

**PROFILE OF PARTICIPANTS IN THE
SURVEY OF ADULTS RECEIVING
DEVELOPMENTAL SERVICES
IN VERMONT
2011 - 2013**

Consumer Survey Project

Report Prepared October 2013

For

The Developmental Disabilities Services Division
Vermont Department of Disabilities, Aging and Independent Living
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This Report describes findings from a survey of adults receiving developmental services across Vermont during the years 2011-2013. 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 2011-2013 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	Not Interviewed	All Participants
	(n=603)	(n=670)	(n=1273)
Age			
Average Age	42	42	42
Minimum	19	19	19
Maximum	89	88	89
Gender			
Male	56%	57%	56%
Female	44%	43%	44%
Marital Status			
Single	90%	93%	92%
Married/Civil Union	4%	3%	4%
Married/Civil Union in past	6%	3%	4%
Unknown	0%	1%	<1%
Race			
White	97%	97%	97%
American Indian/Eskimo/Aleut	<1%	1%	1%
Black	1%	1%	1%
Asian	1%	0%	<1%
Other/Unknown	1%	1%	1%
Primary Language			
English	100%	100%	100%

Table 3.2 – Legal Factors

	Interviewed (n=603)	Not Interviewed (n=670)	All Participants (n=1273)
Guardianship			
No Guardian	29%	21%	25%
Private Guardian	44%	58%	51%
Public Guardian	27%	21%	24%
Payee			
No Payee	15%	15%	15%
Payee	82%	80%	81%
Unknown	3%	5%	4%
Court Restrictions			
No	96%	97%	97%
Yes	4%	2%	3%
Unknown	0%	1%	<1%

Table 3.3 - Family Involvement in People’s Lives

	Interviewed (n=603)	Not Interviewed (n=670)	All Participants (n=1273)
Family Involved			
Yes	88%	84%	86%
No	12%	16%	14%
Unknown	<1%	<1%	<1%
Why Family not Involved	(n=69)	(n=105)	(n=174)
Family gone/not alive/ whereabouts unknown	46%	52%	50%
Family choice	29%	32%	31%
Court restriction	9%	1%	4%
Other	13%	7%	9%
Unknown	3%	8%	6%

COMMUNICATION CAPABILITY

Table 3.4 – Means of Communication

	Interviewed (n=603)	Not Interviewed (n=670)	All Participants (n=1273)
Adequate Reliable Speech			
Yes	84%	53%	68%
No	16%	47%	32%
Primary Means of Communication			
Spoken - Understood by familiar listener	93%	72%	82%
Gesture/body language	3%	24%	14%
Sign language/finger spelling	1%	2%	2%
Communication aid/device	3%	1%	2%
Other/Unknown	0%	1%	<1%

Table 3.5 – Communication Effectiveness for People with Inadequate Speech

	Interviewed (n=99)	Not Interviewed (n=313)	All Participants (n=412)
Communicate with familiar people			
Yes	100%	89%	91%
No	0%	10%	8%
Unknown	0%	1%	1%
Communicate with unfamiliar people			
Yes	78%	38%	48%
No	22%	59%	50%
Unknown	0%	3%	2%
Communicate beyond basic needs			
Yes	83%	41%	51%
No	17%	57%	47%
Unknown	0%	2%	2%
Communication effectiveness in last year			
More effective	28%	14%	17%
As effective	65%	75%	72%
Health prevents fair assessment	5%	6%	6%
Less effective	0%	2%	2%
Unknown	2%	3%	3%

Table 3.6 – Communication Supports for People with Inadequate Speech

	Interviewed (n=99)	Not Interviewed (n=313)	All Participants (n=412)
Communication addressed in ISA			
Yes	54%	45%	47%
No	45%	53%	51%
Unknown	1%	2%	2%
Communication Supports in Place			
Consistent comm. partners	94%	91%	91%
Team support	100%	97%	98%
Access to comm. aids/devices	56%	47%	49%
Training support for support wkers	77%	78%	78%
Expert consultation/support	51%	50%	50%

