

# CNI

COLORADO  
NEUROLOGICAL  
INSTITUTE

Research. Patient Services. Education.



## Community Needs Assessment

2014

*The Mission of Colorado Neurological Institute is to enhance the delivery of personalized, comprehensive and state-of-the-art care to patients with neurological conditions through coordinated research, patient services and education.*

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## **Introduction**

**What is a Community Needs Assessment:** A community needs assessment identifies the strengths and resources available in the community to meet the needs of individuals with neurological conditions, care givers, medical professionals and the general public. The assessment focuses on the capabilities of the community, including its citizens, agencies and organizations. It provides a framework for developing and identifying services and solutions and building communities that support and nurture individuals with neurological conditions, their families and care providers.

**Purpose of Colorado Neurological Institute’s Community Needs Assessment:** The purpose of the assessment was to provide information for Colorado Neurological Institute and the health care community to better understand and recognize the gaps in service for people with neurological conditions.

**How data was obtained:** Colorado Neurological Institute (CNI) conducted a Community Needs Assessment (CNA) in January and February of 2014. The survey was distributed online through Survey Monkey, with participants’ identities kept confidential. The geographical area of focus was Colorado. Data was also conducted through open interviews in support groups. Because so many online surveys were distributed to the neurological community, through organizations such as the National MS Society: Colorado-Wyoming Chapter, Parkinson’s Association of the Rockies and the Epilepsy Foundation, it is unclear how many were received. In total, 429 patient caregivers and health care providers responded.

**Survey participants:** Those responding to the survey were patients, former patients and care givers (typically a patient’s relatives), and health care providers/professionals. Potential survey recipients were contacted through neurological related nonprofits, support groups, hospitals, professional health care provider associations, and directly through CNI. All taking the survey only responded to the survey one time.

**Definition of community served:** CNI serves individuals with neurological conditions and care givers from the Rocky Mountain Region. Medical professionals have access to CNI’s research, patient services and education. CNI also offers public education through community outreach.

## **Background Information**

Statements from two health care professionals that participated in the 2014 Colorado Neurological Institute’s Community Needs Assessment:

1. “The hardest thing to deal with is the change of personality that a neurological disorder causes, and the change to the family dynamic as well as their social life, interests, and personality that result. This is one of the hardest things about a neurological issue, the person may never go back to the way they were. In addition, also learning to deal with the change in ability to perform professional roles and responsibilities, and how to deal with the loss of a job or transition into a new role that works with the person’s abilities.”

2. “There is a lack of direct care assistance to help with activities of daily living. There is also a large need for assistance in helping manage medical, community assistance systems, and finances.”

The **Chronic Care Collaborative** reported in 2012, the following number of reported cases of chronic disease in Colorado and the percentage of population:

Alzheimer's	72,000	1.43%
Cancers	200,000	3.98%
Epilepsy	50,000	1.00%
Brain injuries	100,000	1.99%
Huntington's Disease	467	0.01%
Multiple Sclerosis	11,000	0.22%
Parkinson's Disease	15,000	0.30%
Stroke	49,000	0.97%
Total of the above cases of chronic disease in Colorado	497,467	

\*based on 2010 U.S. Census data for Colorado

The **Colorado Health Institute** conducted a telephone survey in April – July 2013. It was a statewide survey of 10,224 randomly selected homes. Included in the survey, were these questions and these percentages of responses:

Barriers to Receiving Health Care, 2009-2013 (all that apply)

<u>Due to the barriers, you couldn't...</u>	<u>2013</u>
Fill a prescription that you needed due to cost	11.2%
Get doctor care that you needed due to cost	12.3%
Get specialist care that you needed due to cost	11.9%
Get dental care that you needed due to cost	19.3%

<u>Due to the barriers, you couldn't...</u>	<u>2013</u>
Get an appointment at the doctor's office when you needed one	15.0%
Get an appointment because the doctor's office wasn't accepting patients with your type of health insurance	8.2%
Get an appointment because the doctor's office wasn't accepting new patients	8.4%
Find transportation to the doctor's office/it was too far away	4.4%
Take off from work (asked of employed)*	10.1%
Find child care (asked only if had one child 14 or younger)	4.0%

In a report released by the **Center to Advance Palliative Care** in 2012, the following was included:

Today, approximately 90 million Americans are living with serious illness, and this number is expected to more than double over the next 25 years. About 20% of all Medicare beneficiaries have 50 or more chronic conditions, and two-thirds of Medicare spending goes to cover care.

# About the CNI Community Needs Assessment

Title of the survey: Confidential Community Survey by Colorado Neurological Institute

**Introduction to the survey:** *Community Needs Assessment. Please help us serve you, or those with neurological conditions, better through research, patient services, and education. Your responses will help Colorado Neurological Institute (CNI), a non-profit, recognize the gaps in service for people with neurological conditions and will be shared with the health care community to provide better care and inform CNI's future programming.*

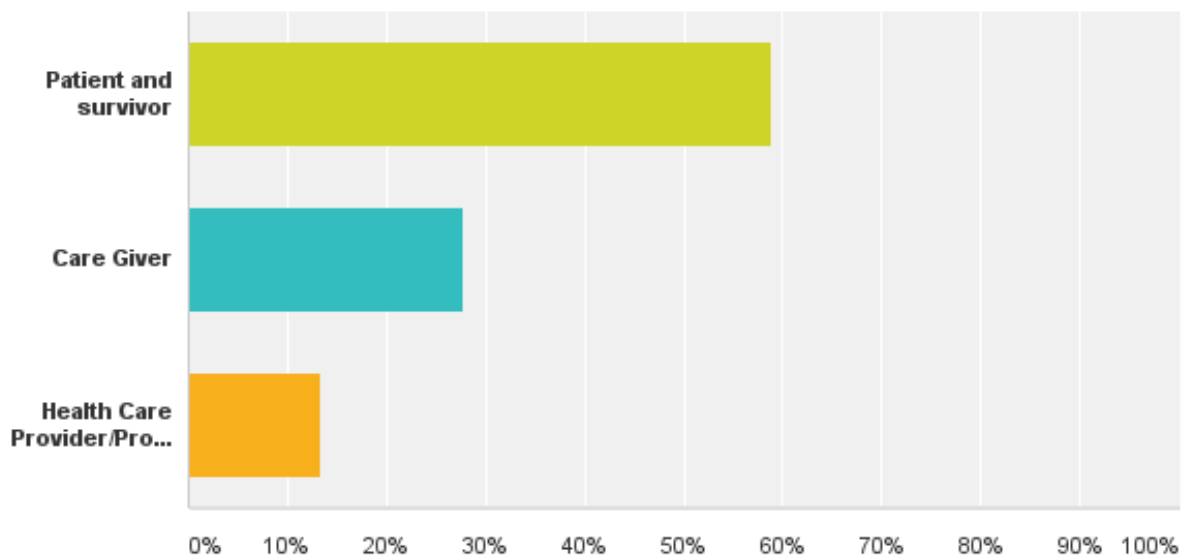
*Thank you, in advance, for taking a few minutes to complete this confidential, anonymous, and very important Community Needs Assessment survey. Please answer the first question below, and then click on "Next".*

*Complete the survey only one time.*

*- Colorado Neurological Institute*

## **Q1 Are you a Patient, Care Giver, or Health Care Provider/Professional (Please take the survey only one time).**

Answered: 429 Skipped: 0



See Appendix A for further information about survey participants.

