

# *Evaluating a Financial Assistance Program for People Living with Multiple Sclerosis*

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## **Abstract**

Worldwide, an estimated 2.3 million people are living with multiple sclerosis (MS). MS is an immune-mediated disease whereby myelin surrounding nerves degenerates and disrupts nerve signaling. Scar tissue plaques form and are referred to as sclerosis. People living with MS experience a wide and varied range of symptoms that can affect how they engage within society. The Financial Assistance Program offered by the National MS Society is intended to provide guidance, support, and resources to help manage the financial impact of MS. The goals of the intervention are to improve independence, safety, health, and quality of life for clients. This study is an evaluation of the Financial Assistance Program offered by the National MS Society, Greater Northwest Chapter. A survey including scaled and open-ended questions assessing the perceived impact of the program was utilized to gather data. Outcome measures included self-efficacy in advocating for needs, awareness of community resources, independent living, and perceptions of impact on family and friends. Survey results offer a nuanced understanding of the Financial Assistance Program. Clients indicated a difference in perceived impact between critical short-term needs and more sustainable forms assistance. Financial assistance eased stress on relationships with clients' friends and families. Qualitative evidence suggested that support group members act as ambassadors within their communities to spread awareness about MS and the mission of the National MS Society. Also, gym memberships are utilized by clients to improve physical and mental health as well as improve their perceived social support. Gym memberships, access to swimming pools, and yoga classes are utilized by clients as substitutions for physical therapy and more expensive medical interventions. Additional engagement of clients' families and friends could broaden the impact of the Financial Assistance Program. Finally, assistance for housing and utilities is a major concern for people living with MS. This program evaluation will inform improvement and expansion of the Financial Assistance Program at the National MS Society, Greater Northwest Chapter and identify areas in which policy efforts from the organization could improve the lives of people living with MS within the Chapter.

## **Introduction**

Multiple sclerosis (MS) is an immune-mediated disease whereby myelin surrounding nerves degenerates, disrupts nerve signaling, and forms scar tissue plaques, referred to as sclerosis (National Multiple Sclerosis Society 2014a). There are currently an estimated 2.3 million people living with multiple sclerosis worldwide (National Multiple Sclerosis Society 2014h). People living with multiple sclerosis can experience a wide range of symptoms including balance and gait issues, fatigue, vertigo and dizziness, cognitive sensory problems, tremors, and visual impairment. These symptoms can affect how individuals living with MS engage in society (National Multiple Sclerosis Society 2014g).

The National Multiple Sclerosis Society, Greater Northwest Chapter, is a tax-exempt, charitable organization under section 501(c)(3) of the Internal Revenue Code dedicated to addressing the needs of people affected by MS and researching for a cure (Internal Revenue Service 2014a); its TIN/EIN is 91-0742424 (National Multiple Sclerosis Society 2014c). The vision of the National MS Society is "a world free of MS," and its mission is to "mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS" (National Multiple Sclerosis Society 2014f).

Regionally, the National MS Society, Greater Northwest Chapter, serves 15,000 people living with MS and 89,000 friends, family members and caregivers in Alaska, Northern Idaho, Montana, and Washington (National Multiple Sclerosis Society 2014d). In 2013, the National MS Society, Greater Northwest Chapter, raised approximately \$9 million dollars in revenue mostly through annual fundraising events such as Bike MS, which raised \$2,053,656, Walk MS, which raised \$1,919,794, Dinner of Champions, which raised \$837,084, and On the Move Luncheon, which raised \$412,035 (National Multiple Sclerosis Society 2014f). Other revenue was raised through individual giving, do-it-yourself fundraising events, and other income (National Multiple Sclerosis Society 2014f). The Greater Northwest Chapter directs this revenue toward research (26%), administration and fundraising (18%), a reserve for future years (5%), and programs and services such as the Financial Assistance Program (51%) (National Multiple Sclerosis Society 2014f).

Each chapter of the National MS Society offers the Financial Assistance Program as an intervention with goals of providing guidance, support, and resources to help manage the financial impact of MS. The intervention is aimed at supporting independence, safety, health and quality of life for clients. People living with MS can access the Financial Assistance Program offered by the National MS Society for “respite services such as short term home care, durable medical equipment and air conditioners, accessibility modifications to homes or automobiles such as ramps and hand controls, transportation to medical appointments, critical short term needs such as emergency help with utilities or rent, and health and wellness support” (National Multiple Sclerosis Society 2014b). Health and wellness support can include gym memberships, yoga classes, community pool memberships, and mental health counseling services. This article reports on a program evaluation aimed to assess the impact of the Financial Assistance Program administered through the National MS Society, Greater Northwest Chapter

## **Methods**

### *Participants*

This program evaluation is listed as Human Subjects Division Study #47397 with the University of Washington Institutional Review Board and has been given the determination of Category 2 exempt status in accordance with federal regulations under 45 CFR 46.101/ 21 CFR 56.104.

Study participants were adults living with multiple sclerosis (MS) within the Greater Northwest Chapter who received financial assistance between October 1, 2013 and March 31, 2014. Clients who did not meet these criteria were excluded from participation in the survey. A total of 165 potential participants were identified from the National MS Society, Greater Northwest Chapter’s agency records (National Multiple Sclerosis Society 2014d). Subjects were approached, informed about the research, and invited to participate via email and telephone.

Subjects were informed that they were being asked to participate in the survey because the National MS Society recently assisted them through its Financial Assistance Program. Clients were informed that the goal of the program was to provide guidance, support, and resources to help manage the financial impact of MS and that their participation in the survey would help the National MS Society evaluate and improve the program. If subjects agreed to

participate, they were asked to answer all of the questions as completely as possible, considering the effects and impact of the assistance they received.

### *Instrumentation*

The study was administered to clients through a survey. The survey was used to gather data on attitudes, impressions, experiences, opinions, and satisfaction level on the National MS Society's Financial Assistance Program. The National MS Society developed the survey for the purpose of evaluating the Financial Assistance Program. The survey previously used to evaluate the Financial Assistance Program had focused on client satisfaction with the National MS Society staff and level of support they received. Clients are consistently pleased with National MS Society staff. To achieve a better assessment of impact and identify potential areas for improvement and expansion, the survey was modified by adding three open-ended questions: 1) How has receiving financial assistance impacted your quality of life and wellbeing? 2) What has receiving financial assistance allowed you to do that you would not have been able to do otherwise? 3) Where do you see gaps in resources or funding for people who are living with multiple sclerosis in your community?

Scaled questions related to demographics, client's relationship with MS, how the client became involved with the National MS Society, perceptions of vendors/service providers, and quality of interactions with National MS Society staff members and the application process were included in the survey. Clients were also asked to report how the financial assistance they received impacted perceptions of their safety, social support, independence, wellbeing, and ability to advocate for themselves. Other questions evaluated the ability of the National MS Society to help clients think about and obtain long-term, sustainable solutions to their needs. In addition to evaluating the impact of the financial assistance program on the individual, the survey also examined the impact the financial assistance has had on the client's friends and family.

The survey was administered to clients with an internet-based service and through telephone interviews based on participant preference and access to the internet. Survey responses were collected between May 2014 and June 2014.

### *Ethics*

*Protection of participants and information.* The primary investigator administered all requests for participation and surveys. Subjects were informed that their answers will not affect the services they receive in the future. No children were included as participants in this study, and there were no foreseeable risks to subjects who participated. The primary investigator and colleagues at the National MS Society, Greater Northwest Chapter were the only people with access to the data. In addition, the data is secured, and there is no way to identify participants from completed survey forms. Study participants were asked for their consent for the National MS Society to quote their responses to open-ended questions. If consent was given, names are not associated with the quotes.

### *Analysis*

Results were reported at the aggregate level, with the exception of several responses to open-ended questions from clients who consented to be quoted that were selected as representative

samples of the qualitative data. Scaled responses were analyzed by stating percentages for each response and levels of confidence at which these percentages can be reported.

### *Generalizability*

Although this study was specific to the National MS Society, Greater Northwest Chapter, some information obtained may be translated more broadly to national and global populations of individuals living with MS.

## **Results**

### *Accuracy*

There were 165 clients who accessed the Financial Assistance Program at the Greater Northwest Chapter during the first half of the 2013-2014 fiscal year, between October 1, 2013 and March 31, 2014. These 165 clients were identified as the population of potential participants. A total of 83 (N= 83) people completed the “Impact of the Financial Assistance Program” survey, yielding a response rate of 50.3%. At a 95% confidence level, this sample size signifies a confidence interval of 7.6%. The magnitude of the confidence interval (CI) increased for certain demographic questions that were skipped by some of the participants.