MEDICAL/HEALTH ISSUES

Table 3.7 - Developmental Disability

Disability Label	Interviewed (n=603)	Not Interviewed (n=670)	All Participants (n=1273)
Mild MR	68%	39%	53%
Moderate MR	17%	21%	19%
Severe MR	3%	11%	7%
Profound MR	2%	13%	8%
Unknown/None reported	10%	16%	13%

Table 3.8 - Other Challenges

Challenge	Interviewed	Not Interviewed	All Participants
	(n=603)	(n=670)	(n=1273)
None Reported	17%	13%	15%
Mental Illness	40%	35%	38%
Autism	13%	19%	16%
Cerebral Palsy	9%	12%	11%
Brain Injury	4%	4%	4%
Chemical Dependence	1%	1%	1%
Physical Disability	8%	14%	11%
Hearing	8%	10%	9%
Vision	14%	14%	14%
Seizures	18%	23%	21%
Communication Disorder	4%	11%	8%
Alzheimers Disease	1%	2%	1%
Prader Willi Syndrome	0%	1%	0%
Down Syndrome	9%	10%	10%
Non-Ambulatory	3%	11%	7%
Other	12%	12%	12%

Table 3.9 – Healthcare

	Interviewed	Not Interviewed	All Participants
	(n=603)	(n=670)	(n=1273)
Last Physical Examination			
In the past year	86%	82%	84%
Over 1 year ago	8%	8%	8%
Unknown	6%	10%	8%
Last Ob/Gyn Examination (female)			
In the past year	58%	40%	49%
Over 1 year ago	15%	22%	19%
Never had an ob/gyn exam	4%	9%	6%
Unknown	23%	29%	26%
Last Dental Examination			
In the past six months	64%	57%	60%
Over 6 months ago	20%	23%	22%
Unknown	16%	20%	18%

Table 3.10 - Health and Lifestyle

	Interviewed (n=603)	Not Interviewed (n=670)	All Participants (n=1273)
Medical Care Required			
Less than once/month	87%	81%	84%
At least once/month	8%	11%	9%
At least once/week or more	2%	3%	3%
Unknown	3%	5%	4%
Seizure Frequency			
No seizures	79%	72%	75%
Less than once/month	15%	17%	16%
At least once/month	2%	3%	2%
At least once/week or more	1%	4%	3%
Unknown	3%	4%	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	97%	89%	93%
Non-ambulatory needs assistance	3%	11%	7%
Unknown	0%	<1%	<1%
Physically Active			
Very physically active	14%	13%	13%
Moderately physically active	66%	55%	60%
Physically inactive	20%	29%	25%
Unknown	0%	3%	2%
Weight concerns			
No weight concerns	56%	64%	60%
Overweight	40%	27%	33%
Underweight	3%	6%	5%
Unknown	1%	3%	2%
Smoke/chew tobacco			
No	89%	92%	90%
Yes	10%	6%	8%
Unknown	1%	2%	2%

RESIDENTIAL INFORMATION

Table 3.11 - Type of Residence

Residential Type	Interviewed (n=603)	Not Interviewed (n=670)	All Participants (n=1273)
Provider Home	49%	48%	48%
Family Home	24%	31%	28%
Own Home w/ Housemate	8%	6%	7%
Own Home Lives Alone	13%	8%	10%
Group Living	2%	2%	2%
Staffed Living	1%	2%	2%
Residential Care Home	1%	1%	1%
Other/Unknown	2%	2%	2%

Table 3.12 – Respondent Guardianship by Residential Type

Residential Type	No Guardian (n=174)	Private Guardian (n=265)	Public Guardian (n=1646)	Total (n=603)
Provider Home	25%	45%	79%	49%
Family Home	24%	39%	0%	24%
Own Home w/ Housemate	20%	3%	3%	8%
Own Home Lives Alone	26%	7%	9%	13%
Group Living	0%	3%	3%	2%
Staffed living	1%	0%	4%	1%
Residential Care Home	1%	1%	1%	1%
Other	3%	2%	1%	2%

