing a level of care algorithm.

- The DDD full assessment is not currently required for clients in institutions and data are therefore sparse for this population. Consequently, the findings presented for this group may represent a subgroup of clients in institutions who were either recently admitted or assessed for specific problems. Establishing a consistent assessment requirement for all DDD clients in the future would permit more thorough and timely analysis of client support needs for those served in all settings.
- Further exploration of the services received by DDD clients served in different settings, including longitudinal analysis and multivariate risk modeling, are recommended next steps in algorithm development.

MEASURES

The Washington State Department of Social and Health Services (DSHS) Division of Developmental Disabilities (DDD) administers assessments 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 individuals. DDD full assessment items are not routinely administered to DDD clients in institutions. Therefore, the assessments available for the Community ICF/MR and RHC clients may represent a subpopulation of DDD clients who were assessed prior to residing in institutional settings or who were assessed for a particular reason or problem. *For this reason, any assessment differences between groups must be interpreted with caution.* Individual assessment scales and items are described in more detail in the following sections.

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. Data are summarized according to the client's residence type: Institutions, which primarily includes clients recently admitted to Community Intermediate Care Facilities for the Mentally Retarded (ICF/MR) and Residential Habilitation Centers (RHC; long-term or respite), Community Residential, or Other Community-based. Clients in Community Residential programs receive services while living in individual or group residences such as Adult Family Homes, Group Homes, or Supported Living (see list of DDD services by residence type in technical appendix). For the purpose of the analyses described here, Other Community-Based services are those received by clients in the community while residing in their own homes or with their parents, family members or guardians. Descriptive analyses for all five residence types are presented in the technical tables at the end of this paper.

For our core statistical comparisons, we combined the community ICF/MR and RHC groups into one group representing clients in institutions. This was necessary because of the small numbers of clients in ICF/MR and RHC facilities who had completed full assessments. Statistical comparisons are presented for differences among the following three group of DDD clients: Institutions, Community Residential, and Other Community Based programs. An analysis of length of stay at time of assessment indicated that the majority of clients in the Institutions group were recently admitted (see Table 10 in technical appendix).

QUALITATIVE REVIEW

In addition, client files recorded by ICF/MR admissions review teams were examined for one calendar year 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.

Background

The Washington State Department of Social and Health Services (DSHS) Division of Developmental Disabilities (DDD), within the Aging and Disability Services Administration (ADSA), provides support services and opportunities 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. DDD clients who require assistance with daily living may receive facility based or non-facility based Community Residential Services. Clients receiving community-based services live in their own homes and contracted agencies provide necessary supports.[2]

DDD is working towards developing an algorithm to determine level of care and to inform placement decisions for DDD clients. The algorithm is intended to determine immediacy of need for admission to an Intermediate Care Facility for Mentally Retarded (ICF/MR) or Nursing Facility (NF) level of care for people with developmental disabilities who otherwise qualify for such levels of care. This priority is 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. As a first step in this process, 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.[1]

ICF/MRs in the community are relatively small (6 to 8 residents), privately run residential programs that provide habilitation training, 24-hour supervision, and medical/nursing services for Medicaid-eligible clients who need the active treatment services provided in these facilities. ICF/MR facilities provide residential, vocational, leisure therapy, and behavior support modalities as well as medical and nursing services and therapies. In addition to the community-based ICF/MR facilities described above, five state Residential Habilitation Centers (RHC) provide services to persons with developmental disabilities either under ICF/MR or NF regulations.[2]

To be admitted to an ICF/MR, DDD clients in Washington are expected to have specific care requirements, including the need for 24-hour support, assistance with activities of daily living (ADL), and continuous and active treatment. An admissions committee meets monthly to review care needs of individuals referred for admission. Federal requirements (42 CFR Chapter IV) also exist that regulate admission to and continued care in ICF/MR facilities. These requirements include comprehensive medical, social, and psychological evaluations of diagnoses, symptoms, medical and social history, mental and physical capacity and consideration of services needed and resources available.

Additionally, 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)[3] 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....*[4]

Since the Olmstead (1999) ruling, the provision of community-based services for clients with developmental disabilities who need long-term care has become a priority for state programs. In Washington State, DDD requested these analyses to continue progress towards providing the most appropriate and least restrictive placements possible for individuals with developmental disabilities (DD) receiving state services. To this end, this report describes DDD clients in various levels of care with respect to their assessed service needs. We have provided comparisons of clients with developmental disabilities living in community residential settings, Community ICF/MR and RHC facilities, and those receiving other community-based services, wherever possible.