## **Demographics of Survey Takers**

Over half (53.98%) of survey respondents were between 40 and 65 years old and almost half (48.3%) were retired. Over 66% live in a urban setting and 70% had a household income under \$100,000. Over 94% identified as White/Caucasian. Only 1.7% had no insurance.

## **Identified Priorities**

When an individual is diagnosed with a neurological condition, it takes more than immediate care to live the best life possible. Education, ongoing rehabilitation, support groups, counseling and clinical trials are valuable to an individual's outcome.

### **Research**

#### **A. Participation**

Survey participants were asked if they were given the opportunity to take part in a clinical trial. Results show that 171 answered the question and 258 skipped the question. 61.99% replied that they have participated in a trial.

The next question asked, "If clinical trials were available, would you be interested in participating?" Of the 172 that replied, 83.56% said yes. This high percentage validates the desire for clinical trials in the community.

### **Patient Services**

#### **A. Support Groups**

While dealing with a chronic neurological condition, many expressed an interest in meeting people with the same neurological condition. For them, it is important to know others who are dealing with the same or similar issues and perhaps learn from their perspective.

When asked if they attended support groups, 32.95% patients/survivors answered no. It appears many of this group would welcome the opportunity to attend a support group but are unable to because of scheduling conflicts, lack of transportation, distance to travel, are unable to leave home, or a lack of knowledge of availability of groups.

Approximately 50% of care givers do not attend support groups, for a variety of reasons.

#### **B. Isolation**

Approximately 50% of the care givers feel isolated and lonely. They believe a similar percentage of their loved ones also feel isolated or lonely. It should be noted that while physicians and caregivers responded that 44.42% of patients are active 0-2 times a week, 23%

of patients replied 0-2 times with 30% reporting 3-4 times a week. Physicians and caregivers may be misinformed as to the activity level of the patient.

## **Education**

### **A. Education Subjects**

Approximately 50% of the patients/survivors do *not* have adequate information on these subjects:

- Chronic disease management
- Recent and relevant disease specific information

Most patients/survivors believe they do *not* have adequate information on these subjects:

- Disability and insurance programs
- Alternative treatments and approaches
- Available research protocols
- State of the art Neuro practice

Participants were asked a few questions about interest in education and information potentially provided by video or webinar. Over all, the greatest interest is in these subjects:

- Care management
- Medication
- Nutrition
- Therapy (rehabilitation)
- Stress management

Most of the responding health care providers believe they do not have adequate information for their patients in the following areas:

- State of the art neuro practice
- Available research protocols
- Transportation
- Disability and insurance programs
- Legal services
- Home upkeep
- Alternative treatments and approaches
- Home remodel to accommodate physical needs

## **B. Education Outlets**

Patients/survivors and care givers were asked where they receive most of their health education for themselves or their patients, respectively. Both groups agreed on their top three:

- Internet
- Sub specialist
- Conferences and Seminars

We asked health care providers the same question. Their top two are:

- Conferences and seminars
- Internet

## **General Needs and Accessibility**

Patients/survivors and care givers living in rural areas face difficulties receiving potentially critical, time sensitive diagnosis. Plus, difficulties accessing long term follow up treatment and rehabilitation.

All three groups, patients, care givers, and health care providers were asked to list the top three neurological needs in their community. There were variations in ranking; however, all three groups had these in their top five:

- Care from a specialist
- Support groups
- Education on their chronic disease
- Connecting with community
- Stress Management

See appendix A for detailed results.

Patient/survivors, as well as care givers, on behalf of patients, were asked about their access to: a community center or recreation center; a church group or spiritual “home”; clubs, service groups or social groups; or webinars, chat groups or social media platforms. Interestingly, the patient/survivors have a more “optimistic” view of this access than care givers do for their patients.



# **Overall Summary**

## **General Concerns**

- More information needed around research and support groups
- Better avenues to decrease both patient and caregiver isolation
- Increased education for patients and caregivers, particularly around chronic disease issues

## **General Interests**

*Patients, caregivers and health providers have interests in the following areas:*

- Care management
- Medications
- Nutrition
- Therapy (rehabilitation)
- Stress management

## **Top Needs**

- Care from a specialist
- More access & info regarding support groups
- Better education
- Resources to better connect with the community
- Stress Management

# **Potential Action Steps**

Action steps are based on the needs and concerns expressed, funding available, personnel available, and the formal strategic planning process conducted by CNI's Board of Directors. The following are suggested recommendations and possible action items, but should not be construed as a formal plan of action.

## **Research**

- Invite other hospitals and health systems to be a part of all CNI research trials.
- Increase visibility of trials through marketing, advertising, social media.

## **Patient Services**

- Offer support groups via the internet.
- Advertise and help market support groups provided by other groups and organizations.
- Expand supportive therapies such as physical, occupational, speech and counseling via donor/foundation support and better advertising.
- Explore telemedicine opportunities (other than stroke) for sub specialists in the areas of specific neurological conditions, such as MS, epilepsy and Parkinson's Disease.

## **Education**

- Increase education through social media, CNI's web site, and expanded classes in chronic disease management.
- Offer educational courses at more hospitals, community centers and other access points.
- Provide additional education in the areas of stress management, medication management, community resources and nutrition.

## **Limitations of Survey Results**

**Location:** The community needs assessment participants were primarily (66%) in the metro Denver area. It would be beneficial to conduct a rural community needs assessment to determine the needs of the entire state of Colorado. While 78.86% of survey respondents said that distance did not keep them from receiving services, the results may differ in a rural community.

**Diversity of participants:** Ninety-four percent of the survey participants identified as White. A future survey should collaborate with communities and organizations with a more diverse population.

**Answer Options:** For question #28, respondents were given a list of possible answers from never to all the time for access to services such as a recreation center or church. Respondents were not given the option of N/A, making it difficult to assess which "never" responses were because the respondent does not want or need these services.

## Appendix A

### Patient/survivor respondent characteristics:

Age	Percentage
18-24	0.57
25-40	3.41
40-65	53.98
65-74	25.57
75+	16.48
Gender	Percentage
Female	58.52
Male	40.91
Community	Percentage
Rural	14
Suburban	16
Urban	66
Out of state	4
Ethnicity	Percentage
American Indian or Alaskan Native	0.00
Asian or Pacific Islander	0.57
Black or African American	0.57
Hispanic or Latino	0.57
White/Caucasian	94.89
Multiracial	1.70
Other	1.70
Military service	Percentage
Yes	15.34
No	84.66

### #1. Are you a patient/survivor, care giver or healthcare provider?

Patient/Survivor	253
Care giver	119
Healthcare Provider/Professional	57

### #2. What is your age?

Age	Percentage	Qty
18-24	.57	1
25-40	3.41	6
40-65	53.98	95
65-74	25.57	45
75+	16.48	29

**#3. What is your gender?**

Gender	Percentage	Qty
Female	58.52	103
Male	40.91	72
Other/Prefer not to answer	.57	1

**#4. In what ZIP code is your home located?**

	Percentage	Qty
Rural	14	24
Suburban	16	29
Urban	66	115
Out of state	4	7

**#5. What is your approximate average household income?**

Income	Percentage	Qty
\$0-24,999	17.61	31
\$25-49,999	19.89	35
\$50-74,999	19.89	35
\$75-99,999	13.64	24
\$100-124,999	9.66	17
\$125-149,999	5.11	9
\$150-174,999	5.11	9
\$175-199,999	1.70	3
\$200,000 & up	7.39	13