Table 3.13 - Residence Characteristics

Residential Characteristic	Interviewed (n=603)	Not Interviewed (n=670)	All Participants (n=1273)
Location			
Remote	49%	55%	52%
Walking distance to town	32%	30%	31%
Centrally located in town	19%	13%	16%
Unknown	0%	2%	1%
Ownership/Lease of Home			
Family/guardian	27%	34%	30%
Individual/family person lives with	49%	48%	48%
Provider agency/affiliate	4%	5%	5%
Person rents home	18%	10%	14%
Person owns home	1%	1%	1%
Other/Unknown	1%	2%	2%
Amount of Paid Residential Support			
No on-site support (Indep./family)	27%	27%	27%
24 hour on-site	52%	54%	53%
Daily on-site	9%	9%	9%
Less frequent than daily	9%	7%	8%
As needed	3%	3%	3%
Unknown	0%	0%	0%
Household Composition			
Non-related individuals	53%	52%	53%
Biological/adoptive parents	21%	30%	26%
Lives alone	13%	8%	10%
Spouse/Civil Union	3%	2%	2%
Other relatives	8%	6%	7%
Domestic partner	1%	2%	1%
Other/Unknown	1%	<1%	1%
Living with Others with Developmental Disability			
Yes	26%	29%	28%
No	74%	71%	72%
Time in current home/with current provider			
More than 5 years	50%	63%	57%
3-5 years	20%	16%	18%
1-2 years	18%	11%	14%
Less than 1 year	12%	9%	10%
Unknown	0%	1%	1%

COMMUNITY ACCESS AND BARRIERS

Table 3.14 – Getting to Places beyond Walking Distance

Means of Transport	Interviewed	Not Interviewed	All Participants
	(n=603)	(n=670)	(n=1273)
Ride from family/friends	57%	54%	55%
Ride in staff member's car	85%	74%	79%
Group transport (provider van)	5%	5%	5%
Public transport	22%	12%	16%
Para transit/volunteer/ride-share	4%	3%	4%
Taxi	6%	3%	4%
Drives self	6%	8%	7%
Other	4%	3%	4%

Table 3.15 – Barriers to More Recreational Activity and Enjoyment

Barrier to more activities	Interviewed	Not Interviewed	All Participants
	(n=603)	(n=670)	(n=1273)
No barrier	69%	62%	69%
Behavioral/emotional concerns	17%	21%	20%
Social skills limitations	12%	20%	17%
Health concerns	8%	13%	11%
Money/cost	16%	9%	13%
Inadequate transportation	12%	7%	10%
No chaperone	5%	6%	6%
Recreational activity shortage	8%	5%	7%
Other barrier	1%	1%	1%

SERVICES

Table 3.16 - Types of Services Received

Service Type	Interviewed	Not Interviewed	All Participants
	(n=603)	(n=670)	(n=1273)
Residential Supports*	52%	52%	52%
Service Coordination	97%	94%	96%
Employment - Individual	44%	29%	36%
Employment - Group	2%	0%	1%
Community Support - Individual	62%	60%	61%
Community Support - Group	13%	7%	10%
Clinical Services	54%	46%	50%
Transportation	47%	40%	44%
Family Supports	49%	53%	51%
Other Supports	4%	4%	4%

* In Provider Home, Group Living, or Staffed Living

Table 3.17 - Self-/Family-Management of Services

	Interviewed	Not Interviewed	All Participants
	(n=603)	(n=670)	(n=1273)
Management of Services			
Self or Shared with Agency	14%	16%	15%
Family or Shared with Agency	18%	25%	22%
Agency Managed	68%	59%	63%
Individually Negotiated Budget			
Yes	90%	84%	87%
No	10%	15%	13%
Unknown	0%	1%	<1%
Individual Support Agreement (ISA)			
Yes	97%	94%	95%
No	3%	6%	5%
Fiscal Intermediary (ISO/private payroll)			
Yes	61%	65%	63%
No	39%	35%	37%
Independent Support Broker (ISB)			
Yes	1%	3%	2%
No	99%	96%	97%
Unknown	0%	1%	1%