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.[1, 5] 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, normative 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.[1]

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, interacting with co-workers	**1D**
Health and Safety Activities	Taking medications, 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.[1] Need for support is rated for each item on a scale of 0-2, indicating none, some monitoring, or extensive support needed to manage 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 residing in institutions (RHCs and community ICF/MRs) had significantly higher support needs in Lifelong Learning, Health and Safety activities, and Social Activities than clients in other community-based services. DDD clients in community residential programs scored higher than those in other community-based programs on needs for support in Home Living, Community Living, Lifelong Learning, Health and Safety, and Social Activities. The overall Support Needs Index was significantly higher for clients in both institutions and community residential settings than for clients receiving other community-based DDD services. There were no significant group differences noted for average Employment Activities standard scale scores. No significant differences were found between DDD clients served in institutions and those in community residential programs on any of these core SIS scales.

TABLE 3

Supports Intensity Scales: Mean SIS Scale Scores by Residence Type

Supports Intensity Scale							
Mean SIS Standard Scale Scores by Residence Types							
N = 14,572	**Institutions** ***Primarily recent admissions*** *n = 76* ICF/MR, RHC		**Community Residential** *n = 5,682*		**Other Community Based** *n = 8,814*		
	a		**b**		**c**		
	MEAN	SD	MEAN	SD	MEAN	SD	Significant at p<.05
SIS Scale Scores							
A. Home Living Activities	10.3	*2.2*	10.1	*2.5*	9.8	*2.7*	b>c
B. Community Living Activities	9.2	*1.5*	9.0	*1.8*	8.7	*2.1*	b>c
C. Lifelong Learning Activities	10.5	*1.3*	10.0	*1.5*	9.8	*2.0*	a>c b>c
D. Employment Activities	9.5	*1.5*	9.2	*1.6*	9.2	*1.9*	
E. Health and Safety Activities	10.2	*1.4*	9.7	*1.8*	9.0	*2.2*	a>c b>c
F. Social Activities	9.8	*1.5*	9.4	*1.7*	8.8	*2.0*	a>c b>c
Support Needs Index	**99.3**	***8.6***	**97.0**	***10.7***	**94.5**	***12.9***	a>c b>c

TABLE NOTES

After combining the ICF/MR and RHC groups into a single group to account for small cell sizes, 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: Institutions, Community Residential, and Community. One-way ANOVAs were used to test for differences in means among groups on continuous variables, 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) Institutions compared to Community Residential; (b to c) Community Residential to Other Community Based; and (a to c) Institutions to Other Community Based. The Community Residential group had an average standard score on Home Living Activities support need that was higher than the mean score for those in Other Community Based services, and this finding was statistically significant (b>c). Note that some apparent group differences may not be statistically significant due to small sample sizes.

Supports Intensity Scale: Exceptional Medical and Behavioral Group Comparisons

Clients in institutions had significantly higher Exceptional Behavioral Support need scores than clients in community residential programs and those receiving other community-based services. Clients residing in community residential settings also had significantly higher exceptional behavioral support need scores than those in other community-based services. No significant differences in average medical support need scores were found between the three groups.

TABLE 4

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

Supports Intensity Scale							
Mean SIS Scale Raw Scores by Residence Types							
N = 14,572	**Institutions** ***Primarily recent admissions*** *n = 76* ICF/MR, RHC		**Community Residential** *n = 5,682*		**Other Community Based** *n = 8,814*		
	a		**b**		**c**		
	MEAN	SD	MEAN	SD	MEAN	SD	Significant at p<.05
SIS Scale Scores							
3a. Medical Supports Needs	3.0	*3.5*	2.6	*2.9*	2.6	*3.5*	
3b. Behavioral Supports Needs	7.7	*4.7*	4.4	*4.1*	3.2	*3.7*	a>b a>c b>c

TABLE NOTES

After combining the ICF/MR and RHC groups into a single group to account for small cell sizes, 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: Institutions, Community Residential, and Community. 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) Institutions compared to Community Residential; (b to c) Community Residential to Other Community Based; and (a to c) Institutions to Other Community Based. All three comparisons were statistically significant, indicating that clients in Institutions 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 and Behavioral Support Needs

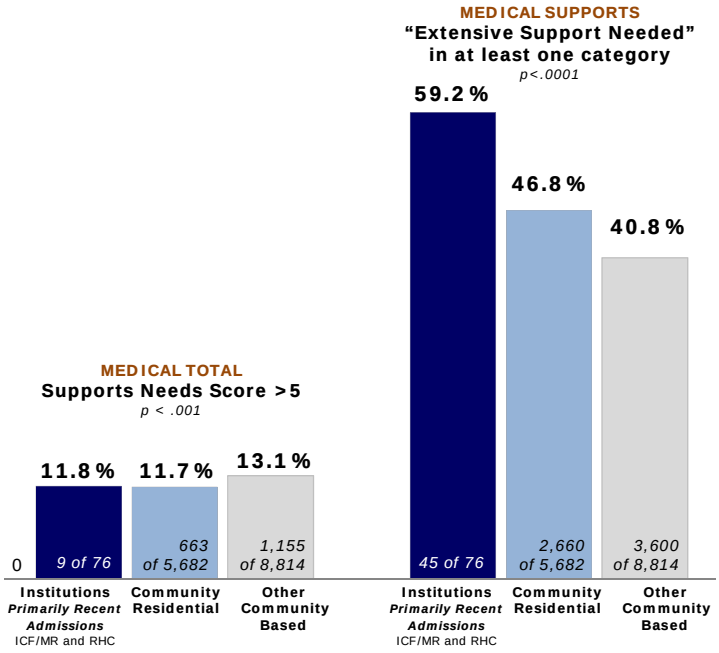
In addition to analyses of differences in *average* need scores, we conducted an additional set of analyses to examine differences in the *proportions* of clients in each group who met criteria for exceptional medical and behavioral support need. According to the SIS manual, the accepted criteria for 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 these criteria for exceptional need for both behavioral and medical support. Therefore, more detailed analyses between each pair of groups were conducted (see below).