### *Survey Duration*

Although there is no way to quantify the length of time spent by clients who completed the survey independently via internet, the duration of interviews administered over the phone was between 10 to 50 minutes depending on the level of detail provided in responses to open-ended survey questions.

### *Participants*

All participants were people living with multiple sclerosis (MS). Their friends, family members, spouses, or caregivers did not complete the surveys for them, although this option was available to encourage participation from clients living with MS who did not feel well enough to complete the survey themselves.

### *Client Information*

Client information obtained during this study included gender, age, race, access to health insurance, and how long clients have lived with a diagnosis of MS.

*Gender.* When asked to report their gender, 3 participants, 3.6% (CI: 7.6), opted to skip the question, 17 identified as male, and 63 identified as female. This indicates that 20.5% (CI: 7.6) of the entire population identified as male and 75.9% (CI: 7.6) identified as female at a confidence level of 95%. No respondents identified as transgendered.

*Age.* No participants reported they were under the age of 20 years old. Clients between the ages of 21 and 30 who accessed the Financial Assistance Program accounted for 1.2% (CI: 7.6) of the population. Clients between the ages of 31 and 40 were 10.8% (CI: 7.6) of the population. Clients between the ages of 41 and 50 were 33.7% (CI: 7.6) of the population. Clients between the ages of 51 and 60 represented 30.1% (CI: 7.6) of the population. Clients above the age of 61 represented 24.1% (CI: 7.6) of the population.

*Race.* Racial and ethnic identities of clients were also collected. Of those who participated in the survey, 93.6% (CI: 8.2) identified as white/European American, 3.9% (CI: 8.2) identified as Black/African American, 2.5% (CI: 7.8) identified as Hispanic or Latino origin or descent. There were no respondents who identified as Native Hawaiian/Pacific Islander, American Indian/Native American, or Asian/Asian American.

*Health insurance.* Health insurance is typically necessary in order for people living with MS to receive the medical care and treatment they need. Of the National MS Society clients who received financial assistance during the first half of the 2013-2014 fiscal year, 96.4% (CI: 7.6) had health insurance and the remaining 3.6% (CI: 7.6) did not. Medicare and Medicaid were the most common providers of health insurance listed by participants who had coverage.

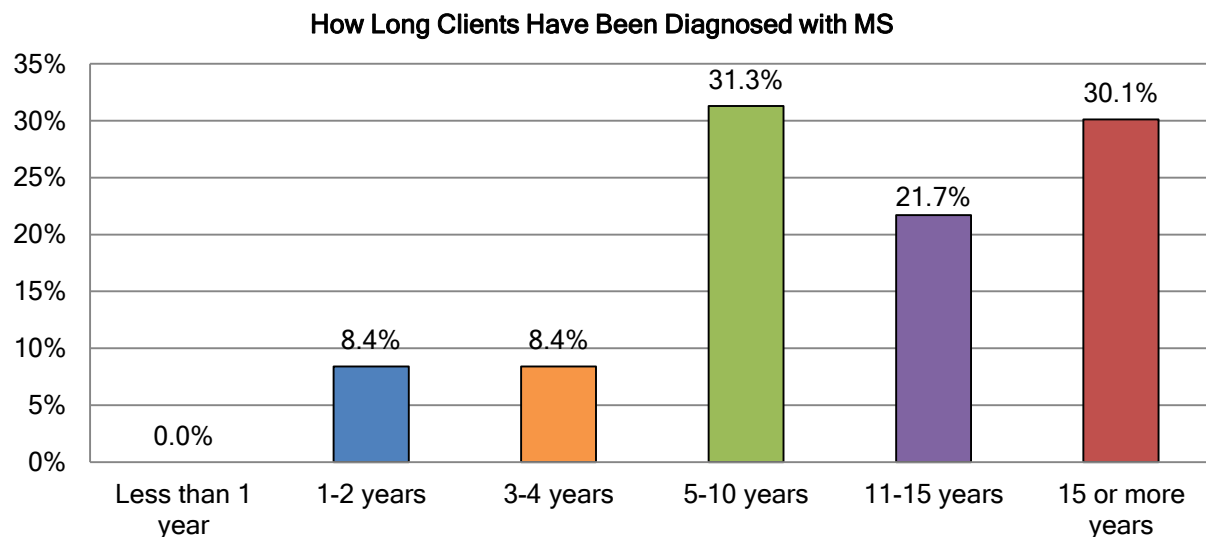


Figure 1, How Long Clients Have Been Diagnosed with MS.

Figure 1 illustrates the length of time clients who received financial assistance within the first half of the 2013-2014 fiscal year had been living with a diagnosis of MS. None of the clients had been diagnosed with MS within that year. Clients who had been living with a diagnosis of MS for 1 to 2 years represented 8.4% (CI: 7.6) of the population, clients who had been living with a diagnosis of MS for 3 to 4 years also represented 8.4% (CI: 7.6) of the population. Clients who had been living with a diagnosis of MS for 5 to 10 years accounted for 31.3% (CI: 7.6) of the population. Clients who had been living with a diagnosis of MS for 11 to 15 years consisted of 21.7% (CI: 7.6). Clients who had been living with a diagnosis of MS 15 years or more consisted of 30.1% (CI: 7.6) of the population.

## Client Experience

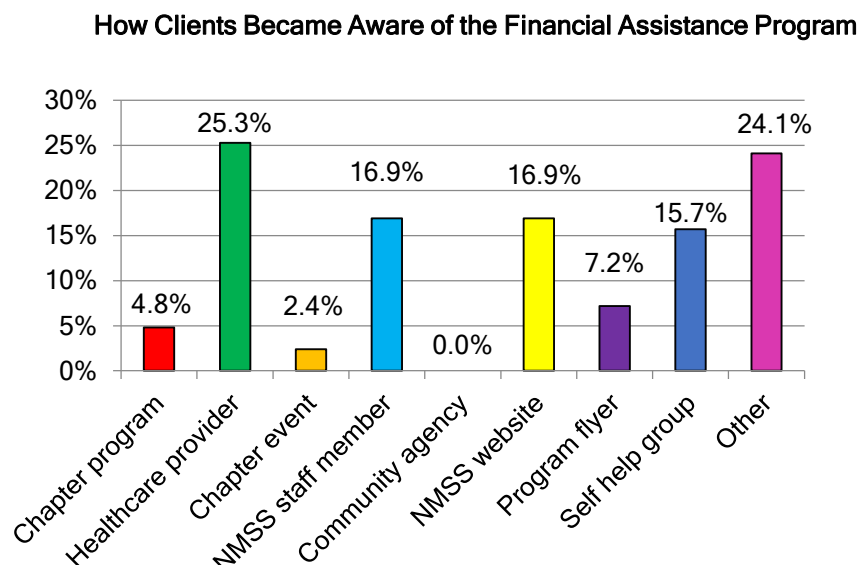


Figure 2, How Clients Became Aware of the Financial Assistance Program.

There were several ways clients learned about the Financial Assistance Program. As Figure 2 illustrates, 4.8% (CI: 7.6) heard about the Financial Assistance Program from a Chapter program, 25.3% (CI: 7.6) from their healthcare provider, 2.4% (CI: 7.6) from a chapter event, 16.9% (CI: 7.6) from a National MS Society staff member, 0.0% (CI: 7.6) from a community agency, 16.9% (CI: 7.6) from the National MS Society web site, 7.2% (CI: 7.6) from a Financial Assistance Program brochure, 15.7% (CI: 7.6) from a self-help group, and 24.1% (CI: 7.6) from another source. The most common sources of awareness within the other category were obtained from optional write-in responses and included: calling the National MS Society (3 respondents), the National MS Society's magazine (4 respondents), and dialing 211 for community information (3 respondents).

As Figure 3 illustrates, funds from the National MS Society were utilized by 3.6% (CI: 7.6) of clients for accessibility modifications, by 37.4% (CI: 7.6) for critical short term needs such as assistance with rent and utilities, by 8.4% (CI: 7.6) for durable medical equipment, by 55.4% (CI: 7.6) for health and wellness needs, by 2.4% (CI: 7.6) for respite services, and by 4.8% (CI: 7.6) for transportation.

