



# **Report of Recommendations to Address the Needs of Persons with Multiple Sclerosis**

Pursuant to Public Act 98-0530  
98<sup>th</sup> Illinois General Assembly

December 2015

## **Executive Summary**

The Illinois General Assembly determined that the State must establish a Multiple Sclerosis Task Force to identify and address the unmet needs of persons with Multiple Sclerosis (MS) and develop ways to enhance the quality of life for Illinoisans suffering from MS. Public Act 98-0530 was signed into law by the Governor on August 23, 2013. The MS Task Force was charged with:

- Identifying and addressing the unmet needs of persons with MS in order to enhance their quality of life, maximize independence, and address resulting emotional, social, financial, and vocational challenges;
- Develop strategies to provide persons with MS greater access to various treatment and other therapeutic options that may be available; and
- Provide recommendations to improve multiple sclerosis education and awareness.

The MS Task Force was comprised of 16 members. The 14 public members, appointed by the Director of the Illinois Department of Public Health, included two neurologists licensed to practice medicine in the State; three registered nurses or other health care professionals with MS certification and extensive expertise with progressed MS; one person recommended by the National MS Society; three representatives from agencies that provide services or support to individuals with MS in this State; three persons who have MS, at least one of whom has progressive MS; and two members of the public with a demonstrated expertise in issues relating to the work of the MS Task Force.

The report's recommendations address a wide array of strategies, including: physical access to medical care; equipment and assistive technology; rehabilitation services; rural access to health care; increasing knowledgeable among health professionals; the financial burden on persons with MS and their families; various clinical and community-based services; pharmacologic access and costs; and research efforts. Finally, the report provides discussion about state-level policy recommendations.

The MS Task Force, after thoroughly discussing issues facing persons with MS and their families, caregivers, and the health care system, is pleased to present this report of strategies and corresponding recommendations to address the needs of persons living with MS to the Governor and the General Assembly.

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## **Introduction**

Multiple Sclerosis (MS) is a chronic, often disabling, disease that attacks the central nervous system, and affects the brain, spinal cord, and optic nerves. According to the National MS Society, MS is the leading non-traumatic, cause of disability among young Americans. MS causes the immune system to malfunction, launching a defensive and damaging attack against its own tissues. The disease damages the nerve-insulating myelin sheath that surrounds and protects the brain, resulting in slowed or blocked messages between the brain and the body.

Most people experience their first symptoms of MS between the ages of 20 and 40, but MS can affect persons of all ages. According to the North American Research Committee on Multiple Sclerosis (NARCOMS), there are between 350,000 and 500,000 people in the United States diagnosed with MS, and more than two million individuals live with the disease worldwide. More than twice as many women as men have MS. Symptoms can include visual disturbances, muscle weakness, trouble with coordination and balance, sensations such as numbness, prickling or pins and needles, and thought and memory problems. MS patients can also experience partial or complete paralysis, speech impediments, tremors, dizziness, stiffness, spasms, fatigue, paresthesias, pain, and loss of sensation.

The cause of MS remains unknown; however, having a first-degree relative, such as a parent or sibling, with MS significantly increases a person's risk of developing the disease. The estimated number of persons with MS in Illinois is 20,000, and at least two geographic areas of the state have a higher than average incidence of MS.<sup>1,2</sup>

According to the National Institute for Neurological Disorders, the course of the disease varies greatly from person to person. It is impossible to predict the severity or progression in any given individual. To help develop appropriate management plans, MS is divided into four classifications:

- Relapsing-Remitting - clearly defined attacks lasting from days to weeks, with full recovery or with some remaining neurological symptoms and deficits upon recovery. Periods between relapses are stable and absent of disease progression. This is by far the most common form of the disease.
- Secondary-Progressive – begins initially with a relapsing-remitting course that becomes consistently progressive and includes occasional relapses and minor remission. Deficits are accumulated without recovery between attacks.
- Primary-Progressive – progressing level of disability from the onset without any distinct relapses or remissions. Temporary, minor improvements may be experienced.
- Progressive-Relapsing – clear progression in disability level from the onset, but also clear acute relapses that may or may not include memory.

Presently, there is no cure for MS. The complex and variable nature of the disease makes it very difficult to diagnose, treat, and research. The cost to a person with MS and their families or caregivers can be overwhelming. Among common diagnoses, non-stroke neurologic illnesses, such as MS, were associated with the highest out-of-pocket annual expenditures (a mean of \$34,167), followed by diabetes (\$26,971), injuries (\$25,096), stroke (\$23,380), mental illnesses (\$23,178), and heart disease (\$21,955). Median out-of-pocket costs for health care among people with MS, excluding insurance premiums, were almost twice as much as costs borne by the general population. The costs associated with MS increase with greater disability. Costs for severely disabled individuals are more than twice than those of persons with a relatively mild form of the disease. A recent study of causes of bankruptcy found that 62.1% of all personal bankruptcies in the United States were related to medical costs.<sup>3</sup>

## **I. Identify and Address Unmet Needs**

### **A. Epidemiology and Surveillance**

There are no federal or state requirements to report MS. Therefore, the incidence, prevalence, and needs of persons living with MS are not consistently tracked. There are approximately 400,000 cases of MS in the United States with an incidence of nearly 200 new cases each week and approximately 2.3 million cases worldwide. The majority of people with MS are diagnosed between 20 and 50 years of age, and women are affected two to three times more often than men. It has a heterogeneous geographical prevalence with higher rates reported in Central and Northern Europe, North America, and Australia than for Asia, Africa, and South America.<sup>4</sup> Currently, there is no cure for MS although there are disease modifying therapies which can help reduce the rate of disease progression. MS is not only one of the most common causes of chronic neurological disability, but also has the second highest economic burden of chronic health conditions with cost estimates as high as \$69,000 per patient per year. The National MS Society - Greater Illinois Chapter reports that more than 20,000 Illinoisans are living with MS. These data estimates only reflect those persons who are registered members of the National MS Society, and is not an accurate accounting of all people living with MS in Illinois. Based on these estimates, it appears Illinois has one of the highest rates of MS prevalence in the United States.

#### **Recommendation 1**

Establish and fund a voluntary MS registry to provide surveillance for MS prevalence in Illinois (annually monitor the number of Illinois residents living with MS).

#### **Recommendation 2**

Encourage the MS registry to establish data collection initiatives related to collecting data related to the direct and indirect health care costs specific to persons with MS.

#### **Recommendation 3**

Develop, fund, and administer a MS-related module for the Behavioral Risk Factor Surveillance System in Illinois to estimate the prevalence of MS.

#### **Recommendation 4**

Identify and report MS and MS related complications (respiratory, urinary tract, decubitus infections, and suicide) that directly caused death on death certificates.

### **B. Comorbidities**

An international initiative, the MS Comorbidities Project, has been launched because people with MS often have other conditions.<sup>5</sup> The project seeks to gain a better understanding of how common comorbidities are in individuals with MS, and how this affects treatment. The first stage, with an emphasis on finding solutions, has been published, and can be found in the MS Journal at:

<http://msj.sagepub.com/content/early/2015/01/13/1352458514564491.full> .

Comorbidities can make an MS diagnosis difficult to determine, but can also affect the progression of the disease and an individual's quality of life. Other disorders share similar risk factors as MS; therefore one goal of the MS Comorbidities Project is to distinguish the types of comorbidities and how often they occur. This will help identify research strategies to be implemented in order to address the gap.

