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# The Marilyn Hilton MS Achievement Center at the UCLA Medical Center Los Angeles, California

## Final Report

A Case Study and Cost Analysis Prepared for:

**National Multiple Sclerosis Society**
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We would particularly like to thank Ms. Fisher for her guidance throughout the process of planning our site visit to the MSAC, for arranging numerous interviews, providing a wide range of documents, contributing many hours of her time for interviews, and coordinating the many people involved.

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# SUMMARY AND CONCLUSIONS

## Introduction and Methods

This case study and cost analysis report is one in a series of five being prepared for the Multiple Sclerosis Adult Day Program (MSADP) Evaluation, a study sponsored by the National Multiple Sclerosis Society (NMSS). The study's goals are as follows:

- Develop effective collaborations with five MSADPs as study partners.
- Identify the key internal and external factors that promote and inhibit the development and expansion of MSADPs.
- Describe the alternate organizational, operational, and service models used by MSADPs.
- Describe the alternate funding strategies that can be used to finance MSADPs.
- Calculate the full costs of developing and maintaining MSADPs.
- Identify the benefits of MSADPs.
- Disseminate the results of the study widely.
- Develop a handbook that summarizes the alternate organizational, operational, service, and financing models and lesson learned across the five study partner MSADPs, to facilitate development of new MSADPs in other cities around the country.

This report was developed using a range of sources. Two site visits conducted by the authors at the Marilyn Hilton MS Achievement Center (MSAC) and related programs in Los Angeles provided opportunities for face-to-face interviews and observation. A wide range of MSAC and NMSS Southern California Chapter documents and financial reports were also reviewed.

## History of MSAC Start-up and Development

The Marilyn Hilton MS Achievement Center (MSAC) at the University of California, Los Angeles (UCLA), opened in June, 2001. A collaborative effort between the Southern California Chapter of the National MS Society and UCLA, the MSAC was founded to provide a wellness-focused day program for people with MS with advanced disabilities. Funding from the Conrad N. Hilton Foundation and several other grants provided substantial support for the MSAC, which was named in honor of Marilyn Hilton, the wife of Conrad Hilton's son, Barron Hilton.

The effort to develop an MSAC in Los Angeles began in 1994, when Dr. Leon LeBuffe, President of the Southern California Chapter, visited the MSAC in Minnesota with Jim Ahern, President of the Upstate New York Chapter. Dr. LeBuffe was impressed with the MSAC, and recommended development of a similar program to the Board of his Chapter.

In 1995, Dr. LeBuffe created a committee to begin the task of developing an MSAC. The committee's first and largest challenge was to find an institutional partner to provide space and share the costs. Several Los Angeles-area medical centers were approached, and an agreement was nearly reached with Cedars-Sinai, but its Board of Directors unexpectedly voted down the

proposal after two years of planning, citing cost concerns. However, Dr. LeBuffe and the committee persevered and their five-year long search for a partner was fulfilled in 1999 when Dr. Robert Collins, Chair of the UCLA Department of Neurology, agreed to work with the Southern California Chapter to develop an MSAC.

UCLA agreed to provide the space, janitorial services, utilities, medical oversight, and insurance. The Chapter agreed to provide funding for the MSAC's staff and operating expenses. A joint Board of Directors was formed, chaired by Dr. Collins. Dr. Bruce Dobkin, the Medical Director of the UCLA Neurologic Rehabilitation and Research Program, was appointed as the MSAC Medical Director.

With the UCLA partnership established, Dr. LeBuffe approached the Conrad N. Hilton Foundation for financial support. Marilyn Hilton, who was Conrad Hilton's daughter-in-law, had MS and the Foundation had been funding MS Society programs since 1988. The Foundation agreed to provide half of the MSAC's operating costs and some funding for expansion.

Detailed MSAC planning efforts next began under the guidance of Denise Nowack, Executive Vice President for Programs at the Southern California Chapter. One of her first steps was to recruit Stephanie Fisher to serve as the Executive Director of the new MSAC. Ms. Fisher had been Vice President for Programs at the Orange County Chapter of the NMSS for five years when she agreed to take on the new role at the MSAC. As a result, she brought a strong background in MS programs and administration. A clinical nurse specialist and health educator, Elise Herlihy, was hired at the same time to provide clinical expertise.

Ms. Nowack and Ms. Fisher shared a common philosophy based on wellness rather than treatment for the MSAC's programming, and organized their planning around a wellness service model. A focus group study found that people with MS associated wellness with positive concepts such as self-empowerment and self-esteem. Site visits to other MSACs in Minnesota and Colorado provided examples of service strategies and operational methods.

When the MSAC opened in 2001, 7 members attended on the first day. The MSAC was open only on Thursdays at the outset in June 2001, but Tuesdays soon followed that July and Wednesdays in October. Fridays were added in August 2002. Members were grouped by functional abilities by day of participation, with the more disabled members attending on Wednesday. The less-impaired members attended on Tuesdays. Mondays were kept open to be available for special programming.

In 2002, Dr. Barbara Giesser joined the Department and became the Medical Director for the MSAC and Chair of its Board of Directors. Dr. Giesser, an advocate for health and wellness promotion for people with MS, worked closely with the MSAC team and Ms. Nowack to strengthen the program.

The MSAC has remained at its original location on the western campus of UCLA since it opened. The program occupies space on two floors of the Veterans Avenue Rehabilitation Building. Group meeting rooms and staff offices are on the first floor, and a gym with adaptive equipment and a pool are available to MSAC members on the floor below.

The vision of the MSAC includes the development of innovative programs and their replication at other sites in order to reach as many people as possible at various stages of MS. Wellness modules are developed at the MSAC and then adapted by the Chapter for use in other day programs and other community-based programs. This entrepreneurial spirit is a hallmark of both the MSAC and the Southern California Chapter.

Several new and related programs have already been implemented at the MSAC in addition to the Day Program. A professional education program provides continuing education units for neurologists, nurses, physical therapists, and occupational therapists.

The Living Well program includes two types of educational courses for wellness education. One is for people who are newly diagnosed with MS, and the other is for those who are experiencing some disabilities but do not yet need to attend the MSAC's day program. Living Well is designed for people who are still working, so it meets for three hours per session on Mondays, for 12 weeks. MSAC staff provide instruction on physical, mental, social, intellectual and spiritual health. They emphasize the activities a person with MS can do to complement and support their medical care, and bring a balance back to their lives.

A Lifestyle Education and Assessment Program (LEAP) was launched in the spring of 2005 to provide a range of expert neurological and functional assessments for people with MS who have difficulty accessing specialty care, such as residents of rural or outlying areas. The intensive assessment process takes half a day and is offered to two patients per month.

CogniFit is an eight-week course developed and facilitated by the MSAC's two speech pathologists, one of whom has MS. It helps people with MS improve their cognitive abilities through a series of eight modules, offered on consecutive weeks. A detailed curriculum is provided for each week, including objectives, tailored content, exercises, follow-up assignments for the next week, and handouts.

**MSAC Organization and Operations in 2006**

The MSAC serves as an umbrella agency for several programs, and operates as a clinical program within the Department of Neurology at UCLA. The MSAC's programs include the Day Program, two Living Well programs, Professional Education, CogniFit, and LEAP. The MSAC has a six-member Board of Directors, with equal representation from the Department of Neurology and the Chapter. In 2006, the Chair of the Board was Dr. Giesser, who also served as Medical Director for the MSAC.

The Executive Director in 2006 was Ms. Fisher, who reported to the Chief Administrative Officer of the UCLA Department of Neurology. She and all of the other MSAC staff are UCLA employees, hired according to UCLA personnel policies and procedures.

The primary mission of the MSAC is to provide a client-centered, community-based program to enhance the quality of life people with MS and their care partners. Program objectives for participating members are as follows:

- To maintain or increase an optimal level of independent functioning through improved abilities and increased mobility
- To maintain or increase health-related quality of life
- To improve, or when appropriate, maintain emotional status through reduction of stress and increased self-esteem.
- To provide opportunities for socialization and community integration to decrease isolation and loneliness

The MSAC's services are organized around four components of its wellness model. They include physical wellness, emotional wellness, recreational and social wellness, and health education. The services provided within these components include:

- Nursing
- Recreational therapy
- Exercise and movement
- Physical therapy
- Speech therapy
- Art therapy
- Social work and counseling
- Nutrition and meals
- Family and caregiver involvement

Quality assurance and improvement efforts are led by the core MSAC staff, with oversight from Dr. Giesser. Collaborative problem solving is well established in the organizational culture at the MSAC. In addition, members complete a questionnaire every five months to provide feedback about the program.

The MSAC is open every weekday, but the Day Program operates only on Tuesday through Friday. Mondays are reserved for special programming, such as aquatics and the Living Well program. Day Program members are only permitted to attend one day per week, which allows the MSAC to serve more people with MS. Staff indicated that another advantage of this schedule is that it encourages members to be more independent during the other four weekdays, which is consistent with the goals of the wellness model.

The daily schedule consists of two morning group sessions, lunch, and afternoon activities. The sessions begin at 10:00am and end at 3:00pm, although the MSAC is open somewhat earlier and later to allow for arrival and pick-up time. The daily itinerary with sample classes is as follows:

| | |
|---|---|
| 10:00am | First morning session (e.g., cognitive stimulation, fitness) |
| 11:00am | Second morning session (e.g., yoga, fitness) |
| 12:00pm | Lunch |
| 1:00pm | First afternoon session (e.g., fitness, art therapy, education) |
| 2:00pm | Second afternoon session (e.g., fitness, recreation, education) |
| 3:00pm | Day Program ends |

Attendance has remained steady for the past three years at about 65-75 members. The maximum enrollment possible for the current program (Tuesday through Friday) is 85 members.

In addition to the executive director, the core staff also include the clinical nurse specialist, a recreation therapist, and a physical activity specialist, each of whom is full-time. Several other therapists are contracted, and Chapter staff, volunteers, student interns, and members also assist at the center.

Each of the four full-time staff brings many years of professional experience to the team, and they have worked together for five years. They are noted for their depth of knowledge and dedication to the promotion of wellness among people with MS. The team enjoys autonomy and freedom to experiment with new programs, in part because they are not limited by state regulations, but also because the MSAC's organizational culture encourages trust, empowerment, and creativity. The core staff meet regularly, consult on major decisions, and work to foster cross-training and flexibility.

The total paid staff includes 12 individuals, representing about five FTEs since many are on part-time contracts. The total for all staff, including volunteers and in-kind staff, is 24 individuals representing about six FTEs. As a result, the MSAC has developed a good balance between the continuity provided by the four full-time staff and the program enrichment provided by the large number of contracted, volunteer, and in-kind staff.

Notably, the MSAC has experienced almost no staff turnover since it began in 2001. The core staff has remained stable, and has developed a strong sense of community among themselves and with the members. A number of factors were cited by staff as contributing to their high levels of job satisfaction, including continuity with members, self-motivated members, ongoing professional challenges, the positive impact of the program, highly qualified staff colleagues, autonomy in staff roles, freedom to experiment with creative problem-solving, support of senior staff, and others.

Members were very positive about their experiences with the MSAC staff. They describe the staff as friendly, compassionate, accepting, fair, and appropriately firm about the rules.

The Operating Agreement between the Chapter and UCLA specifies that the MSAC will be located in the Veterans Avenue Rehabilitation Building on the west campus at UCLA, and that the MSAC will have access to the Fit Center South and the rehabilitation facilities on the lower level of the building. The Agreement also specifies that the MSAC space will be available to the Chapter when needed for other programs. This area encompasses about 2,100 square feet, and includes a large multipurpose room with lots of natural light from an exterior glass wall, a waiting area, three staff offices, and two meeting rooms.

**MSAC's Clients (Members)**

Several admission criteria are used as guidelines for determining if a potential applicant is appropriate for the Day Program at the MSAC, including an MS diagnosis of five years or

more, one or more functional areas impacted, ability to actively participate in all types of MSAC programming, ability to self-care for most activities including feeding and toileting, absence of debilitating emotional problems, and others. These criteria are used in combination with a discussion with the applicant regarding his or her goals, logistical constraints, and level of commitment to pursuing wellness. The MSAC does not require members to receive routine care at UCLA. Members make the following commitments upon joining the center:

- To participate actively for the full program day
- To attend for a minimum of six months
- To attend at least 75 percent of the time
- To work toward achieving wellness goals
- To arrange for reliable transportation

Member turnover at the MSAC has been low, but steady over time. Some members leave because they reach their own self-defined goals or find that their personal goals are not a match for the program. Some are discharged for inconsistent attendance. Some become unable to attend due to logistical issues.

The MSAC's Day Program had 68 members in January 2006, an average of 17 enrolled members per day. About half had been attending the program since it began. The MSAC's Day Program provided 2,720 member-days of service in 2005.

All members of the MSAC have MS, and most are in moderate to severe stages of the disease. The average EDSS score is 6.5, with a range of about 4.5 - 8.5. At the time of entry into the program, the average member is impaired in multiple areas of functioning, which may include physical, cognitive, visual, bladder, or bowel disabilities. About 32% are wheelchair dependent. Eighty-five percent of the members are over the age of 35. Women comprise 83 percent of the membership. Ethnically, 46 percent are Caucasian, 40 percent African-American, 8 percent Latino, and 6 percent Persian.

**Community Context**

The Southern California Chapter of the NMSS is the second oldest chapter (founded in 1947) and one of the three largest in the country. It had 48 staff in 2006, who served 12,500 people with MS in its region, as well as their families, caregivers, providers, and employers. The Chapter had revenue of $8.4 million in 2006, and is known for its support for research, success in fundraising, and excellent programs.