Medical Support Needs by Residence Type

Clients who received community-based services were slightly more likely than those in community residential placements to have a total medical support needs scores greater than 5 ($p = .02$).

Clients in institutions were significantly more likely to have extensive medical support needs in at least one category than those living in community residential settings ($p = .03$) and than those receiving other community-based services ($p = .002$).

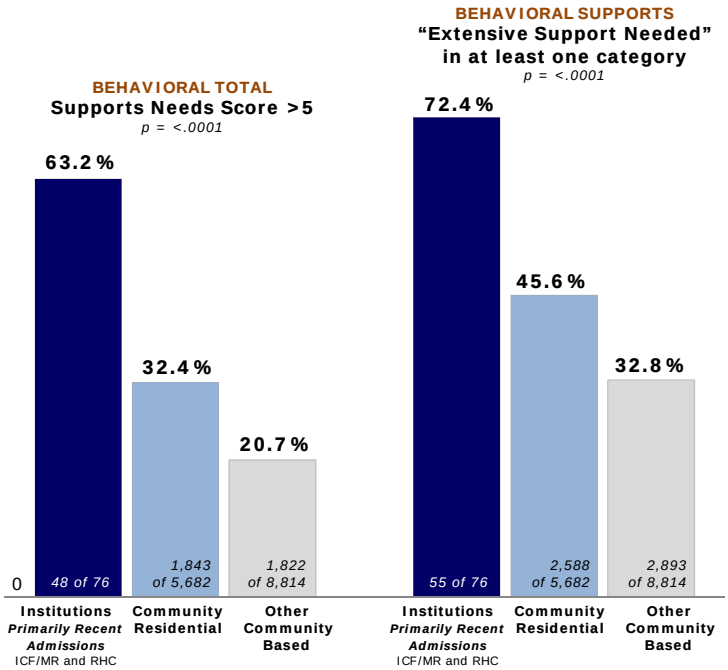
In addition, clients living in community residential settings were much more likely to have extensive medical support needs in at least one category than those receiving other community-based services ($p = .0001$).



Behavioral Support Needs by Residence Type

Clients in institutions were significantly more likely to meet both extensive behavioral support criteria than those in community residential settings or receiving other community-based services.

In addition, clients in community residential programs were more likely to meet both criteria than those receiving other community-based services ($p < .0001$).