Participants reported utilizing financial assistance for obtaining goods and services from a variety of vendors and service providers including the YMCA, utility companies, and mental health counselors. Among clients accessing financial assistance, 92.5% (CI: 7.9) were satisfied with the vendor from which goods or services were obtained. The remaining 5.0% (CI: 7.9) of the population was somewhat satisfied, and 2.5% (CI: 7.9) of the population was unsatisfied.

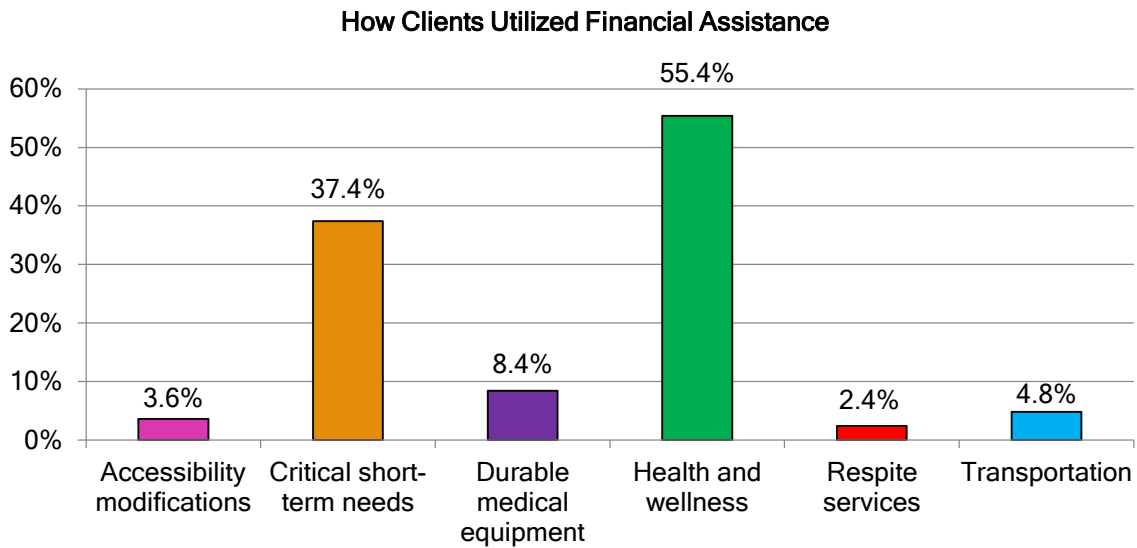


Figure 3, How Clients Utilized Financial Assistance.

*Experience with staff and application process.* Figure 4 illustrates client experience with the Financial Assistance Program application process at the National MS Society, Greater Northwest Chapter. Table A1 provides additional supporting data. When asked to rate their agreement with whether National MS Society staff working in the Financial Assistance Program responded quickly, 90.1% (CI: 7.6) of clients who accessed the Financial Assistance Program in the first half of the 2013-2014 fiscal year either agreed or strongly agreed. The level of client agreement and strong agreement that National MS Society staff working in the Financial Assistance Program showed them courtesy and respect was 95.2% (CI: 7.6). Clients who either agreed or strongly agreed when asked whether the Financial Assistance Program staff explained things in ways that were easy to understand was 95.2% (CI: 7.6) of the population. When asked to rate their agreement with whether the National MS Society staff explored other resources with them, 65.1% (CI: 7.6) of clients either agreed or strongly agreed and 14.5% (CI: 7.6) indicated the statement was not applicable. When asked to rate their agreement with whether the Financial Assistance Program application forms were easy to fill out, 84.4% (CI: 7.6) of clients either agreed or strongly agreed and 3.6% (CI: 7.6) indicated the statement was not applicable. Clients who agreed or strongly agreed that they were satisfied with the application process overall totaled 91.6% (CI: 7.6) of the population.

#### *Impact*

*Impact on client.* Figure 5 illustrates the perceived impact the Financial Assistance Program on clients who received funding during the first half of the fiscal year and is supported by data provided in Table A2 and Table A3. Results indicated 56.7% (CI: 7.6) either agreed or strongly agreed that receiving financial assistance helped them be more mobile, and 28.9% (CI: 7.6) responded that the statement was not applicable. Additionally, 22.9% (CI: 7.6) of participants reported improved accessibility of their home or car, and 63.9% (CI: 7.6) reported the statement

being not applicable. About 62.7% (CI: 7.6) of clients stated they either agreed or strongly agreed that receiving financial assistance helped them be more independent, and the statement did not apply to 25.0% (CI: 7.6). Clients who agreed or strongly agreed that receiving financial assistance helped them learn about other National MS Society, Greater Northwest Chapter services accounted for 50.6% (CI: 7.6). Participants who agreed or strongly agreed that receiving financial assistance helped them cope better with their situation accounted for 83.2% (CI: 7.6) of the population. Of the clients surveyed, 84.4% (CI: 7.6) reported they agree or strongly agree that the financial assistance improved their quality of life. When asked whether receiving assistance helped them feel less alone when dealing with MS, 75.9% (CI: 7.6) agreed or strongly agreed with the statement. Additionally, 28.9% (CI: 7.6) of clients agreed or strongly agreed that receiving assistance improved their access to medical care, and the statement did not apply to 53.0% (CI: 7.6) of clients. When clients were asked to rate their agreement that receiving financial assistance made them feel more confident advocating for their needs, 71.1% (CI: 7.6) agreed or strongly agreed with the statement. Clients who agreed or strongly agreed that engaging with the Financial Assistance Program helped them increase their awareness of other community resources equaled 65.1% (CI: 7.6) of the respondents. Also, 57.8% (CI: 7.6) of clients agreed or strongly agreed that the Financial Assistance Program helped them think about long-term solutions to their needs. Clients who agreed or strongly agreed that the program helped clients find sustainable solutions to their needs totaled 53.0%. (CI: 7.6), and the statement did not apply to 22.9% (CI: 7.6) of participants. Notably, 12.0% of participants either disagreed or strongly disagreed that the program helped them find sustainable solutions to their needs. Combined levels of disagreement and strong disagreement did not exceed 10% in any other category within this section of the questionnaire. Disagreement and strong disagreement was also relatively high (8.4%) in comparison to other categories when clients were asked whether the Financial Assistance Program helped them think about long-term solutions to their needs and when asked whether the program helped them learn about other chapter services.