The Chapter's census showed that 2,000 people with MS lived within a 10-mile radius (about a one hour drive) of the MSAC when it was being planned in 2000. An MS community survey conducted at about the same time found that 39% of people with MS in Southern California had a progressive form of the disease, who are more likely to become members of the MSAC. This meant that the MSAC had a potential market of about 780 people (39% of 2,000).

From the early development stage, the Chapter planned replications of the MSAC's programs, so that the benefits of the MSAC and the lessons learned can spread beyond its

immediate vicinity. Two of these new Day Programs are now in operation, in Long Beach and Downey, California.

The MSAC has been successful in maintaining a relatively steady Day Program membership of about 65-70 people for the past several years. However, keeping the census at this level has been a challenge, as the flow of new members is almost evenly matched by those leaving for various reasons. The Day Program has never quite reached capacity, which is 85 members given the current physical space. Factors affecting recruitment and retention may include travel distances, freeway traffic problems, degree of visibility of the MSAC among providers, and the relative newness of the adult day wellness program for people with MS. As a staff member indicated, "Once they're in the door it's an easy sell; getting them to the door is hard."

The main source of referrals for the MSAC has been word of mouth. Most new applicants have come from recruitment efforts of members, staff, and Chapter volunteers. Some neurologists have been afraid to send patients to the MSAC for fear of losing their patients to UCLA. However, this is misinformation; the goal is to complement care provided by other neurologists, not to replace it. Only about one-quarter of MSAC members have a neurologist at UCLA.

The MSAC benefits substantially from the Chapter's fundraising, as well as from the Chapter's efforts to publicize the program. The great bulk of the costs of the program are paid for by restricted gifts to the Chapter from individuals and foundations for the Achievement Center, and by in kind contributions from UCLA Neurology. There have also been two corporate gifts and two smaller county grants for accessibility and modifications to bathrooms. Dr. LeBuffe frequently brings people to see the program, and he ensures that Chapter staff visit the MSAC each year. Programs and activities of the MSAC are included in the Chapter's newsletters and website.

Chapter and MSAC staff stressed the importance of having a physical facility such as the MSAC for visitors to see to facilitate fundraising. Individuals and foundations can visit the MSAC and see first-hand how the program helps members as they strive to meet wellness goals. They observe the enthusiasm, the hard work, the joys of achieving success, and the hard realities of the daily challenges faced by members. After one visit the California Community Foundation actually increased its grant to the MSAC to twice the amount requested, from $100,000 to $200,000! That had never happened at the Chapter before.

MSAC staff have also been creative in developing naming opportunities for donor recognition. A number of areas and objects at the MSAC are named after specific donors, such as the gardening table, benches, meeting rooms, the adaptive computer center, and the relaxation room. Donors' names are artfully displayed along a long wall at the main entrance to the MSAC. The wall serves as an excellent background for photographs of receptions and other events.

The affiliation with UCLA has also been positive for marketing the MSAC. Members have indicated they value the opportunity to attend a UCLA program. As one said, "I'm going to UCLA."

Members are responsible for their own transportation to the MSAC. A few members drive or are driven by family members, but the majority use a paratransit service. Most MSAC members use Access, which charges from $1.80 - $2.70 per ride, depending on the distance traveled. On average, an Access trip to the MSAC takes over an hour each way, and the driver takes up to four passengers with varying destinations. Access provides curb-to-curb transportation throughout Los Angeles County.

**MSAC Finances and Cost Analysis**

Over 80 percent of the MSAC's revenue is generated by the Chapter, through grants and fundraising. Several large grants have provided substantial funding for the MSAC. For example, the naming grant from the Hilton Foundation that helped establish the MSAC in 2001; it was renewed in 2004 for an additional $690,000 over three years. The MSAC is unique among the five MS adult day programs in this study in not receiving any Medicaid revenue.

Membership fees represent eight percent of the MSAC's revenues, and all members are expected to contribute some payments to indicate their commitment to the program. The full fee for the program is $75 per day, but most members are on a sliding scale and pay less. The average payment is about $15 per day, with most paying $5 - $10. About eight pay the full $75 fee. Only two receive a complete exemption and pay $0.

The Operating Agreement specifies that UCLA will contribute the space and utilities at no charge to the MSAC. The Agreement also specifies that the Department of Neurology will provide in-kind staff support for administration, information technology, fund management, human resources, and student intern volunteers. The Chapter contributes some staff support to the MSAC, especially for social work services. Community volunteers also lead some of the Day Program's classes and groups.

Personnel costs represent 83 percent of total MSAC expenses, including salaries and benefits. Contracted staff are an additional 11 percent. As a result, staff costs combined represent over 90 percent of the MSAC's budget.

In 2005, total MSAC revenue was $409,776 and total expenses were $387,567. As a result, the MSAC was operating at a surplus of $22,209, or about five percent of its total revenue.

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Table SC-1 presents data on unit costs. The MSAC is unique among the five MS adult day programs in this study in having multiple services provided in addition to its Day Program. As a result, an estimate of the percentage of total costs associated with Day Program services is needed to calculate a unit cost comparable to those of the other MSADPs. Table SC-1 includes an estimate that 80% of MSAC costs are for the Day Program, which yields a unit cost of $114

per member-day of service provided. In the absence of the percentage adjustment, the total unit cost would be calculated as $143.

**Table SC-1**
**MSAC 2005 Day Program Unit Costs**

| Cost Category (MSAC overall) | (A) MSAC Expenses in 2005 | (B) Day Program Member-days Provided in 2005 | (C) Cost per Day Program Member-day (A) ÷ (B) x 80%* |
|---|---|---|---|
| Expenses | $387,567 | 2,720 | $114 |

*Assumes 80% of total MSAC costs are for the Day Program

**Benefits of the MSAC for Members and Families**

MSAC staff, Chapter staff, members, and family members all identified a range of benefits provided by the MSAC for both clients and family. They are described in seven categories below.

***Social Support and Improved Quality of Life.*** Both staff and members stressed the MSAC's success in building and maintaining social support systems and in improving quality of life for members. They have many opportunities to strengthen social ties through sharing experiences and information. The feeling of being understood is important to members. Just being with other people with MS who have experienced some of the same losses and disabilities is valuable. As one member said, "We need to be around other people with MS. Your family loves you, but they don't really understand since they don't have the disease."

In a recent outcomes research study at the MSAC, depression was one domain that showed a statistically significant improvement over time. Mean scores for members on the Beck Depression Inventory dropped from the mild-to-moderate depression level of 12 at baseline to a non-depressed level of 8 after 18 months.

***Empowerment.*** Through their sharing of experiences and the professional education provided by staff, members learn that they can help themselves and help each other. This builds self-empowerment, another goal of the program. As one member put it, "I can do more for me." Members talk with each other a lot about strategies for managing the disease and their lives.

***Better Maintenance of Functioning.*** Members report a range of physical benefits from the MSAC's physical wellness program. For example, several members who were unable to walk upon entry into the program later became able to walk. The emphasis on members doing

"homework" in between physical activity classes has produced a number of benefits according to staff. Most members have been able to maintain or improve functional abilities in activities of daily living, such as transferring, grooming, eating, toileting, and others. Training for strength and balance has also reduced the incidence of falls among members.

***Staff with Extensive MS Expertise.*** Each of the four core staff members has at least ten years of professional experience, and they have worked together at the MSAC for more than five years. As a result, they jointly have an extensive knowledge of MS and how to implement the wellness model in an effective way for members.

***Early Detection of Medical Problems***. The frequent contact that staff have with members means that they are able to detect some types of medical problems early, when treatment can prevent or mitigate potentially serious complications. For example, urinary tract infections can sometimes be detected by staff through observing unusual patient behavior. Lab tests can then be ordered to determine if treatment is needed. Early referral for assessment and treatment of this type of infection has the potential to prevent lengthy hospitalizations.

***Improved Access to Medical Treatment and Coordination of Care.*** The clinical nurse specialist takes an active role in coordinating care with members' primary care providers and neurologists. Physicians must submit an annual referral to the MSAC for each member with an updated health summary. The nurse also monitors members' hypertension, blood sugars, and weights on an as-needed basis. Changes in members' health status are communicated with the appropriate providers.

***Respite and Support for Family Members.*** The MSAC provides one day of respite each week for family caregivers, and families appreciate this aspect of the program. Families also find it reassuring to know that their relatives are learning how to deal with MS under the guidance of highly skilled professionals in a safe environment.

## Conclusions

The Marilyn Hilton MSAC provides a number of "lessons learned" that can help facilitate the development of new MSADPs in other cities around the country. They may also provide ideas for new services or operational strategies at other existing MSADPs. Conclusions from each section of this case study are reviewed in turn below.

### *History of MSAC Start-Up and Development*

- The MSAC's development depended on a close collaboration between the Southern California Chapter of the NMSS and the Department of Neurology at UCLA. Both partners contributed to the program's operations and funding.

- Planning and partnership development efforts extended over more than five years. Perseverance of stakeholder organizations and individual "champions" over multiple years may be required for the development of MSACs in some situations.

- The Chapter's success in fundraising for large grants to support the MSAC was an important element in its development. Moreover, grant funding provides more flexibility for program design than is possible with Medicaid funding.

- The MSAC began operations on just two days per week, and gradually expanded over time to four days per week. This pattern is common among the MS adult day programs in this study. It allows new programs to become established on a smaller scale at the outset, and build up their member populations gradually over time.

- The staff at the MSAC and the Southern California Chapter are noteworthy for their entrepreneurial spirit. They have developed a number of related programs under the MSAC "umbrella" that go well beyond the Day Program. This is unique among the MSADPs in this study, and provides a model for diversification of MSADP services to broaden their impact and improve financial stability.

***MSAC Organization and Operations in 2005***

- The MSAC is unique among MSADPs in this study in organizing its services around a wellness model. Members have responded positively to this model, with its four components of physical wellness, recreational/social wellness, emotional wellness, and health education. New MSADP start-up efforts in other cities should consider this service model.

- Close relationships often develop between members and staff. A sense of community has developed over time that has led to a high level of trust between members and staff.

- The MSAC's very low staff turnover is noteworthy. Staff indicated a range of factors supporting their high levels of job satisfaction, including the ability to provide continuity of service with self-motivated members, the positive impact of the program, the autonomy they enjoy in their roles, the high levels of expertise and collaborative spirit of their colleagues, and the openness, flexibility, and support of senior staff.

***MSAC Clients (Members)***

- The MSAC serves a member population that is less disabled that those at the other MSADPs in this study, with about 32% wheelchair dependent. This is consistent with the wellness service model, as it enables on average earlier intervention and more opportunities to promote independence. New MSADP start-up efforts in other cities should consider what member case-mix to target, and the fit with their service models.

***Community Context***

- The MSAC benefits from close collaboration with the Southern California Chapter, both in terms of fundraising and program development. That collaboration has led to replication of MSAC programs at other sites in its region, which is unique among the MSADPs in this study.

- The lack of competition for the MSAC in the Los Angeles region is consistent with the findings for other MSADPs. These programs have unique marketing benefits in terms of offering services to clients with significant needs who usually do not have other options.

***MSAC Finances and Cost Analysis***

- About 90 percent of the MSAC's revenue comes from grants and fundraising, mostly resulting from Chapter initiatives. That is much higher than any other MSADP in this study.

- The MSAC also benefits from the willingness of its parent organization, UCLA, to provide in-kind support for the services it provides its members. This is one of the benefits of organizing an MSADP as a unit within an academic medical center.

- The MSAC is unique among the MS adult day programs in this study in not receiving any funding from Medicaid. This has enabled it to avoid the operational requirements of state licensure, and maintain its culture of flexibility and innovation.

***Benefits of MSAC for Clients and Families***

- Broad acknowledgement of the value of the benefits provided by the Marilyn Hilton MSAC to its members is a finding also consistent with the other MSADPs in this study. Members have few other options for receiving the range, quality, and frequency of services needed for their high levels of disability and symptom burdens.

- The MSAC is noteworthy for conducting detailed outcomes research as a part of its program, including a wide range of scales and measures. The improvement found over time for one measure, the Beck Depression Inventory, provides valuable quantitative documentation of the MSAC's benefits.

## SECTION 1: INTRODUCTION AND METHODS

### *Background and Goals*

Although some people with multiple sclerosis (MS) remain stable, most become increasingly disabled as the disease progresses. As a result, many people with MS require increasing levels of support from family and friends, and eventually long-term care services may be needed. Long-term care is often associated with nursing homes, but they may not provide the best care or most desirable setting for MS medical treatment and rehabilitation services. Moreover, people with MS often have different social needs since they are generally younger than the other residents of nursing homes.

In response to the desire by people with MS and other disabilities to remain in the community, a broad range of home- and community-based alternatives to nursing home care have been developed in recent years. MS adult day programs (MSADPs) represent an important element in the range of long-term care options, but one that is currently not widely available. In addition, the specific programs available in the limited number of MSADPs that have been developed are not well documented, and there is little data on their costs and benefits. MSADPs represent a promising long-term care service that may be able to provide more effective rehabilitation services, help maintain independence, and improve the quality of life for people with MS, but more information is needed to guide future program development and advocacy efforts.

