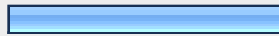

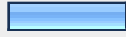

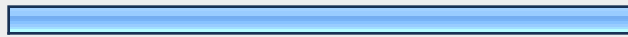




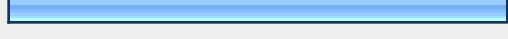




















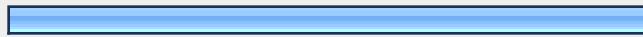

Survey of a Segment of Adults with Autism Spectrum Disorder in Massachusetts

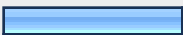

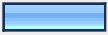







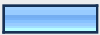

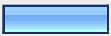

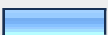
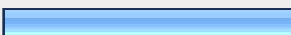
1. Age			
		Response Percent	Response Count
14-17		41.6%	109
18-21		34.0%	89
22-35		17.9%	47
36-64		6.9%	18
64+		0.0%	0
		answered question	262
		skipped question	0

2. Was the person with the disability ever classified by a professional (i.e., psychiatrist, psychologist, or neurologist) as having an Autism Spectrum Disorder?			
		Response Percent	Response Count
Yes		95.7%	245
No		4.3%	11
		Other (please specify)	9
		answered question	256
		skipped question	6

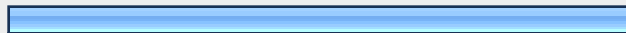

3. What is the primary diagnosis?			
		Response Percent	Response Count
Angelman Syndrome		0.0%	0
Anxiety		2.7%	7
Asperger's Syndrome		12.1%	31
Attention Deficit Disorder		1.9%	5
Autism/PDDNOS		77.0%	198
Bi-polar Disorder		2.3%	6
Cerebral Palsy		0.8%	2
Childhood Disintegrative Disorder		0.0%	0
Chromosome Disorder		0.8%	2
Complex medical needs		0.4%	1
Cri du Chat Syndrome		0.0%	0
Depression		0.4%	1
Down syndrome		0.0%	0
Emotional or behavioral disability		1.2%	3
Fetal Alcohol Syndrome		0.0%	0
Fragile X Syndrome		1.6%	4
Gastrointestinal disease (e.g., reflux, irritable bowel syndrome, celiac disease)		1.2%	3
Head injury		1.2%	3
Hearing impairment		0.4%	1
Intellectual limitations		1.6%	4
Lesch-Nyhan Syndrome		0.0%	0
Mental retardation		7.8%	20

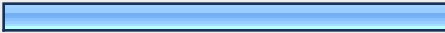
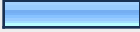





Neurological disorders (inc. epilepsy or seizures)		3.9%	10
Obsessive Compulsive Disorder		1.9%	5
Physical limitations		0.4%	1
Pica		0.0%	0
Prader-Willi Syndrome		0.4%	1
Rett Syndrome		0.4%	1
Spina Bifida (Myelomeningocele type "MMC")		0.0%	0
Tuberous Sclerosis		0.0%	0
Visual impairment		0.0%	0
Williams Syndrome		0.4%	1
Other (please specify)		6.6%	17
<i>answered question</i>			257
<i>skipped question</i>			5

4. Do you have or can you obtain this diagnosis in writing from a qualified professional (i.e., psychiatrist, psychologist, or neurologist)?			
		Response Percent	Response Count
Yes		98.4%	246
No		1.6%	4
Other (please specify)			0
<i>answered question</i>			250
<i>skipped question</i>			12

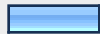
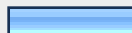
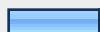
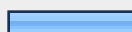
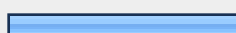
5. Secondary/additional diagnosis(es) (select any that apply):			
		Response Percent	Response Count
Angelman Syndrome		0.0%	0
Anxiety		27.2%	55
Asperger's Syndrome		3.5%	7
Attention Deficit Disorder		15.3%	31
Autism/PDDNOS		10.9%	22
Bi-polar Disorder		9.9%	20
Cerebral Palsy		1.0%	2
Childhood Disintegrative Disorder		0.5%	1
Chromosome Disorder		1.0%	2
Complex medical needs		1.0%	2
Cri du Chat Syndrome		0.0%	0
Depression		8.9%	18
Down syndrome		0.0%	0
Emotional or behavioral disability		13.9%	28
Fetal Alcohol Syndrome		0.0%	0
Fragile X Syndrome		0.5%	1
Gastrointestinal disease (e.g., reflux, irritable bowel syndrome, celiac disease)		15.8%	32
Head injury		0.0%	0
Hearing impairment		1.0%	2
Intellectual limitations		15.3%	31
Lesch-Nyhan Syndrome		0.0%	0
Mental retardation		44.1%	89