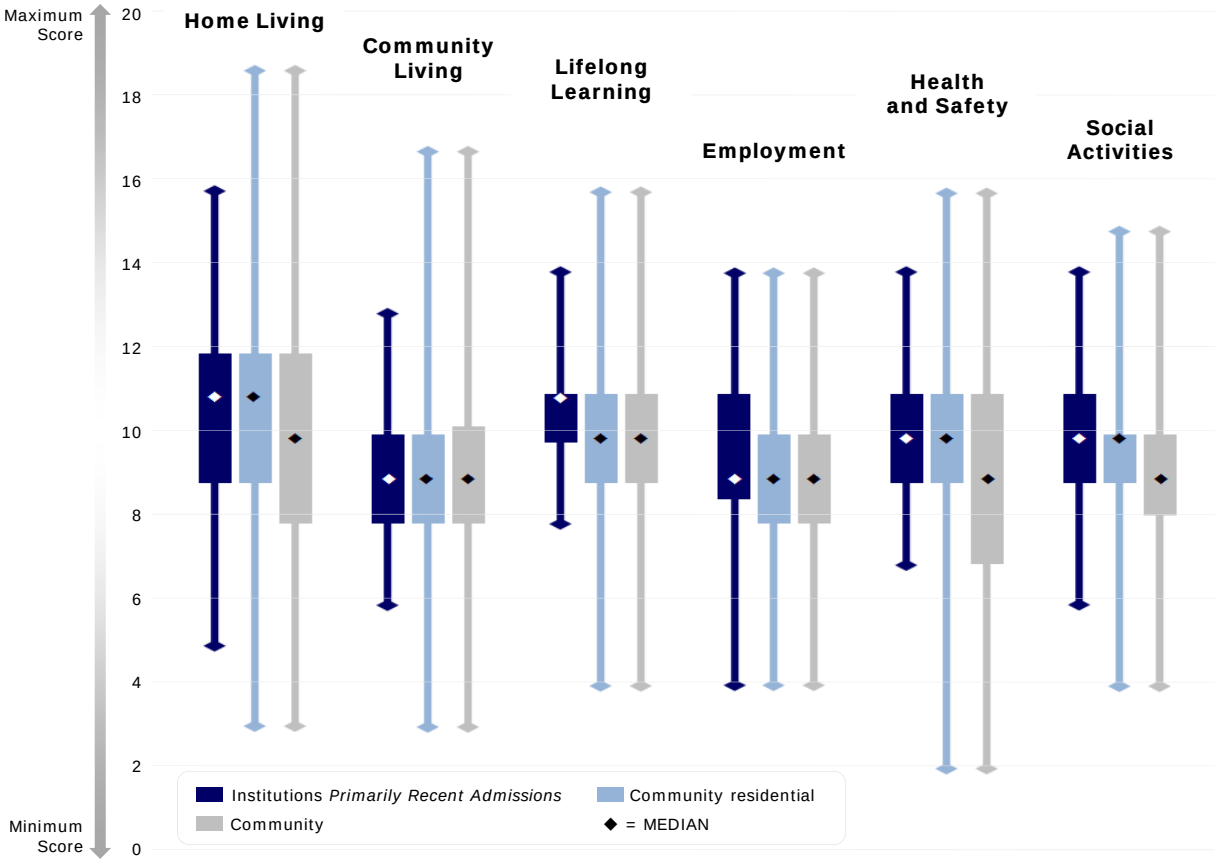


Range of Support Needs for Basic Living Activities

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). Some clients served in the community have extreme scores at the low and high ends of the ranges on all scales. For all categories except employment, there is more dispersion among clients served in community residential facilities and in other community-based programs than among those in institutions, as shown by the full range of scores for each group.

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, clients receiving community-based services have a broader range of support needs for home living, community living, and health and safety activity than do clients living in institutions or community residential settings. Some of the DDD clients living in community residential settings or receiving community-based services, however, had higher support needs on all scales except employment than clients in institutions, as shown by the highest scores, the upward pointing arrow on each line, for each group.

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

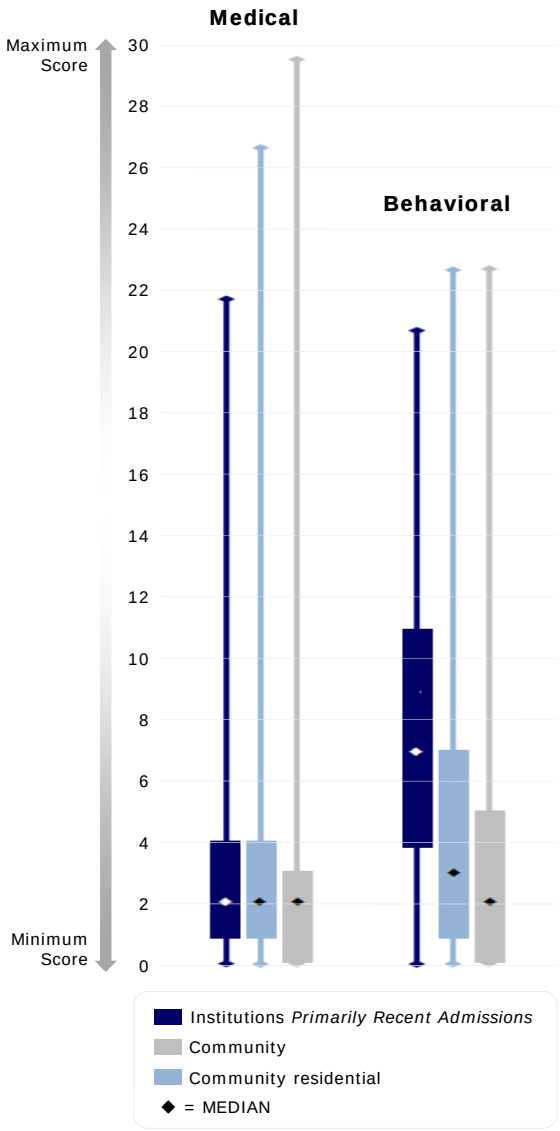


Range of Exceptional Medical and Behavioral Support Needs

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 institutions or community residential settings.

There is much 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 institutions tend to have a much higher interquartile range than clients in the other two groups. In contrast, at least some of the clients living in either of the community settings appear to have higher support needs than those in institutions 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. 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 (line of sight, periodic monitoring), caregiver and backup availability and risk of caregiver loss, and seizures. Acuity levels of none, low, medium, and high represent the urgency and severity of needed assistance for a particular client in areas such as medical, mobility, activities of daily living (ADL), behavior, and risk of losing or not having a caregiver. 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 our use in 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. For the Medical Acuity scale, the SIS Exceptional Medical Support Needs items are used with a slightly different scoring algorithm. For the Behavior Acuity scale, a list of problem behaviors is obtained from the SIS Exceptional Behavior Support Need scale and DDD staff then gathers details on frequency, severity, and assistance provided for the most prominent problem behavior.