**#6. What is your ethnicity?**

Race	Percentage	Qty
American Indian or Alaskan native	0	0
Asian or Pacific Islander	0.57	1
Black or African American	0.57	1
Hispanic or Latino	0.57	1
White / Caucasian	94.89	167
Multiracial	1.70	3
Other	1.70	3

**#7. Regarding your health insurance, please check all that apply:**

	Percentage	Qty
Private health insurance	48.86	86
Medicaid	11.36	20

Medicare	42.05	72
Medicare supplement	35.80	63
None	1.70	1.70

**#8. Does your health coverage insurance meet your needs?**

	Percentage	Qty
Yes	82.39	145
No	17.61	31

**#9. What is your employment status?**

	Percentage	Qty
Full time	12.50	22
Part time	6.82	12
Retired	48.30	85
On disability	22.73	40
Unemployed	7.95	14
Other*	7.39	13

**#10. How many people currently live in your household (including yourself)?**

Persons	Percentage	Qty
1	25	44
2	60.80	107
3	9.09	16
4	3.41	6
5	1.70	3

**#11. Have you ever served in any branch of the United States military, or not?**

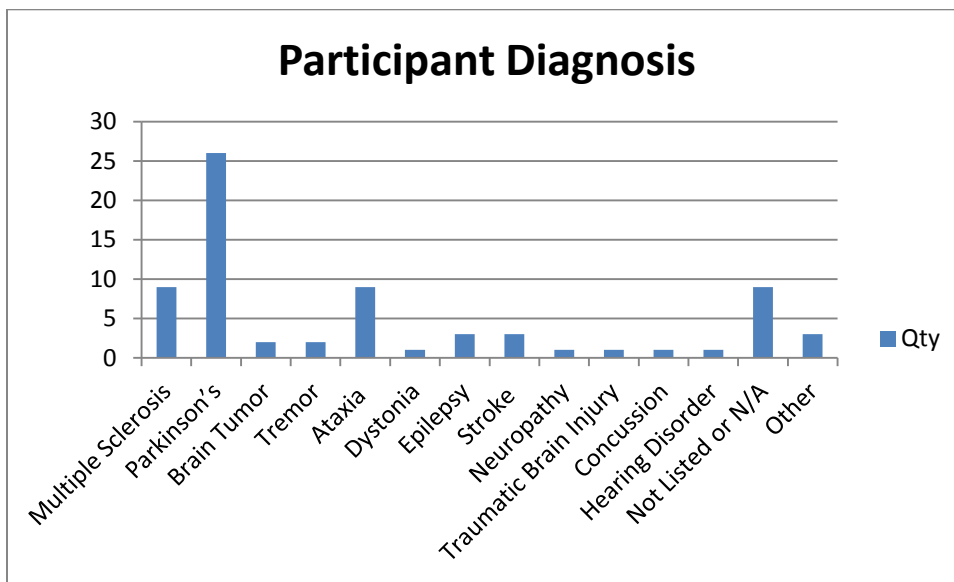
	Percentage	Qty
Yes	15.34	27
No	84.66	149

**#12. As a patient, if you received a diagnosis of a neurological disease, what year did you receive the diagnosis, and what disease was the diagnosis for? If this is not applicable to you: type N/A.**

**Responses:** (the 20 most frequent words or phrases)

Ataxia, Brain Diagnosis, Dystonia, Epilepsy, Essential Tremor, Head Injury, Hearing Impairment Loss, MSA, Neuropathy, Parkinson's Disease, Progressive PSP, RRMS, Sclerosis, Stroke Syndrome, TBI, Tumor

Diagnosis	Qty
Multiple Sclerosis	9
Parkinson's	26
Brain Tumor	2
Tremor	2
Ataxia	9
Dystonia	1
Epilepsy	3
Stroke	3
Neuropathy	1
Traumatic Brain Injury	1
Concussion	1
Hearing Disorder	1
Not Listed or N/A	9
Other	3



**#13. Do you attend a support group?\***

	Percentage	Qty
Yes	67.05	116
No	32.95	57

**\*Comments** (11 most frequent words or phrases)

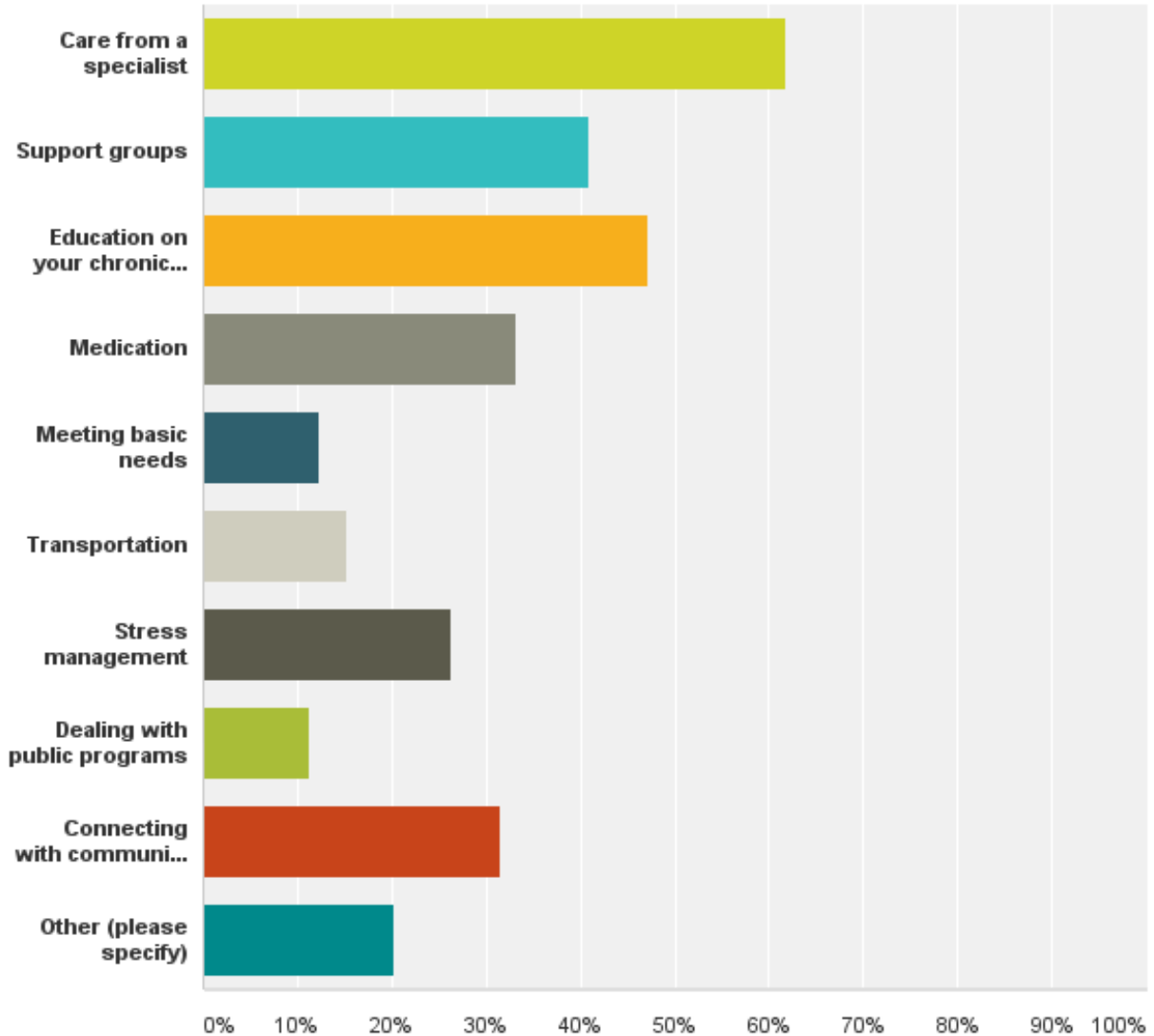
Attended, Conflict, Desire, Distance, Family, Friends, Group, Occasionally, Patients, Stories, Transportation