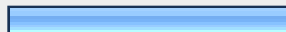
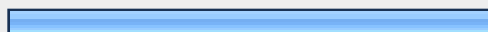
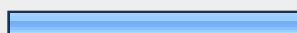
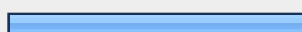
Neurological disorders (inc. epilepsy or seizures)		12.9%	26
Obsessive Compulsive Disorder		23.3%	47
Physical limitations		5.0%	10
Pica		4.5%	9
Prader-Willi Syndrome		0.0%	0
Rett Syndrome		1.0%	2
Spina Bifida (Myelomeningocele type "MMC")		0.0%	0
Tuberous Sclerosis		0.5%	1
Visual impairment		1.5%	3
Williams Syndrome		0.0%	0
Other (please specify)		18.8%	38
answered question			202
skipped question			60

6. Do you have or can you obtain this secondary diagnosis(es) in writing from a qualified professional (i.e., psychiatrist, psychologist, or neurologist)?			
		Response Percent	Response Count
Yes		95.5%	193
No		5.0%	10
Other (please specify)			10
answered question			202
skipped question			60





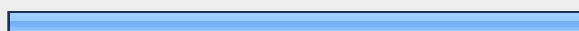
7. Current residential setting?			
		Response Percent	Response Count
Home with family		68.4%	175
Residential school		20.7%	53
24/7 Group home		5.5%	14
Shared living home or apartment		0.8%	2
Generally independent living situation with individual supports		1.6%	4
Generally independent living situation with no supports		0.4%	1
Other (please specify)		2.7%	7
	answered question		256
	skipped question		6


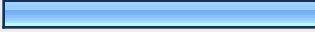
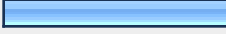
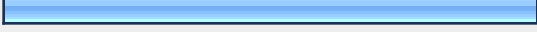
8. With respect to activities of daily living (ADLs): Do you require help with?				
	Yes	No	Sometimes	Response Count
Dressing	41.5% (97)	37.2% (87)	21.8% (51)	234
Toileting	31.7% (73)	50.9% (117)	17.4% (40)	230
Bathing	52.7% (125)	32.5% (77)	14.8% (35)	237
Other personal hygiene	60.1% (143)	16.8% (40)	24.4% (58)	238
Eating	26.8% (60)	56.7% (127)	16.5% (37)	224
Scheduling/arranging personal activities	89.2% (214)	1.3% (3)	10.0% (24)	240
	answered question			243
	skipped question			19

9. How many of the above ADLs do you need assistance with?			
		Response Percent	Response Count
one		13.8%	33
two		18.8%	45
three		13.8%	33
four		18.8%	45
more		35.1%	84
		answered question	239
		skipped question	23

10. How much assistance do you need with the above ADLs? (Check as many as may apply)			
		Response Percent	Response Count
reminder		43.0%	102
verbal prompts		74.3%	176
physical prompts		44.7%	106
greater assistance		45.6%	108
		answered question	237
		skipped question	25

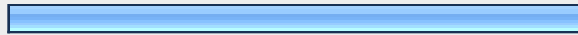

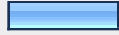

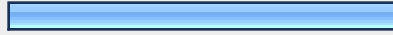
11. With respect to household chores or instrumental activities of daily living(IADLs): Do you require help with?				
	Yes	No	Sometimes	Response Count
Laundry	84.8% (206)	7.8% (19)	8.2% (20)	243
Cleaning	84.3% (204)	5.8% (14)	10.3% (25)	242
Shopping	89.3% (216)	4.1% (10)	6.6% (16)	242
Meal prep and cleanup	88.0% (212)	5.0% (12)	7.5% (18)	241
Transportation	89.7% (218)	6.6% (16)	4.1% (10)	243
Basic household finance and paperwork	91.3% (219)	5.0% (12)	3.8% (9)	240
	<i>answered question</i>			243
	<i>skipped question</i>			19

12. How many of the above IADLs do you need assistance with?			
		Response Percent	Response Count
one		1.2%	3
two		1.2%	3
three		2.1%	5
four		7.1%	17
more		88.4%	213
	<i>answered question</i>		241
	<i>skipped question</i>		21