TABLE 5
DDD Assessment Acuity Scales and Sample Items

DDD ACUITY SCALE	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 $\geq$ 56
Medical Acuity	Inhalation or oxygen therapy, suctioning, dialysis	Any item requires extensive support or total score $\geq$ 8
Mobility Acuity	Ambulating or moving about (SIS item E4)	Type of Support = full physical, or frequency is $\geq$ 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
Caregiver Acuity	Stress level of caregiver, other caregiving responsibilities, caregiver decline in physical health, how long plan to care for client	Ability to care for client reduced due to health or safety problems; plans to provide care < 6 months
Backup Caregiver Risk	Conditions and availability of backup care	No backup
Seizure Acuity	Existence of seizures, type, severity, and support needs	$\geq$2 ER visits in past year or seizure duration > 5 minutes

Acuity Scale Scores Group Comparisons

A large percentage of clients living in institutions have indications of high acuity levels (and therefore elevated or urgent need) for protective supervision needs (77.6 percent) and interpersonal support (57.9 percent), and over a third have high acuity levels for daily living (36.8 percent) and behavioral difficulties (36.8 percent).

Clients in institutions were significantly more likely than those in community residential or other community-based programs to have high acuity levels noted for behavior problems. High behavioral acuity scores indicate that the most prominent problem behaviors for these clients are potentially dangerous or life threatening. Those in community residential programs were more likely than those receiving other community-based services to score in the high range on behavioral acuity.

Clients living in institutions and in community residential facilities were 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). Clients in other community-based services had increased risk scores pertaining to availability of caregivers, which is likely due to the administrative procedures whereby the caregiver scale is only required for those who are living with a natural caregiver.

TABLE 6
DDD Clients SFY 2008 Acuity Scale Scores

Assessment Scale Scores							
Number and Percent of Clients at Immediate or High Acuity Level (%)							
TOTAL N = 14,572	**Institutions** ***Primarily recent admissions*** *n = 76* ICF/MR, RHC		**Community Residential** *n = 5,682*		**Other Community Based** *n = 8,814*		p-value Significant at p<.05
	a		**b**		**c**		
Acuity Scales	NUMBER	PERCENT	NUMBER	PERCENT	NUMBER	PERCENT	
ADL Acuity	28	36.8%	2,338	41.1%	3,368	38.2%	b>c
Interpersonal Support Acuity	44	57.9%	2,698	47.5%	3,289	37.3%	a>c b>c
Medical Acuity	12	15.8%	925	16.3%	1,478	16. 8%	
Mobility Acuity	4	5.3%	430	7.6%	735	8.3%	
Behavior Acuity	28	36.8%	1,158	20.4%	1,363	15.5%	a>b a>c b>c
Protective Supervision	59	77.6%	3,917	68.9%	3,726	42.3%	a>c b>c
Caregiver Acuity [1,2]	2	2.6%	38	0.7%	445	5.0%	c>b
Backup Caregiver Risk [1]	1	1.3%	26	0.5%	854	9.7%	c>b
Seizure Acuity [1]	2	2.6%	159	2.8%	287	3.3%	

TABLE NOTES

The likelihood ratio chi-square test of proportional differences was used to test for differences between groups on categorical variables. 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 services.

[1] Group cell sizes for institutions too small for statistical comparison. No analyses were conducted with groups where cell sizes were smaller than 5.

[2] The high level includes both “Immediate” and “High” acuity levels for the Caregiver Scale.

ICF/MR Admissions Committee File Review

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. Two project staff reviewed each file. After the first review, codes were devised for emerging themes, which are listed in the table below. Files were then reviewed again and each client record was coded for the presence of each theme.

The table below summarizes the findings for these themes for the 31 cases that were reviewed. A clear pattern of severe behavioral difficulties and the presence of psychiatric diagnoses emerged. A majority of the client cases reviewed for ICF/MR admissions in one calendar year (84 percent) had indicated "severity of challenging behaviors." Safety risk was also indicated for most (84 percent). Physical assault towards others (81 percent) and psychiatric diagnoses (71 percent) were also common among those referred.

Aggressive behaviors described in the files were typically severe enough to cause physical harm (for example, broken bones, burns, stab wounds) to others, including facility staff and guardians. Many of these clients were admitted to an RHC facility pending the availability or establishment of an appropriate community residential placement (16 committee decisions to admit/divert, 52 percent).

TABLE 7

ICF/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%

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 indicated a great deal of overlap in range and some clear differences in average support needs among DDD clients receiving care in Washington State institutions, community residential, and other community-based programs. Behavioral problems and support needs were associated with level of care in all of our analyses. Individuals in other community-based programs had lower average measured support needs than those in more restrictive settings. Differences between these groups on acuity scale scores supports these findings.