In a systematic review of the incidence and prevalence of comorbidity in MS, the MS Comorbidities Project identified the following:

- The five most prevalent disorders occurring in conjunction with MS are depression, suicide, anxiety, high blood pressure, high cholesterol, and chronic lung disease.
- The most prevalent autoimmune diseases occurring with MS are thyroid disease and psoriasis.
- The types of cancer that occur most often in people with MS are cervical, breast, and digestive system cancers. There appears to be a higher than expected risk of meningiomas and urinary system cancers, and a lower than expected risk of pancreatic, ovarian, prostate, and testicular cancer, compared to the general population.
- Some disorders are found more often than expected by the investigators based on previous research, such as heart disease, congestive heart failure, stroke, arthritis, inflammatory bowel disease, irritable bowel syndrome, seizure disorders, bipolar disorder, sleep disorders, and alcohol abuse.

The National MS Society webpage is a valuable resource for locating health care professionals (HCPs) with certification or experience in neurology, mental health, and rehabilitation to assist with the diagnosis of MS and comorbidities. More information can be found at [www.nationalmssociety.org](http://www.nationalmssociety.org).

#### **Recommendation 1**

Develop public education programs and tools for HCPs and patients about comorbidities related to MS.

#### **Recommendation 2**

Share information with HCPs and patients regarding managing MS and other conditions.

#### **Recommendation 3**

Disseminate suicide prevention information to HCPs and patients.

#### **Recommendation 4**

Require certified mental health providers and counselors to become proficient in understanding MS and related mental health issues.

### C. Health Care and Disability Disparities

The Affordable Care Act of 2010 requires the US Secretary of Health and Human Services to establish data collection standards for race, ethnicity, sex, primary language, and disability status, and calls for these categories to be consistently collected and reported in all national population health surveys that rely on self-reporting. For the diagnosis of MS; however, much of this data set is lacking. In the case of race, particularly African American patients with MS, data suggests an earlier onset of disability, based on studies related to the admission of African American patients to nursing homes.<sup>6</sup> Another study showed more aggressive, inflammatory MS disease in African American patients<sup>7,8</sup>, and another showed that intervention with effective therapies was associated with better disease control in this population.<sup>9</sup>

With regard to ethnicity, similar findings have been documented in Hispanic white patients with MS compared to non-Hispanic whites with a significantly younger age at diagnosis ( $p = 1.38E-02$ ) and age at exam ( $p = 2.36E-05$ ) in Hispanic whites. However, age at first symptom did not differ significantly between the two groups. Interestingly, within Hispanic whites, the mean age at first symptom and age at diagnosis was significantly younger in those born in the United States ( $p < 1.00E-03$  for both). An increase in ambulatory disability in Hispanic white patients has been documented, primarily among those with relapsing remitting disease ( $p = 4.18E-03$ ).<sup>10</sup> Similar to data shown in African Americans, treatment with effective MS therapies controls MS well in the Hispanic population, and thus should be a goal of disease management.<sup>11</sup>

MS affects adult females more than males by a ratio of 3:1 in contrast with a 1:1 ratio in pre-pubertal persons. Puberty may influence MS risk differentially in males and females.<sup>7</sup> Additionally, youth affected by MS, who are transitioning through normal life phases (school, sports, etc.) represent a vulnerable group subject to potentially poor outcomes.<sup>12</sup>

Adverse socio-economic status is associated with increased risk of MS, adding to the growing evidence linking lower socioeconomic status to poorer general health outcomes.<sup>13</sup> One study found that older adults with MS were less likely to utilize health promotion and wellness services, resulting in further disability.<sup>14</sup> Data related to health care disparities among persons with MS parallel similar disparities seen in other chronic health conditions, and certainly warrants careful attention.

Persons with MS experience disparities in accessing health care. Although the term *disparity* is often interpreted to mean racial or ethnic disparity, many dimensions of disparity exist in the United States, particularly in health. If a health outcome is seen to a greater or lesser extent between populations, there is disparity. Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve optimal health. It is important to recognize the impact that social determinants have on health outcomes of specific populations.



Twenty-eight percent of insured people with disabilities reported needing particular therapies and equipment or medications that were not covered by their health plans, compared to seven percent of those without disabilities.<sup>15</sup>

Disability and gender are predictive of lack of access to health care. Another study indicated that women with disabilities had less access to health care than women without disabilities and men with disabilities. Those who are disabled are 2.26 to 3.78 times more likely to not to have access to health care, and women were 1.26 times more likely not to have access to health care. <sup>16</sup>

Some persons with disabilities have unmet medical needs and poorer overall health throughout their lives, and as a result should be recognized as a health disparity group in order to bring more attention their needs and to the efforts necessary to improve their health and overall quality of life.<sup>17</sup>

### **Recommendation 1**

Educate health policy experts on health care disparity and include disability in data collection and public health program inclusion, planning and implementation activities.

### **Recommendation 2**

Provide funding for the Illinois Department of Public Health (IDPH), Disability and Health Program to reduce health care barriers for persons with disabilities.

### **Recommendation 3**

Encourage state, federal, and local decision-makers to broaden the definition of health disparity at every level, so persons with disabilities are considered in data collection, program implementation, and policy development at all levels.

## **II. Access to Treatments and Therapeutic Options**

### A. Physical Access to Medical Care

The physical accessibility of doctor's offices, clinics, and hospitals is essential to providing medical care to people with disabilities, including people with MS.<sup>18</sup> Inaccessible medical settings negatively affect patient safety, quality of care, and outcomes.<sup>19</sup> The Americans with Disabilities Act (ADA) of 1990 prohibits discrimination of people with disabilities when those people engage in everyday activities, including medical care. The ADA requires that medical professionals provide accessible services to people with disabilities. Section 504 of the Rehabilitation Act of 1973 also guaranteed rights to persons with disabilities. Together, these statutes require that medical professionals must provide accessible services. Therefore, efforts are needed to provide equal access to medical care for people with MS. In addition to providing access for people with disabilities, the creation of physically accessible environments and procedures can help promote safety and efficiency.<sup>20</sup>

Health care providers should be encouraged to review the “Disabled Tax Credit” (Internal Revenue Code, Title 26, Section 44) (which enables an eligible small business to elect to take a nonrefundable tax credit equal to half of the expenditures it makes on eligible accommodations that exceed \$250), for making accessibility changes to medical offices, clinics, and hospitals. The maximum credit a business can elect to take in any tax year is \$5,000 for eligible expenditures of \$10,250 or more. The following link contains more information on Federal tax incentives for improving accessibility:  
<http://www.ada.gov/archive/taxpack.htm> .

Training should be provided to medical and health care professionals to improve physical accessibility to medical care. Standards exist related to technical criteria for medical diagnostic equipment that is accessible to and usable by patients with disabilities. The standards provide for independent access to and use of diagnostic equipment by patients with disabilities to the maximum extent possible. Information regarding Access Board Proposed Standards for accessible medical diagnostic equipment can be found at:  
<http://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/proposed-standards/text-of-the-proposed-standards> .

### **Recommendation 1**

Require the recommendations in the *Access to Medical Care for Individuals with Mobility Disabilities (2010)*. U.S. Department of Justice, Civil Rights Division, Disability Rights Section & U.S. Department of Health and Human Services, Office of Civil Rights to be followed and enforced, and educate the public about these recommendations.

### **Recommendation 2**

Enforce safe patient lifting policies, as specified by Public Act 97-0122, which require hospitals to minimize the risk of injury to patients, nurses, and other HCP when lifting, transferring, repositioning, or otherwise moving patients; and Public Act 097-0866 which mandates requirements for safe lifting of residents in nursing homes. Expand safe patient lifting mandates to other settings such as primary care facilities and federally qualified health care centers.