**#14. As a Patient, click on the top three neurological needs in your community.**

	Percentage	Qty
Care from a specialist	61.36	108
Support groups	41.48	73
Education on your chronic disease	47.73	84
Medication	32.95	58
Meeting basic needs	12.50	22
Transportation	15.34	27
Stress management	26.14	46
Dealing with public programs	11.36	20
Connecting with community resources	30.68	54
Other	20.45	36

## Q14 As a Patient, click on the top three neurological needs in your community.

Answered: 178 Skipped: 253



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### \*Comments (11 most frequent words and phrases)

Awareness, Brain, Education , Exercise, Isolation, Management, Needs, Research, Services, Therapy, Yoga



**#15. Rate yourself overall in the following areas (1-5):**

	Very poor	Poor	Good	Very good	Excellent	Total	Ave. Rating (out of 5)
<b>Educational knowledge of your neurological disease</b>	1.15 2	4.02 7	33.91 59	43.10 75	17.82 31	174	3.72
<b>Social/emotional health</b>	2.30 4	17.24 30	36.78 64	30.46 53	13.22 23	174	3.35
<b>Medical/physical health</b>	0.57 1	14.77 26	44.89 79	31.82 56	7.95 14	176	3.32

**#16. Does distance from adequate neurological services, support and resources keep you from receiving services?**

	Percentage	Qty
No	78.86	138
Yes	21.14	37

**#17. As a Patient, do you have regular access to a General Neurologist?**

	Percentage	Qty
Yes	82.95	146
No	17.05	30

**#18. As a patient, do you have a specialist that treats you for your specific neurological disease?**

	Percentage	Qty
Yes	79.31	138
No	20.69	36

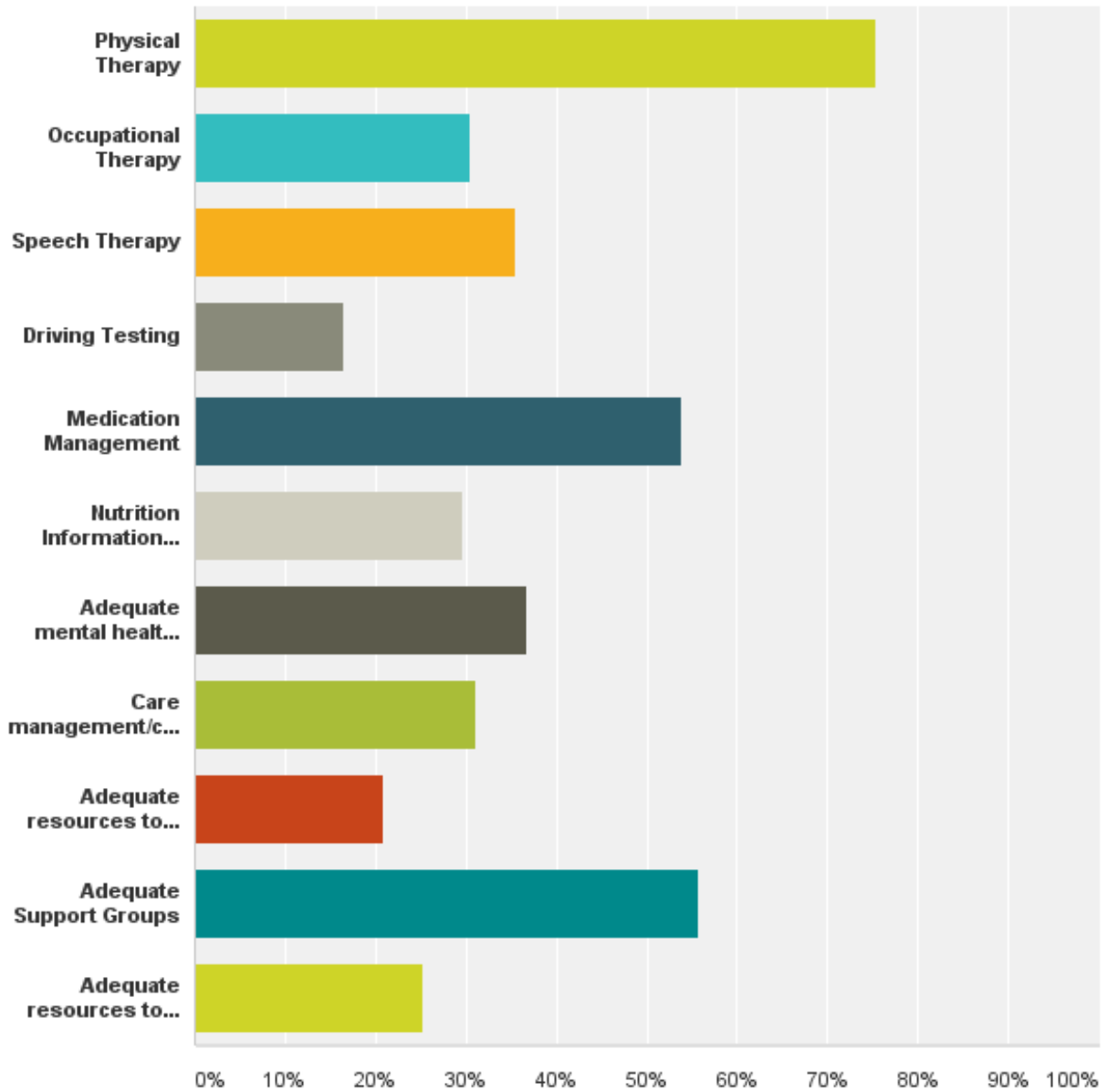
**#19. As a patient, check those areas you have access to neurospecific care:**

	Percentage	Qty
Physical therapy	75.32	119
Adequate Support Groups	55.70	88
Medication Management	53.80	85
Adequate mental health services	36.71	58
Speech therapy	35.44	56
Care management/care navigation	31.01	49
Occupational therapy	30.38	48

Nutrition Information Counseling	29.75	47
Adequate resources to manage your stress?	25.32	40
Adequate resources to help with family challenges	20.89	33
Driving Testing	16.46	26

**Q19 As a patient, check those areas you have access to neurospecific care:**

Answered: 158 Skipped: 273



**#20. As a Patient, if the above services were offered by computer video or webinar, would you use them?**

	Percentage	Qty
Yes	61.40	105
No	38.60	66

**Comments:** (the 16 most frequent words and phrases)

Advances, Care Management, Checked, Driving, Education, Live, Medication, Nutrition, Occupational Therapy, Patient, Quality, Rehab, Speech Therapy, Stress Management, Stress Mgmt, Support

**#21. How many times have you been hospitalized in the past 12 months?**

Stays	Percentage	Qty
0	73.99	128
1	16.76	29
2	5.20	9
3	1.73	3
5	1.16	2
4	0.58	1
9	0.58	1