DDD clients in institutions and community residential programs have higher support needs in most life areas than those served in other community-based programs.

Clients residing in both institutions and community residential programs had higher overall support needs than those receiving other community-based services as indicated by their significantly higher Support Needs Index scores.

As a group, clients residing in institutions (primarily recent admissions to RHCs and Community ICF/MRs) had significantly higher support needs than clients in community residential programs who, in turn, had higher needs than those receiving community-based services for activities in the following life areas: Lifelong Learning, Health and Safety, and Social activities. Also, clients in community residential programs had higher support needs, on average, than those in other community-based programs in two additional areas: Home Living and Community Living.

Clients in institutions and community residential programs were also more likely than those in other community-based programs to be categorized as “high acuity” in terms of interpersonal support and protective supervision needs.

DDD clients served in institutions and community residential programs have higher behavioral support needs on average compared to individuals receiving other community-based services.

Behavioral problems appear to be a greater concern for DDD clients living in institutions or community residential programs as compared to those receiving other community-based services. This finding was supported through several analyses, including group comparisons on the Supports Intensity Scale Exceptional Behavioral Support Needs scale and the DDD Assessment Problem Behavior acuity scale.

Increased behavioral acuity and support needs are the major differences between DDD clients placed in institutions and those in community residential programs, in that, clients in institutions were more likely to meet all SIS extensive behavioral support criteria than those in community residential settings or other community-based programs.

Additionally, a qualitative 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. These individuals, however, were likely to have been diverted to an RHC or other community residential facility.

Overlap exists in support needs for all DDD clients and some clients served in the community had the highest support need scores.

There were clients with very high support need scores who were served 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.

The need for extensive medical support in at least one category of care appears to be related to the client's type of residential setting—the more restrictive the setting, the greater the likelihood of meeting this criterion of medical support need.

Although there were no differences in *average* SIS medical support scores between the three client groups examined in this report, the groups differed significantly in the proportion meeting one of the criteria for establishing Exceptional Medical Support Needs—having extensive medical support needs in at least one area of care. Specifically, clients served in institutions were more likely to have such 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 receiving other community-based services.

The other criterion for identifying an exceptional medical support need was having an overall score on the Exceptional Medical Support scale greater than five. Roughly 12 to 13 percent of clients in the three groups met this criterion. Further analyses using administrative data, including medical services received and medical expenditures for those in ICF/MR and RHC facilities, could be helpful in establishing similarities and differences in medical support needs among clients served in institutions compared to those served in the community.

Longitudinal analyses and multivariate predictive risk modeling are recommended as next steps in the development of an algorithm for determining level of care.

This report provides empirical information about the level of assessed support needs among DDD clients receiving services in institutions, community residential programs, and other community-based programs. This is a preliminary step toward developing an algorithm for level of care determination based on standardized and objective measures of client support needs.

In addition to comparing assessment information for DDD clients receiving services in different settings, it would be worthwhile to analyze the associations between DDD client characteristics, assessment scores, and specific types of services received. In particular, it would be possible to replicate prior work that has found that the SIS can reliably predict extraordinary support needs.[6, 7] Such analyses would also contribute to the development of a level-of-care predictive model.

Finally, a longitudinal study should be conducted to examine the degree to which community-based assessments can be used to predict the level of care that is appropriate and least restrictive while still meeting a client's needs. Such analyses could give DDD a better understanding of what kinds of support need assessment findings predict the need for institutional placement or identify the potential need for certain services to better support a client residing in the community.

More assessment data are needed in order to develop predictive models of institutional placement.

To conduct a full-scale longitudinal analysis of DDD assessments, service utilization, and placement decisions and outcomes, DDD will need complete assessment data on more clients. Since the implementation of full assessments began in 2007, the necessary data are gradually accumulating over time. The predictive models that could result from the proposed longitudinal analysis could support the development of an algorithm that would allow DDD case managers to make empirically based placement decisions that would take a comprehensive set of client factors into consideration.

The DDD full assessment is not currently required for clients in or entering RHC or ICF/MR facilities, as it is for those entering community residential or other community-based programs. Adding such a requirement would not only facilitate the development of level of care algorithm more quickly, it would also give DDD case managers immediate and empirically-based information on client support needs.

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TECHNICAL NOTES

Data Notes

CARE/CMIS, the DDD information system, was the primary data source for this study. Client information extracted directly from CARE/CMIS included assessment, demographic, service dates, and residence details for clients served by DDD during SFY 2008. Data for ICF/MR clients reported here represent DDD clients residing in an RHC or ICF/MR at the time of assessment. Residence type was defined based on client residence type codes from CARE/CMIS: (SFY 2008 residence type based CLRS_TYPECODE). There were 591 clients (3.84 percent) who had undetermined residence codes and were not included in any statistical comparisons (these were classified as other, unknown, or "old" categories by DDD research staff).