### **Recommendation 3**

Explore how to regulate and monitor use of accessible examination and diagnostic equipment by health care facilities and develop a mechanism for penalizing noncompliance.

### **Recommendation 4**

Work with the Illinois Department of Revenue to explore ways to provide state tax incentives for making accessibility changes to medical offices, clinics, and hospitals.

**Recommendation 5**

Educate HCPs about the “Disabled Tax Credit” (Internal Revenue Code, Title 26, Section 44), which allows a tax credit for expenditures incurred during improvement of health care facilities in order to comply with the ADA requirements.

**Recommendation 6**

Partner with medical and health professional organizations to increase awareness among, and training for, members about physical accessibility to medical care. Topics should include, but not be limited to: choosing appropriate medical equipment, using accessible equipment, using proper patient handling techniques including safe patient lifting, positioning of individuals with disabilities, and understanding legal rights of individuals with disabilities.

**Recommendation 7**

Encourage HCPs and their staff to participate in webinars and training opportunities about the ADA. Such training may be available through various health professional associations and can be accessed via <http://www.adaconferences.org/Health/Archives/>

**Recommendation 8**

Encourage HCPs to partner with the National MS Society to provide educational tools and training for persons with MS and other disabilities to advocate for accessible medical care.

**Recommendation 9**

Create and maintain a list of medical facilities in Illinois that are accessible to people with MS and other physical disabilities.

**Recommendation 10**

Engage the Illinois Hospital Association and other organizations to encourage hospitals, medical offices, and clinics to document accommodation needs for all patients prior to the appointments to ensure accessibility (e.g., equipment, transfer team, larger room, extra time, prepared health professionals), and document accessibility needs in the medical record is available at the time of appointment.

**Recommendation 11**

Promote awareness about the grievance process, available through the ADA, for people with disabilities for whom full access to medical/health care has been denied and educate the public about this process.

**B. Equipment and Assistive Technology**

For a person living with MS, assistive technology and devices, durable medical equipment (DME) (e.g., raised toilet seats, shower chairs, grab bars, walking devices) and specialized wheelchairs may allow them to remain independent for a longer period of time. Assistive technology allows persons with severe disabilities to maintain autonomy and self-

sufficiency when compared to physical assistance from a caretaker. This decreases the burden on caregivers, which in turn improves overall health, quality of life, and sense of independence for persons with MS. Additionally, with appropriate equipment at home, a person's risk for falling, injury, or hospital admission may decrease.

Power mobility devices can increase a person's overall function and independence, decrease impact of disability, decrease fatigue levels, and increase participation in daily activities.<sup>21,22,23</sup> With decreased fatigue levels and increased independence with mobility, a person with MS can participate more often and more fully in their self care, activities of daily living, and work and leisure activities.<sup>21,22,23</sup> Improved health and quality of life can lead to psychosocial benefits and may decrease the use of state provided mental health resources. The use of adaptive equipment for a person with MS can allow someone to remain working for a longer period of time and decrease the amount of caregiver hours needed, which may delay the need for admission to an assisted living or nursing facility. Given the variability of MS symptoms and the progressive nature of the disease, it would prove beneficial to partner with health insurance organizations to develop mechanisms to reduce the current 5-year qualification period for a person with MS to receive another assistive device/wheelchair.

Personal vehicle modification is sometimes necessary for persons with MS to drive safely and with ease. Such modification provides an individual with the ability to transport one's self around the community. Unfortunately, the cost of vehicle modification, including the vehicle, can be more than \$60,000. Some automobile companies provide reimbursement for modification costs between \$500- \$1,000, which may cover only the tax and delivery costs. Currently, funding is available for persons qualifying for Medicaid, but the majority of people must utilize home equity or other methods to fund this technology. It is essential that members of the automobile industry take more responsibility for providing affordable and accessible vehicles for persons with mobility limitations.

Once diagnosed with MS, it is difficult for individuals to remain in the workforce<sup>24</sup>, with reports of early retirement (40% retired within the first three years of diagnosis<sup>25</sup> and rates of unemployment reaching up to 60-80%<sup>26,27</sup>). Full employment status has a positive effect on mental health, quality of life, and physical health.<sup>28</sup> Overall, the use of adapted medical, assistive technology, and specialized seating and mobility devices provides empowerment for this population.<sup>25</sup>

### **Recommendation 1**

Explore third-party coverage and publicly-supported subsidies for the purchase of specialized seating and mobility devices, necessary DME, and appropriate assistive technology for people with MS.

## **Recommendation 2**

Engage health insurance organizations to develop mechanisms to reduce the five-year qualification period required for persons with MS before they are able to receive another assistive device/wheelchair.

## **Recommendation 3**

Explore the potential of regulations requiring coverage of wheelchair seat elevator as “medically necessary” when prescribed by a physician or therapist.

## **Recommendation 4**

Encourage the automobile industry to consider solutions to reduce the high cost of personal vehicle modifications. Streamline the vehicle modification process in the factory versus after market.

### C. Rehabilitation Services

People with MS benefit from rehabilitation including physical, occupational, and speech therapy in order to improve their overall independence and function. Generally, people with MS present with decreased aerobic capacity and maximal muscle strength, reduced gait velocity, and lower quality of life,<sup>29</sup> which all can lead to decreased independence and increased rate of falls. Currently, a monetary cap exists for physical, occupational, and speech therapy, which hinders reimbursement for "skilled" therapy along with "maintenance therapy" for many persons with MS.

Additionally, there are health consequences associated with a sedentary lifestyle such as increased risk of obesity, cardiovascular disease, osteoporosis, and fatigue. Because people with MS are already at-risk for some of these health problems, leading a sedentary lifestyle can lead to further deterioration and an increased risk of developing chronic diseases related to a sedentary lifestyle.<sup>29</sup>

Corticosteroids are often used as a treatment for exacerbations in people with MS. Research has shown a correlation between corticosteroid use and decreased bone mineral density. People with MS may be at higher risk for fractures and abnormal gait patterns due to corticosteroid use, potentially leading to more frequent falls.<sup>30</sup> Exercise has been shown to improve bone density, balance, and strength, which may decrease the rate of falls in people with MS.

There have been several studies evaluating the effectiveness of home-based exercise programs compared to hospital or clinic-based programs for patients with MS. Both groups showed improvements with balance, quality of life, and functional and psychological status after completing the exercise program. However, the hospital-based exercise group reported higher change scores for balance tests and a statistically significant improvement in Hospital Anxiety Depression Inventory change scores.<sup>31</sup> The evaluators speculated this was likely because a patient can be challenged more in a therapy-based

setting compared to a home setting. Overall, physical, occupational, and speech therapy have shown positive improvements on quality of life, decreased fall rates, and increased independence for people with MS, thus decreasing the burden of care.<sup>31</sup> The federal government should be encouraged to provide financial support for gym memberships for people with MS and the fitness industry should offer wheelchair accessible equipment and trained personnel to assist persons using wheelchairs at gym facilities.

#### **Recommendation 1**

Increase or eliminate the therapy cap for physical, occupational, and speech therapy and allow reimbursement for "skilled" therapy along with "maintenance therapy".

#### **Recommendation 2**

Decrease co-payments and co-insurance for therapy-based services for persons diagnosed with MS.

#### **Recommendation 3**

Encourage Medicaid to provide home-based therapy for people with Medicaid if they are considered home-bound.

#### **Recommendation 4**

Partner with public transportation entities to advocate for reduced cost transportation to allow persons with MS to attend therapy appointments. Transportation should include assistance from the vehicle to the residence.