This case study and cost analysis report is one in a series of five prepared for the Multiple Sclerosis Adult Day Program Evaluation, a study sponsored by the National Multiple Sclerosis Society (NMSS) and being conducted by Research Triangle Institute. The MSADPs participating in this study are as follows:

- Marilyn Hilton MS Achievement Center, UCLA Medical Center, Los Angeles, California
- King Adult Day Enrichment Program, Rocky Mountain MS Center, Denver, Colorado
- Unity Health System MS Achievement Center, Rochester, New York
- Fairview MS Achievement Center, St. Paul, Minnesota
- Day Treatment Program, Mellen Center For MS Treatment and Research, Cleveland Clinic, Cleveland, Ohio

Overall, this study includes three components: case studies, cost analyses, and outcomes research. The case study and cost analysis components for the Marilyn Hilton MS Achievement Center are included in this report. The goals of the MSADP Evaluation study are as follows:

- Develop effective collaborations with five MSADPs as study partners.
- Identify the key internal and external factors that promote and inhibit the development and expansion of MSADPs.
- Describe the alternate organizational, operational, and service models used by MSADPs.
- Describe the alternate funding strategies that can be used to finance MSADPs.

- Calculate the full costs of developing and maintaining MSADPs.
- Identify the benefits of MSADPs, in terms of quality of life, health status, functional status, institutionalization, complications, and other outcomes they achieve for patients and family members.
- Disseminate the results of the study widely, among existing MSADPs, local chapters of the NMSS, MS Centers, other organizations that may be considering development of MSADPs, throughout the larger MS community, and among key external policy makers and stakeholders who may affect the availability of funding for these programs.
- Develop a handbook that summarizes the alternate organizational, operational, service, and financing models and lesson learned across the five study partner MSADPs, to facilitate development of new MSADPs in other cities around the country.

### *Methods*

This report was developed using a range of sources. A two-day site visit conducted by the authors at the Marilyn Hilton MS Achievement Center (MSAC) in Los Angeles provided opportunities for face-to-face interviews and observation. An additional two days of site visits included related programs developed by the Southern California Chapter of the NMSS at other provider institutions in the Los Angeles region. A wide range of documents were also reviewed. Specifically, the sources included:

- In-person interviews with MSAC staff
- In-person interviews with MSAC clients and family members
- Observation of MSAC group activity sessions and informal discussions with clients, staff, interns, and volunteers
- Interviews with UCLA and NMSS Southern California Chapter staff
- Review of MSAC and NMSS Southern California Chapter planning and operational policy documents, reports, websites, and newsletters
- Review of MSAC budget spreadsheets and financial statements

The authors integrated information from all of those sources to prepare each section of this report. Review and comment will next be provided by MSAC and NMSS Southern California Chapter staff, and their comments will be incorporated into the final version of this report.

### *Structure of this Report*

Section 2 describes the history of MSAC, including the development and planning period prior to its opening in 2001. Section 3 presents MSAC's organizational structure, operational methods, and services provided at the time of this study, in 2006. Section 4 describes the members attending MSAC. Section 5 reviews the community context in which MSAC operates. Section 6 describes MSAC's finances and presents the cost analysis. Section 7 includes a summary of the range of benefits provided by MSAC, as identified by clients, family members, and staff.

## SECTION 2: HISTORY OF MSAC START-UP AND DEVELOPMENT

### *The Start-up Effort*

The Marilyn Hilton MS Achievement Center (MSAC) at the University of California, Los Angeles (UCLA), opened in June, 2001. A collaborative effort between the Southern California Chapter of the National MS Society and UCLA, the MSAC was founded to provide a wellness-focused day program for people with MS with advanced disabilities. Funding from the Conrad N. Hilton Foundation and several other grants provided substantial support for the MSAC, which was named in honor of Marilyn Hilton, Conrad N. Hilton's daughter-in-law.

The effort to develop an MSAC in Los Angeles began in 1994, when Dr. Leon LeBuffe, the President of the Southern California Chapter, visited the MSAC in Minnesota with Jim Ahern, President of the Upstate New York Chapter. Dr. LeBuffe was impressed with the MSAC, and recommended development of a similar program to the Board of his Chapter. Mr. Ahern remained an advisor throughout the process of the California MSAC's development.

In 1995, Dr. LeBuffe created a committee comprised of Southern California Chapter Board and staff members to begin the task of developing an MSAC. The committee's first and largest challenge was to find an institutional partner to share the costs. The ideal partner would provide the physical space, medical oversight, and insurance. Initially, the committee approached UCLA, but the university was struggling at that time with space limitations in the aftermath of the 1994 earthquake. The committee then began discussions with the University of Southern California, but concerns were raised about liability issues and that attempt failed as well in 1996.

The Chapter next pursued a collaboration with Cedars-Sinai Medical Center. Planning and negotiations continued for two years and eventually funding and senior staff approvals were obtained. However, the Cedar-Sinai Board unexpectedly voted the proposal down, stating that they could not afford to provide the space required for an MSAC, which would have cost about $250,000 per year.

At this point the committee became somewhat discouraged and considered abandoning the project. However, Dr. LeBuffe was determined to continue the search, and with his encouragement, the committee made one more approach to UCLA. By this time UCLA had substantially rebuilt after the earthquake, and space was not as limited as it had been during the earlier discussions. The committee's five-year long search for an institutional partner was fulfilled in 1999 when Dr. Robert Collins, Chair of the UCLA Department of Neurology, agreed to provide space and enter into a partnership with the Chapter for development of an MSAC.

An operating agreement was drawn up outlining the respective commitments of the Chapter and UCLA, and the services to be provided at the MSAC. The MSAC would operate as a clinical program within the Department of Neurology at UCLA, as it has done to the present time. UCLA agreed to provide the space, janitorial services, utilities, medical oversight, and insurance. The Chapter agreed to provide funding for the MSAC's staff and operating expenses, totaling approximately $280,000 per year. Reimbursement was planned to recover about

$100,000 of those costs, leaving the Chapter to raise about $180,000 per year from foundations, individuals, and corporations. A joint Board of Directors was formed, chaired by Dr. Collins, with membership including three representatives each from the Chapter and UCLA. Dr. Bruce Dobkin, the Medical Director of the UCLA Neurologic Rehabilitation and Research Program, was appointed as the MSAC Medical Director.

With the UCLA partnership established, Dr. LeBuffe approached the Conrad N. Hilton Foundation for financial support. Marilyn Hilton, who was Conrad Hilton's daughter-in-law, had MS and the Foundation had been funding MS Society programs since 1988. The Foundation agreed to provide half of the MSAC's operating costs and some funding for expansion.

By early 2001, the Chapter had secured gifts and pledges totaling $535,000. They included $400,000 from the Hilton Foundation, a $50,000 challenge grant from the Flora L. Thornton Foundation to help launch the MSAC, three smaller gifts $25,000, and one for $10,000.

Renovation costs at the outset were $209,201, with $100,000 raised by the Chapter and the remaining $109,201 raised by the UCLA Neurology Department. This included $159,976 for remodeling and build-out of the space provided, and $49,225 in furniture and equipment costs.

***Designing the MSAC's Programs***

With the UCLA partnership and funding in place, detailed MSAC planning and design efforts began under the guidance of Denise Nowack, Executive Vice President for Programs at the Southern California Chapter. One of her first steps was to recruit Stephanie Fisher to serve as the Executive Director of the new MSAC. Ms. Fisher had been Vice President for Programs at the Orange County Chapter of the NMSS for five years when she agreed to take on the new role at the MSAC. As a result, she brought a strong background in MS programs and administration. A clinical nurse specialist and health educator, Elise Herlihy, was hired at the same time to provide clinical expertise.

The Chapter and MSAC staff explored the option of organizing the MSAC as a state-licensed adult day health care (ADHC) program, eligible to bill Medicaid (known as MediCal in California) like the Rochester MSAC and other MSACs. However, they found that in California that approach would not be cost-effective, and could also create access problems for private pay clients. There were several reasons behind the decision to avoid becoming a licensed ADHC:

- Program staffing requirements would have increased the annual operating cost of the program from $282,000 to over $350,000. Requirements for licensure included provision of physical therapy, meals, and transportation.
- Space, oversight, and medical requirements for a licensed ADHC's medical model would have limited the program to about 10 attendees, about half of what had been envisioned.
- Medicaid reimbursement was only $61.61 per client per day. It was uncertain whether there was a large enough number of individuals with MS who were also eligible for Medicaid reimbursement and within commuting distance of the MSAC to

warrant the added expense of the ADHC program. Private pay clients were expected to have trouble covering daily costs that high.

- Licensure might also limit the use of the MSAC to just day program participants. This would inhibit the ability to also integrate the Chapter's community-based programs into the operations of the center.
- The approval process by the State of California took from six months to a year. That would have meant that the MSAC would not be able to open on its planned timetable as an ADHC even if that model were desired.

Ms. Nowack and Ms. Fisher also chose to move away from a medical model because they shared a common philosophy based on wellness rather than treatment for the MSAC's programming. As part of the planning process, the Chapter conducted a study with its members to explore opinions about adult day programs and the concept of wellness. Focus group participants were selected from several segments of the MS population who resided within a reasonable commuting distance of the MSAC. The results showed that people with MS associated wellness with positive concepts such as self-empowerment and self-esteem, while adult day care was associated with mental illness, Alzheimer's disease, and older adults.

The next step in developing the program was to explore the lessons learned from other MSACs. With Dr. LeBuffe's encouragement, the Chapter sent Ms. Fisher and Ms. Herlihy on site visits to the Fairview MSAC in Minnesota and the King Adult Day Enrichment Program (KADEP) in Colorado. Each of these programs shared their service models, policies, funding strategies, operational procedures, and many other details regarding their programs. Ms. Fisher and Ms. Herlihy also learned a great deal from observing the programs in action and talking with staff.

At the Fairview MSAC they were impressed with the comprehensive nature of the program. It also showed them that group activities were possible, that MSAC services did not have to be one-on-one. They were impressed by the number of members who had attended for many years, and their commitment to attend despite at times long travel distances and inclement weather. Operational insights they gained included the following:

- Comprehensive nature of services needed to serve clients with multiple needs
- Benefits of grouping members by their abilities
- Value of having a spiritual component in the program
- Flexibility and advantages of groups over one on one services
- High degree of creativity possible in approaches to teaching wellness

The site visits and focus group results helped cement the commitment to a wellness model. The final model for the Marilyn Hilton MSAC included with four components:

- Physical wellness
- Recreational/social wellness
- Emotional wellness
- Health education and health promotion

To complement the wellness model, the goals for the MSAC at its inception included the following objectives for its members and their families:

- Maximize independent functioning
- Decrease depression
- Provide opportunities for socialization and community integration
- Provide respite for care partners

To implement the wellness model a recreation therapist and an exercise specialist were also hired. Each had experience working with people with MS and an interest in wellness education. The budget did not allow for a social worker, so a contract was developed with an art therapist and the Chapter also provided social work services from its staff. The Chapter was interested in providing physical therapy services through the MSAC, but licensure issues did not allow for billing for PT services.

The MSAC leadership team also designed the program with a research component to document the benefits of participation. A battery of tests was selected, including physical, emotional, and social outcome measures. Upon admission to the MSAC, each participant consented to participate in both the program and the research component.

***The Early Years***

When the MSAC opened in 2001, 7 members attended on the first day. The program included cognitive and exercise modules in the morning, lunch, and then a recreational activity and health education class in the afternoon. Each of the classes was focused on wellness education. Individual times with a physical therapist or another exercise staff member were interspersed throughout the day. This basic format has remained consistent at the MSAC to the present day.

From the beginning, the program has been tailored to meet the needs of each individual member. This included adjusting the daily schedule to accommodate member differences. For example, small group composition was based on the functional abilities of members, and those who fatigued more easily would have physical activities in the morning.

The MSAC was open only on Thursdays at the outset in June 2001, but Tuesdays soon followed that July and Wednesdays in October. Fridays were added in August 2002. Members were grouped by functional abilities by day of participation, with the more disabled members attending on Wednesday. The less-impaired members attended on Tuesdays. Mondays were kept open to be available for special programming.

The Chapter provided substantial staff support during the first year the MSAC was in operation. Ms. Nowack worked closely with Ms. Fisher to provide resources and develop programming for the center.

In 2002, Dr. Barbara Giesser joined the department and became the Medical Director of the MSAC and Chair of its Board of Directors. Dr. Giesser, an advocate for health and wellness

promotion for people with MS, worked closely with the MSAC team and Ms. Nowack to strengthen the program.

The MSAC has remained at its original location on the western campus of UCLA since it opened. The program occupies space on two floors of the Veterans Avenue Rehabilitation Building. Group meeting rooms and staff offices are on the first floor, and a gym with adaptive equipment and a pool are available to MSAC members on the floor below.

The success of the MSAC's development effort was highlighted in April, 2005 when a second five-year operating agreement was signed between the UCLA Department of Neurology and the Southern California Chapter of the NMSS. As with the original agreement, it includes formal commitments for the services, finances, and other contributions each party will provide to promote the growth and sustainability of the MSAC.

***Diversification Initiatives***

The vision of the MSAC is one that includes the development of innovative programs and their replication at other sites in order to reach as many people as possible at various stages of MS. The MSAC thus serves as a "Petri dish" in which wellness modules can be first developed and then adapted by the Chapter for use in other day programs and other community-based programs. This entrepreneurial spirit is a hallmark of both the MSAC and the Southern California Chapter.

Several new and related programs have already been implemented. Four that are located at the MSAC are described in this section. Those that are located at other sites are described in Section 5.