13. How much assistance do you need with the above IADLs? (Check as many as apply):			
		Response Percent	Response Count
reminder		25.2%	60
verbal prompts		47.9%	114
physical prompts		34.5%	82
greater assistance		82.4%	196
<i>answered question</i>			238
<i>skipped question</i>			24

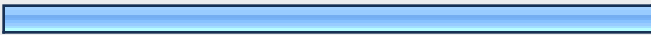
14. I need help:				
	Yes	Sometimes	No	Response Count
To use public transportation	86.8% (203)	6.0% (14)	7.7% (18)	234
To use specialized transportation for people with disabilities (e.g., the Ride or vans)	68.8% (154)	10.3% (23)	21.0% (47)	224
I need help from a monitor when I ride a van	41.9% (95)	16.7% (38)	41.9% (95)	227
I need help walking in my neighborhood I need help to cross streets safely	73.8% (172)	10.3% (24)	15.9% (37)	233
I need help to keep from bolting	32.3% (74)	27.1% (62)	40.6% (93)	229
<i>answered question</i>				243
<i>skipped question</i>				19

15. I need help:				
	Yes	Sometimes	No	Response Count
To participate in social opportunities	87.9% (211)	11.7% (28)	0.8% (2)	240
To participate in events and activities with my family or friends	70.8% (167)	21.6% (51)	8.1% (19)	236
To communicate with friends and family (phone, email, letters)	77.3% (180)	18.0% (42)	4.7% (11)	233
	answered question			240
	skipped question			22

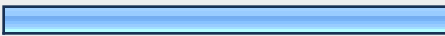

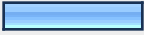
16. I have applied for eligibility for services from the following state agency(ies)(check all that apply):			
		Response Percent	Response Count
Dept. of Developmental Services (formerly DMR)		88.2%	186
Division of Autism (within DDS (formerly DMR))		33.2%	70
Mass. Rehabilitation Commission		16.6%	35
Mass. Commission for the Blind		0.0%	0
Mass. Commission for the Deaf/Hard of Hearing		0.5%	1
Mass. Health		59.7%	126
	Other (please specify)		27
	answered question		211
	skipped question		51

17. I have been told I am eligible for services from the following state agency(ies) as a child:			
		Response Percent	Response Count
Dept. of Developmental Services (formerly DMR)		84.7%	171
Division of Autism (within DDS (formerly DMR))		33.2%	67
Mass. Rehabilitation Commission		8.9%	18
Mass. Commission for the Blind		0.0%	0
Mass. Commission for the Deaf/Hard of Hearing		0.5%	1
Mass. Health		56.4%	114
		Other (please specify)	19
		answered question	202
		skipped question	60

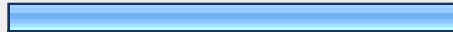

18. I have been told I am eligible for services from the following state agency(ies) as an adult:			
		Response Percent	Response Count
Dept. of Developmental Services (formerly DMR)		80.1%	129
Mass. Rehabilitation Commission		23.0%	37
Mass. Commission for the Blind		0.0%	0
Mass. Commission for the Deaf/Hard of Hearing		0.0%	0
Mass. Health		72.0%	116
		Other (please specify)	37
		answered question	161
		skipped question	101

19. If a state agency(ies)listed above has rejected your eligibility application, what was the explanation?			
		Response Percent	Response Count
Not Applicable		100.0%	120
		Other (please specify)	42
		answered question	120
		skipped question	142




20. Please describe the type and level of services you are receiving or expect to receive as an adult (e.g., 24/7 residential supports, no residential supports, supported employment, day habilitation, family support)			
			Response Count
			214
			answered question
			214
			skipped question
			48

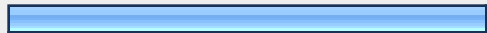



21. I need help finding a doctor, dentist or other basic health care specialist.			
		Response Percent	Response Count
Yes		68.0%	151
Sometimes		11.7%	26
No		21.2%	47
		Other (please specify)	39
		answered question	222
		skipped question	40



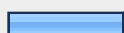

22. I need help accessing specialized health care services like psychiatric services, physical therapy, occupational therapy, speech therapy, or home nursing care.