#### **Recommendation 5**

Explore the potential of regulations requiring federal government subsidies and tax breaks for gym memberships for people with MS and fitness industry provisions of wheelchair accessible equipment and trained personnel to assist persons using wheelchairs at gym facilities.

#### **D. Rural Access to Healthcare**

Preliminary information collected by the National MS Society indicates that the vast majority of Illinois citizens with MS who live in rural areas have medical insurance and are receiving medical care from a qualified neurologist, despite the lack of neurologists and MS centers in or near these areas. In fact, one in six Illinoisans live in a primary health care professional shortage area. Patients often travel long distances to receive proper medical evaluation and treatment. The Illinois MS Society is currently conducting a mapping exercise that will better define the location and availability of qualified neurologists and MS centers in relation to the population demographics present in rural areas of Illinois. This project will identify specialized neurological care in rural Illinois and potentially improve the availability of care to all Illinoisans, regardless of where they live.

According to preliminary information compiled by the National MS Society, a surprising number of rural Illinoisans living with MS are not on disease-modifying therapies (DMT). This seems to be an issue of choice considering that quality insurance and drug company co-pay assistance often offset the high cost of DMT. Because having access to DMT, and adhering to those DMT, is vital to controlling the progression of MS, this appears to be an excellent educational opportunity for the state of Illinois and the National MS Society to inform patients of the importance of DMT and to encourage the regular use of these drugs as part of their regular MS treatment protocol.

Conducting regular outreach to rural Illinois citizens who are not familiar with the National MS Society and the resources available to them is a continuing priority and should be a focus of public health outreach efforts. Identifying individuals with MS and providing information to assist them in accessing all available resources regarding issues often faced by MS patients is critical to providing optimum health care to all Illinoisans.

More resources are needed for rural health care facilities according to a report issued by IDPH's Center for Rural Health and the Illinois Rural Health Association. Like other states throughout the United States, rural hospitals are having difficulty attracting needed physicians and other health care providers. Because almost one in six rural Illinoisans lives in a primary health care professional shortage area, the presence and availability of medical specialists, such as neurologists who specialize in the treatment of MS and other chronic neurological diseases, continues to be a critical health care issue in rural Illinois. Although the efforts made by IDPH's Center for Rural Health and its many partners have made progress in improving the viability of Illinois' rural health care infrastructure, persistent and serious resource and access issues continue to characterize rural health in Illinois. This is an important issue facing rural residents living with MS and other chronic diseases and should be a continued public health focus.<sup>32</sup> In metropolitan areas of Illinois, patients with MS have access to numerous neurologists who specialize in MS. In addition, they have access to nurse practitioners, physician assistants, MS certified nurses, physiatrists, neuro-ophthalmologists, and rehab professionals.

Transportation to and from critical health care visits is a key issue for rural Illinoisans living with MS. The Illinois Department of Transportation funds a pilot project which provides medical transportation for rural Illinoisans. MedTrans is a one-of-a-kind project in Illinois, created to act as a centralized clearinghouse for HCP to access non-emergency medical transportation for their patients. The primary goal is to facilitate the non-emergency transportation of patients by providing mobility management services via a "one-call center." The services provided by MedTrans also assist in transitioning patients who are inappropriately using EMS or ambulance services to public transit and assisting patients who are missing health care appointments and treatments due to transportation issues, by serving as a liaison between the patient, health care and transit providers. Costs associated with MedTrans are often covered by Medicaid.

Many MS specialists visit rural clinics on a regular basis to see patients. When transportation is needed, most public transportation providers are able to offer accessible vehicles. Through a mobile integrated health care program being conducted in many rural areas, EMS professionals are following up with elderly and disabled individuals who have been recently released from the hospital to provide any needed services to reduce the incidence of re-hospitalization. EMS professionals are able to take vitals and administer needed medications to help avoid unnecessary return trips to the hospital and allow rural patients to stay at home during treatment/recovery. This also reduces the use of emergency medical transportation for non-emergency purposes. Education and funding are vital components to providing efficient medical transportation for rural Illinoisans.

Telemedicine offers one solution to provide specialized neurologic care to MS patients in rural areas of Illinois. It is a rapidly growing method of care delivery that expands access to specialty care in health professional shortage areas. Telemedicine can be provided in different ways, through live communication with video communication or through stored and forward communication. With this method a physician can log into a telemedicine device at his/her convenience to review medical data and patient history. Stored and forward communication does not require a live connection between the health professional and the patient, thus reducing the need for individuals to have wi-fi or internet access. Second opinions regarding treatment with disease-modifying drugs could be offered in this manner.

One major advantage of telemedicine is that it allows people with MS to access quality care. Telemedicine overcomes other potential limitations such as the travel costs and the lack of transportation options available to disabled individuals in rural areas. Many Illinois insurance companies do not provide coverage if patients receive care out of their area or network. Without telemedicine, disabling conditions like MS may limit access to specialty centers and optimal treatment. One of the major disadvantages to telemedicine in Illinois is reimbursement. Currently, in Illinois, Medicare and Medicaid will cover telemedicine services if the originating site is located in a designated rural health professional shortage area. The originating site cannot be a person's home, but instead has to be the office of a physician or practitioner, a hospital, a rural health clinic, or federally qualified health center. Currently, for both Medicare and Medicaid, the originating site is only reimbursed about \$25. The distant site where the specialist is located would be reimbursed equal to the current fee for services rendered. Coverage by private insurance companies varies by plan. Twenty states and Washington D.C. have laws that provide private payer coverage for telemedicine; however, Illinois is not one of those states.

### **Recommendation 1**

Educate rural Illinoisans living with MS about the value of DMT in controlling disease progression and lessening the severity of attacks.



**Recommendation 2**

Encourage the recruitment and retention of qualified HCPs (including neurologists who specialize in MS care) in regional MS Centers serving rural populations throughout Illinois.

**Recommendation 3**

Maintain state funding for MedTrans and public transit professionals in rural areas to coordinate and provide essential medical transportation for the elderly and disabled, as well as those living with chronic diseases such as MS.

**Recommendation 4**

Provide effective outreach and education to rural Illinoisans on the availability and logistics for medical transportation to regional HCPs and specialists.

**Recommendation 5**

Explore the expanded use of telemedicine to patients in rural areas to facilitate access to specialized MS care, education and counseling which could improve patient adherence, and better treatment outcomes; resulting in decreased costs of care over time.

**Recommendation 6**

Educate HCPs about the different ways telemedicine can be provided, through live communication with video communication or through stored and forward communication.

**Recommendation 7**

Consider the availability of grant funds for critical access hospitals and HCPs in rural areas to encourage telemedicine program participation.

**Recommendation 8**

Promote legislation which prohibits insurers from discriminating between regular medical and telemedicine services in terms of reimbursement and mandate that private insurers provide reimbursement for telemedicine services in Illinois.

**Recommendation 9**

Explore sources to provide funding to nonprofit medical clinics or hospitals for the purchase of specialized telecommunications equipment in order to enhance the delivery of medical care to MS patients in rural areas of Illinois.

**E. Knowledgeable Professionals**

While ideally all patients will have access to comprehensive health care, it is important that persons diagnosed with MS have access to a physician who specializes in the field of MS. Although there is no board-certification exam to identify physicians who are MS specialists, some physicians complete a fellowship in the field of MS. However, some of the most influential physicians in the field may or may not have completed a fellowship in this field. Currently, the most practical way to identify a specialist in this field is based on whether

the physician considers himself/herself a MS specialist and whether the physician provides access to all or most of the DMT that are currently FDA approved.