As the DDD full assessment was only implemented in 2007 and is not required for all clients residing in institutions, these data represent information only for the subset of clients for whom assessment information is available. Therefore all findings pertaining to this population must be interpreted as findings for the subpopulation of DDD clients who received full assessments. *Clients were included if:*

1. There was DDD eligibility noted for at least one day during State Fiscal Year 2008 (SFY 2008).
2. There was a "non-pending" DD assessment based on existence of data in tables containing DDD assessment data). About half of the DDD eligible clients in SFY 2008 had assessment data. This included 43 percent of those in ICF/MR facilities, 32 percent of those in RHCs (long-term), 98 percent of those in RHCs for respite stays, 90 percent of those in community residential programs, and 51 percent of those served in other community-based programs.
3. Clients were age 16 or older. This adjustment was made because the SIS was only administered to DDD clients who were 16 or older, as this tool was designed and normed with DD adults.
4. Once those with undefined residential categories (other/unknown) and those with incomplete SIS data were removed, data for 14,572 unduplicated client were available for comparative analyses.

Statistical Comparisons

After collapsing the ICF/MR and RHC groups to account for small cell sizes, 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: Institutions, 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 assess for differences between groups on categorical variables. When significant group differences were detected, pairwise comparisons were conducted. No analyses were conducted with groups where cell sizes were smaller than 5, as noted in the tables. Missing values (nonresponses) on these scales may represent a combination of differences in policy 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.

Demographics

Demographics and disability diagnoses by residence type are presented in the following table. Disability diagnosis is based on the latest DDD determination through June 30, 2008. Multiple determination codes are included when present and so total numbers are greater than 100 percent for this category in the demographics table.

TABLE 8
DEMOGRAPHICS

	DDD Clients by Residence Type					
	Institutions ***Primarily recent admissions**** n = 76		**Community Residential** n =5,682		**Other Community Based** n = 8,814	
	Age					
	Number	Percent	Number	Percent	Number	Percent
16 to 24 years	40	53%	570	10%	3,611	41%
25 to 34 years	10	13%	1,009	18%	2,512	29%
35 to 44	10	13%	1,283	23%	1,416	16%
45 to 54	6	8%	1,500	26%	844	10%
55 to 64 years	5	7%	918	16%	324	4%
65 and over	5	7%	402	7%	107	1%
	Gender					
Female	33	43%	2,474	44%	3,863	44%
Male	43	57%	3,208	56%	4,951	56%
	Race | Ethnicity					
Hispanic	3	4%	135	2%	674	8%
American or Alaska Native	1	1%	129	2%	212	2%
Asian	0	0%	100	2%	416	5%
Black or African American	5	7%	224	4%	495	6%
Native Hawaiian/Pacific Islander	2	3%	20	0%	77	1%
White	65	86%	5,031	89%	6,818	77%
Multiple Race	0	0%	36	1%	109	1%
Unknown	0	0%	7	0%	13	0%
	Disability (CCDB Eligibility) Diagnosis					
Autism	14	18%	160	3%	407	5%
Cerebral Palsy	4	5%	340	6%	847	10%
Developmental Delay	0	0%	1	0%	2	0%
Epilepsy	0	0%	121	2%	236	3%
Medically Intensive	0	0%	0	0%	2	0%
Mental Retardation	54	71%	4,694	83%	6,204	70%
Another Neurological Condition	2	3%	40	1%	145	2%
Other Condition	4	5%	351	6%	1,145	13%

* Represents DDD clients in RHC or ICF/MR at time of assessment.

TECHNICAL TABLES

TABLE 9

Detail on Residential Categories

Institutions

Intermediate Care Facility for the Mentally Retarded (ICF/MR)

Intermediate Care Facility
Community IMR

Residential Habilitation Center (RHC)

Residential Habilitation Center, Long-term
Residential Habilitation Center, Respite

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

Residence Types and Length of Stay

The following table summarizes length of stay at the time of assessment for each residence category. Length of stay was calculated based on the date of assessment and the residence start date stored in CMIS. DDD clients receiving Other Community-Based Services had the longest average length of stay (7.5 years), followed by those served in Community Residential programs (5.3 years). DDD clients in Institutions were primarily recent admissions or respite placements. In fact, 62 out of the 76 clients served in Institutions (82%) had a length of stay that was under 36 months. However, there were 9 clients served in Institutions who had been in their residences for more than 10 years and 8 of those 9 were in ICF/MRs. There were five clients for whom length of stay could not be calculated due to invalid start dates.

TABLE 10

Length of Stay by Residence Type

Residence Types and Length of Stay						
Mean Length of Stay (Years in Current Residence Type)						
N = 14,567	**Institutions** ***Primarily recent admissions*** ICF/MR, RHC n = 76		**Community Residential** n = 5,681		**Other Community Based** n = 8,810	
	MEAN	SD	MEAN	SD	MEAN	SD
Length of Stay in Current Residence Type	3.1	*6.3*	5.3	*5.7*	7.5	*7.4*

Supports Intensity Scale Findings—All Residence Types

The following table summarizes all of the SIS scale scores and total Support Needs Index separately for each residence category. The highest mean scores for overall support needs (measured by the Support Needs Index) were found for clients in RHC and community residential settings, and the lowest overall support need scores were for those in ICF/MR and community-based programs. As a group, DDD clients in RHC facilities, both short and long-term placements, tended to have the highest scores on the SIS scales. This is particularly noticeable with respect to the Behavioral Support Needs scale.