**Professional Education.** A professional education program was implemented in 2003 at the MSAC. Focused on wellness programs for people with MS, it offers half-day lectures with continuing education units for neurologists, nurses, physical therapists, and occupational therapists. The lectures are arranged by Dr. Giesser, Ms. Fisher, and Ms. Herlihy. Speakers stay on to meet with members and their families in the afternoons. This program won an award for the best MS educational program in 2005. It is funded by unrestricted grants from pharmaceutical companies, so it only needs to charge a small fee.

**Living Well.** The Living Well program includes two types of educational courses for wellness education. One is for people who are newly diagnosed with MS, and the other is for those who are experiencing some disabilities but do not yet need to attend the MSAC's day program. Living Well is designed for people who are still working, so it meets for three hours per session on Mondays, for 12 weeks. These programs were designed by Ms. Nowack to enable the MSAC to serve a broader range of people with MS and at a lower overall cost per person.

The goal of Living Well is to empower people with MS by helping them build a sense of control and confidence for living with MS. Outcomes include:

- Improved management of MS and related symptoms

- Enhanced psychosocial well-being
- Improved lifestyle and health practices

MSAC staff provide instruction on physical, mental, social, intellectual and spiritual health. They emphasize the activities a person with MS can do to complement and support their medical care, and bring a balance back to their lives. In a nurturing group atmosphere, participants gain a better understanding of MS and the lifestyle strategies that can help diminish the effects of the disease. Participants have the opportunity to:

- Build a framework for wellness
- Develop their own personal fitness and nutrition plan
- Understand and manage fatigue and stress
- Develop coping skills to effectively manage the challenges faced with MS

The fee for the 12-week program is $300. About 70% of the participants pay the full fee, but ample scholarship money is available and no one is turned away due to a lack of ability to pay. Participants must sign an informed consent to enroll, and pre- and post-tests are administered to track outcomes. Results to date show that the program is having a positive impact. The maximum number of participants possible per session is 18, and the program has averaged 13 participants per session over the past four years.

Past Living Well participants also have the opportunity to reconvene with other program alumni on a quarterly basis to continue their commitments to health education and to find ongoing support for maintenance of their individual wellness plans. Each three-hour alumni session highlights a range of topics, including MS research updates, educational and fitness sessions, and an emotional or spiritual wellness component.

Currently, three Living Well programs are offered each year. The September and January cycles are for those newly diagnosed, and focus on participants who meet one or more of the following three criteria: 1) recent MS diagnosis of less than 5 years; 2) possessing minimal MS symptoms; and 3) employed. The Spring cycle serves participants who have lived with MS for a longer period and are experiencing new challenges related to MS symptoms. For example, the disease may have created a need to change something in participants' lives, such as discontinuing employment, working less, changes in family roles (such as no longer performing chores), a reduction in social or leisure activities, or discontinuing a fitness program as a result of symptoms.

Participants in the Spring cycles are often integrated into activities serving the MSAC day program participants. Some may ultimately become candidates for enrollment in the day program as their disease progresses. One participant from the Spring 2005 Living Well program has since joined the day program.

Both of the Living Well programs were designed to be easily-replicable modules that can be translated to other service settings and delivered in partnership with other community-based organizations. In this way, the Chapter is fulfilling the vision of the MSAC as a model for program development and replication.

**Lifestyle Education and Assessment Program (LEAP).** Launched in the spring of 2005, LEAP was designed by Dr. Giesser and the MSAC team to provide a range of expert neurological and functional assessments for people with MS who have difficulty accessing specialty care, such as residents of rural or outlying areas. The intensive assessment process takes half a day and is offered to two patients per month.

The LEAP team consists of Dr. Giesser, a mental health practitioner, and the MSAC's clinical nurse specialist, physical activity specialist, recreation therapist, occupational and physical therapists, dietitian, and speech and language pathologist. Each meets individually with the patient. A Chapter representative also meets with the patient to provide information about Chapter resources. A comprehensive report is provided to both the patient and the patient's physician.

Unlike other initiatives, LEAP is not supported by the MSAC's budget, but is its first program that bills health insurance. Support from Teva Neurosciences provided start-up funds and also allows the MSAC to offer sliding-scale scholarships for those who lack insurance coverage or the ability to privately pay for the service.

**CogniFit.** CogniFit is an eight-week course developed and facilitated by the MSAC's two speech pathologists, one of whom has MS. It is offered on Mondays, Tuesdays, and Thursdays at the MSAC, and has also been given in other cities, including Pasadena and Riverside. The goal is to help people with MS improve their cognitive abilities through the following modules:

Week 1 – Attention: Concentration & Focus
Week 2 – Memory: Auditory Emphasis
Week 3 – Memory: Visual Emphasis
Week 4 – Reasoning
Week 5 – Executive Skills
Week 6 – Pragmatics
Week 7 – Math & Calculations
Week 8 – Creativity

The course is based on research in these areas, and also benefits from the personal experiences of the therapist who has MS. A detailed curriculum is provided for each week, including objectives, tailored content, exercises, follow-up assignments for the next week, and handouts.

## SECTION 3: MSAC ORGANIZATION AND OPERATIONS IN 2006

### *Organizational Structure*

The MSAC operates as a clinical program within the Department of Neurology at UCLA. An operating agreement between UCLA and the Southern California Chapter of the NMSS outlines their respective responsibilities and the structure and function of the MSAC. It is currently running for a five-year period from April 1, 2005 through March 31, 2010.

The MSAC has a six-member Board of Directors, with equal representation from the Department of Neurology and the Chapter. The board meets quarterly, and addresses issues such as the budget, staffing, new programs, and marketing strategies. The Board elects a Chair from among its members. Board members serve for two year terms that are renewable. In 2006, the Chair was Dr. Giesser, a neurologist who also served as Medical Director for the MSAC. The Medical Director of the MSAC is appointed by the Chair of the Department of Neurology.

The Executive Director in 2006 was Ms. Fisher, who reported to the Chief Administrative Officer of the UCLA Department of Neurology. She and all of the other MSAC staff are UCLA employees, hired according to UCLA personnel policies and procedures. Ms. Fisher recommends new staff for the MSAC, and all staff must be approved by the Board before hiring. Appendix A includes an organization chart for the MSAC.

The MSAC serves as an umbrella agency for several different programs described in the last section. They include the Day Program, two Living Well programs, Professional Education, CogniFit, and LEAP.

### *Mission and Goals*

The primary mission of the MSAC is to provide a client-centered, community-based program to enhance the quality of life people with MS and their care partners. Program objectives for participating members are as follows:

- To maintain or increase an optimal level of independent functioning through improved abilities and increased mobility
- To maintain or increase health-related quality of life
- To improve, or when appropriate, maintain emotional status through reduction of stress and increased self-esteem.
- To provide opportunities for socialization and community integration to decrease isolation and loneliness

Additional goals are to increase knowledge about MS for members and their families, and to develop new programs so that more people with MS can benefit. As noted, replication of the MSAC's programs to other areas in Southern California is being actively pursued.

### *MSAC Services*

This section first presents an overview of the MSAC's services, using the four components of the program's wellness model. A more detailed description of its services then follows, using more traditional service categories.

#### Wellness Model Components

**Physical wellness.** This module focuses on adaptive exercises that improve endurance, coordination, posture, balance, flexibility, and strength. Members engage in these activities to attain personal goals, as well as to increase their knowledge of fitness concepts and strategies for their own at-home exercise plans. Activities include individual workouts in the Rehabilitation Building's Fitness Center, group music and movement therapy, adaptive yoga and aerobics, T'ai Ch'i, chair dancing, exercise ball training, Feldenkrais, and Pilates.

Classes and one-to-one assistance are led by the physical activity specialist and rehabilitation therapists. Workshops are also presented by the nurse clinician and others dealing with falls prevention, relaxation, nutrition, and other topics related to physical well-being.

**Emotional wellness.** This module provides support for coping with the emotional burdens of MS. Participants enhance their self-esteem and self-worth to foster comfort in living with the disease, to develop reliance on other members and support systems, and to empower themselves to cope more effectively with MS. Programming includes one-to-one and group counseling, art therapy, emotional support groups, and psychosocial educational programs.

Additional support and case management services are provided through the Chapter. The MSAC works closely with Chapter staff to assist with specific client needs. All MSAC members receive an with a licensed social worker from the Chapter during the first six months of program participation.

**Recreational and social wellness.** This module delivers accessible, therapeutic recreation opportunities. Through these activities members learn new recreational skills, increase or maintain socialization, decrease isolation, increase or maintain cognitive skills, improve feelings of self-worth, and increase integration into the community. Activities are led by a recreational therapist, speech therapists, and occupational therapists.

A range of cognitive stimulation is provided, including adaptive computing, speech and cognitive stimulation exercises, and games for improving memory skills. Other activities include animal-assisted therapy, group outings, and adaptive bowling. MSAC staff are also developing a creative writing class online for members. This is intended as the beginning effort for a new pilot program called Wellness Without Walls (WWW), that will offer Internet-based services to Day Program members and eventually to the MS community at large.

**Health education.** Seminars are facilitated by the clinical nurse specialist to provide education for members on a range of MS issues. Guest physician lectures on MS-related topics are also provided periodically in a "Lunch and Learn" program.

It is important to note that there is overlap among these four wellness modules, in both interactions of the therapies employed and their potential benefits. For example, self-empowerment, self-worth, and emotional support have the potential to be improved through most of the MSAC's activities, and several modules incorporate physical activities. Staff often remarked upon the interconnectedness of the modules and therapies, and how the program's structure facilitates communication among the staff and therapists.

**Services Provided**

**Nursing**. The clinical nurse specialist provides education at both the group and individual levels to members. She also plays an important role in the MSAC leadership team in discussing members' health issues and the best use of health resources. She works with Dr. Giesser in an MS clinic every Monday afternoon, which provides an opportunity for continuous education under Dr. Giesser's mentorship.

The MSAC's emphasis is on health education and promotion rather than treatment, so the majority of the nurse's time is spend in education. She teaches classes on MS issues, such as Tysabri and MS symptoms, and provides preventive health care research updates on topics such as osteoporosis, hypertension, and cardiovascular disease. Another class on how to navigate the health care system was offered to members through a teleconference.

Education of individual members occurs frequently but usually on an unscheduled basis as problems arise, such as an exacerbation of MS or a urinary tract infection. The nurse often spends from one to two hours per day in individual meetings with members to address their health concerns, perform some tests (blood pressure, blood sugar, weight measurements, and others), and answer questions about medications. She does not administer medications, but can discuss side effects, proper administration and timing of medications, and recommend further medical follow-up when needed.

Continuity of care is facilitated by the nurse through these on-going assessments and by referrals to appropriate health providers and other community resources. Other activities include the following:

- Phone calls and follow-up with absentees
- Interviewing new members
- Obtaining necessary paperwork from physicians (releases, authorization to be in the program)
- Obtaining information about members' health status from physicians, such as results for respiratory or cardiac tests

**Recreational therapy.** Recreational therapy encompasses a broad range of activities, including scheduled group activities at the MSAC, outings for the entire center, organization of the MSAC team for the MS Walk, and contributing to the Chapter's newsletter. Examples of class activities include adaptive computers, journaling, newsletter, Mah Jongg, current events discussions, cognitive stimulation, and a movie club.

Outings provide an opportunity for all of the MSAC's members to socialize together. Sometimes families attend as well. Trips have included the Armand Hammer museum, the farmer's market, and bowling day. Staff noted that outings that include families also provide an opportunity for informal communication with staff about members' progress at the MSAC and their needs at home.

The annual MS Walk has become a popular event for members, their families, and staff. The MSAC now has its own team, the MS Achievers, that first walked together in 2002. Some members were afraid to go at first, due to concerns that it would be too far or that there might not be enough bathroom access. However, these concerns were resolved by changing the walk to just one kilometer, ensuring accessible toilets were provided at frequent intervals, having staff available at the end to assist as needed, and providing prior training at the regular MSAC program to build confidence. Staff work closely with the Chapter and the members to make the walk an enjoyable and successful experience for all who participate. Families get very involved in providing support. As one member said, "I thought I couldn't do it before, as I can't walk. Now I love it. A whole gang of us with MS do it."

The recreational therapist (RT) runs most of the group activities, but volunteers also occasionally teach groups, such as an actor who teaches drama, speech, and poetry reading at the Tuesday group. Staff noted several advantages of having a certified recreational therapist instead of a less formal activities director leading this part of the program. They indicated that an RT has a better understanding of disability issues, better programming and clinical skills, stronger case management abilities, and can understand and spot problems more quickly.

**Exercise and movement.** Physical activities that focus on fitness, weight training, yoga, tai chi, or movement therapy are offered twice daily at the MSAC. Members select one of them as their activity preference each day. Most exercise and fitness classes are taught by the exercise specialist, while volunteers teach yoga. The yoga program has been adapted by one of the volunteers, Eric Small, so it can be done by people in wheelchairs. Mr. Small is a nationally-recognized yoga teacher who has worked extensively with people with MS and other disabilities. The exercise specialist and the recreational therapist can also cover the yoga classes as needed. A volunteer teaches movement therapy and T'ai Ch'i several times per month.

The exercise specialist takes 3-4 members at a time each day to the fitness complex reserved for UCLA faculty and staff. It is located in the same building as the MSAC's offices and main meeting rooms. The exercises are guided by a PT evaluation that indicates what to start each patient on, and what parts of the body to work on. Guest instructors and motivational speakers supplement the physical wellness program on Tuesdays with classes such as Pilates or "Smart Women Do Dumbbells." Staff indicated that having guest instructors makes the members feel special.