Persons with MS, their families and caregivers could be well-served by the development of regional MS Comprehensive Care Centers designated to serve specific geographic areas of Illinois. Similar to the existing Illinois regional Alzheimer's Disease Assistance Centers (ADA Centers), these entities could provide top-tier MS care providing diagnostic evaluation, treatment, referral and research; be a postsecondary higher educational institution having a medical school affiliated with a medical center; and, be staffed by a network of physicians, medical specialists, social workers, educational specialists and research scientists with expertise in MS care and research.

### **Recommendation 1**

Medicaid plans should contract with MS Comprehensive Care Centers and physicians specializing in care for persons with MS which currently exist in Illinois.

### **Recommendation 2**

Require Illinois-based public and private insurance plans to utilize physicians who specialize in MS to provide services to persons with MS. General neurologists are not interchangeable with physicians who specialize in the care and treatment of persons with MS.

### **Recommendation 3**

Publish information on the IDPH website to assist persons with MS in identifying knowledgeable health care professionals who specialize in care and treatment for persons with MS including, but not limited to, centers for comprehensive MS care, neurologic care, rehabilitation, and mental health.

### **Recommendation 4**

Explore establishing MS assistance centers in Illinois which provide comprehensive care to persons with MS, similar to Alzheimer's Disease Assistance Centers, which provide comprehensive care to persons affected by Alzheimer's Disease.

## **F. Financial Burden**

### ***1. Rehabilitation***

Rehabilitation is a critical component of comprehensive care for people with MS, and can include occupational, physical, and speech therapy services. Rehabilitation professionals can provide treatments and education to address mobility, daily living skills, fatigue, speech, cognition, and other areas. Rehabilitation services can improve and maintain independence, function, safety, and quality of life for people with MS. Access to these services, including financial access, is critical to people with MS in Illinois, however

regulations and the costs to beneficiaries are major barriers to receiving rehabilitation. Studies have shown cost as a major barrier to accessing and continuing medical care.<sup>33</sup>

Approximately 62% of all personal bankruptcies in the U.S. were related to medical costs. Among common diagnoses, non-stroke neurologic illnesses such as MS, were associated with the highest out-of-pocket expenditures (mean \$34,167), followed by diabetes (\$26,971), injuries (\$25,096), stroke (\$23,380), mental illnesses (\$23,178), and heart disease (\$21,955). Regulations are needed to provide financial access to rehabilitation for people with MS.<sup>3</sup>

The high cost of some co-payments for rehabilitative services, including the deductible and co-insurance, can be a financial barrier to receiving therapy for people with MS (and other disabilities). Recently, with the insurance mandate under the Affordable Care Act, some beneficiaries have elected plans with high co-payments in order to keep their monthly payments lower. As a result, high co-payments can be a financial barrier or disincentive to seeking rehabilitation services.

Insurance plans also place caps or limitations on the amount of physical, speech and occupational therapy visits covered in a year. Persons with MS often require more visits and can suffer physically from the lack of therapy and financially from the already burdensome out-of-pocket costs. Given the high cost of therapy services, and the often progressive nature of MS as a long-term neurodegenerative disease, these caps are a financial barrier to the services that people with MS need to improve and maintain their functioning. Limited access to rehabilitation services due to financial constraints can lead to negative consequences including, but not limited to: loss of function and independence; falls and other injuries; under or unemployment; increased burden on family/caregivers; institutionalization; and/or need for government financial assistance (e.g., unemployment insurance, state medical assistance).

The Medicare Part B Out-Patient Therapy Cap, part of the Balanced Budget Act of 1997, placed an annual \$1,500 cap on rehabilitative therapy services a beneficiary can receive each year under Medicare, regardless of medical necessity. Since the implementation of the therapy cap in 1999, Congress has realized the possible negative effects of the cap, and has taken measures to prevent some of these consequences. In 2014, the outpatient therapy cap for occupational therapy, which is adjusted for inflation, was \$1,920 per calendar year, and the combined cap for physical therapy and speech-language pathology services was \$1,920.<sup>34</sup> Caps and limitations should be removed from medically necessary therapy services. Medical necessity is defined as health care services that a physician exercising prudent clinical judgment as an expert in the field of MS would provide to a patient for the purpose of evaluating, diagnosing or treating the disease or its symptoms, and that are in accordance with the generally accepted standards of medical practice. These services should be available to both privately- and publicly-insured patients.

Many persons with MS could benefit from the creation of an MS specific insurance coverage law, similar to state and federal laws currently in existence for autism:

<http://insurance.illinois.gov/HealthInsurance/autism.asp>. These statutes allow for health care coverage of autism spectrum disorders despite pre-existing conditions and consequently, health insurance plans cannot deny or exclude coverage for a pre-existing condition, including related conditions. In Illinois, all individual and group health insurance policies and HMO contracts (and voluntary health service organization contracts) must offer coverage for autism spectrum disorders. Health coverage provided to state, county, and municipal employees (and employees subject to the Schools Code (105 ILCS 5/1-1 et seq.) must also provide benefits.

Inadequate financial access to rehabilitation services can lead to many negative consequences including, but not limited to: loss of function and independence, falls and other injuries, under or unemployment, increased burden on family, caregivers, institutionalization, and/or need for government financial assistance (e.g., unemployment insurance, state medical assistance).<sup>34</sup>

A two-tier exception process exists which can extend rehabilitative services beyond the limits of the Medicare cap, when the therapist determines that services above the cap are considered reasonable and necessary. The therapist can use the exception process to deliver services beyond the cap if warranted, e.g. if the person with MS is showing improvement in functional skills and needs to attain a higher functional level to live at home independently, or if more therapy is needed to teach compensatory skills to maintain function. However, heavy use of the exceptions process is likely to result in an audit. Once the charges for therapy reach \$3,700 in a calendar year, there may be a medical review to determine if the services were truly needed. Many claims at this level are closely scrutinized and some are denied. This \$3,700 limit is typically exceeded by about 5% of beneficiaries receiving therapy. Therapists must let patients know that they are responsible for the bill if Medicare denies the therapy charges above \$3,700. Many patients end therapy early rather than risk to paying high fees.<sup>35</sup>

On April 16, 2015 President Obama signed the Medicare Access and Children's Health Insurance Program Reauthorization Act of 2015 (P. L. 114-10), into law, extending the "exceptions process" for outpatient therapy caps through December 31, 2017. However, lack of knowledge about this two-tiered exceptions process (by Medicare beneficiaries and their families, rehabilitation professionals and claim processors) has led to beneficiaries not receiving needed rehabilitation services to which they are entitled. Unfortunately, the exceptions process must be reauthorized by Congress every two years. This unpredictability is stressful and results in confusion and possible deprivation of needed services.<sup>36</sup>

The U.S. Department of Health and Human Services agreed to clarify that skilled rehabilitation is a covered service under Medicare, even in cases where the goal of that rehabilitation is not improvement, but rather maintenance. While the results of this case

were a very positive development for people with MS in need of rehabilitation service to maintain their level of functioning, there continues to be Medicare beneficiaries with MS and their families, rehabilitation professionals, and claim processors who are unaware of maintenance rehabilitation being a covered benefit, which limits access to needed therapy. There have been reports of beneficiaries wrongly denied Medicare coverage for maintenance therapy.

### **Recommendation 1**

Advocate for the federal repeal of the rehabilitation cap and limitations on medically necessary therapy to ensure medical necessity for rehabilitation is determined collaboratively between the physical, speech and occupational therapists, and patient.