TABLE 11

Supports Intensity Scales: Mean SIS Scale Standard Scores by Residence Type

Supports Intensity Scale										
Mean SIS Scale Scores by Residence Type										
	Community ICF/MR n = 14		RHC Long-term n = 15		RHC Respite n = 47		Community Residential n = 5,682		Other Community Based n = 8,814	
N = 14,572	MEAN	SD	MEAN	SD	MEAN	SD	MEAN	SD	MEAN	SD
SIS Scale Scores										
A. Home Living Activities	8.7	*2.6*	10.7	*2.6*	10.6	*1.7*	10.1	*2.5*	9.8	*2.7*
B. Community Living Activities	7.8	*1.3*	9.5	*1.5*	9.6	*1.2*	9.0	*1.8*	8.7	*2.1*
C. Lifelong Learning Activities	9.2	*0.7*	10.7	*1.5*	10.8	*1.1*	10.0	*1.5*	9.8	*2.0*
D. Employment Activities	8.5	*1.3*	9.8	*1.5*	9.6	*1.5*	9.2	*1.6*	9.2	*1.9*
E. Health and Safety Activities	9.4	*1.3*	10.5	*1.7*	10.4	*1.3*	9.7	*1.8*	9.0	*2.2*
F. Social Activities	8.4	*1.3*	10.1	*1.7*	10.1	*1.2*	9.4	*1.7*	8.8	*2.0*
Support Needs Index	**90.7**	***7.8***	**101.5**	***9.8***	**101.2**	***6.8***	**97.0**	***10.7***	**94.5**	***12.9***

TABLE 12

Exceptional Medical/Behavioral Supports Intensity Scales: Mean Scores by Residence Type

Supports Intensity Scale										
Mean SIS Scale Scores by Residence Type										
	Community ICF/MR n = 14		RHC Long-term n = 15		RHC Respite n = 47		Community Residential n = 5,682		Other Community Based n = 8,814	
N = 14,572	MEAN	SD	MEAN	SD	MEAN	SD	MEAN	SD	MEAN	SD
SIS Scale Scores										
3a. Medical Supports Needs	3.0	*3.6*	3.2	*5.3*	2.9	*2.8*	2.6	*2.9*	2.6	*3.5*
3b. Behavioral Supports Needs	4.3	*2.9*	8.2	*4.9*	8.6	*4.7*	4.4	*4.1*	3.2	*3.7*

Acuity Scale Scores—All Residence Types

Table 13 presents the number and percentage of those in each residence type with an indicated level of "high" (or immediate) acuity on the following scales: Activities of Daily Living (ADL), Interpersonal Support, Medical, Mobility, Behavior, Protective Supervision, Caregiver, Backup Caregiver Risk, and Seizure.

TABLE 13
DDD Assessment Acuity Scales by Residence Type

Assessment Scale Scores										
Number and Percent of Clients at Immediate or High Acuity Level (%)										
	Community ICF/MR n = 14		RHC Long-term n = 15		RHC Respite n = 47		Community Residential n = 5,682		Other Community Based n = 8,814	
N = 14,572	NUMBER	PERCENT	NUMBER	PERCENT	NUMBER	PERCENT	NUMBER	PERCENT	NUMBER	PERCENT
Acuity Scales										
ADL Acuity	3	21.4%	7	46.7%	18	38.3%	2,338	41.2%	3,368	38.2%
Interpersonal Support Acuity	1	7.1%	10	66.7%	33	70.2%	2,698	47.5%	3,289	37.3%
Medical Acuity	1	7.1%	1	6.7%	10	21.3%	925	16.3%	1,478	16.8%
Mobility Acuity	1	7.1%	1	6.7%	2	4.3%	430	7.6%	735	8.3%
Behavior Acuity	1	7.1%	7	46.7%	20	42.6%	1,158	20.4%	1,363	15.5%
Protective Supervision	12	85.7%	11	73.3%	36	76.7%	3,917	68.9%	3,726	42.3%
Caregiver Acuity[1]	0	0%	0	0%	2	4.3%	38	0.7%	445	5.5%
Backup Caregiver Risk	0	0%	0	0%	1	2.1%	26	0.5%	854	9.7%
Seizure Acuity	0	0%	0	0%	2	4.3%	159	2.8%	287	3.3%

[1] The High level includes both Immediate and High acuity levels for the Caregiver Scale.

Additional copies of this paper may be obtained from http://www.dshs.wa.gov/RDA/
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Washington State Department of Social & Health Services
Research and Data Analysis Division
Report Number 5.35