		Response Percent	Response Count
Yes		68.4%	154
Sometimes		14.7%	33
No		17.3%	39
Other (please specify)			35
		<i>answered question</i>	225
		<i>skipped question</i>	37

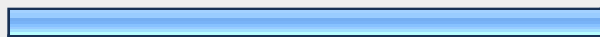


23. I need help planning and coordinating my health care services.



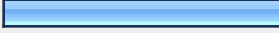



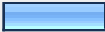

		Response Percent	Response Count
Yes		85.4%	193
Sometimes		6.6%	15
No		8.0%	18
Other (please specify)			24
		<i>answered question</i>	226
		<i>skipped question</i>	36

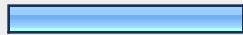
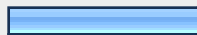
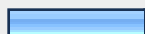


24. I need help taking medications.			
		Response Percent	Response Count
Yes		73.6%	167
Sometimes		8.8%	20
No		9.7%	22
Not taking any medications		9.7%	22
		Other (please specify)	20
		answered question	227
		skipped question	35

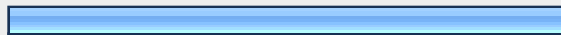





25. In coordinating my health care support, I need help:			
		Response Percent	Response Count
Daily		69.5%	141
Weekly		8.4%	17
Monthly		17.2%	35
Not at all		6.4%	13
		Other (please specify)	32
		answered question	203
		skipped question	59

26. I need help in asking questions, understanding my medical conditions and remembering discussions with my health care providers.

		Response Percent	Response Count
Yes		91.3%	200
Sometimes		5.0%	11
No		4.1%	9
Other (please specify)			26
		<i>answered question</i>	219
		<i>skipped question</i>	43

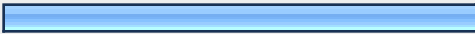
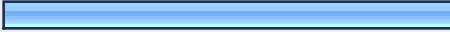
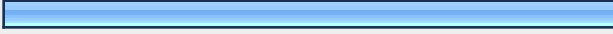
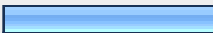
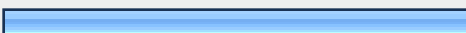
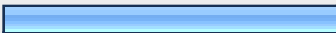

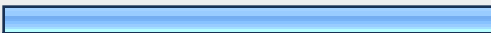
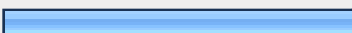

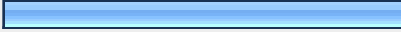
27. During the day I (check all that apply):			
		Response Percent	Response Count
Attend school in my public school		28.3%	56
Attend a collaborative		12.6%	25
Attend a private 766 school		42.4%	84
participate in the DOE/DMR program		13.6%	27
Attend a day habilitation program (day programs funded and licensed by MassHealth, typically structured around social and recreational activities, with ancillary supports such as occupational therapy, physical therapy, speech and language, and other assistance)		10.1%	20
Work in a supported work environment (sometimes referred to as enclaves or sheltered workplaces; generally in a group with staff supervision)		6.1%	12
Work in the community with a job coach		15.2%	30
Work in the community independently		0.5%	1
		Other (please specify)	48
		answered question	198
		skipped question	64

28. The ratio of staff or direct care assistants to students or attendees in my day setting is:			
		Response Percent	Response Count
One to one		36.1%	74
One to Two		28.8%	59
One to Three		20.5%	42
One to Four		10.2%	21
One to Six		9.3%	19
		Other (please specify)	30
		answered question	205
		skipped question	57

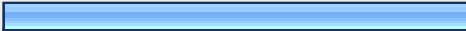
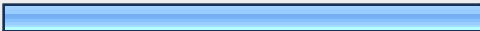
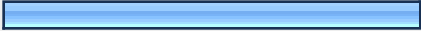
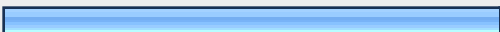
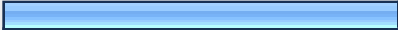

29. In this area I need support			
		Response Percent	Response Count
Throughout the day		85.7%	186
Daily		10.6%	23
A few times a week		2.3%	5
Weekly		1.4%	3
A few times each month		0.5%	1
Monthly or at different times each year		0.9%	2
		Other (please specify)	9
		answered question	217
		skipped question	45

30. In my day setting as an adult, I will need or need:			Response Percent	Response Count
A highly structured program			73.5%	161
A somewhat structured program			23.3%	51
A loosely structured program			3.2%	7
			Other (please specify)	16
			<i>answered question</i>	219
			<i>skipped question</i>	43