### **Recommendation 2**

Require that insurance companies provide skilled rehabilitation services as a covered benefit for beneficiaries when the goal of rehabilitation is to prevent worsening of the disease.

### **Recommendation 3**

Amend the Illinois Insurance Code to remove any treatment limitations or calendar year maximum in health insurance coverage for medically necessary preventive physical, speech, and occupational therapy for insured individuals living with MS.

### **Recommendation 4**

Enact an MS specific insurance coverage law, similar to the law currently in existence for autism: <http://insurance.illinois.gov/HealthInsurance/autism.asp>

### **Recommendation 5**

Educate rehabilitation professionals and referring physicians about the availability of an “exceptions process” for the manual medical review of therapy claims above the \$3,700 threshold.

### **Recommendation 6**

Educate people with MS and their families, rehabilitation professionals, referring physicians and Medicare claims processors that skilled care, including rehabilitation, is a covered service under Medicare, even in cases where the goal of that rehabilitation is not improvement (i.e., services to prevent or slow decline).

### **Recommendation 7**

Establish limits on co-payments for rehabilitation services for Illinois health insurance providers similar to the limits established by other states (e.g., Connecticut, Arkansas, Kentucky, South Dakota and Tennessee). These cost-sharing measures could involve: specific dollar amounts; limits on coinsurance and deductibles; and/or copayments for a therapy session that are the same as for a primary physician office visit.

## **2. Home and Community-Based Services**

MS is a significant financial burden on patients and families living with the disease. The average annual costs for someone with MS in the United States, including both direct and indirect costs (lost wages) is approximately \$69,000. Of this total, approximately \$39,000 consists of health care costs. Total costs for all people with MS in the United States are approximately \$28 billion annually.<sup>37</sup>

The National Disability Institute and the MS Association of America in 2010 conducted a survey and focus group to assess the financial stability of persons with MS. The average age of respondents was between 41 and 60 years of age and the majority were female, married, and living with a partner. Results of the survey, titled "Financial Wellness Among Individuals Living with MS" indicated that finances were worse for 67% of respondents after MS diagnosis due to co-payments and prescription costs, non-medical equipment costs, decreased income due to reduced productivity, and insurance costs during the 24-month waiting period for Medicare once they received approval for social security disability income (SSDI) benefits, which can exceed disability payments. Only 24% of respondents reported knowing where to find accurate information about public benefits and provisions within public benefits programs which allow for earnings and savings at levels that increase finances while protecting critical health care. Persons with MS would qualify for additional financial assistance for home and community based services by exempting retirement assets, as well as spousal life insurance policy limits. This would prevent depletion of assets which may be needed for future care.

The average SSDI monthly payment in 2014 was \$1,110.50 with required gross earnings less than \$1,000 a month to maintain eligibility. Qualified Medicare Beneficiary Fund Program monthly income limits were \$923 for an individual and \$1,235 for a married couple. Medicaid monthly disabled adult income limits in the State of Illinois average \$1,293. Sixty one percent of MS patients reported household income below \$50,000 per year and half of those were below \$25,000 per year.<sup>37</sup>

Massachusetts developed a program to assist people with disabilities with home modification costs - the Massachusetts Home Modification Loan program - which provides loans for access modifications to the principal residence of seniors, adults with disabilities, and families with children with disabilities. Examples of the modifications that may be eligible under the Massachusetts program include ramps, lifts, bathroom and kitchen accessibility features, widening doorways, and accessible door hardware; also, increasing housing square footage or adding an addition to the floor may be eligible under this program. These are far less costly than assisted living or nursing home costs. More information on home modifications is available at:

<http://www.livingwellwithadisability.org/2011/12/are-there-tax-incentives-for-home-modifications/>

Many people with MS will need greater assistance as their disease worsens. The cost of medical caregiving is \$360 billion annually (\$10,400 per caregiver per year). Home

modifications to help people living with MS stay in their homes can range in price from \$100-\$50,000 according to the Center for Universal Design. Average assisted living costs are \$3,805 monthly and average nursing home costs are approximately \$170 per day in Illinois.<sup>38</sup>

### **Recommendation 1**

Exempt retirement assets and spousal life insurance policy limits to increase eligibility for home and community services for persons with MS.

### **Recommendation 2**

Develop programs to assist persons with disabilities with home modification costs, similar to the Massachusetts Home Modification Loan Program, which provides loans for access modifications to the principal residence of seniors, adults with disabilities and families with children with disabilities.

### **Recommendation 3**

Offer financial assistance for family caregivers unable to work outside the home through the availability of tax exemptions or deductions.

### **Recommendation 4**

Educate patients, families and caregivers about community resources and financial planning available to person with disabilities by establishing partnerships with community colleges and other community-based organizations.

- Subsidize programs for home safety courses for patients, medical alert bracelets and “Skype” type home check-ins and call-out devices for spouses/family members.
- Provide training for home health professionals and subsidize classes for family members to become home health professionals. Facilitate access to support groups and resources available for those living with a disability and in low income brackets.
- Provide information about tax breaks available to home health professionals and families.

### ***3. Respite Care***

Respite Care provides temporary relief to caregivers from the ongoing responsibility of caring for an individual of any age with special needs who may be at risk of abuse or neglect. Respite care is often provided through community-based organizations, such as adult day programs. Special needs may include any disability, any chronic or terminal physical, emotional, cognitive, or mental health condition requiring ongoing care and supervision.

More than one million people in Illinois provide unpaid help to family members who have special needs. It is estimated that if the work of these caregivers had to be duplicated by paid staff, the cost to the state would be \$1.3 billion.

The goal of the caregiver is to promote independence and dignity of the person with MS by promoting their role as a parent, spouse, and/or sibling, not as a “patient” or burden. However, persons with MS may not qualify for respite because of retirement and/or spousal assets. Therefore, the family members or others must provide daily support. Until the asset limit issue is resolved, respite care can provide a temporary short term relief.

More information on respite care, is available at:

<http://www.illinoisrespitecoalition.org/home.html>

<http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=1450&ChapterID=31>

## **Recommendation**

Ensure that persons living with MS, their families and caregivers are informed and knowledgeable about the services available to them through the Illinois Respite Care Program, implemented by the Illinois Department of Human Services.

### **4. Persons Living with High-Level Disability**

Multiple studies document that chronic progression of MS is associated with significant increases in the economic burden on the patient, family, health system, and society.<sup>39</sup> Depending on disease severity or stage of disease, the distribution of costs can change from direct to indirect. Additionally, current studies are researching trends in how early treatment with DMT can affect lowering the financial burden of treatment for persons with MS. However, patients with advanced MS or progressive forms of MS do not have full access to therapy as the current DMTs approved by the FDA are not indicated for progressive forms of MS.<sup>4</sup>

Medical costs for severely disabled individuals are more than twice those for persons with relatively mild disease.<sup>41</sup> Compared to an individual with an Expanded Disability Status Scale (EDSS) score of 2, costs for an individual with an EDSS score of 8 are almost three times as high.<sup>42</sup>

Additionally, the financial burden of living with a high level of disability includes the cost of modifying the

The Kurtzke Disability Status Scale (DSS) was developed by Dr. John Kurtzke in the 1950s to measure the disability status of people with multiple sclerosis. The scale was modified over time to reflect clinically observed levels of disabilities. Renamed the Kurtzke Expanded Disability Status Scale (EDSS), the scale ranges from 0 to 10, with half points for greater specificity. Lower numbers indicate less severe disability. Higher numbers reflect a greater degree of disability, mostly in relation to mobility:

- 0 = Normal
- 1-1.5 = No disability, but some abnormal neurological signs
- 2-2.5 = Minimal disability
- 3-4.5 = Moderate disability, affecting daily activities, but can still walk
- 5-8 = More severe disability, impairing daily activities and requiring assistance with walking
- 8.5-9.5 = Very severe disability, restricting to bed
- 10 = Death



home and vehicle for accessibility, and purchasing supplies for physical needs such as incontinence, skin irritation, and skin ulcers, none of which are covered by insurance.

