

**PROFILE OF PARTICIPANTS IN THE
SURVEY OF ADULTS RECEIVING
DEVELOPMENTAL SERVICES
IN VERMONT
2008 - 2010**

Consumer Survey Project

Report Prepared July 2010

For

The Division of Disability and Aging Services
Vermont Department of Disabilities, Aging and Independent Living
103 South Main Street
Waterbury, VT 05671-1601

This Report describes findings from a survey of adults receiving developmental services across Vermont during the years 2008-2010. The survey was conducted on a sample of the people served (50% from larger agencies and 100% from smaller agencies) by members of the Vermont Consumer Survey Project. The coordinating members of the Vermont Consumer Survey Project are:

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This Report is intended to give an overall picture of the adults receiving services statewide. It reports findings from the 2008-2010 Demographics Surveys as follows:

- **Basic Demographics (Tables 3.1-3.3)** covers Personal Characteristics, Legal Factors, and Family Involvement.
- **Communication Capability (Tables 3.4-3.6)** covers Means of Communication, Communication Effectiveness, and Communication Supports.
- **Medical/Health Issues (Tables 3.7-3.10)** covers Developmental Disability, Other Challenges, Healthcare and Health, and Lifestyle.
- **Residential Information (Tables 3.11-3.13)** covers Type of Residence, Residential Characteristics, and Guardianship by Residential Type.
- **Community Access and Barriers (Tables 3.14-3.15)**, a new category, covers Getting to Places and Barriers to More Recreational Activity and Enjoyment.
- **Services (Tables 3.16-3.17)** covers Type of Services Received and Self-/Family Management of Services.

Each of the tables includes percentages for those interviewed, those not interviewed, and all participants. For ease of reading, the definition of the data reported (left hand column) and the data for all participants served statewide (right hand column) are shown in bold.

BASIC DEMOGRAPHICS

Table 3.1 – Personal Characteristics

Characteristic	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Age			
Average Age	42	41	42
Minimum	18	18	18
Maximum	89	90	90
Gender			
Male	55%	56%	55%
Female	45%	44%	45%
Marital Status			
Single	91%	93%	92%
Married/Civil Union	4%	3%	3%
Married/Civil Union in past	5%	3%	4%
Unknown	0%	1%	1%
Race			
White	97%	94%	95%
American Indian/Eskimo/Aleut	<1%	<1%	<1%
Black	<1%	<1%	<1%
Asian	<1%	<1%	<1%
Other/Unknown	1%	4%	3%
Primary Language			
English	100%	98%	99%
Not reported	0%	2%	1%

Table 3.2 – Legal Factors

	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Guardianship			
No Guardian	32%	20%	26%
Private Guardian	42%	52%	47%
Public Guardian	26%	26%	26%
Unknown	0%	2%	1%
Payee			
No Payee	18%	16%	17%
Payee	79%	79%	79%
Unknown	3%	5%	4%
Court Restrictions			
No	97%	96%	96%
Yes	3%	2%	3%
Unknown	0%	2%	1%

Table 3.3 - Family Involvement in People’s Lives

	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Family Involved			
Yes	85%	84%	84%
No	14%	15%	15%
Unknown	1%	1%	1%
Why Family not Involved	(n=79)	(n=98)	(n=177)
Family gone/not alive/ whereabouts unknown	38%	50%	45%
Family choice	41%	29%	34%
Court restriction	1%	2%	2%
Other	14%	5%	9%
Unknown	6%	14%	10%

COMMUNICATION CAPABILITY

Table 3.4 – Means of Communication

	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Adequate Reliable Speech			
Yes	85%	48%	65%
No	15%	51%	34%
Unknown	<1%	1%	1%
Primary Means of Communication			
Spoken - Understood by familiar listener	95%	70%	82%
Gesture/body language	1%	25%	14%
Sign language/finger spelling	1%	2%	2%
Communication aid/device	2%	1%	1%
Other/Unknown	1%	2%	1%