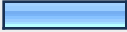
31. In my day setting as an adult, I will need or need a program that includes (check all that apply or will apply):

		Response Percent	Response Count
Functional communication training		72.6%	162
Adaptive skill development		69.1%	154
Social skill development		94.2%	210
Opportunities for independent employment in the community		32.3%	72
Opportunities for employment in the community with a job coach		71.7%	160
Opportunities for employment in a supported work environment (sometimes referred to as enclaves or sheltered workplaces; generally in a group with staff supervision)		51.1%	114
Strategies to address my sensory challenges		61.0%	136
Strategies to address my behavioral challenges		75.8%	169
Opportunities for volunteer work in the community		53.8%	120
Opportunities for social and recreational activities		92.8%	207
Therapeutic ancillary supports (such as occupational therapy, physical therapy, speech and language, and other assistance)		61.9%	138
		Other (please specify)	21
		answered question	223
		skipped question	39

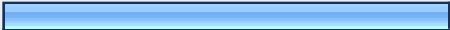
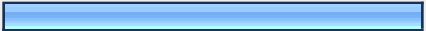
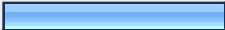
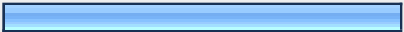
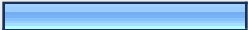


32. With respect to my residential, day and/or educational program, I require a behavior support plan that assists me in the following areas (check all that apply):

		Response Percent	Response Count
Functional communication training		71.3%	154
Adaptive skill development to replace challenging behaviors		73.6%	159
Environmental modifications and other antecedent management strategies (e.g., picture schedules)		63.9%	138
Strategies for increasing desirable behaviors		76.4%	165
Strategies to address my sensory issues		60.6%	131
Not applicable		6.0%	13
Other (please specify)			15
		answered question	216
		skipped question	46

33. With respect to my residential, day and/or educational program, I need access to a structured program that has highly trained and specialized staff in the area of behavior support strategies (such as applied behavior analysis principles or other comprehensive, positive approaches).

		Response Percent	Response Count
Yes		81.5%	181
No		18.5%	41
Other (please specify)			17
		answered question	222
		skipped question	40

34. With respect to my residential, day and/or educational program, I need access to the following types of specialists (check all that apply):

		Response Percent	Response Count
Speech Pathologist		68.5%	146
Occupational Therapist		64.3%	137
Physical Therapist		33.8%	72
Behavior Psychologist		61.0%	130
Developmental Psychologist		37.1%	79
Board Certified Behavior Analyst		53.5%	114
Other (please specify)		13.1%	28
		<i>answered question</i>	213
		<i>skipped question</i>	49

35. With respect to my residential, day and/or educational program, the current level of education/training of the direct care staff is (check all that apply):

		Response Percent	Response Count
High school diploma or equivalent		23.3%	51
Bachelor's degree in related field		53.9%	118
Master's degree in related field		50.7%	111
In-service training offered by employer		29.7%	65
Special education certification/license/endorsement		44.7%	98
Do not know		18.7%	41
Certification as Board Certified Behavior Analyst		30.1%	66
Other (please specify)		11.4%	25
		answered question	219
		skipped question	43

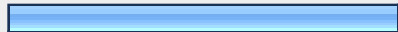

36. With respect to my residential, day and/or educational program, I need to have access to professional consultation from an expert on autism experienced in comprehensive, positive approaches to write my behavior support plan, monitor its implementation and/or provide consultation.

		Response Percent	Response Count
Yes		88.6%	186
No		11.9%	25
		Other (please specify)	16
		answered question	210
		skipped question	52

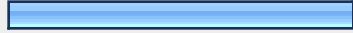
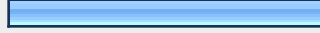
37. I need a behavior support plan that requires:			
		Response Percent	Response Count
Ongoing behavior consultation (weekly)		48.8%	103
Behavior consultation every 2 weeks		15.2%	32
Behavior consultation once a month		17.1%	36
Behavior consultation once every 3 months		7.1%	15
Not applicable		13.7%	29
		Other (please specify)	18
		answered question	211
		skipped question	51


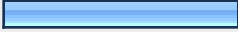
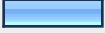
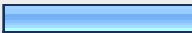
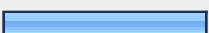
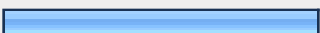
38. Due to my behavior challenges, I need access to extensive staffing resources (1:1 or enriched patterns during certain times of the day).			
		Response Percent	Response Count
Yes		63.4%	135
No		37.1%	79
		Other (please specify)	25
		answered question	213
		skipped question	49

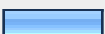
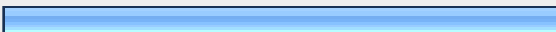
39. At times I have significant challenging behaviors (self-injury, aggression) that may require access to behavior management programming.