**Recommendation 1**

Promote research to identify the economic burden of patients with a higher level of disability (Expanded Disability Status Scale greater than 5.5).

**Recommendation 2**

Identify strategies to increase awareness among HCPs regarding funds available for patients with advanced and progressive MS for neuro rehabilitation repair. The current DMTs do not help persons with advanced or progressive MS.

**Recommendation 3**

Create an Illinois medical income tax deduction similar to the federal medical income tax deduction that is offered.

**Recommendation 4**

Require health insurance coverage for incontinence supplies.

**Recommendation 5**

Provide a home modification income tax credit as provided in the amended (2015) Illinois Income Tax Act for taxpayers who purchase a new accessible residence, or retrofit an existing residence to improve accessibility and provide universal visitability.

**Recommendation 6**

Increase the current credit for disabled persons' homestead exemption under the Property Tax Code to 10%.

**Recommendation 7**

Promote research grants that focus on ways to improve quality of life for MS patients in the population.

***5. Pharmacologic Access and Costs***

Pharmacologic costs associated with DMT are a major barrier to therapy and the majority of costs are associated with biologic and bio-similar medications used to manage the disease. Adherence to therapy is considered cost-effective as this can decrease the frequency and severity of relapses, prevent hospitalizations, and slow progression. Manufacturers of these medications have co-payments assistance programs to attempt to minimize the costs. However, prior authorization and restrictions on types of medications can cause access challenges. With the current prior authorization process, valuable resources in physicians' offices are spent navigating managed care and securing insurance approvals. Also, the current system can result in patients experiencing long delays in getting prescriptions filled, leading to potentially adverse health impacts.

More information about assistance for persons who cannot afford medications and healthcare costs is available at: <http://www.needymeds.org/index.htm>

### **Recommendation 1**

Partner with the Illinois MS Society to increase awareness among persons with MS and caregivers about the amendment to the Illinois Public Aid Code and the Illinois Insurance Code requiring a uniform prior authorization form for prescription drug benefits.

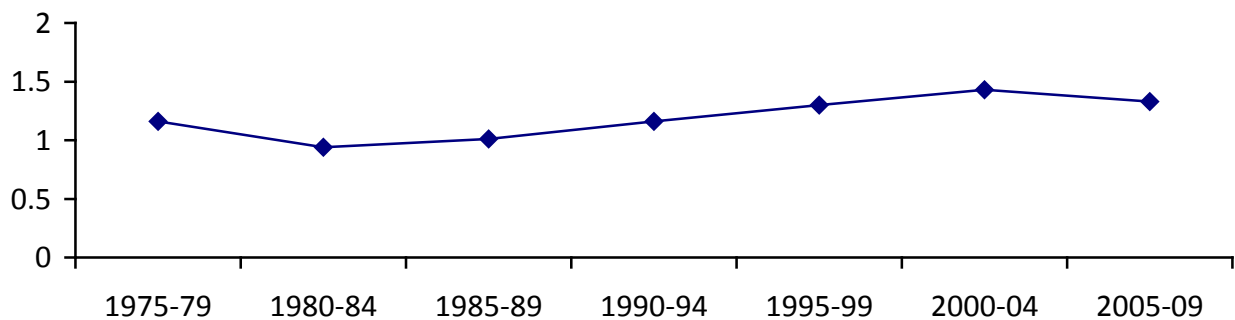
### **Recommendation 2**

Implement regulations prohibiting health insurance plans from imposing prescription co-payments (that are higher than the insurer's co-payment thresholds for generic medications) for disease-modifying and symptom-management medications for MS.

### G. Advanced MS

Studies in the past 30 years have documented shortened life spans in persons with MS by as much as 15 years.<sup>43</sup> More recent therapeutic trials and population studies have shown reversal of those shortened life spans, possibly due to improved health care.<sup>44</sup> A recent large longitudinal study reviewing mortality rates in Canada from 1975-2009 has been published.<sup>45</sup> The average annual Canadian MS mortality rate, 1975-2009 was 1.23/100,000; five-year rates for 1975-1979, 1980-1984, 1985-1989, 1990-1994, 1995-1999, 2000-2004, 2005-2009 were: 1.16, 0.94, 1.01, 1.16, 1.30, 1.43, 1.33. (Figure 1)

Figure 1. Five-Year MS Mortality Rates per 100,000, Canada, 1975-2009



Source: Multiple Sclerosis Mortality Rates in Canada, 1975-2009. *Canadian Journal of Neurological Sciences*, 2015.

Thus mortality rates over the entire 35 years were stable (average annual percent change of less than one percent). The average annual 1975-2009 rates for females and males were 1.45 and 0.99. Five-year female rates were always higher than males. Regardless of gender, there was a decrease in MS mortality rates in the 0-39 age group and increases in the 60-69, 70-79, and 80+ groups over time. In contrast, there were decreases in all-cause mortality rates across each age group. The highest MS mortality rates for 1975-2009 were

consistently in the 50-59 and 60-69 groups for both genders, while the highest all-cause mortality rates were in the 80+ group.

Another study from Germany studied the spectrum of disability in a large cohort of patients with MS, some of whom were followed longitudinally for nearly 50 years, finding some predictors of disability included age of onset in men. The risk of needing gait-assist devices was 50% at 55 years of age, and very high, nearly terminal states of disability for MS patients age 80 and older reached over 80%,<sup>46</sup> suggesting this particular decade is more vulnerable. A study from Norway showed shorter median time from onset to death and a higher relative risk of dying in patients with primary progressive forms of MS, particularly women.<sup>47,48</sup>

A Canadian group looked at the effect of comorbidities on mortality in MS. Using population-based administrative data, they identified 5,797 persons with MS and 28,807 controls matched on sex, year of birth, and region and then estimated annual mortality rates. Using Cox proportional hazards regression, they evaluated the association between comorbidity status and mortality, stratifying by birth cohort, and adjusting for sex, socioeconomic status, and region. They compared causes of death between populations and found that median survival from birth in the MS population was 75.9 years versus 83.4 years in the matched population. MS was also associated with a two-fold increased risk of death (adjusted hazard ratio 2.40; 95% confidence interval: 2.24-2.58). Slightly more than two of every five people with MS died from the disease or from complications common to MS patients, such as infected pressure sores, pneumonia or bladder infection. Several comorbidities were associated with increased risk of death in both populations, including diabetes, ischemic heart disease, depression, anxiety, and chronic lung disease. The magnitude of the associations of mortality with chronic lung disease, diabetes, hypertension, and ischemic heart disease was lower in the MS population than the matched population. The most common causes of death in the MS population were diseases of the nervous and circulatory systems. Mortality rates due to infectious diseases and diseases of the respiratory system were higher in the MS population.<sup>49</sup>