**#21. You were hospitalized for what issues?**

**Responses:** (12 most frequent words or phrases)

Brain, DBS, Head Injury, Laminectomy, PAIN, Pneumonia, Removal, Seizure, Stroke, Surgery, Thoughts

**#21. Were you re-hospitalized, again, within 30 days of any of the above hospital stays? Yes or no.**

- 10 respondents answered “yes”

**#22. Where do you receive most of your health education for yourself, regarding your disease? Please check the top three.**

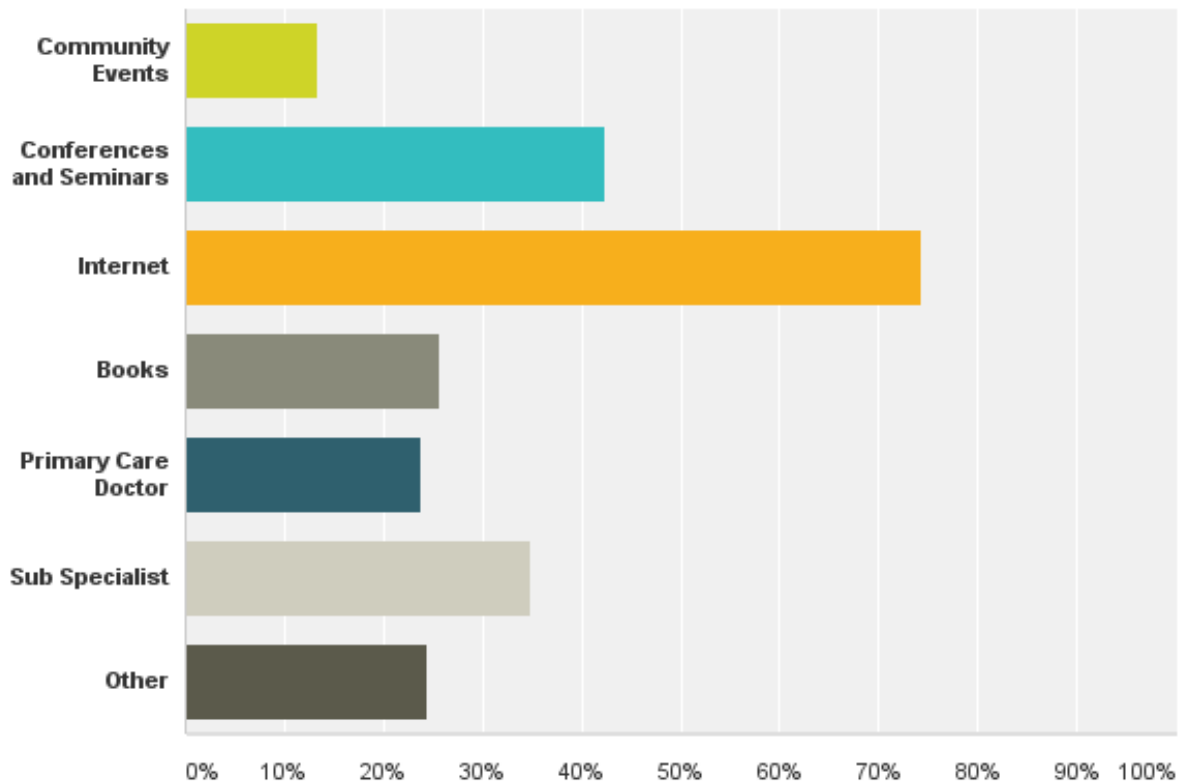
	Percentage	Qty
Internet	74.12	126
Conferences and Seminars	42.94	73
Sub Specialist	34.71	59
Books	25.88	44
Other*	24.71	42
Primary Care Doctor	24.12	41
Community Events	13.53	23

**Other:** (the 8 most frequent words or phrases)

Audiologist, Center, Disease, Meetings, Neurologist, Neurology, Support Group, Therapist

**Q22 Where do you receive most of your health education for yourself, regarding your disease? Please check the top three.**

Answered: 172 Skipped: 259



**#23. For yourself, check the areas you have adequate information on:**

	Percentage	Qty
Medications and side effects	74.50	111
Recent and relevant disease specific information	51.01	76
Chronic Disease Management	49.66	74
Alternative treatments and approaches	30.87	46
State of the art Neuro practice	30.20	45
Disability and insurance programs	28.86	43
Available research protocols	24.16	36
Home health resources	20.81	31

Home upkeep	20.13	30
Transportation	19.46	29
Home remodel to accommodate physical needs	18.79	28
Legal services	12.75	19

**#24. If the above services were offered by computer video or webinar, would you use them?**

	Percentage	Qty
Yes	72.78	123
No	27.22	46

**Responses:** (the 10 most frequent words or phrases)

Alternative, Treatments, Art Neuro Practice, Checked, Disability, Disease, Home Health Resources, Home Remodel, Insurance, Medications, Research Protocols

**#25. Do you have other health educational needs regarding your disease?**

	Percentage	Qty
Yes	19.41	33
No	80.59	137

**#26. Does your Primary Care Doctor have enough education and information to meet your specific needs? If no, please provide specific suggestions.**

	Percentage	Qty
Yes	59.17	100
No	40.83	69

**Responses:** (the 18 most frequent words or phrases)

Aware, Brain Injury, Consider, Discussed, Issues, Kaiser, Little, Medical, Movement, Neurologist, Parkinson's, PCP, Primary Care Doctor, Refers, SEND, Specialist, Stroke, Think

**#27. Do you have access to the following?**

	Never	Some of the time	Most of the time	All the time	Total	Ave Rating (of 4)
Clubs, service groups, or social groups that meet the needs of a Neurological patient?	27.27% 45	30.30% 50	20.61% 34	21.82% 36	165	2.37
A community center or rec center with adequate and appropriate programs to meet the needs of a Neurological patient?	33.94% 56	20.61% 34	20.61% 34	24.85% 41	165	2.36

A church or other spiritual "home" with adequate and appropriate programs to meet the needs of a Neurological patient?	42.24%	16.77%	15.53%	25.47%	161	2.24
	68	27	25	41		
Webinars, chat groups or social media platforms that meet the needs of a Neurological patient?	36.36%	25.32%	17.53%	20.78%	154	2.23
	56	39	27	32		

**#28. Please provide the number of times you leave your home weekly.**

	Percentage	Qty
0	1.71	3
1-2	12.00	21
3-4	13.71	24
5-7	26.86	47
8+	45.71	80

**#29. Please provide the number of times you are physically active for 20 minutes, or more, in cardiovascular, weight training, or active stretching activities, per week.**

	Percentage	Qty
0	14.20	25
1-2	19.89	35
3-4	30.11	53
5-7	25.57	45
8+	10.80	19

**#30. Please provide the number of times you feel isolated or lonely per week.**

	Percentage	Qty
0	44.51	77
1-2	27.17	47
3-4	10.98	19
5-7	9.25	16
8+	8.09	14

**#31. Check those you, overall, have adequate financial resources for of the following:**

	Percentage	Qty
Regular primary care visits	87.65	149
Regular visits with a Neurologist or specialist	81.76	139
Your prescriptions	89.41	152
Regular neuro-specific rehabilitation (Physical therapy, occupational therapy, or speech therapy)	54.12	92
Mental health services	44.12	75
Regular counseling	37.06	63

Groceries	87.06	148
Rent/mortgage payments	83.53	142
Utilities	85.88	146
Wheel chair services and upgrades	28.82	49
Other devices to aid independence	31.76	54
Technology to aid independence	29.41	50

**#32. Do you have the opportunity to be in clinical trials?**

	Percentage	Qty
Yes	61.99	106
No	38.01	65

**#33. If clinical trials were available, would you be interested in participating? (Please note, we do not have knowledge of what individuals answer this question, so you would not be contacted for a trial by your answer to this question.)**

	Percentage	Qty
Yes	82.56	142
No	17.44	30

**#34. Do you have access to medical updates specific to your disease?**

	Percentage	Qty
Yes	73.99	128
No	26.01	45

**#35. Is there anything else you'd like us to be aware of?**

Some responses:

“It would be helpful for all doctors that treat any patient that has had brain surgery or any brain disease to be referred for physical, speech and occupational therapists as soon as the patient can get in. The patient may need only one therapy, but they may not know unless they are evaluated.”