A goal of the physical activity classes is to provide members with skills and exercises that can be easily incorporated into their daily lives outside the program. "Homework" is encouraged so members can multiply the benefits of their one day per week at the MSAC. For example, members are taught to do a posture check and shift their weight after they brush their teeth while in front of the mirror. They learn to do ankle circles while watching television, and how to use their core muscles (torso and abdominal) to sit down without "flopping."

Members are encouraged to seek outlets for physical activity in the community, and many work out at a gym once or twice a week in addition to the MSAC. Some use yoga tapes at home several times a week. After a while, members start on a home exercise program as well, and staff send a sheet home to remind them. The key is motivating members to do the home exercises. Even doing one thing has been found to help, such as stretching to prevent spasticity.

These skills also translate into daily living by helping to prevent falls. A two-hour falls prevention course is offered every year in which members learn preventive techniques as well as how to roll and get up off the floor. Learning how to roll is difficult for some people with MS, but they can practice this on the table in the fitness center. Members who have a tendency to fall are encouraged to wear an alert button.

Aquatic therapy is an additional option for some members, and it is helpful with maintaining and improving balance. Ambulatory members with good bowel and bladder control can enroll in the 8-week pool program, which is offered in the pool on the first floor of the MSAC's building. Members have to be independent in the pool or bring a family member to assist them. Two groups of up to seven members each can use the pool for one hour on Mondays. Members come from various days of the week since the Day Program does not operate on Mondays. The water temperature is allowed to drop over the weekend to accommodate the lower heat tolerance of people with MS, and there are places to sit and rest in the pool.

The pool activity is now in its third semester and has been quite popular, with several members repeating it. The exercise specialist teaches the class, and on occasion invites staff from the aquatic department to assist. Pool exercises include using noodles, dumbbells, and walking bars to help improve balance and strength. Members who are unable to lift extremities outside the pool find that they can lift them underwater. Successful experiences in the pool help to build members' confidence to use their pool skills elsewhere. Some members had not been in a pool in 10-15 years, and were afraid of the water.

**Physical therapy.** Every member receives a PT evaluation upon admission into the program and then every six months thereafter. The evaluations include recommendations for interventions for the exercise specialist to implement. The PT staff member is at the highest technical level, PT3, and has been with the program since the start of the MSAC.

Members are sometimes concerned about the regular PT evaluations because they may have had a recent relapse and are concerned about having lost some functionality. In order to help empower them, the physical therapist focuses on what the member can do rather than their

losses or weakness. In addition to the testing conducted during the evaluation, the PT discusses the member's activity preferences and makes recommendations to the care team. The PT attends the MSAC staff meeting on alternate weeks to ensure regular communication about individual members' needs and progress, and also speaks with the exercise specialist on an ad hoc basis as members' needs change.

Individual maintenance PT is not reimbursable by health insurance plans, so only acute exacerbations or injuries such as from falls can be treated by the therapist. Group activities are also not covered by insurance, so at this point only one-to-one services are available from the physical therapist.

The PT helps to evaluate which types of wheelchairs are best for individual members, and develops lists of changes needed for members who have wheelchairs. She also helps members learn how to negotiate with wheelchair vendors. She checks on how members use other types of assistive equipment as well. If they have problems it is often found to result from body mechanics or posture.

The PT evaluations have shown that most members can gain in strength, range of motion, and posture control. Some members have been able to avoid declines in walking ability. A lack of increase in disability is considered a sign of success in this population. Some people with MS may not have to lose mobility if they can adjust to the deficits they experience. Staff indicated that members sometimes say, "I don't know where my feet are," due to a lack of sensation. However, this may not be due to a neurological deficit, but rather due to loss of sensation and depression. If members can reconnect with the feelings in their feet they may be able to avoid loss of mobility.

**Speech therapy.** As many as 40-60 per cent of people with MS may experience difficulties in cognitive abilities as the disease progresses. Two speech and language pathologists are contracted by the MSAC to provide classes that can help members retain and strengthen their cognitive skills. Members learn innovative techniques to improve attention, memory, concentration, problem solving, organization, and critical thinking skills.

**Art therapy.** Art therapy plays an integral role in the MSAC's wellness model. Self-expression through art can facilitate members' healing and empowerment. Many people with MS have identity and self-worth issues, and art therapy can help them explore and improve their relationship with the MS diagnosis.

Members often experience losses as MS progresses, including work, sense of value to society, and strained relationships at home. Through art therapy they can express things visually and experience a sense of being in control. This process of building self esteem helps shift the emphasis "from what we do to who we are." Art therapy can also help with stress, depression, and pain management. It includes both talk and non-verbal therapy. Members can talk about more personal things as they discuss their art projects. The sense of community at the MSAC is also reinforced when art therapy is conducted as a group session.

Two art therapists provide weekly classes for the Tuesday, Thursday, and Friday groups, and occasionally for the Wednesday group. Media include collages, which are easier for those with fine motor skill disabilities, and painting with easy-grip pastels and acrylics. Limited time can be an issue for painting in class. Several members paint at home as well. Some of the members' art is displayed on the walls of the MSAC. Sharing their accomplishments in this way helps create connections with members who attend the MSAC on other days.

**Social work, counseling.** Social workers from the Chapter provide counseling and resource referral. Monthly support groups are also provided at the MSAC. The groups last about an hour.

**Nutrition and meals.** The MSAC does not provide meals, so members bring their own lunches and snacks to the program. Staff indicated that sharing food from home helps some members connect with each other. A nutritionist is contracted to teach classes on nutrition about once per month.

**Family and caregiver involvement.** The MSAC has found it challenging to get families and caregivers involved in the program. Support groups for families and caregivers have had limited participation. The majority of family contact occurs during outings such as the MS Walk and bowling day.

Members had very positive comments on the services and programs provided by the MSAC. Some of their comments were as follows:

"I will do this the rest of my life."

"I cannot imagine not coming here."

"This program, the MSAC, is fantastic."

"I don't get the same things at support groups as here at the MSAC. Support groups are too short, only one hour."

***Ideas for Additional MSAC Services***

While members and staff were very satisfied with the MSAC's services, they did have several suggestions for additional services that could be added. One idea was for a one hour session for information sharing and discussion of "unmet life needs," such as how to find an attorney or other services in the community. This type of group might not require a counselor, but would need a staff member to facilitate and offer ideas. It would provide a time and place for information sharing rather than members "sneaking a few minutes on the side" with individual staff to answer their many questions.

Some other ideas were to:

- Provide more opportunities for relaxation, such as classes on meditation and massage

- Offer a monthly educational program for caregivers and families
- Link to more volunteer opportunities for members

***Quality Improvement***

Quality assurance and improvement efforts are led by the core MSAC staff, with oversight from Dr. Giesser. Collaborative problem solving is well established in the organizational culture and procedures of the MSAC. In addition, members complete a questionnaire every five months to provide feedback about the program.

A Members Council has also been active at the MSAC since 2004. The members attending on each day of the program elect two volunteers to serve on the council for a one year term. An additional member is chosen to represent issues of concern to bilingual members. Originally the council met monthly, but the logistics for getting members to the MSAC so frequently on days they did not normally attend proved difficult. As a result, the meetings are held quarterly and rotate by the day of the week. A board member from the Chapter also meets with the council to provide information and guidance.

The Council provides input for programs and outings, and coordinates the MSAC's fund-raising team, the MS Achievers, for the annual MS Walk. The MS Achievers recently raised $90,783, the highest amount raised by any team. Fifty members participated on this team – as well as two Day Program alumni, one of whom flew in from Mississippi for the Walk day event – and nearly 100 other team volunteers, including family members, friends, UCLA students, and staff. Over the past five years, the MS Achievers have raised $233,000.

The Council also developed an annual award for an outstanding MSAC member, The Carmen D. Bell "Spirit of Achievement" Award. Named after a charter member of the MSAC, the award is given to a member who serves as a role model for others living with MS and exemplifies the spirit of shared support and empowerment. Member nominees must meet a specific list of criteria, such as having made a positive effort to meet achieve their personal wellness goals, encouraging others to strive toward wellness, and having been proactive about sharing information about the Chapter or the MSAC with others in the community. The names of award recipients are listed on a plaque at the MSAC, and each is presented with a plaque to keep as well.

***Program Schedule and Attendance***

The MSAC is open every weekday, but the Day Program operates only on Tuesday through Friday. Mondays are reserved for special programming, such as aquatics and the Living Well program.

Day Program members are only permitted to attend one day per week, which allows the MSAC to serve more people with MS. Staff indicated that another advantage of this schedule is that it encourages members to be more independent during the other four weekdays, which is consistent with the goals of the wellness model. Members can focus on wellness activities,

community activities, and self-management during the other four weekdays, thus decreasing the likelihood that members will become dependent upon the Day Program for all of their exercise and support.

Members are grouped according to their functional abilities into different days of the week. Over time, strong identities have developed for each day's group. The Tuesday group is more mobile than the others, although some Tuesday members have cognitive problems. This group is mostly women, and over time is has been dubbed the "Women's Day." Staff are able to do more physically challenging activities with these members. It is also a good day for visitors or newer members who may be fearful of "equipment" such as walkers and wheelchairs and being around people with disabilities.

The Wednesday group has the more physically-impaired or cognitively-impaired members. Family caregivers are more likely to be present on that day. More Wednesday members use wheelchairs or power wheelchairs.

Thursday's group is "the oldest group and proud of it." They were the first day that started the MSAC in 2001. Some Thursday members who started together call themselves the "Women on Wheels." They are an intelligent group, very talkative and strong-minded people. They are also independent; they sometimes stay after MSAC closes to go to the nearby Farmer's Market together, and then arrange to have the Access transportation service pick them up from there.

Those who attend on Friday tend to be less cognitively affected, but have some mobility limitations. Most still walking, but may need a wheelchair or scooter part of the day. They have several characters, and there is a lot of joking around on Fridays.

The daily schedule consists of two morning group sessions, lunch, and afternoon activities. The sessions begin at 10:00am and end at 3:00pm, although the MSAC is open somewhat earlier and later to allow for arrival and pick-up time. The daily itinerary with sample classes is as follows:

| | |
|---|---|
| 10:00am | First morning session (e.g., cognitive stimulation, fitness) |
| 11:00am | Second morning session (e.g., yoga, fitness) |
| 12:00pm | Lunch |
| 1:00pm | First afternoon session (e.g., fitness, art therapy, education) |
| 2:00pm | Second afternoon session (e.g., fitness, recreation, education) |
| 3:00pm | Day Program ends |

Physical activities are generally scheduled in the morning, since most members have more energy before lunch. Recreational therapy and health education groups are usually held in the afternoons. Classes or program groups tend to run from 8 to 12 weeks in duration. The schedule varies when there is an outing into the community or if there is a lunchtime guest speaker.

The Day Program emphasizes meeting the needs of the individual, and members' schedules are customized accordingly. Given the variation in members' abilities and staff availability, this is an ongoing challenge. Members may split into smaller groups according to abilities and interests during some periods. For example, several members may be in the gym for exercise while others attend a cognitive group during the first morning session. In addition, individuals may be taken out of group sessions for one-on-one physical therapy evaluations. Staff use an Excel spreadsheet to track each member's activities.

Attendance has remained steady for the past three years at about 65-75 members. The MSAC averages about one or two new members per month. New members are asked to participate for a minimum of six months, and to maintain an average attendance of 75 percent. The maximum enrollment possible for the current program (Tuesday through Friday) is 85.

### *Staffing*

In addition to the executive director, Ms. Fisher, the core staff also include the clinical nurse specialist, Ms. Herlihy, a recreation therapist, and a physical activity specialist, each of whom is full-time. Several other therapists are contracted, and volunteers, student interns, and members also assist at the center.

Each of the four full-time staff brings many years of professional experience to the team, and they have worked together for five years. They are noted for their depth of knowledge and dedication to the promotion of wellness among people with MS.

The team enjoys autonomy and freedom to experiment with new programs, in part because they are not limited by state regulations, but also because the MSAC's organizational culture encourages trust, empowerment, and creativity. The core staff meet regularly, consult on major decisions, and work to foster cross-training and flexibility. Members appreciate the strength of the staff team. As one member stated, "Teamwork, good planning, and good and clear intentions about what's supposed to happen here make it work so well."

Table 1 presents the overall staffing and the full-time equivalent (FTE) positions in 2006 for salaried and contract staff, as well as volunteer and in-kind staff support from UCLA and the Chapter. The total paid staff includes 12 individuals, representing about five FTEs since many are on part-time contracts. The total for all staff, including volunteers and in-kind, is 24 individuals representing about six FTEs. As a result, the MSAC has developed a good balance between the continuity provided by the four full-time staff and the program enrichment provided by the large number of contracted, volunteer, and in-kind staff.

The physical activity specialist is in charge of recruiting student volunteers, most of whom are undergraduates in neuroscience. Three of them help with yoga and fitness classes. Physical therapy students also volunteer from other universities. Several individual classes are conducted by volunteer professionals in art therapy, movement and music therapy, and yoga. Several of the members also volunteer to teach at the MSAC. A member who was a former actor taught a class on drama and public speaking, including speaking on the phone. Others have led classes in personal finance, computers, and conversational Spanish.