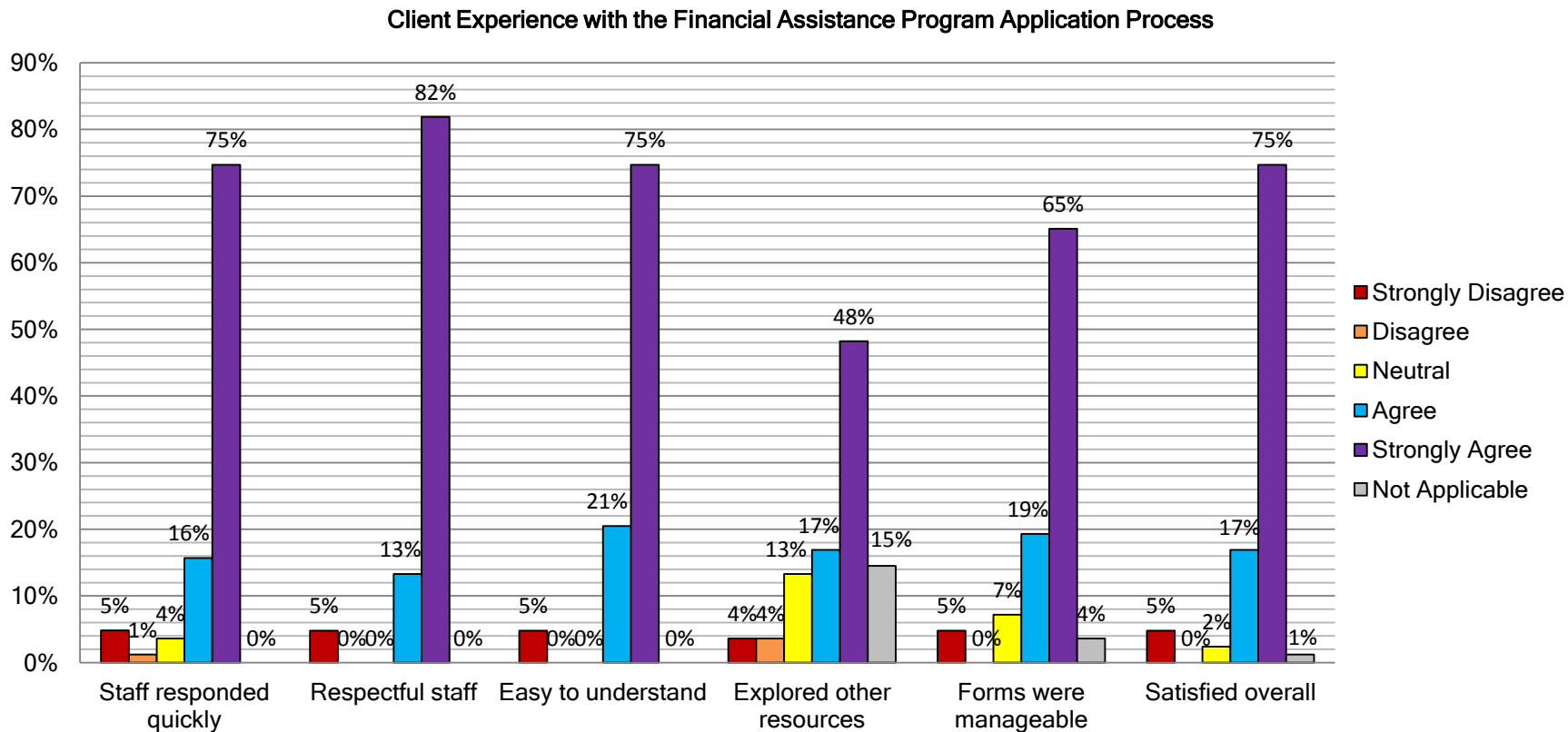


Figure 4, Client Experience with the Financial Assistance Program Application Process.

*Impact on clients.*

Impact of Financial Assistance Program on Clients

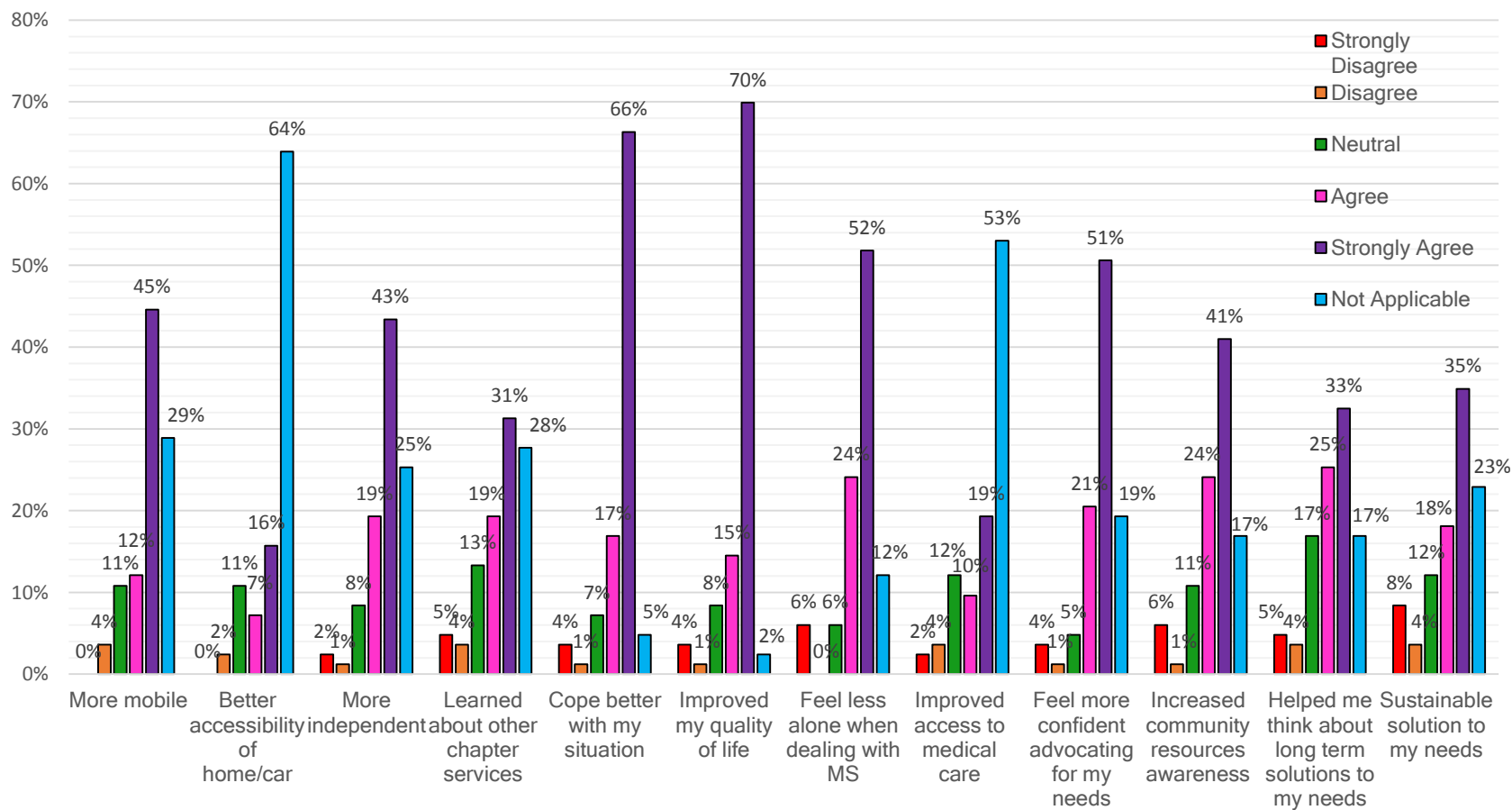


Figure 5, Impact of the Financial Assistance Program on Clients.

*Impact on friends and family of client.*

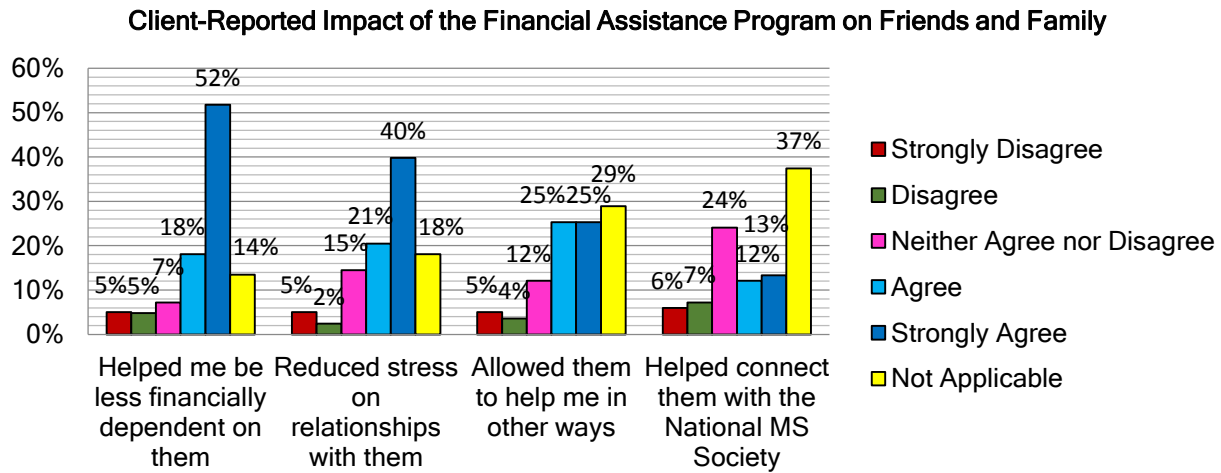


Figure 6, Client-Reported Impact of the Financial Assistance Program on Friends and Family.

Figure 6 illustrates the perceived impact of the Financial Assistance Program on the friends and families of clients who received assistance and is supported by Table A4. Results obtained in the survey indicated 4.8% (CI: 7.6) strongly disagree that they are less financially dependent on their friends and family as a result of receiving financial assistance, 4.8% (CI: 7.6) reported they disagree with the statement, 7.2% (CI: 7.6) reported they neither agree nor disagree with the statement, and 13.5% (CI: 7.6) reported the statement was not applicable to their situation. Participants who agreed or strongly agreed they were less financially dependent on their friends and family as a result of receiving financial assistance consisted of 69.9% (CI: 7.6) of the population.