“It would be extremely beneficial to have a stroke survivor mentor a new patient at beginning stage of treatment. No offense to professionals but, a survivor can relate better than anyone to this life altering event. It helps to know you're not alone.”

“As a person with open head injury and brain damage since 1986 I have not found any help with living with brain damage as you age? I would love this help as I suffer with memory problems and it is getting worse as I age. I cannot find any help with this in Colorado Springs and I have tried to find it.”

“I did 7 months of cognitive skill therapy with CNI & Porter Hosp., July 2008-Feb. 2009. Then I realized I needed anger mgt. and learning to socialize again skills. They were not part of CNI's programs.”

“CNI helped teach me details about stroke that were valuable - and I am happy volunteering to tell my story.”

“Support means so much to me. It can feel very scary to have my disease.”

“Tech for cell phone of my kind of typing”

“no support for those who are not married / no children / no family support. No free / low cost social activities on a regular basis”

“People with no family or friends need more/better support or they have no hope for a quality of life and it makes chronic illness that much worse”

“tough to get connected to a neuro community before going "public" with diagnosis. Cannot join chat rooms or post with my email - and attending would risk seeing someone I know from large workplace”

“Short term memory and cognitive skills are rarely addressed with ms. I don't look like I have ms, but dang it I do. These symptoms need more clinical trials and need to be addressed more.”

“I feel very safe given the treatment I receive from CNI employees.”

“please start to focus research and assistance for the 80% or more of people who are "chronically" homeless because we can't get treatment or supports for our brain injuries, hydrocephalus, etc, and become homeless as a result of family and societal neglect and abuse and we need help to get off the streets and to not die out here. PLEASE DON'T IGNORE US OR FIGURE THAT SOMEONE ELSE OR SOME OTHER AGENCY WILL CARE FOR US BECAUSE THEY DO NOT AND WE WIND UP HOMELESS FOR YEARS AND YEARS OR DEAD OR IN JAIL AND PRISON> WE NEED HELP AND SUPPORTS FOR BASIC NEEDS AND BRAIN INJURY REHAB AND SCHOOL?HIGHER EDUCATION?TRADES AND FULL COMMUNITY INCLUSION NOT SEGREGATED TO THE STREETS OR JAILS OR PRISONS OR MENTAL INSTITUTIONS OR EARLY DEATH> thank you.”

“I think part of the problem is knowing what resources are available in the community for people with hearing loss as audiologists don't have any information to share.”

“When Brain injuries involve the brain stem, the whole body is affected. I don't see those issues being addressed at all. Additionally since I was very high functioning before my accident and have good days and bad days, it is not recognized the complex needs I have...for instance difficulty swallowing, knowing when I need oxygen.”

“relative to clinical trials, it seems as though many exclude patients because of the meds they are on, yet the researchers complain that they have very few participants - catch 22.”

**Responses:** (the 23 most frequent words or phrases)

Answer, Assistance, Binaural Cochlear Implants, Brain Injuries, Chronic Illness, Clinical Trials, CNI Dedicated, Denver, Effects, Look, Makes, Met, Patients, Public, Responses, Services, Support, Survey, Therapy, Think, Treatment, Understand



## Appendix B

Care Giver Respondent Characteristics:

### **#36. As a Care Giver, what year did your patient/loved one receive diagnosis of a neurological disease and what disease was the diagnosis for?**

**Responses:** (the 12 most frequent words or phrases)

Alzheimers, Ataxia, Bilateral Hearing Loss, Deafness, Dementia, Diagnosis, Disease, Epilepsy, GBM, Months, PSP, Stroke

### **#37. As a Care Giver, rate yourself in the following areas:**

	Very poor	Poor	Good	Very good	Excellent	Total	Ave. rating (out of 5)
Knowledge of the specific neurological disease of your patient/loved one	1.11% 1	5.56% 5	31.11% 28	40% 36	22.22% 20	90	3.77
Medical/Physical health	0.00% 0	5.56% 5	40% 36	32.22% 29	22.22% 20	90	3.71
Social/Emotional health	2.20% 2	6.59% 6	45.05% 41	29.67% 27	16.48% 15	91	3.52

### **#38. Click on the top three neurological needs in your community.**

	Percentage	Qty
Connecting with community resources	50.00	46
Support groups	47.83	44
Stress management	43.48	40
Care from a specialist	38.04	35
Education on the chronic disease you treat	33.70	31
Dealing with public programs	25.00	23
Medication	22.83	21
Meeting basic needs	15.22	14
Transportation	14.13	13
Other	11.96	11

### **#39. If the above services were offered by computer video or webinar, would you use them?**

	Percentage	Qty
Yes	76.14	67
No	23.86	21

**Responses:** (the 4 most frequent words or phrases)

Community Resources, Education, Programs, Support

**#40. Does distance from adequate neurological services, support and resources keep your patient/loved one from receiving services?**

	Percentage	Qty
No	90.11	82
Yes	9.89	9

**#41. Does your patient/loved have access to a general Neurologist?**

	Percentage	Qty
Yes	93.33	84
No	6.67	6

**#42. Does your patient/loved one have access to a specialty neurologist for treatment of their specific neurological disease?**

	Percentage	Qty
Yes	86.67	78
No	13.33	12

**#43. Check those areas in which your patient/loved one has access to neurospecific care:**

	Percentage	Qty
Physical Therapy	77.22	61
Speech Therapy	67.09	53
Occupational Therapy	53.16	42
Medication Management	44.3	35
Counseling and psychological therapy	34.18	27
Nutrition Counseling	27.85	22
Driving Testing	15.19	12

**#44. If the above services were offered by computer video or webinar, would you use them?**

	Percentage	No
Yes	55.68	49
No	44.32	39

**#45. As a Care Giver, do you feel isolated and lonely? Yes or No.**

	Percentage	Qty
Yes	50.56	45
No	49.44	44

**#46. As a Care Giver, check those areas your patient/loved one has access to neurospecific care:**

	Never	Some of the time	Most of the time	All the time	Total	Ave. rating (out of 4)
adequate counseling services	27.59% 24	34.48% 30	28.74% 25	9.20% 8	87	2.20
adequate resources to help with family challenges	21.18% 18	42.35% 36	27.06% 23	9.41% 8	85	2.25
adequate mental health services such including pharmaceutical and/or formalized therapy	21.59% 19	39.77% 35	27.27% 24	11.36% 10	88	2.28
adequate support groups	23.86% 21	32.95% 29	30.68% 27	12.50% 11	88	2.32
adequate resources to manage your stress	24.14% 21	39.08% 34	29.89% 26	6.90% 6	87	2.20