**Table 1**
**MSAC Paid, Volunteer, and In-Kind Staff and Total FTEs**

| **Staff Positions** | **Number of staff** | **FTEs** |
|---|---|---|
| **Paid Staff** | | |
| Executive Director | 1 | 1 |
| Medical Director | 1 | 0.2 |
| Clinical nurse specialist | 1 | 1 |
| Recreation therapist | 1 | 1 |
| Physical activity specialist | 1 | 1 |
| Contracted staff: | | |
| Physical therapist | 1 | 0.25 |
| Occupational therapist | 1 | 0.1 |
| Speech therapist | 2 | 0.15 |
| Art therapist | 2 | 0.25 |
| Dietitian | 1 | 0.025 |
| | | |
| ***Subtotal - Paid Staff*** | ***12*** | ***4.975*** |
| | | |
| **Volunteers** | | |
| Speech therapist | 1 | 0.4 |
| Yoga instructor | 3 | 0.05 |
| Music and movement therapist | 1 | 0.025 |
| Clerical support | 1 | 0.015 |
| | | |
| ***Subtotal - Volunteers*** | ***6*** | ***0.49*** |
| | | |
| **In-Kind Staff** | | |
| Southern California Chapter, NMSS: | | |
| Social worker | 1 | 0.025 |
| UCLA Department of Neurology: | | |
| Finance, accounting | 2 | 0.2 |
| Human resources | 1 | 0.1 |
| Information technology | 2 | 0.1 |
| | | |
| ***Subtotal – In-Kind Staff*** | ***6*** | ***0.425*** |
| | | |
| **ALL STAFF TOTAL** | **24** | **5.89** |

Notably, the MSAC has experienced almost no staff turnover since it began in 2001. The core staff has remained stable, and has developed a strong sense of community among themselves and with the members. A number of factors were cited by staff as contributing to their high levels of job satisfaction:

- Continuity with members; the ability to follow their changes in functioning and understand their medical issues and medications
- Self-motivated members
- Ongoing professional challenges, since the needs of members are always changing
- Being part of a program that has such a positive impact
- Management culture of openness, listening, and valuing all staff
- Mentoring from Dr. Giesser
- Highly qualified and talented staff with extensive experience
- Staff dedication to wellness and empowerment of members
- Staff willing to cross-train and cover for each other
- High degree of autonomy in each staff role
- Freedom to choose best practices and be creative without the restrictions of licensure
- Opportunities to do health education

Staff report that the freedom to experiment with creative approaches to problem-solving is very motivating. They indicated that "fluidity and dynamism" characterize their work culture. The core staff each have over ten years of experience and are confident in their skills and dedicated to the MSAC's mission. As one staff member remarked, "We are all working for the greater good of people with MS."

Members were very positive about their experiences with the MSAC staff. They describe the staff as friendly, compassionate, accepting, fair, and appropriately firm about the rules. The following are typical of members' comments:

> "Staff care a great deal about the work they are doing. It's not just a job; none feel like they're here 'just 9 to 5.' "
>
> "Staff are very compassionate, very understanding."
>
> "It's like an extension of your family."
>
> "You can talk to any of them about anything."

***Communication Systems***

The MSAC staff meet regularly for an hour and a half on alternate Tuesdays. Each member is reviewed every few months at these meetings. Other topics of discussion include prospective members, results of members' recent physical therapy evaluations, and new health developments among members, such as medication changes or functional changes. Ad hoc meetings to address acute problems also occur as needed.

All of the staff and volunteers are invited to attend an annual day-long retreat to provide input for the program. The retreat is held for half the day at the MSAC, and then off-campus for the other half of the day.

***Facilities and Equipment***

The Operating Agreement between the Chapter and UCLA specifies that the MSAC will be located in the Veterans Avenue Rehabilitation Building on the west campus at UCLA, and that the MSAC will have access to the Fit Center South and the rehabilitation facilities on the lower level of the building. The Agreement also specifies that the MSAC space will be available to the Chapter when needed for other programs.

Staff offices and most of the group meeting areas are on the first floor. This area encompasses about 2,100 square feet, and includes a large multipurpose room with lots of natural light from an exterior glass wall, a waiting area, three staff offices, and two meeting rooms. Appendix B includes a floor plan.

Activities such as yoga, crafts, and cognitive exercises occur in the multipurpose room. Colorful artwork from members decorate some of the walls. Restrooms and two rest areas are also on the first floor. Other UCLA administrative and clinical offices occupy the rest of this level. Outdoor activities such as gardening occur in the patio just outside the multipurpose room. A furnished garden area is also available outdoors for sessions and lunch on nice days.

The entrance area is spacious and has large windows providing ample natural light. The lobby on the first floor has a long wall filled with plaques honoring donors to the MSAC. The plaques are attractively mounted along the wall with colorful lines. This area is used for receptions and provides photo opportunities that are appealing to donors.

The rehabilitation facilities are on the lower level, easily accessed by an elevator on the first floor. Physical and occupational therapy activities take place in the large gym. For a reduced rate, members may also use the fitness center shared by UCLA staff and faculty. The pool can be used by members on Mondays.

The rehabilitation area has equipment adapted for people with MS. There are different types of bicycles, including some without backs and some with tall backs, since the types of seats and backs influence the muscles needed to pedal. There is also a standing frame, ambulation equipment, weight equipment, balance cushions and boards, and treadmills. The treadmills can operate at speeds as low as 0.1 miles per hour to accommodate people with disabilities, who may ambulate very slowly. Cooling jackets and hats are also available for members.

## SECTION 4: MSAC CLIENTS (MEMBERS)

### *Admission and Discharge Criteria*

**Admission.** Several criteria are used as guidelines for determining if a potential applicant is appropriate for the Day Program at the MSAC:

- MS diagnosis for five years or more (the average is 10+ years)
- Willing to commit to a long-term program (request six months at a minimum)
- Behaviorally appropriate
- One or more functional areas impacted by MS
- Able to actively participate in all areas of MSAC programming (with adaptations if needed)
- Cognition may be impacted but there should be some carryover (can learn strategies and implement to some degree)
- Mobility can be assisted, with the member independently and safely using a suitable mobility device, and transferring independently
- Emotional health can include presence of depression or anxiety, but not debilitating to the point of preventing benefit from the program; people are usually not admitted if Beck depression scale scores are > 30, indicating high levels of depression.
- Able to self-care for most activities (or have a caregiver attend with them), including ability to feed self, can manage toileting needs independently, and adequate vision and hearing to participate in the group-based programming

These criteria are used in combination with a discussion with the applicant regarding his or her goals, logistical constraints (geography, transportation, work, family), and level of commitment to pursuing wellness activities. The MSAC does not require members to receive routine care at UCLA. About one-third of the members see neurologists in the UCLA Department of Neurology.

The first step in the admission process is an interview with the nurse clinician. If that goes well, the applicant is invited to attend the next team meeting as a guest. Next, the team meets with the applicant, and then reconvenes later to decide on admission and determine which day of the week is the best fit for the person's abilities. The new member then attends the MSAC as a guest for one day to test their fit into that day's group. A member can change to a different day if necessary, but this is not encouraged and is allowed only once.

Members make the following commitments upon joining the center:

- To participate for the full program day, from 10:00am to 3:00pm, and participate actively
- To attend for a minimum of six months
- To attend at least 75 percent of the time
- To work toward achieving wellness goals
- To arrange for reliable transportation

In order to track members' progress, staff conduct a range of tests on every member upon admission into the program and at six-month intervals. The outcome measures include staff assessments and self-report questionnaires:

- Expanded Disability Status Scale (EDSS)
- Mini Mental Status Examination (MMSE)
- MS Functional Composite (MSFC)
- MS Quality of Life-54 (MSQOL-54)
- Beck Depression Inventory
- Modified Fatigue Impact Scale (MFIS)
- Clinical measures (height, weight, blood pressure, etc.)
- Physical therapy assessments (bilateral strength, walk speed, single-limb balance, and a subset of the Functional Independence Measure scores)

**Discharge.** Member turnover at the MSAC has been low, but steady over time. Some members leave because they reach their own self-defined goals or find that their personal goals are not a match for the program. Some are discharged for inconsistent attendance. Some become unable to attend due to logistical issues such as moving out of the area, health care problems, or a change in their caregiver situation. Five members have died.

***Member Statistics***

The MSAC's Day Program had 68 members in January 2006, an average of 17 enrolled members per day. About half of those members had been attending the program since it began. Table 2 includes statistics on the total member-days of service provided and numbers of members for 2005.

**Table 2**
**MSAC Day Program Member Statistics in 2005**

| **Statistics** | **2005** |
|---|---:|
| Total Member-Days of Service | 2,720 |
| Member Census on 12/31 | 68 |

Eighty-five percent of the members are over the age of 35. Women comprise 83 percent of the membership. Ethnically, 46 percent are Caucasian, 40 percent African-American, 8 percent Latino, and 6 percent Persian. Most of the Latino population speak English or are bilingual, so language has not been an issue for service delivery. Most members live within 10 miles or about an hour's drive from the MSAC.

Members are diverse economically and all are private pay, with a sliding fee scale. Upon admission, staff conduct an assessment to determine the appropriate fee for each member. About 61 percent of members pay $10 or less per session.

***Case Mix***

All members of the MSAC have MS, and most are in moderate to severe stages of the disease. The average EDSS score is 6.5, with a range of about 4.5 - 8.5. At the time of entry into the program, the average member is impaired in multiple areas of functioning, which may include physical, cognitive, visual, bladder, or bowel disabilities. About 32% are wheelchair dependent.

## SECTION 5: COMMUNITY CONTEXT

### *Local MS Society Chapter and MS Population*

The Southern California Chapter of the NMSS is the second oldest chapter (founded in 1947) and one of the three largest in the country. It covers almost half the state, encompassing eight counties reaching from Riverside and Los Angeles on the south to San Luis Obispo and Inyo on the north. The Chapter's headquarters are in Los Angeles, and five field offices are located throughout the region. The Chapter had 48 staff in 2006, who served 12,500 people with MS in its region, as well as their families, caregivers, providers, and employers. The Chapter had revenue of $8.4 million in 2006.

The Chapter is known for its support of research, success in fundraising, and excellent programs. In three of the past four years it received the large chapter award from the NMSS for best programs and services. The NMSS has approximately $10 million invested in research projects within the Chapter's region, primarily at UCLA, USC, the Brentwood Biomedical Research Center, and UC Riverside.

The Chapter's Board has nearly 50 trustees and is known for its success in raising funds. They sponsor two large fundraising events annually, the Champions Dinner and the MS Walk. In these two events alone the Chapter raised over $3 million in 2005.

The Chapter's census showed that 2,000 people with MS lived within a 10-mile radius (about a one hour drive) of the MSAC when it was being planned in 2000. An MS community survey conducted at about the same time found that 39% of people with MS in Southern California had a progressive form of the disease, who are more likely to become members of the MSAC. This meant that the MSAC had a potential market of about 780 people (39% of the 2,000 people with MS within an hour's drive).

The Chapter takes an active role in support of the MSAC, which is often described as a "Flagship" program. The Chapter's President, Dr. LeBuffe, and Executive Vice President for Chapter Programs, Ms. Nowack were instrumental in the development of the MSAC and remain deeply involved in guiding and replicating its programs. The Chapter and MSAC staff share a vision of developing innovative programs that can be disseminated to meet the needs of the wider MS population. An entrepreneurial spirit motivates their efforts to replicate MSAC programs throughout the Chapter and beyond.

In 2005, the Chapter's replication efforts received support from a six-year $1 million grant from the Flora L. Thornton Foundation. It established the Eric Small Centers for Optimal Living with MS at four sites in the great Los Angeles area. The funds support the MSAC and several replicated and related programs:

- The MSAC as a Flagship Center, including the Day Program, Living Well, LEAP, Cognifit, and Professional Education Symposium.

- Rancho Los Amigos National Rehabilitation Center, in Downey, California, a new MS Day Program described below.

- Casa Colina Center for Rehabilitation, in Pomona Valley, a new Living Well program, with Fall, Winter, and Spring cycles for newly-diagnosed people with MS and those with greater MS symptoms.

- University of Southern California Medical Center, in East Los Angeles, a new 12-week program on Optimal Living with MS. This is a partnership with the USC graduate programs in PT and OT to integrate those services with group exercise, adaptive Iyengar yoga, education, and social support. It is intended for individuals with mild to moderate MS and beginning levels of functional change, and meets several hours each week for 12 weeks.

***Day Program Replications***

From the early development stage, the Chapter has planned replications of the MSAC's programs. The original white paper for the MSAC indicated that other adult day programs would be opened in Southern California, with the MSAC at UCLA envisioned as a model operation. In this fashion the benefits of the MSAC and the lessons learned can spread beyond its immediate vicinity. Two of these new adult day programs are now in operation, in Long Beach and Downey, California.

**Long Beach Active Adult Day Health Care.** The first replication of the MSAC's Day Program began operation in 2004. It involves a partnership between the Chapter and Long Beach Active Adult Day Health Care, which is a for-profit, medical model, adult day health care agency, licensed by the State of California. It is unique as the first for-profit agency to provide an MS adult day program.

The agency has 30 staff overall, with RNs, PTs, OTs, MSWs, and activity coordinators. It is licensed for up to 120 clients per day, and treats about 100 mostly elderly and mental health clients per day. The MS program is one day per week, on Fridays, for about 15 members. Staffing for the MS program includes clinical staff for supervision and assessments from the agency, social work interns for management, and MS programming staff for physical therapy, Yoga, Cognifit, and other services from the Chapter.

This program has several differences from the MSAC, including serving lunch, paying for transportation to the center, charging a fee of $75 per day, providing service from 8:00am to 3:00pm, and using just one meeting room for its program. The staffing resources of the agency allows some MS clients to be served that are more disabled than those that can be members at the MSAC, such as those that need toileting assistance and feeding assistance. For example, members include two residents of the agency's affiliated nursing home. The agency bills Medicaid at the adult day program daily rate for eligible members. Other attendees have NMSS scholarships to cover the daily fee.