When clients reported whether financial assistance reduced stress on relationships with friends and family, 4.8% (CI: 7.6) reported they strongly disagree with the statement, 2.4% (CI: 7.6) disagreed with the statement, 14.5% (CI: 7.6) neither agreed nor disagreed with the statement, 20.5% (CI: 7.6) agreed with the statement, 39.8% (CI: 7.6) strongly agreed with the statement, and 18.1% (CI: 7.6) reported the statement is not applicable. Those who agreed or strongly agreed that financial assistance reduced stress on relationships with friends and family accounted for 60.3% (CI: 7.6) of the population.

The next statement aimed at assessing the impact of the financial assistance on clients' friends and families was whether it allowed them to be of help in other ways. Participants reported 4.8% (CI: 7.6) strongly disagreed with the statement, 3.6% (CI: 7.6) disagreed with the statement, 12.1% (CI: 7.6) neither agreed nor disagreed with the statement, 25.3% (CI: 7.6) agreed with the statement, 25.3% (CI: 7.6) strongly agreed with the statement, and 28.9% (CI: 7.6) reported the statement was not applicable to their situation. Therefore, 50.6% (CI: 7.6) of participants either agreed or strongly agreed that financial assistance allowed their friends and family to be of assistance to them in other ways.

When clients were asked to report their level of agreement with whether receiving financial assistance helped connect client's friends and family to the National MS Society, 6.0% (CI: 7.6) of participants strongly disagreed, 7.2% (CI: 7.6) disagreed, 24.1% (CI: 7.6) neither agreed nor disagreed, 12.1% agreed (CI: 7.6), 13.3% (CI: 7.6) strongly agreed, and 37.4% (CI: 7.6) reported the statement was not applicable. Those who either disagreed or strongly disagreed totaled 13.2% (CI: 7.6) of the population, which is the only category strong disagreement and disagreement totaled over 10%. Those who agreed or strongly agreed receiving financial assistance helped connect friends and family with the National MS Society represented 25.4% (CI: 7.6) of the population.

*Client Assessment of Financial Assistance Program*

**Resolution of Client Needs by Financial Assistance Program**

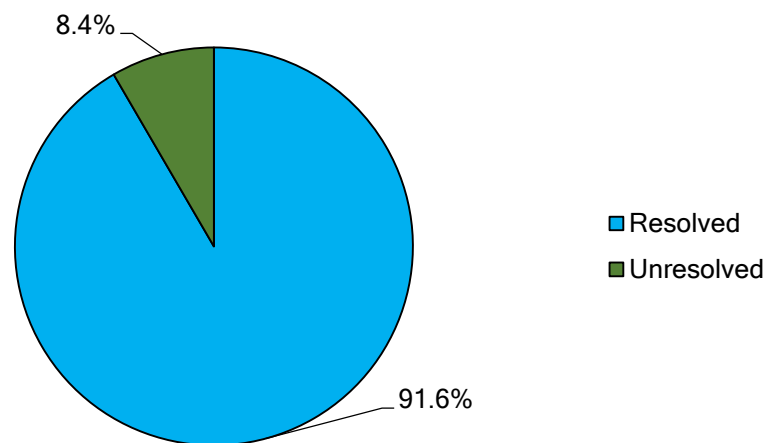


Figure 7, Resolution of Client Needs by Financial Assistance Program.

Clients confirmed that participating in the National MS Society Financial Assistance Program resolved the need or problem 91.6% (CI: 7.6) of the time and did not resolve the need or problem 8.4% (CI: 7.6) of the time, as shown in Figure 7. Those who indicated their need or problem had not been resolved asserted the financial assistance was only a temporary solution and more assistance was needed. There was a correlation between the clients who reported the Financial Assistance Program did not resolve their need or problem and the type of Financial Assistance they received. The assistance that did not completely resolve the needs of clients was usually in the critical short term needs category, which is meant to help with rent or utilities only temporarily.

*Necessary improvements.*

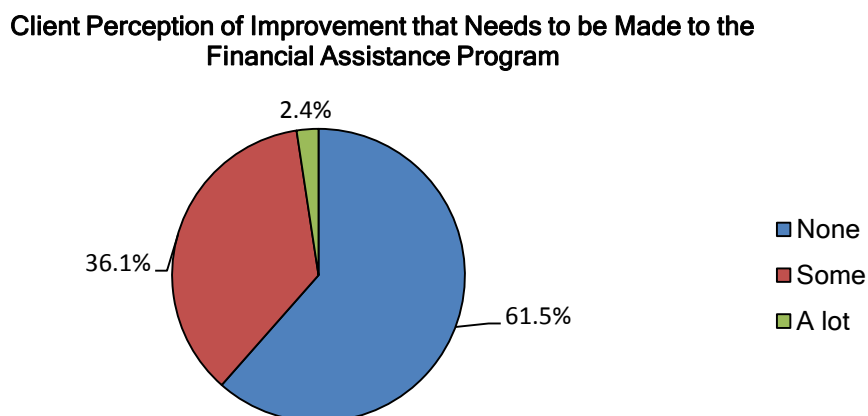


Figure 8, Client Perception of Necessary Program Improvement.

When asked how much improvement the National MS Society's Financial Assistance Program needs, 61.5% (CI: 7.6) thought it needs no improvement, 36.1% (CI: 7.6) thought it needs some improvement, and 2.4% (CI: 7.6) of the population thought it needs a lot of improvement, as shown in Figure 12. Participants who identified ways the Financial Assistance Program could be improved stated more funding needs to be made available and the financial assistance process should be quicker. Participants also requested the guidelines to receive funding and amounts available be made more accessible to those who are seeking assistance at the beginning of the process.

Results indicated there were usually no other funds leveraged from other community agencies to meet the needs of clients. Survey respondents identified MS Helping Hands and MS Foundation as community organizations whose funds have occasionally been leveraged to contribute to client needs. Clients also contributed to the cost of goods and services with their own money.

*Responses to Open-Ended Questions*

Participants were asked whether they were willing to allow de-identified responses to three open-ended questions be quoted in future publications. Of the 83 participants surveyed, 90.1% of them agreed to allow the National MS Society to quote their answers to open-ended questions.

When participants were asked how receiving financial assistance has impacted their quality of life and wellbeing, many expressed gratitude for the assistance they received. One participant said, "The financial assistance I've received has been a true blessing for me and my family."

Many participants said the financial assistance helped relieve stress, which is known to worsen MS symptoms. Another participant stated, "Receiving financial assistance has taken a lot of stress, which exacerbates MS, off my shoulders. Also, the National MS Society has been

instrumental in getting me the information I need about my MS. I do not have a computer, but they will always print things for me and send it to me in the mail.”

Others indicated the financial assistance they received improved their overall wellbeing. “Being able to use the YMCA pool helps keep me active and healthy. It's one of the few forms of exercise I can tolerate due to overheating issues. I feel regular exercise helps my mental health as well as my physical health and has played a role in keeping me as strong as possible,” a study participant said.

Similarly, another participant stated, “Covering the cost of the YMCA has been my everything. It is my physical therapy. It is keeping me going. It means everything to me. It is keeping me mobile and helps me get social support.”

When participants were asked what receiving financial assistance has allowed them to do that they would not have been able to do otherwise, one participant said, “I wouldn't be able to take the class. I would be sitting at home, lonely and bored and feeling crappy and sorry for myself, and that is not a good life,”

Another participant said, “The assistance has helped me to pay for my utility bill, other services couldn't help since I did not have children.”

The last open-ended question asked clients to identify where they see gaps in resources or funding for individuals who are living with multiple sclerosis within their communities. Many individuals stated that they could not identify gaps in funding or resources and did not know any other individuals who are living with MS in their communities. Other individuals stated there is a lack of awareness about MS and its effects, even within the medical community. Additionally, participants mentioned a lack of awareness about the National MS Society and the programs and services it provides among individuals living with MS. This sentiment is exemplified in the following quote from a study participant, “Not knowing what resources are available is a real problem for people living with MS in my community. They do not know about the National MS Society and the information, resources, and services they provide.”