Table 3.5 – Communication Effectiveness for People with Inadequate Speech

	Interviewed (n=83)	Not Interviewed (n=328)	All Participants (n=411)
Communicate with familiar people			
Yes	99%	94%	95%
No	1%	6%	5%
Communicate with unfamiliar people			
Yes	78%	36%	45%
No	21%	61%	52%
Unknown	1%	3%	3%
Communicate beyond basic needs			
Yes	77%	41%	48%
No	21%	57%	50%
Unknown	2%	2%	2%
Communication effectiveness in last year			
More effective	19%	14%	15%
As effective	67%	78%	75%
Health prevents fair assessment	10%	2%	4%
Less effective	0%	2%	2%
Unknown	4%	4%	4%

Table 3.6 – Communication Supports for People with Inadequate Speech

	Interviewed (n=83)	Not Interviewed (n=328)	All Participants (n=411)
Communication addressed in ISA			
Yes	47%	49%	48%
No	51%	47%	48%
Unknown	2%	4%	4%
Communication Supports in Place			
Consistent comm. partners	96%	93%	93%
Team support	95%	96%	96%
Access to comm. aids/devices	51%	50%	50%
Training support for support wkers	73%	76%	76%
Expert consultation/support	54%	52%	52%

MEDICAL/HEALTH ISSUES

Table 3.7 - Developmental Disability

Disability Label	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Mild MR	69%	39%	53%
Moderate MR	19%	22%	20%
Severe MR	3%	15%	10%
Profound MR	<1%	9%	5%
Unknown/None reported	9%	15%	12%

Table 3.8 - Other Challenges

Challenge	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
None Reported	18%	19%	19%
Mental Illness	40%	30%	35%
Autism	11%	12%	12%
Cerebral Palsy	10%	13%	12%
Brain Injury	3%	11%	8%
Chemical Dependence	1%	1%	1%
Physical Disability	9%	14%	12%
Hearing	5%	9%	7%
Vision	14%	16%	16%
Seizures	13%	24%	20%
Communication Disorder	3%	10%	7%
Alzheimers Disease	1%	1%	1%
Prader Willi Syndrome	0%	0%	0%
Down Syndrome	9%	11%	10%
Non-Ambulatory	3%	11%	8%
Other	11%	9%	10%

Table 3.9 – Healthcare

	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Last Physical Examination			
In the past year	85%	79%	82%
Over 1 year ago	10%	9%	9%
Unknown	5%	12%	9%
Last Ob/Gyn Examination (female)			
In the past year	54%	36%	45%
Over 1 year ago	20%	25%	22%
Never had an ob/gyn exam	6%	11%	8%
Unknown	20%	28%	25%
Last Dental Examination			
In the past six months	61%	54%	57%
Over 6 months ago	20%	25%	23%
Unknown	19%	21%	20%

Table 3.10 - Health and Lifestyle

	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Medical Care Required			
Less than once/month	83%	81%	82%
At least once/month	8%	8%	8%
At least once/week or more	4%	3%	3%
Unknown	5%	8%	7%
Seizure Frequency			
No seizures	81%	70%	75%
Less than once/month	15%	17%	16%
At least once/month	1%	3%	2%
At least once/week or more	1%	4%	3%
Unknown	2%	6%	4%
Vision			
Sees well (with/without correction)	91%	79%	84%
Vision problems limit activities	6%	11%	9%
Limited or no vision (legally blind)	3%	6%	5%
Unknown	<1%	4%	2%
Level of Mobility			
Walks or uses wheelchair	96%	88%	92%
Non-ambulatory needs assistance	4%	11%	8%
Unknown	0%	1%	<1%
Physically Active			
Very physically active	15%	15%	15%
Moderately physically active	64%	57%	60%
Physically inactive	20%	24%	22%
Unknown	1%	4%	3%
Weight concerns			
No weight concerns	54%	64%	60%
Overweight	41%	26%	33%
Underweight	3%	6%	4%
Unknown	2%	4%	3%
Smoke/chew tobacco			
No	87%	90%	89%
Yes	12%	5%	8%
Unknown	1%	5%	3%

RESIDENTIAL INFORMATION

Table 3.11 - Type of Residence

Residential Type	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Provider Home	48%	49%	48%
Family Home	25%	30%	27%
Own Home w/ Housemate	9%	6%	7%
Own Home Lives Alone	11%	9%	10%
Group Living	3%	2%	3%
Staffed Living	1%	2%	2%
Residential Care Home	1%	1%	1%
Other/Unknown	2%	1%	2%