**#47. If the above services were offered by computer video or webinar, would you use them?**

	Percentage	Qty
Yes	50.00	44
No	50	44

**Comments:** (the 4 most frequent words or phrases)  
Counseling, Resources, Stress Management, Support Groups

**#48. Where do you receive your disease specific health education for your patient/loved one regarding their condition? Please check the top three.**

	Percentage	Qty
Specialist	70.33	64
Internet	63.74	58
Conferences and Seminars	36.26	33
Other	36.26	33
Books	32.97	30
Primary Care Doctor	29.67	27
Community Events	8.79	8
Other	5.49	5

**Responses: (the 5 most frequent words or phrases)**

Alzheimer's Association, Care, Home Health, Parents, Support Group

**#49. Check the areas in which you are adequately informed:**

	Percentage	Qty
Medications and side effects	71.62	53
Chronic disease management	45.95	34
Recent and relevant disease specific information	36.49	27
Home modification to accommodate physical needs	32.43	24
Disability and insurance programs	27.03	20
Alternative treatments and approaches	25.68	19
Home health resources	25.68	19
Home upkeep	21.62	16
State of the art neuro practice	20.27	15
Available research protocols	20.27	15
Transportation resources	14.86	11
Legal services	10.81	8

**#50. Do you have other health educational needs regarding your patient/loved ones condition?**

	Percentage	Qty
No	70.00	56
Yes	30.00	24

**Comments:** (7 most frequent words and phrases)

Care, Disability, Financial, Learning ,Needs, Programs, Side Effects

**#51. Does your patient/loved one have access to the following?**

	Never	Some of the time	Most of the time	All the time	Total	Ave. rating (out of 4)
A community center or recreation center with adequate and appropriate programs?	32.58% 29	33.71% 30	13.48% 12	20.22% 18	89	2.21
A church or other spiritual "home" with adequate and appropriate programs?	41.67% 35	20.24% 17	19.05% 16	19.05% 16	84	2.15
Clubs, service groups, or social groups?	32.18% 28	40.23% 35	16.09% 14	11.49% 10	87	2.07
Webinars, chat groups or social media platforms?	59.09% 52	29.55% 26	9.09% 8	2.27% 2	88	1.55

**#52. Do you attend a support group?**

	Percentage	Qty
Yes	53.33	48
No	46.67	42

**#53. Please provide the number of times your patient/loved one leaves their home weekly.**

	Percentage	Qty
0	7.78	7
1-2	14.44	13
3-4	24.44	22
5-7	27.78	25
8+	26.67	24

**#54. Please provide the number of times your patient/loved one is physically active for 20 minutes, or more, in cardiovascular, weight training, or active stretching activities, per week.**

	Percentage	Qty
0	15.56	14
1-2	28.89	26
3-4	21.11	19
5-7	18.89	17
8+	16.67	15

**#55. In your opinion, does your patient/loved one feel isolated or lonely?**

	Percentage	Qty
Yes	52.81	47
No	47.19	42

**#56. Check those your patient/loved one, overall, has adequate financial resources for of the following:**

	Percentage	Qty
Prescriptions	92.94	79
Regular primary care visits	91.76	78
Regular visits with a Neurologist or specialist	90.59	77
Groceries	82.35	70
Utilities	74.12	63
Regular neuro-specific rehabilitation (Physical therapy, occupational therapy, speech therapy)	70.59	60
Regular neuro-specific rehabilitation (Physical therapy, occupational therapy, speech therapy)	70.59	60
Rent/mortgage payments	70.59	60
Other devices to aid independence	47.06	40
Technology to aid independence	44.71	38
Wheel chair services and upgrades	42.35	36
Mental health services	38.82	33
Regular counseling	37.65	32

**#57. Do you have access to medical updates specific to the disease(s) you treat?**

	Percentage	Qty
Yes	69.41	59
No	30.59	26

**#58. Is there anything else you'd like us to be aware of?**

**Responses:** (the 16 most frequent words and phrases)

Some Responses:

Care, Child, Dementia, Disease, Job, Level, Limited, Medications, Needs, Patients, Physically, Research, Savvy, Situation, Specialist, Support Group

“Patient's activity level limited by snow on sidewalks. He was attending the gym more regularly when the weather was warmer.”

“Critical needs: care giver support and training for progressive MS patients, insurance counseling and support, legal counseling.”

“As a care giver this disease is not only killing her but taking its toll on me as well. It would be nice to have a list of people (CNA) which could be hired independently to avoid the high cost of going thru an agency.”

“Although we have access to these things, we are unable to take advantage of them. My mother is with Innovage, but has dementia complicating her Parkinson's. Because Innovage requires her to come to their center to see any specialist, and doing so requires either me taking her (I work) or her taking their bus and staying several hours, she does not have the stamina (physically or emotionally) to do this often. As for me, I have found that a support group for myself has been very difficult to find, as they are either set up to include both the care giver and the patient, or they are too far from my home to make regular attendance possible.”

“Some kind of index or directory of Alzheimer's Research Studies and Opportunities, what their targets are, and who their sponsors are, etc.”

“need a PSP, MSA support group”

“we travel 50 miles for most service. many things have changed in the 26 years that we have been on this journey. my son has moved to a larger community, had a solid deaf community, has made amazing use of his cochlear implant, what a blessing. has a job and is an active member of the community. His cochlear implant has made much of this possible. raising a deaf child (even with a CI) in a rural environment is hard.”

“Additional information on latest medications and what research is taking place for Dementia and Alzheimer's.”

“We need a support groups for kids with disabilities, regular schools with teachers with more education about kids with special needs, support and educational groups for parents, parks where they can play safely.”

“My son ignores his condition but realizes he needs help for many daily living needs. Cooking paying bills etc. dealing with medications medicaid and all the legal issues is overwhelming for me. He seems to only want support from me and being alone don't have anyone to get support from.”

“We need more options for day programs near where we live with staff who "get it" and are respectful to the patient with Alzheimer's diagnosis. Care givers are in doer are beef if support.”

“Bringing more public awareness to dementia and Alzheimer's. 90% of the people I talk to know of or are taking care of someone with the disease, and most know very little how to handle it. There are very few resources available other than the Alzheimer's Association the provide information. Most of us stumble into the disease and miss all of the early signs and stages and are uninformed as to what to do.”

“We are doing fine as long as I do everything. He is thriving with a one to one situation and I sometimes feel I am drowning.”

“I have found that there is no "one stop shopping" for information- most if the resources I discovered through word of mouth or after a situation occurred and we were desperate for services. I wish there was a specialist that could coordinate/recommend people/services. I have been on the lookout for an occupational therapist that makes home visits for months now and still am unable to find.”