## **Discussion**

### *Limitations*

Limitations of this study include self-report methodology, small sample size, and possible interviewer effects. Because the survey was based on self-report methodology, responses given were subjective. Additionally 83 of 163 potential participants completed the program evaluation survey, indicating a 50.3% response rate. Barriers to achieving a higher response rate included disconnected phone numbers, lack of internet access, inability of clients to speak due to MS-related complications, and clients being in the hospital for MS-related complications and comorbidities. A higher response rate could have been achieved had surveys also been mailed using postal service and had all client telephone numbers been in service.

### *Suggestions for Survey Modifications*

There are some suggestions for modifications that could improve the survey. First, bi-racial and multi-racial options should be included. Another demographic question that would provide

greater insight into client experience is whether clients live in rural, urban, or suburban areas. Rural areas typically have fewer community organizations and services that could help address the needs of clients living with MS, so the National MS Society may want to evaluate whether to play a larger role in these social service-deprived areas. Furthermore, there is a high occurrence of veterans who are living with MS, and questions about military service should be included in the client information portion of the survey. “Calling the National MS Society,” “dialing 211 for community resources,” and the “National MS Society magazine” should be added as options for how the client first heard about the Financial Assistance Program because they were written in most often in the “Other” category (Figure 2). Questions relating to coping strategies and personality should be included to see if there are correlations between personality traits and how the program is rated by individuals. Finally, a question should be added to the end of the survey to seek feedback from clients as to whether the survey was perceived to be an effective tool for evaluation.

#### *Areas for Future Research*

Although the analysis is outside the scope of this paper, additional studies of how survey results vary among the different offices within the Greater Northwest Chapter would elucidate areas for training, funding, and presence of other community resources to address the needs of people affected by MS.

It would also be interesting to implement the same survey and study design to evaluate the Financial Assistance Program at other National MS Society Chapters throughout the United States to obtain a better understanding of how the Financial Assistance Programs at various chapters is delivered. This information would be useful throughout the nationalization process because it could combine best practices across many chapters to inform a new national model of operating the Financial Assistance Program.

Another enlightening study could be to delve deeper into understanding the critical short term needs assistance provided by the National MS Society. The impact of this type of assistance is not as sustainable as assistance in other categories, such as health and wellness and durable medical equipment because the nature of the aid is short term. Aid in this category is critical because it helps clients stay in their homes and have utility service. What will be important is finding sustainable solutions for clients who repeatedly access this category of funding. Past program evaluation results in the critical short term needs category of financial assistance has raised questions nation-wide of whether the National MS Society should continue funding this category of financial assistance. Because critical short term needs category funding addresses survival issues rather than improving quality of life issues, an evaluation focusing on the impact the Financial Assistance Program has had on the ability of clients to survive might provide more robust data for this category of assistance. Representing the sentiment of many clients who have utilized funding for critical short term needs assistance, one client stated, “I received money toward my house payment, This saved it from going into foreclosure. I will not lose my house now.”

#### *Survey Implementation*

Surveys were initially administered via internet and later administered over the telephone.

Although there was some concern of interviewer effects during telephone surveys, this mode of administration was an effective tool for engagement. Conducting surveys via telephone allowed for more nuanced information to be gathered. Telephone surveys also presented an avenue for clients to discuss additional needs and to connect them with the appropriate resources.

### *Client Information*

Survey respondents most often received health and wellness grants such as gym memberships (55.4%) and funding for critical short term needs (37.4%) such as assistance for rent and utilities (Figure 3). It is possible that individuals who have received these types of funding are most able to complete the survey and the survey is geared toward able-bodied and able-minded individuals. One question that arises is whether health and wellness and critical short term needs were in fact the most needed or most requested categories of financial assistance. Presumably, individuals who need other types of financial assistance, such as durable medical equipment, transportation, respite services, and home/auto modifications either do not have awareness that the National MS Society funds these items or are not physically well enough to complete the application process. Perhaps individuals who feel less capable of completing application materials are not aware of the level of assistance MS Navigators are willing to give in completing the financial assistance application process. This data also suggests the importance of both health and wellness and critical short term needs funding from the National MS Society.

A strong majority, 75.9%, of respondents identified as female, which is more than National MS Society data indicating two to three times more women are living with MS than men (National Multiple Sclerosis Society 2014i). Only 20.5% of clients identified as male. The disproportionate amount of women accessing the Financial Assistance Program may be due to the income disparity that exists between women and men. The intersecting targeted identities of being a woman and living with a disability is an area that could be further addressed by the National MS Society through scientific research, policy efforts, and programming. One client said, "I am a single woman without children. I had great difficulty finding help. I called the MS Society and they gave me instructions for help. The service paid my electricity. Thanks to them I was able to keep my lights on. So thankful for help! MS cognitive difficulties make it difficult to stay employed. Thank You MS Society!"

Alternatively, the societal perception that men should be able to take care of themselves may have also played a role in the underrepresentation of men who have received financial assistance.

Consistent with what is known about the demographics of individuals who most commonly get MS, 93.6% of participants identified as white/European American (National Multiple Sclerosis Society 2014i). Only 3.9% identified as Black/African American and 2.5% of participants identified as Hispanic/Latino. While the majority of people living with MS are white/European American, it is important for the National MS Society to make the financial assistance application process inclusive of all races. One suggestion is to adapt the application and resources provided to be more and culturally responsive. Engaging diversity is a nation-wide concern for the National MS Society, and its representatives are committed to making the Financial Assistance Program more culturally responsive.



Of the participants who completed the survey, 83.1% had been living with a diagnosis of MS for at least 5 years (Figure 1). Some had received financial assistance from the National MS Society more than once. This speaks to the commitment the National MS Society has to its clients and identifies the need for outreach to newly diagnosed patients who may not have awareness of the programs and services offered by the National MS Society.

### *Client Experience*

*Barriers to Seeking Assistance.* There are several barriers to clients engaging with the Financial Assistance Program. Many survey respondents indicated being involved with the National MS Society for years, attending support groups and fundraisers, before they were informed about the Financial Assistance Program. For individuals who were aware of the Financial Assistance Program, many believed they would not qualify for assistance because they did not think they were “disabled enough,” or because their income was not below the poverty level.

Awareness needs to be spread about the Financial Assistance Program, including what can be covered and who is eligible. It is the responsibility of the National MS Society to make information about the Financial Assistance Program and application process accessible and manageable for individuals who may be struggling most. Figure 4 illustrates that 25.3% of respondents indicated they heard about the Financial Assistance Program from their healthcare providers. There were no clients who indicated being referred to the National MS Society Financial Assistance Program by other community organizations. Because the National MS Society is in contact with other community organizations regularly to advocate for clients and leverage funding, it would be appropriate for community organizations to refer clients to the National MS Society. Evidence suggests, however, that the National MS Society is usually the main resource for people living with MS. Therefore, some clients may not attempt to engage with other agencies before accessing resources at the National MS Society.

At the client level, there may be psychosocial barriers to seeking financial assistance. MS is an acquired disability. It is normal for individuals with an acquired disability to feel resistant to making the transition from considering oneself able-bodied and able-minded to considering oneself disabled. There is also resistance to other people considering people living with MS to be disabled. Additionally, many people living with MS do not consider themselves to be disabled. Regardless of the terminology that is assigned when someone is greatly affected by a disease like MS, an individual living with MS has a new and different set of abilities in comparison to before the onset of their MS-related symptoms.

Adjusting to a new or different level of abilities can feel isolating and may make seeking assistance more difficult. One client said, “I have been able to receive financial support as well as personal encouragement through the program. It is often very isolating for me, living with a chronic illness (MS) and the program support I received has been such a huge help in dealing with this. I can hardly put into words how it helps me just to know that I have support at the other end of the phone and folks that are dedicated to helping me live the best life possible.”

Regarding the impact of financial assistance on clients’ relationships with friends and families, clients indicated they did not want to burden their loved ones, their loved ones did not understand what they were going through, or that they had an overall lack of social support.

There were comments in the survey indicating a desire for more support from the National MS Society in making life transitions.

For individuals who are accustomed to being self-sufficient, it is often difficult for them to reach out to community organizations to ask for help. The bootstrapping mentality ingrained into many people in America who are living with MS causes further internalized oppression when they need assistance. One client stated, “I feel I am still new to the difficulties that MS forces me to look at. I try not to rely on the MS Society, but I assure you that the staff I deal with is a truly secure group and always does the best work for me. These folks have become a true blessing and always provide a valuable link for needed answers.”