Table 3.12 – Respondent Guardianship by Residential Type

Residential Type	No Guardian (n=174)	Private Guardian (n=233)	Public Guardian (n=146)	Total (n=553)
Provider Home	33%	38%	81%	48%
Family Home	17%	45%	1%	25%
Own Home w/ Housemate	21%	4%	1%	9%
Own Home Lives Alone	23%	6%	6%	11%
Group Living	2%	2%	6%	3%
Staffed living	1%	1%	2%	1%
Residential Care Home	1%	1%	1%	1%
Other	2%	3%	2%	2%

Table 3.13 - Residence Characteristics

Residential Characteristic	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Location			
Remote	47%	54%	50%
Walking distance to town	31%	29%	30%
Centrally located in town	21%	15%	18%
Unknown	1%	2%	2%
Ownership/Lease of Home			
Family/guardian	25%	33%	29%
Individual/family person lives with	48%	46%	47%
Provider agency/affiliate	5%	6%	6%
Person rents home	17%	11%	14%
Person owns home	3%	2%	2%
Other/Unknown	2%	2%	2%
Amount of Paid Residential Support			
No on-site support (Indep./family)	24%	24%	24%
24 hour on-site	54%	57%	55%
Daily on-site	9%	7%	8%
Less frequent than daily	8%	7%	7%
As needed	5%	4%	5%
Unknown	0%	1%	1%
Household Composition			
Non-related individuals	54%	54%	54%
Biological/adoptive parents	22%	28%	25%
Lives alone	12%	7%	9%
Spouse/Civil Union	3%	2%	3%
Other relatives	6%	7%	7%
Domestic partner	3%	1%	2%
Unknown	0%	1%	<1%
Living with Others with Developmental Disability			
Yes	25%	31%	28%
No	75%	69%	72%
Time in current home/with current provider			
More than 5 years	48%	63%	56%
3-5 years	20%	16%	18%
1-2 years	17%	10%	13%
Less than 1 year	14%	9%	11%
Unknown	1%	2%	2%

COMMUNITY ACCESS AND BARRIERS

Table 3.14 – Getting to Places beyond Walking Distance

Means of Transport	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Ride from family/friends	55%	51%	54%
Ride in staff member's car	83%	76%	80%
Group transport (provider van)	5%	5%	5%
Public transport	20%	12%	16%
Para transit/volunteer/ride-share	5%	3%	4%
Taxi	7%	3%	5%
Drives self	5%	5%	5%
Other	3%	5%	4%

Table 3.15 – Barriers to More Recreational Activity and Enjoyment

Barrier to more activities	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
No barrier	64%	62%	64%
Behavioral/emotional concerns	16%	19%	18%
Social skills limitations	15%	15%	15%
Health concerns	9%	10%	10%
Money/cost	15%	9%	12%
Inadequate transportation	11%	5%	8%
No chaperone	7%	4%	6%
Recreational activity shortage	9%	5%	7%
Other barrier	3%	3%	3%

SERVICES

Table 3.16 - Types of Services Received

Service Type	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Residential Supports*	52%	53%	52%
Service Coordination	95%	92%	93%
Employment - Individual	50%	31%	40%
Employment - Group	2%	1%	2%
Community Support - Individual	60%	59%	60%
Community Support - Group	13%	11%	12%
Clinical Services	55%	48%	51%
Transportation	53%	43%	48%
Family Supports	51%	53%	52%
Other Supports	6%	5%	5%

* In Provider Home, Group Living, or Staffed Living

Table 3.17 - Self-/Family-Management of Services

	Interviewed (n=553)	Not Interviewed (n=664)	All Participants (n=1197)
Management of Services			
Self or Shared with Agency	9%	10%	9%
Family or Shared with Agency	11%	18%	15%
Agency Managed	79%	68%	73%
Unknown	1%	4%	3%
Individually Negotiated Budget			
Yes	77%	78%	78%
No	21%	19%	20%
Unknown	2%	3%	2%
Individual Support Agreement (ISA)			
Yes	93%	91%	92%
No	6%	9%	8%
Unknown	1%	0%	<1%
Fiscal Intermediary (ISO/private payroll)			
Yes	58%	59%	59%
No	41%	38%	39%
Unknown	1%	3%	2%
Independent Support Broker (ISB)			
Yes	1%	4%	2%
No	97%	91%	94%
Unknown	2%	5%	4%