## **Appendix C**

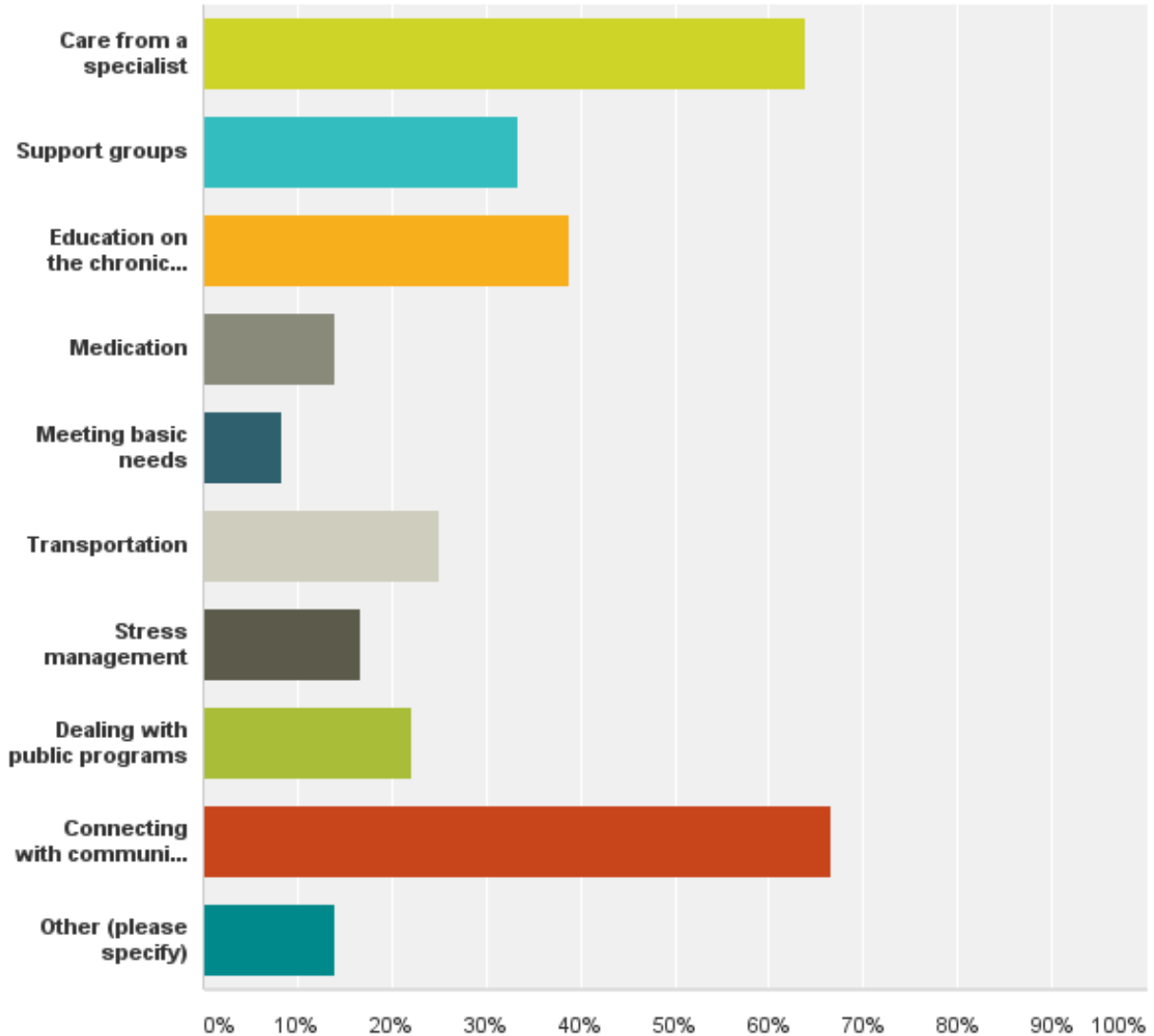
Health Care Provider Respondent Characteristics:

### **#59. Click on the top three neurological needs in your community.**

	Percentage	Qty
Connecting with community resources	66.67	24
Care from a specialist	63.89	23
Education on the chronic disease(s) you treat	38.89	14
Support groups	33.33	12
Transportation	25.00	9
Dealing with public programs	22.22	8
Stress management	16.67	6
Medication	13.89	5
Other	13.89	5
Meeting basic needs	8.33	3

## Q59 Click on the top three neurological needs in your community.

Answered: 36 Skipped: 396



### **#60. Does distance from adequate neurological services, support and resources keep your patient(s) from receiving services?**

	Percentage	Qty
Yes	63.89	23
No	36.11	13



**#61. As a Health Care Provider/Professional, do you have regular access to a general Neurologist?**

	Percentage	Qty
Yes	80.56	29
No	19.44	7

**#62. Do you have regular access to a specialist for specific neurological diseases?**

	Percentage	Qty
Yes	66.67	24
No	33.33	12

**#63. Check those areas your patients have access to neurospecific care:**

	Percentage	Qty
Physical therapy	100.00	33
Speech therapy	96.97	32
Occupational therapy	93.94	31
Medication management	66.67	22
Driving testing	57.58	19
Nutrition counseling	57.58	19
Counseling and psychological therapy	51.52	17

**#64. If the above services were offered by computer video or webinar, would your patients use them?**

	Percentage	Qty
Yes	53.13	17
No	46.88	15

**#65. Where do you receive most of your medical/health education for yourself or your patients? Please check the top three.**

	Percentage	Qty
Conferences and Seminars	80.56	29
Internet	77.78	28
Community Events	33.33	12
Books	25.00	9
Sub Specialist	13.89	5
Other	11.11	4

**#66. For your patients, check the areas you have adequate information on:**

	Percentage	Qty
Chronic disease management	63.33	19
Medications and side effects	63.33	19
Home health resources	63.33	19
Recent and relevant disease specific information	56.67	17
State of the art neuro practice	33.33	10
Home remodel to accommodate physical needs	26.67	8
Disability and insurance programs	23.33	7
Transportation	23.33	7
Available research protocols	20.00	6
Legal services	20.00	6
Home upkeep	16.67	5
Alternative treatments and approaches	13.33	4

**#67. Do your patients have access to the following?**

	Never	Some of the time	Most of the time	All the Time	Total	Ave. rating (out of 4)
A community center or rec center with adequate and appropriate programs to meet the needs of a neurological patient?	2.86% 1	68.57% 24	22.86% 8	5.71% 2	35	2.31
Clubs, service groups, or social groups that meet the needs of a neurological patient?	5.88% 2	70.59% 24	20.59% 7	2.94% 1	34	2.21
A church or other spiritual "home" with adequate and appropriate programs to meet the needs of a neurological patient?	11.76% 4	67.65% 23	14.71% 5	5.88% 2	34	2.15
Webinars, chat groups or social media platforms that meet the needs of a neurological patient?	15.15% 5	66.67% 22	15.15% 5	3.03% 1	33	2.06

**#68. Do patients with neurological issues in your area leave their home enough?**

	Percentage	Qty
No	70.97	22
Yes	29.03%	9

**#69. Do patients with neurological issues in your area exercise enough?**

	Percentage	Qty
No	82.76	24
Yes	17.24	5

**#70. Do your patients feel isolated or lonely?**

	Percentage	Qty
Yes	84.85	28
No	15.15	5

**#71. Check those areas your patients, overall, have adequate financial resources for of the following:**

	Percentage	Qty
Regular primary care visits	92.86	26
Regular visits with a Neurologist or specialist	64.29	18
Groceries	57.14	16
Your prescriptions	46.43	13
Utilities	42.86	12
Regular neuro-specific rehabilitation (Physical therapy, occupational therapy, or speech therapy)	39.29	11
Rent/mortgage payments	39.29	11
Mental health services	25.00	7
Regular counseling	21.43	6
Wheel chair services and upgrades	14.29	4
Other devices to aid independence	7.14	2
Technology to aid independence	7.14	2

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