Framing the Financial Assistance Program in empowering terms, such as how it allows clients to advocate for themselves so they can continue living independently, could reduce some of the resistance to seeking assistance. Speaking to the empowerment the Financial Assistance Program has given them, one client stated it “took me from dependence to independence and it couldn’t be better!”

*Experience with staff and the application process.* The Financial Assistance Program application requires clients to seek assistance from resources or community organizations outside the National MS Society whenever possible. MS Navigators working within the Financial Assistance Program engage with clients to help them access at least three other community resources or organizations before funds from the National MS Society are distributed. This allows clients to gain a greater sense for other community resources available to them and in theory allows National MS Society funding to reach as many eligible clients as possible. Some clients find the process of identifying and applying to other types of assistance both futile and frustrating because they do not always meet the eligibility requirements of other organizations. One client stated, “When you get the different Society literature, it should spell out what the Society does, and what the parameters and limitations of the program are. What is hard is when you are feeling sick and need help and have to fill out the paperwork and wait for responses and once you get a response, you have to approach other community resources. When you are so sick already, it's really hard!”

A study determining the success rate of engaging with community financial assistance programs could help determine the necessity to continue this formality. This is also frustrating for clients because it slows down the process of receiving financial assistance from the National MS Society and because organizations outside the National MS Society tend to not understand or take into consideration the nuanced set of barriers clients living with MS face. The Financial Assistance Program offered by the National MS Society is unique in comparison to financial assistance offered by other agencies in that clients are not required to meet the definition of living in poverty or to have dependents in their households for approval to receive financial assistance. Instead, eligibility is more heavily determined by a client’s relationship to MS and their ability or inability to meet their financial obligations.

#### *Suggestions for Program Improvement and Expansion*

There are several suggestions for program improvement and expansion that can be gleaned from survey results and interviews via telephone. To begin, it is necessary to expedite the process of

receiving financial assistance to ensure clients obtain assistance in a timely manner. It can be difficult and time consuming to obtain the documents the National MS Society requires for verifying diagnosis. Additionally, there were numerous comments from survey participants about the length of time that had elapsed between being approved to receive financial assistance and when the vendor received the funds from the National MS Society. The long wait time is due to the process of ordering checks through the mandated system. The National MS Society needs to make changes at the national level to expedite the process for clients to receive financial assistance. This could be achieved with improved software or internet-based platforms for ordering and distributing approved funding. One client stated, “There needs to be a faster process in order to receive funding. It has taken up to 2 months to get funding.”

Additional outreach efforts could increase awareness of the services the National MS Society provides to potential clients. Outreach is also needed to spread awareness to families, friends, and colleagues of people who live with MS. Most clients reported the impact of the Financial Assistance Program did not often reach their families and friends and that client involvement with the Financial Assistance Program did not help connect their family and friends with information, resources, programs, or services at the National MS Society (Figure 6). One client whose family was connected to the National MS Society as a result of their involvement with the Financial Assistance Program stated the National MS Society “...has made it easier for all of the family to discuss the changes that I am going through.”

The National MS Society could also offer information and resources to individuals who employ and work in professional settings with individuals with MS. Clients expressed frustration about the lack of awareness they see about MS. Spreading awareness can also spread sensitivity and empathy. Committing the time and resources to educate people about MS will create more passionate stakeholders to drive the mission of the organization. By promoting outreach and using the program as a tool for engaging important constituents, the Financial Assistance Program could create a ripple effect through the social networks of individuals who live with MS, potentially resulting in increased community support for people living with MS.

Although support groups are not part of the Financial Assistance Program, more support groups was one of the most requested additions to the National MS Society. Social contact with other individuals who can empathize with what it is like to experience the unique symptomatology of MS plays a valuable role in the health and mental health of clients. Also, individuals who were active in support groups tended to feel most connected to the National MS Society and reported educating other people within their communities about MS.

Formally training support group members as National MS Society Ambassadors may be beneficial to group members and to the National MS Society because being ambassadors and consciousness-raisers about MS seems to be the roles support group members take within their communities regardless of formal training or title. Formal training could provide support group members with better tools for spreading awareness and could help the National MS Society have even more engagement from their passionate clients. Because of the profound benefit of support groups to mental health, perceived social support, and symptomatology and due to the way

support groups can act as a nexus to other chapter programs and services, more funding needs to be invested in creating support groups and maintaining strong, involved membership.

*Critical short term needs.* Results indicated that funding for critical short term needs such as rent and utilities was the second most utilized category of financial assistance (Figure 3). Critical short term needs covers the cost of up to \$300 for mortgage, rent, and/or utilities. When costs exceed \$300, the National MS Society works to leverage additional funding through other community resources.

More funding needs to be available for clients, and there needs to be fewer restrictions on types of aid received. Some clients commented on having received financial assistance in every category offered by the National MS Society, while others stated they only need assistance in one of the categories but have reached their maximum amount of financial assistance allowed in that category. Although the National MS Society has a responsibility to implement financial assistance policies that ensure fairness and equality to all clients, equity should also be of concern.

Additionally, it could be seen as unethical to refuse financial assistance to individuals who are truly in need. For example, due to restrictions on the dollar amount, number of times per year, and number of times within a lifetime a client can receive each category of financial assistance, there are sometimes cases in which a client is at risk of being evicted from their home and they have run out of assistance they are entitled to receive in the critical short term needs category yet still qualify to receive a gym membership through a wellness grant. Again, this presents an ethical dilemma the National MS Society needs to address.

With progressing symptoms that can be drastically exacerbated by stress, people living with MS need the security of accessible, affordable housing. People living with MS sometimes need to work fewer hours or stop working entirely due to MS-related symptoms and complications. MS-related symptoms can also make it much more difficult to relocate to another residence than it would be for an individual who is not living with MS. Therefore, it is of utmost importance for people living with MS to be able to remain living in their homes.

The short term, unsustainable nature of financial assistance for rent and utilities has consistently received lower ratings for improvements to quality of life than financial assistance for health and wellness grants such as gym memberships. The National MS Society is currently reevaluating the types of programs and services it provides. At the national level, some representatives have suggested offering only the resources that have been shown in program evaluations to improve the quality of life of clients most and to discontinue offering financial assistance in the critical short term needs category altogether. For people living with MS, this type of funding is not available through any other community organization within the Greater Northwest Chapter. Expressing the sentiment of many of the phone interviews with clients utilizing financial assistance for critical short terms needs, one client said, "The only rental assistance available in my area is the Salvation Army and they will not help until you have an eviction notice. I have already met my lifetime limit for rental assistance from the NMSS."

The National MS Society has a long history of filling gaps in community resources, and it is necessary for the National MS Society to continue to address the gaps in financial assistance for rent and utilities. Working toward long term, sustainable, and pragmatic solutions for addressing the financial burdens associated with rent and utilities, instead of only focusing on critical short term needs, would be a more proactive approach that could generate extraordinary improvements to quality of life of people living with MS, including perceptions of independence and safety.

The need for supplemental financial resources for rent and utilities for people living with MS is so widespread and systemic that the issue should be addressed by the National MS Society at the policy level. As a 501(c)(3) tax-exempt, charitable organization, there are limitations to the number of staff and volunteer hours, amount of financial resources, and types of political and legislative activities the National MS Society can perform within each fiscal year (Internal Revenue Service 2014b), (Internal Revenue Service 2014c). Until this important issue can be addressed at the policy level and/or pragmatic solutions can be identified within the organization in partnership with communities, there is a strong need for the continuance and expansion of financial assistance for critical short term needs such as rent and utilities.