The agency benefits by utilizing space that is otherwise only filled for four days per week by mental health support groups. The support group services are capped at two days per week per client by Medicaid, so only four days of those services can be provided per week. On the fifth day per week the space is available for the MS adult day program.

**Rancho Los Amigos National Rehabilitation Center.** Located in Downey, about 25 miles southeast of UCLA, this internationally-recognized rehabilitation center is owned and operated by Los Angeles County. Approximately 160 people with MS receive care at Rancho Los Amigos.

Its MS adult day program opened in 2006, and is supported in part by the grant that established the Eric Small Centers for Optimal Living with MS. It is organized through the Los Amigos Research and Education Institute (LAREI), an independent non-profit organization that has operated a general adult day health program at Rancho Los Amigos for a number of years. The program has been initially offered for one day per week, with plans to expand to two days per week, with space for 20-30 members per day. One day will be for Spanish-speaking MS clients, and the other for MS clients who speak English. The remaining three days will serve other disabled populations, such as men's spinal cord patients, women's spinal cord patients, Parkinson's disease patients, and stroke patients. This type of multi-diagnosis day program is envisioned as a possible model for smaller cities, where MS-specific adult day programs may not have sufficient numbers of clients to be financially viable.

LAREI provides space and oversight for the program. An old wing of the county hospital was given to LAREI since the space was not being used. Other benefits of being located at Rancho Los Amigos include access to a large shop for repair or wheelchairs and other assistive devices, and a specialist staff person with expertise in seating people in wheelchairs, many kinds of rehabilitation equipment, many external gardens, a link to PT and OT teaching programs provided through USC, and an on-site MS clinic staffed by neurologists.

Staffing is provided by existing Rancho Los Amigos staff hired at an hourly rate as contractors. MSAC staff provide training for them. Members pay on a sliding scale similar to the one used at the MSAC in order to facilitate participation from the large low-income and disabled population served by the county-operated site.

### *MSAC Referral Sources, Marketing Methods, and Competition*

The MSAC has been successful in maintaining a relatively steady Day Program membership of about 65-70 people for the past several years. However, keeping the census at this level has been a challenge, as the flow of new members is almost evenly matched by those leaving for various reasons. The Day Program has never quite reached capacity, which is 85 members given the current physical space.

Factors affecting recruitment and retention may include travel distances, freeway traffic problems, degree of visibility of the MSAC among providers, and the relative newness of the adult day wellness program for people with MS. As a staff member indicated, "Once they're in the door it's an easy sell; getting them to the door is hard." Physician referrals outside of the

UCLA Department of Neurology have been limited, but MSAC staff and Chapter volunteers are working to increase awareness of the MSAC's programs.

At the time of its inception, the MSAC had the only Day Program exclusively designed for people with MS in the west coast. As a result, it had no direct competition from programs with similar services for people with MS. While it has since been replicated on a smaller scale in Long Beach at the Active Adult Day Health Care Center and at the Rancho Los Amigos National Rehabilitation Center in Downey, those sites do not compete geographically with each other or with the MSAC for members.

**Referral Sources.** The most powerful source of referrals for the MSAC has been word of mouth. Most new applicants have come from recruitment efforts of members, staff, and Chapter volunteers.

Physician referrals have proven to be a challenge. The MSAC is a fairly unique concept that may need better understanding among health care providers. Some referrals from a physician and nurse in the San Fernando Valley resulted from a talk given by the nurse clinician to providers, but few others have made referrals. Some neurologists have been afraid to send patients to the MSAC for fear of losing their patients to UCLA. However, this is misinformation; the goal is to complement care provided by other neurologists, not to replace it. Only about one-quarter of MSAC members have a neurologist at UCLA.

**Fundraising and Marketing.** The MSAC benefits substantially from the Chapter's fundraising, as well as from the Chapter's efforts to publicize the program. The great bulk of the costs of the program are paid for by restricted gifts to the Chapter from individuals and foundations for the Achievement Center, and by in kind contributions from UCLA Neurology. There have also been two corporate gifts and two smaller county grants for accessibility and modifications to bathrooms. Dr. LeBuffe frequently brings people to see the program, and he ensures that Chapter staff visit the MSAC each year. Programs and activities of the MSAC are included in the Chapter's newsletters and website.

Chapter and MSAC staff stressed the importance of having a physical facility such as the MSAC for visitors to see to facilitate fundraising. Individuals and foundations can visit the MSAC and see first-hand how the program helps members as they strive to meet wellness goals. They observe the enthusiasm, the hard work, the joys of achieving success, and the hard realities of the daily challenges faced by members. After one visit the California Community Foundation actually increased its grant to the MSAC to twice the amount requested, from $100,000 to $200,000! That had never happened at the Chapter before. Donors contributing $1,000 or more are recognized on the donor's wall at the MSAC.

Members are also enthusiastic about participating in fundraising activities. As one member stated, "We ask all our friends and relatives. We fundraise shamelessly." Members in different stages of the disease also participate in the annual MS Walk, or as volunteers to support walkers.

Promotional videos have also been produced for the MSAC and with the help of entertainment industry volunteers at the Chapter. The first video was made during the early months of the MSAC's operation, and was timed so that it would be ready for the annual Dinner of Champions. It includes vignettes about the MS Walk, activities and services provided at the MSAC, conversations with individual members and staff, and a feature on Eric Small as one of the Hall of Fame Honorees. It was so effective that additional videos about the MSAC have also been produced. They are shown to donors, members, and new trustees.

The Chapter designed a new promotional flyer for the MSAC and distributed it to 5,000 individuals. It highlighted both the Day Program and Living Well. Several other mailings have also been sent out to promote the Living Well program.

A Living Well flyer was created as an insert in the Chapter's Next Steps literature. These packets were distributed to patients by their physicians at the time of receiving an MS diagnosis. The materials were disseminated to more than 85 Los Angeles area neurologists, with the potential of reaching over 500 MS patients.

MSAC staff have also been creative in developing naming opportunities for donor recognition. A number of areas and objects at the MSAC are named after specific donors, such as the gardening table, benches, meeting rooms, the adaptive computer center, and the relaxation room. Donors' names are artfully displayed along a long wall at the main entrance to the MSAC. The wall serves as an excellent background for photographs of receptions and other events.

The affiliation with UCLA has also been positive for marketing the MSAC. Members have indicated they value the opportunity to attend a UCLA program. As one said, "I'm going to UCLA."

***Transportation***

Members are responsible for their own transportation to the MSAC. A few members drive or are driven by family members, but the majority use a paratransit service. Chapter staff provide education to members about their transportation options.

Two paratransit services operate in the Los Angeles region: access-a-RIDE (Access) and Paratransit. Most MSAC members use Access, which charges from $1.80 - $2.70 per ride, depending on the distance traveled. On average, an Access trip to the MSAC takes over an hour each way, and the driver takes up to four passengers with varying destinations. Access was established in 1994 in response to the Americans with Disabilities Act (ADA). The ADA mandated that complementary paratransit service be available for individuals whose disability prevents them from using traditional public transportation systems. Access provides curb-to-curb transportation throughout Los Angeles County. MSAC staff work to ensure members meet the eligibility requirements for Access, and negotiate pick-up and return times for members using this service.

Transportation can be an issue for members, since Los Angeles freeway traffic is often challenging and often extends commuting time. A commute of about an hour each way was in the original plan for the MSAC, but many members travel longer than that. One highly motivated member commutes two hours each way in order to participate in the Day Program. In a few instances, transportation problems have caused a member to leave the program, but staff are usually able to resolve the problems before they become too severe.

One challenge with Access is that traveling in different counties means calling different telephone numbers. Access provides a confirmation number for each ride. Most MSAC members have cell phones to make their arrangements, or they have standing appointments for rides to and from the MSAC. Access arrives a few minutes late at times, but is mostly on time, and the majority of members seem satisfied with the service. As one member said, "I live 20 miles away and can come here for $1.80 and $1.80 to get home. I couldn't do it with a regular car. When I rode busses I had to take three different buses." Another said, "I'm so thankful for Access."

***Collaborative Services***

About one-quarter of the MSAC's members are patients at the Department of Neurology at UCLA, but most see a community neurologist outside of the UCLA system. The MSAC's nurse, coordinates care with members' medical providers on a daily basis. She meets individually with members as needed regarding medical issues and maintains communication with providers regarding health status changes and medications.

To assist with repairs to members' wheelchairs and other walking aides, the Chapter provides referrals to durable medical equipment (DME) companies. The Chapter has vetted a number of DME companies and provides three alternatives when asked for a referral.

UCLA's Center for Study of Women recently partnered with the MSAC to present a cognitive and intellectual stimulation program to members. This series provided monthly presentations by UCLA faculty and scholars on contemporary and historical issues regarding women and gender. A discussion period was included to encourage members to ask questions and exchange ideas.

## SECTION 6: MSAC FINANCES AND COST ANALYSIS

### *Revenue Sources*

About 90 percent of the MSAC's revenue is generated by the Chapter, through grants and fundraising. The UCLA MSAC is unique among the five MS adult day programs in this study in not receiving any Medicaid revenue. Table 3 presents a breakdown of annual revenue by source.

Several large grants have provided substantial funding for the MSAC. For example, the four-year, $400,000 naming grant from the Conrad N. Hilton Foundation helped to establish the MSAC in 2001. It was renewed in 2004 for an additional $690,000 over three years. Another major funder is the California Community Foundation (CCF), which provided a two-year, $200,000 grant in 2001; CCF renewed its support for the MSAC in 2005 through an additional two-year, $200,000 award.

The Operating Agreement between UCLA and the Chapter that was recently renewed in 2005 indicates that the Chapter will provide total support of $2,011,078 over five years for operation of the MSAC. The Agreement also specifies that all fees paid by program participants and direct gifts made to UCLA for the benefit of the MSAC will be applied directly to the program operating budget.

Membership fees represent eight percent of the MSAC's revenues, and all members are expected to contribute some payments to indicate their commitment to the program. The full fee for the program is $75 per day, but most members are on a sliding scale and pay less. The average payment is about $15 per day, with most paying $5 - $10. About eight pay the full $75 fee. Only two receive a complete exemption and pay $0.

**Table 3**
**MSAC 2005 Revenue**

| Revenue Source | Revenue | Percent |
|---|---|---|
| Balance from previous year | $33,290 | 8% |
| Payment from NMSS (grants & fundraising) | $331,000 | 81% |
| Membership Fees | $32,387 | 8% |
| 12 Week Program | $11,715 | 3% |
| MS Walk & T-shirts | $1,241 | 0% |
| Bowling | $143 | 0% |
| | | |
| TOTAL | $409,776 | 100% |

### *In-kind Contributions*

The Operating Agreement specifies that UCLA will contribute the space and utilities at no charge to the MSAC. The Agreement also specifies that the Department of Neurology will

provide in-kind staff support for administration, information technology, fund management, human resources, and student intern volunteers. In addition, UCLA agreed to waive its usual 5% administration fee for the grant provided by the Chapter to UCLA for support of the MSAC.

The Chapter contributes some staff support to the MSAC, especially for social work services. Community volunteers also lead some of the Day Programs' classes and groups.

***Expenses***

Table 4 presents a breakdown of MSAC's annual expenses. Personnel costs represent 83 percent of total expenses, including salaries and benefits. Contracted staff are an additional 11 percent. As a result, staff costs combined represent over 90 percent of the MSAC's budget.

**Table 4**
**MSAC 2005 Direct Expenses**

| **Type of Direct Expense** | **Expense** | **Percent** |
|---|---|---|
| Salaries | $264,851 | 68% |
| Benefits | $56,680 | 15% |
| Insurance | $761 | 0% |
| Physical & Occupational Therapists | $24,578 | 6% |
| Speech & Art Therapists | $17,750 | 5% |
| Supplies - Operating | $2,228 | 1% |
| Supplies - Program | $3,792 | 1% |
| Office Equipment | $360 | 0% |
| Fit Center | $1,650 | 0% |
| Travel | $1,919 | 0% |
| Meetings | $753 | 0% |
| Telephone | $7,088 | 2% |
| Administrative | $3,798 | 1% |
| Housekeeping & Facilities | $190 | 0% |
| Marketing | $1,168 | 0% |
| | | |
| TOTAL | $387,567 | 100% |

***Overall Surplus/Deficit***

Table 5 combines the revenue and expense figures from the last two tables to present an overall "bottom line" picture of the MSAC's finances. It indicates that the MSAC was operating at a surplus of $22,209 in 2005, or about five percent of its total revenue.
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**Table 5**
**MSAC 2005 Surplus/Deficit**

| **Line Item** | **Amount** |
|---|---|
| Revenues | $409,776 |
| Expenses | $387,567 |
| | ---------- |
| Surplus/Deficit from Operations | $22,209 |

***Output Measures and Unit Costs***

Table 6 presents data on unit costs. The MSAC is unique among the five MS adult day programs in this study in having multiple services provided in addition to its Day Program. As a result, an estimate of the percentage of total costs associated with Day Program services is needed to calculate a unit cost comparable to those of the other MSADPs. Table 6 includes an estimate that 80% of MSAC costs are for the Day Program, which yields a unit cost of $114 per member-day of service provided. In the absence of the percentage adjustment, the total unit cost would be calculated as $143.