		Response Percent	Response Count
Yes		59.7%	129
No		40.3%	87
Other (please specify)			16
		answered question	216
		skipped question	46

40. Due to my behavior challenges I need environmental modifications to the places I live and work to maintain my safety.

		Response Percent	Response Count
Yes		52.8%	114
No		48.1%	104
Other (please specify)			19
		answered question	216
		skipped question	46

41. My current environmental modifications include (check all that apply):			
		Response Percent	Response Count
Wall modifications		10.4%	20
Alarms on doors and windows		35.8%	69
Window modifications		15.0%	29
Lock boxes for cleaning products, toiletries, and other hazards		29.0%	56
Transportation modifications		31.1%	60
Not applicable		48.2%	93
		Other (please specify)	33
		answered question	193
		skipped question	69

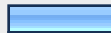
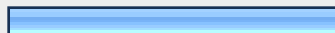

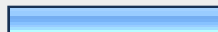
42. Due to my behavior challenges I require supportive and protective equipment to maintain my safety.			
		Response Percent	Response Count
Yes		15.0%	32
No		85.4%	182
		Other (please specify)	7
		answered question	213
		skipped question	49

43. The following supportive and protective equipment is part of my current programming (check all that apply):



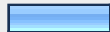

		Response Percent	Response Count
Helmet	<input type="checkbox"/>	4.7%	8
Splints	<input type="checkbox"/>	1.2%	2
Mitts	<input type="checkbox"/>	3.5%	6
Goggles	<input type="checkbox"/>	1.2%	2
Not Applicable	<input type="checkbox"/>	93.0%	160
Other (please specify)			21
answered question			172
skipped question			90

44. Due to my behavior challenges and/or a co-existing diagnosis I require collaboration with psychiatry for psycho pharmacological treatment. I have the following diagnosis that must be treated in addition to my primary diagnosis:

		Response Percent	Response Count
Depression	<input type="checkbox"/>	11.5%	24
Anxiety	<input type="checkbox"/>	47.6%	99
OCD	<input type="checkbox"/>	25.5%	53
Bi-polar disorder	<input type="checkbox"/>	13.0%	27
Seizure Disorder	<input type="checkbox"/>	25.5%	53
Not applicable	<input type="checkbox"/>	29.8%	62
Other (please specify)			34
answered question			208
skipped question			54

45. I currently require psycho pharmacological medication(s) (check all that apply):			
		Response Percent	Response Count
once a day		15.8%	35
twice or more per day		50.5%	112
on a prescribed as needed basis (prn)		4.5%	10
Not applicable		32.4%	72
		Other (please specify)	12
		answered question	222
		skipped question	40

46. Any final comments that you feel might be helpful for the purposes of this survey?		
		Response Count
		75
		answered question
		75
		skipped question
		187

47. The person who completed this survey is:			
		Response Percent	Response Count
the individual about whom the information was provided		0.9%	2
a parent or other family member of the individual on whose behalf the survey was completed		89.2%	189
a legal guardian of the individual on whose behalf the survey was completed		15.1%	32
staff of an agency serving the individual on whose behalf the survey was completed		6.1%	13
		Other (please specify)	6
		<i>answered question</i>	212
		<i>skipped question</i>	50

48. The only required demographic information below is your city, state and zip code. The additional information, while not required, would be helpful to us. Your answers will be kept confidential. The "name" should be completed for the person actually filling out the Survey. Thank you so much for your participation in this Survey.

		Response Percent	Response Count
Name:	<input type="text"/>	59.5%	128
Company:	<input type="text"/>	7.0%	15
Address:	<input type="text"/>	56.3%	121
Address 2:	<input type="text"/>	1.9%	4
City/Town:	<input type="text"/>	100.0%	215
State:	<input type="text"/>	100.0%	215
ZIP/Postal Code:	<input type="text"/>	100.0%	215
Country:	<input type="text"/>	48.4%	104
Email Address:	<input type="text"/>	54.0%	116
Phone Number:	<input type="text"/>	44.2%	95
		<i>answered question</i>	215
		<i>skipped question</i>	47