## References

- Internal Revenue Service. 2014a. "Exemption Requirements - 501(c)(3) Organizations." *Internal Revenue Service*. Accessed December 31, 2014. [http://www.irs.gov/Charities-&-Non-Profits/Charitable-Organizations/Exemption-Requirements-Section-501\(c\)\(3\)-Organizations](http://www.irs.gov/Charities-&-Non-Profits/Charitable-Organizations/Exemption-Requirements-Section-501(c)(3)-Organizations).
- . 2014b. "Lobbying." *Internal Revenue Service*. Accessed December 31, 2014. <http://www.irs.gov/Charities-&-Non-Profits/Lobbying>.
- . 2014c. "Political and Lobbying Activities." *Internal Revenue Service*. Accessed December 31, 2014. <http://www.irs.gov/Charities-&-Non-Profits/Charitable-Organizations/Political-and-Lobbying-Activities>.
- National Multiple Sclerosis Society. 2014a. "Definition of MS." *National Multiple Sclerosis Society*. Accessed June 15, 2014. <http://www.nationalmssociety.org/What-is-MS/Definition-of-MS>.
- . 2014b. "Financial Assistance Program." *National Multiple Sclerosis Society*. Accessed June 15, 2014. <http://www.nationalmssociety.org/Resources-Support/Insurance-and-Financial-Information/Financial-Resources/Financial-Assistance-Program>.
- . 2014c. "Giving Circles." National Multiple Sclerosis Society. Accessed December 31, 2014. <http://www.nationalmssociety.org/Chapters/WAS/Donate/Giving-Circles>
- . 2014d. "Greater Northwest Chapter." *National Multiple Sclerosis Society*. Accessed June 15, 2014. <http://www.nationalmssociety.org/Chapters/WAS/About-this-Chapter>
- . 2014e. "Heat & Temperature Sensitivity." *National Multiple Sclerosis Society*. Accessed June 15, 2014. <http://www.nationalmssociety.org/Living-Well-With-MS/Health-Wellness/Heat-Temperature-Sensitivity>.
- . 2014f. "Made Stronger: A 2013 Achievement Report to our Chapter Community." *National Multiple Sclerosis Society*. Accessed June 15, 2014. [http://www.nationalmssociety.org/NationalMSSociety/media/Greater-Northwest/About%20this%20Chapter/Files/2013\\_AnnualReport.pdf?ext=.pdf](http://www.nationalmssociety.org/NationalMSSociety/media/Greater-Northwest/About%20this%20Chapter/Files/2013_AnnualReport.pdf?ext=.pdf).
- . 2014g. "MS Symptoms." *National Multiple Sclerosis Society*. Accessed June 15, 2014. <http://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms>.
- . 2014h. "Multiple Sclerosis FAQs." *National Multiple Sclerosis Society*. Accessed June 15, 2014. <http://www.nationalmssociety.org/What-is-MS/MS-FAQ-s>.
- . 2014i. "Who Gets MS?" *National Multiple Sclerosis Society*. Accessed June 15, 2014. <http://www.nationalmssociety.org/What-is-MS/Who-Gets-MS>.

## Appendix A

## Supporting Tables:

<b>Client Experience with Staff and Application Process</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>	<b>Not Applicable</b>	<b>Total</b>
Staff responded quickly	<b>4.8%</b> 4	<b>1.2%</b> 1	<b>3.6%</b> 3	<b>15.7%</b> 13	<b>74.7%</b> 62	<b>0.0%</b> 0	83
Respectful staff	<b>4.8%</b> 4	<b>0.0%</b> 0	<b>0.0%</b> 0	<b>13.3%</b> 11	<b>81.9%</b> 68	<b>0.0%</b> 0	83
Easy to understand	<b>4.8%</b> 4	<b>0.0%</b> 0	<b>0.0%</b> 0	<b>20.5%</b> 17	<b>74.7%</b> 62	<b>0.0%</b> 0	83
Explored other resources	<b>3.6%</b> 3	<b>3.6%</b> 3	<b>13.3%</b> 11	<b>16.9%</b> 14	<b>48.2%</b> 40	<b>14.5%</b> 12	83
Forms were manageable	<b>4.8%</b> 4	<b>0.0%</b> 0	<b>7.2%</b> 6	<b>19.3%</b> 16	<b>65.1%</b> 54	<b>3.6%</b> 3	83
Satisfied overall	<b>4.8%</b> 4	<b>0.0%</b> 0	<b>2.4%</b> 2	<b>16.9%</b> 14	<b>74.7%</b> 62	<b>1.2%</b> 1	83

Table A1: Client Experience with Staff and Application Process

<b>Impact on Clients</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>	<b>Not Applicable</b>	<b>Total</b>
More mobile	<b>0.0%</b> 0	<b>3.6%</b> 3	<b>10.8%</b> 9	<b>12.1%</b> 10	<b>44.6%</b> 37	<b>28.9%</b> 24	83
Improved the safety or accessibility of home/car	<b>0.0%</b> 0	<b>2.4%</b> 2	<b>10.8%</b> 9	<b>7.2%</b> 6	<b>15.7%</b> 13	<b>63.9%</b> 53	83
More independent	<b>2.4%</b> 2	<b>1.2%</b> 1	<b>8.4%</b> 7	<b>19.3%</b> 16	<b>43.4%</b> 36	<b>25.3%</b> 21	83
Learned about chapter services	<b>4.8%</b> 4	<b>3.6%</b> 3	<b>13.3%</b> 11	<b>19.3%</b> 16	<b>31.3%</b> 26	<b>27.7%</b> 23	83
Cope better	<b>3.6%</b> 3	<b>1.2%</b> 1	<b>7.2%</b> 6	<b>16.9%</b> 14	<b>66.3%</b> 55	<b>4.8%</b> 4	83
Improved my quality of life	<b>3.6%</b> 3	<b>1.2%</b> 1	<b>8.4%</b> 7	<b>14.5%</b> 12	<b>69.9%</b> 58	<b>2.4%</b> 2	83
Feel less alone when dealing with MS	<b>6.0%</b> 5	<b>0.0%</b> 0	<b>6.0%</b> 5	<b>24.1%</b> 20	<b>51.8%</b> 43	<b>12.1%</b> 10	83
Improved access to healthcare	<b>2.4%</b> 2	<b>3.6%</b> 3	<b>12.1%</b> 10	<b>9.6%</b> 8	<b>19.3%</b> 16	<b>53.0%</b> 44	83
Feel more confident advocating for my needs	<b>3.6%</b> 3	<b>1.2%</b> 1	<b>4.8%</b> 4	<b>20.5%</b> 17	<b>50.6%</b> 42	<b>19.3%</b> 16	83
Increased community resources awareness	<b>6.0%</b> 5	<b>1.2%</b> 1	<b>10.8%</b> 9	<b>24.1%</b> 20	<b>41.0%</b> 34	<b>16.9%</b> 14	83
Helped me think about long term solutions	<b>4.8%</b> 4	<b>3.6%</b> 3	<b>16.9%</b> 14	<b>25.3%</b> 21	<b>32.5%</b> 27	<b>16.9%</b> 14	83
Found sustainable solution to my needs	<b>8.4%</b> 7	<b>3.6%</b> 3	<b>12.1%</b> 10	<b>18.1%</b> 15	<b>34.9%</b> 29	<b>22.9%</b> 19	83

Table A2: Impact of the Financial Assistance Program on Clients



Impact of Financial Assistance Program on Clients	Agree or Strongly Agree
More mobile	<b>56.7%</b>
Improved accessibility to home or car	<b>22.9%</b>
More independent	<b>62.7%</b>
Learned about other chapter services	<b>50.6%</b>
Cope better with my situation	<b>83.2%</b>
Improved my quality of life	<b>84.4%</b>
Feel less alone when dealing with MS	<b>75.9%</b>
Improved access to medical care	<b>28.9%</b>
Feel more confident advocating for my needs	<b>71.1%</b>
Increased community resources awareness	<b>65.1%</b>
Helped me think about long term solutions to my needs	<b>57.8%</b>
Helped me find a sustainable solution to my needs	<b>53.0%</b>

Table A3: Impact of the Financial Assistance Program on Clients, Percentages of Clients who Agree or Strongly Agree with Statements

Impact on Friends and Family	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable	Total
Less financially dependent on them	<b>4.8%</b> 4	<b>4.8%</b> 4	<b>7.2%</b> 6	<b>18.1%</b> 15	<b>51.8%</b> 43	<b>13.3%</b> 11	83
Reduced stress on relationships	<b>4.8%</b> 4	<b>2.4%</b> 2	<b>14.5%</b> 12	<b>20.5%</b> 17	<b>39.8%</b> 33	<b>18.1%</b> 15	83
Allowed them to help to me in other ways	<b>4.8%</b> 4	<b>3.6%</b> 3	<b>12.1%</b> 10	<b>25.3%</b> 21	<b>25.3%</b> 21	<b>28.9%</b> 24	83
Connected them with the National MS Society	<b>6.0%</b> 5	<b>7.2%</b> 6	<b>24.1%</b> 20	<b>12.1%</b> 10	<b>13.3%</b> 11	<b>37.4%</b> 31	83

Table A4: Impact of the Financial Assistance Program on Friends and Family of Clients