**Table 6**
**MSAC 2005 Day Program Unit Costs**

| **Cost Category (MSAC overall)** | **(A) MSAC Expenses in 2005** | **(B) Day Program Member-days Provided in 2005** | **(C) Cost per Day Program Member-day (A) ÷ (B) x 80%*** |
|---|---|---|---|
| Expenses | $387,567 | 2,720 | $114 |

*Assumes 80% of total MSAC costs are for the Day Program

## SECTION 7: BENEFITS OF THE MSAC FOR MEMBERS AND FAMILIES

MSAC staff, Chapter staff, members, and family members all identified a range of benefits provided by the MSAC for both clients and family. They are described in seven categories below.

### *Social Support and Improved Quality of Life*

Both staff and members stressed the MSAC's success in building and maintaining social support systems and in improving quality of life for members. They have many opportunities to strengthen social ties through sharing experiences and information.

**Social Support.** Staff view the MSAC as a template for members to build their social networks, with the goal of improving their quality of life beyond the center. The program provides a sense of community that builds self-esteem and confidence. Staff encourage members to socialize with each other and participate in activities outside the program. Members often share phone numbers, check on each other, and participate in outside events, lectures, classes, and shopping trips together. This is especially important for those who live alone and are thus more vulnerable to isolation and depression.

The lunch hour is an important networking time for members. It is a time to share ideas and knowledge among themselves. Staff are not involved in the lunch hour; they pull back and let members talk among themselves.

The feeling of being understood is important to members. Just being with other people with MS who have experienced some of the same losses and disabilities is valuable. As one member said, "We need to be around other people with MS. Your family loves you, but they don't really understand since they don't have the disease."

**Depression.** Whether depression is caused by the MS disease process, by the losses and disabilities experienced, or by a medication side effect, it is a common comorbidity among people with MS. Many members openly discuss how isolated and depressed they were prior to joining the MSAC. As one member said, "I had a rich, full life, flying all over the world, then suddenly nothing. I didn't realize how depressed I was. The family gets really scared when you get sick."

Staff report that the sense of community and caring at the MSAC helps members acknowledge and deal with their depression. As a staff member indicated, "They help each other come out of it. They are like cheerleaders for each other. They want to help one another." The sense of hope that the MSAC offers was also credited by some members with helping to alleviate depression. As one put it, "I just needed some glimmer of hope. I was just holed up in my apartment, just hopeless, living alone, children already gone."

In a recent outcomes research study at the MSAC, depression was one domain that showed a statistically significant improvement over time. Mean scores for members on the Beck

Depression Inventory dropped from the mild-to-moderate depression level of 12 at baseline to a non-depressed level of 8 after 18 months.

***Empowerment***

Through their sharing of experiences and the professional education provided by staff, members learn that they can help themselves and help each other. This builds self-empowerment, another goal of the program. As one member put it, "I can do more for me." Another said, "Other members see you getting better and it helps them do better." And from the staff point of view, "The members feel less vulnerable. They have support from friends."

Members talk with each other a lot about strategies for managing the disease and their lives. This often focuses on what to do when they are not at the MSAC, since they are only there one day per week. Empowerment has also helped some members move from low self-esteem and depression to becoming volunteer instructors at the MSAC or returning to work. For example, one member who was formerly a teacher was able to return to work on a part-time basis.

***Better Maintenance of Functioning***

Members report a range of physical benefits from the MSAC's physical wellness program. For example, some members who were unable to walk upon entry into the program later became able to walk. In particular, this has happened for several members whose bodies had atrophied during exacerbations, causing them to become unable to walk. Intangible benefits are also reported. One member stated, "Yoga in the wheelchair helped me to care for myself better. I got so much more self worth through yoga."

The emphasis on members doing "homework" in between physical activity classes has produced a number of benefits according to staff. Most members have been able to maintain or improve functional abilities in activities of daily living, such as transferring, grooming, eating, toileting, and others. Training for strength and balance has reduced the incidence of falls among members.

The MSAC has collected data on a number of physical outcome measures as part of its research program, including the EDSS, MSFC, muscle strength measurement, and others. Analysis of these data has shown no statistically significant decreases in mean values over time, which is viewed as a positive result given the progressive nature of MS.

The MSAC has also collected data on cognitive outcome measures, including the Paced Auditory Serial Addition Test (PASAT) and the Mini Mental Status Examination (MMSE). As with the physical function data, analysis of these cognitive data has shown no statistically significant decreases in mean values over time, which is again viewed as a positive result given the progressive nature of MS.

### *Staff with Extensive MS Expertise*

Both members and Chapter staff had very positive comments regarding the skills, teamwork, and commitment of the MSAC staff. The level of satisfaction is very high. Each of the four core staff members has at least ten years of professional experience, and they have worked together at the MSAC for more than five years. As a result, they jointly have an extensive knowledge of MS and how to implement the wellness model in an effective way for members.

### *Early Detection of Medical Problems*

The frequent contact that staff have with members means that they are able to detect some types of medical problems early, when treatment can prevent or mitigate potentially serious complications. For example, urinary tract infections can sometimes be detected by staff through observing unusual patient behavior. Lab tests can then be ordered to determine if treatment is needed. Early referral for assessment and treatment of this type of infection has the potential to prevent lengthy hospitalizations. One member experiencing low blood pressure was identified by their response to the standing frame and was referred for a medical evaluation. Staff can also identify members at risk for decubitus ulcers, and sometimes detect them as well.

The MSAC's wellness model emphasizes health education rather than direct care, but the program does include routine medical screenings twice per year. The clinical nurse specialist monitors blood pressures and weights, assesses health and functional status, and makes referrals for those who need further assessment or treatment to their primary care providers. The nurse also provides counseling about medication management and health issues. Some problems can be averted by simply readjusting the timing of a medication regime, such as taking a medication with a fatigue side effect in the evening rather than in the morning, or learning to rotate injections sites properly. Staff also provide ad hoc assessments when needed for timely referrals and intervention.

### *Improved Access to Medical Treatment and Coordination of Care*

The clinical nurse specialist takes an active role in coordinating care with members' primary care providers and neurologists. Physicians must submit an annual referral to the MSAC for each member with an updated health summary. The nurse also monitors members' hypertension, blood sugars, and weights on an as-needed basis. Changes in members' health status are communicated with the appropriate providers. Medication orders are kept up-to-date in the program's records, and the nurse can report members' responses to changes in medications and information about member follow-through to physicians and other providers.

### *Respite and Support for Family Members*

The MSAC provides one day of respite each week for family caregivers, and families appreciate this aspect of the program. Families also find it reassuring to know that their relatives are learning how to deal with MS under the guidance of highly skilled professionals in a safe

environment. Families also have other opportunities to meet with each other and with MSAC staff during outings and center-wide activities such as the MS Walk. In addition, a support group for caregivers is provided by the Chapter.

Family members commented on how much members benefit, and this provides them with reassurance and aids them in their roles as caregivers. As one said, “You don’t know how much happier [member] is.” Another said, “He is always happy when he comes home from the MSAC.”

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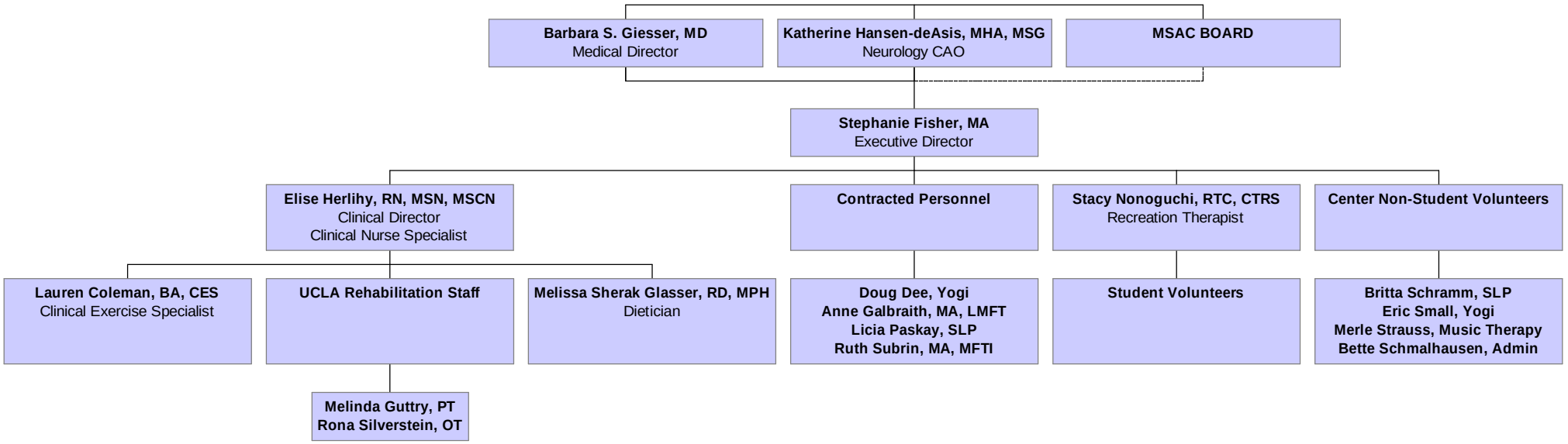
# APPENDIX A

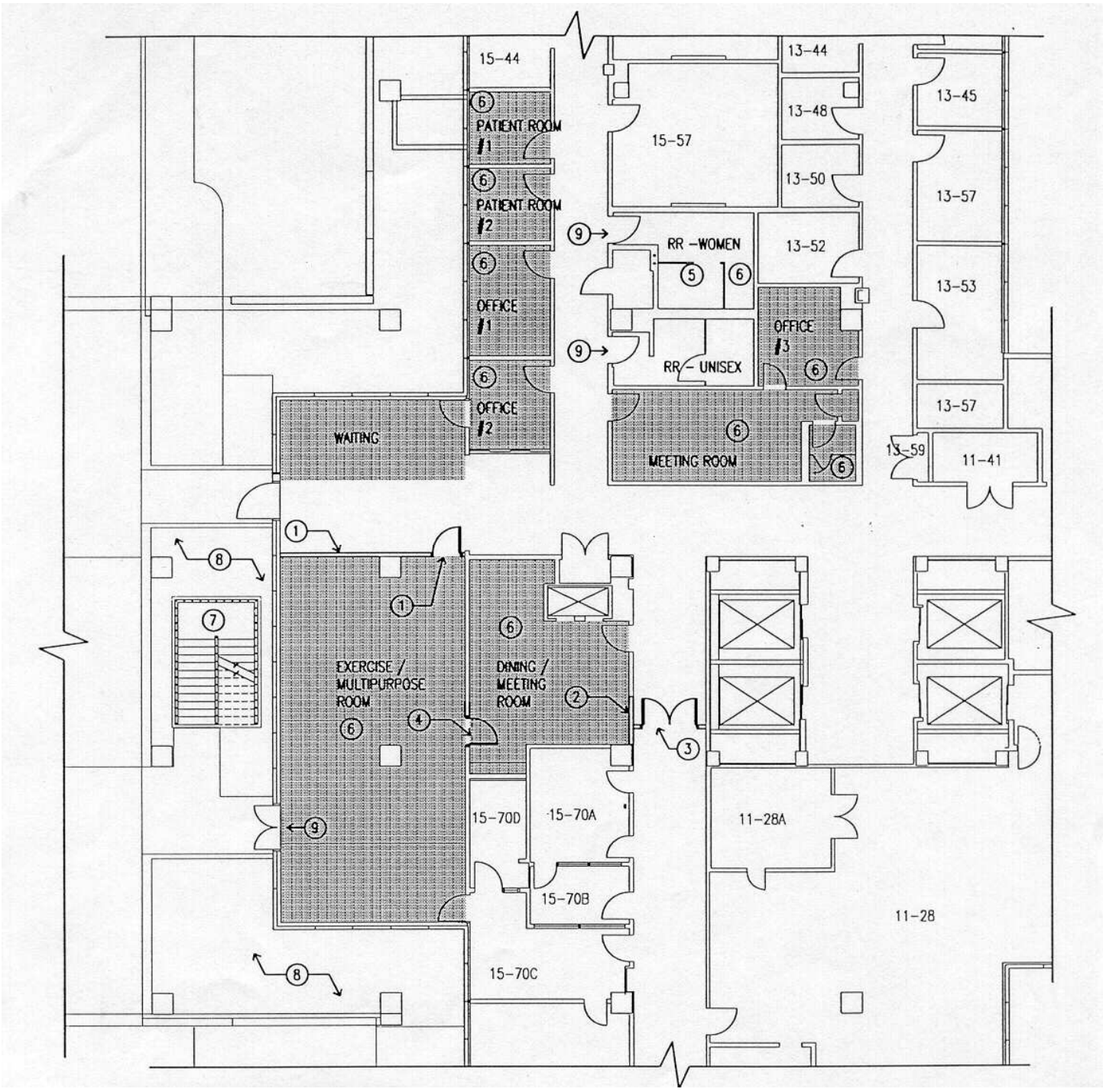
# Marilyn Hilton MSAC at UCLA Organization Chart

# Marilyn Hilton MS Achievement Center at UCLA



# APPENDIX B

# Marilyn Hilton MSAC at UCLA Floor Plan


15-44
PATIENT ROOM 1
PATIENT ROOM 2
OFFICE 1
OFFICE 2
WAITING
15-57
13-44
13-48
13-50
13-52
RR - WOMEN
RR - UNISEX
OFFICE 3
MEETING ROOM
13-45
13-57
13-53
13-57
13-59
11-41
EXERCISE / MULTIPURPOSE ROOM
DINING / MEETING ROOM
15-70D
15-70A
15-70B
15-70C
11-28A
11-28