In a related study, the group was examined for Intensive Care Unit (ICU) admissions. From January 2000 to October 2009, the age- and sex-standardized annual incidence of ICU admission among prevalent cohorts was 0.51% to 1.07% in the MS population and 0.34% to 0.51% in matched controls. The adjusted risk of ICU admission was higher for the MS population (hazard ratio 1.45; 95% confidence interval [CI] 1.19-1.75) than for matched controls. The MS population was more likely to be admitted for infection than the matched controls (odds ratio 1.82; 95% CI 1.10-1.32). Compared with the general population, the risk of ICU admission is higher in MS, and 1-year mortality after admission is higher. Compared with the matched controls admitted to ICUs, one-year mortality was higher in the MS population (relative risk 2.06; 95% CI 1.32-3.07) and was particularly elevated in patients with MS who were younger than 40 years (relative risk 3.77; 95% CI 1.45-8.11). Causes of death were MS (9.3%), infections (37.0%), and other causes (52.9%).<sup>50</sup>

These findings have contributed to an emphasis on early diagnosis and treatment with DMT. Management with DMT has become a standard of care, and a guideline of the American Academy of Neurology. Emphasis should be made on early diagnosis and treatment to prevent shortened survival, and improved quality of life, as a shift to longer survival times with MS has been observed. Additionally, since comorbidities have been shown to confer increased mortality risk, efforts should be made toward identifying and managing these as well. Greater attention to preventing infection and managing comorbidities is needed in the MS population.

### **Recommendation 1**

Promote research on incidence, etiology, and methods to reduce premature death in MS.

### **Recommendation 2**

Facilitate the education of HCPs and persons with MS on the importance of early intervention and treatment of infection, skin breakdown, respiratory and urinary tract disorders, and their link to premature death.

### **Recommendation 3**

Ensure affordable access to preventative therapies such as physical therapy, wound management, respiratory therapy, and urological care, in order to avoid deconditioning, skin breakdown, decubitus ulcers, pneumonia, and urosepsis.

### **Recommendation 4**

Advance affordable access to materials such as incontinence supplies and medical equipment critical to prevention of deterioration of status.

## **H. Research**

The causes, consequences, treatment, and prevention of MS have been a focus of research in Illinois for decades. Based in part on the Illinois MS Lottery Fund, MS-related research within Illinois is rapidly increasing. The [www.clinicaltrials.gov](http://www.clinicaltrials.gov) website contains a repository of biomedical human research trials, which lists more than 125 trials focusing on MS in Illinois. It is important to note that these numbers are a conservative estimate and do not take into account research that is privately funded (e.g. basic pharmaceutical research) and/or unfunded preliminary investigations. The review of the research trials in this repository highlights the vast number of pharmaceutical and physical rehabilitation trials being conducted in persons with MS. Research topics encompass a broad spectrum of biomedical research ranging from understanding how cells of the nervous system are impacted by MS to determining if various exercise-based programs are effective in an individual with MS. Funding for this research was obtained from a variety of sources including the National MS Society, the National Institutes of Health, as well as other agencies. The National MS Society is currently funding an estimated 30 research projects on a range of MS specific topics in Illinois. These research projects have been based at leading Illinois research institutions including Northwestern University, University of

Chicago, University of Illinois at Chicago and the University of Illinois at Urbana-Champaign.

Since 2007, MS instant lottery ticket sales have raised more than \$7 million for MS research in Illinois. Proceeds fund competitive grants to Illinois researchers, the first of which were awarded in 2009. Grants considered for funding must propose to research repair of damage caused by acquired demyelinating disease of the central nervous system; and develop and advance the understanding, techniques, and modalities effective for maintaining function, mobility, and strength through preventive physical therapy or other treatments and restoration of function. Research recipients are selected through a peer-review process established by IDPH and the National MS Society.

### **Recommendation 1**

Continue to support Illinois as a leader in biomedical research in MS by funding research that will have a positive impact on the lives of those living with MS.

### **Recommendation 2**

Double the funding limit from \$100,000 to \$200,000 and increase the project duration to 18 months on individual research awards from the MS Lottery Fund.

## **III. Education and Awareness**

### A. Public Awareness

There are more than 20,000 individuals living with MS in Illinois. The impact of the disease stretches much further to family members, friends and loved ones who are caring for the individual living with MS. For some living with MS, their symptoms may be very manageable, with little assistance needed from others; while in other situations, the person living with MS may need daily, if not hourly assistance, from a care partner or care professional, to help them manage their symptoms or manage regular tasks of daily living such as getting out of bed, bathing, and eating. MS is unique in that it impacts each person differently. Programs and education for individuals who are newly diagnosed or for caregivers on how to assist the patient, while also taking care of their own personal needs, are essential to fully understand the scope and impact of the disease.

Among minority populations, including African Americans and the Latino/Hispanic population, there is misinformation regarding the prevalence and likelihood of developing MS. The belief that African Americans do not get MS is a myth. For years, researchers have assumed that African Americans were less likely to develop MS than whites, but a recent study suggests the opposite may be true. Researchers found African American women were more likely than white women to be diagnosed with MS. Likewise, HCPs assumed that MS was uncommon in the Hispanic-Latino population. However, recent studies are showing an increase in the number of people throughout Latin America who have MS — a figure that is rising faster than the growth rate of that region's total population.

It is essential to provide more information related to MS to the general population to assist them with furthering their education and knowledge about the disease, locating resources available to them in their community, linking families to government programs and financial assistance options to help manage the disease, and providing resources for the newly diagnosed - not only about how to physically deal with their symptoms, but also the emotional aspect that comes with an MS diagnosis.

Additionally, during times of emergency or in disaster situations, people with disabilities are less likely to be evacuated and can be especially vulnerable. System-level response which ensures that people with disabilities and their support systems must be included in all phases of preparedness, evacuation, and recovery within communities, including adaptive strategies for in-place and shelter accommodations on a community-wide scale. Persons with MS and their families should become aware of individual-level planning and training in advance of, during, and following events.

#### **Recommendation 1**

Maintain a MS webpage on the IDPH website which provides current information about MS, managing symptoms, resources for newly diagnosed and family caregivers, government programs available in the state, the Illinois MS Lottery Fund, and links to statewide MS Centers and other institutions providing care to those affected by MS.

#### **Recommendation 2**

Establish annual recognition of MS Awareness Week in Illinois, in conjunction with the week acknowledged by the National MS Society to promote awareness of MS across the country.

#### **Recommendation 3**

Develop a statewide public awareness campaign to educate the public on autoimmune diseases including MS. Better education can help individuals and families address the challenges that they are facing and connect them with others in similar circumstances.

#### **Recommendation 4**

Design awareness and education campaigns for persons with MS and their families to increase preparation for natural disasters and other emergencies.

#### **B. Professional Education**

Although the number of citizens in Illinois diagnosed with MS is not known, estimates place the number of patients around 20,000. Fewer than 200 board-certified neurologists provide care and treatment to those patients in Illinois.<sup>51</sup> Many are treated by primary care physicians who are not MS specialists. These physicians can be a targeted “high yield” group for professional education, because of their direct contact with patients and their caregivers.

Also, there is a lack of physical therapists (PT) who are knowledgeable and certified in treating persons with MS in Illinois. In North Carolina, a similar problem was addressed through establishing a PT education program at the University of North Carolina: <http://msstepup.org/about/step-up-model-key-focus-areas/>

While MS therapies can help slow, or potentially even stop the disease, they are not a cure, and they are not designed to treat many of the symptoms of MS. Patients need multidisciplinary care and access to effective therapies. Medically necessary treatments and aids include access to physical therapy, occupational therapy, and speech and cognitive therapy; access to specialists knowledgeable in the management of MS-related symptoms, including urologists, psychiatrists, and psychologists; access to transportation services; mobility aids including appropriately fitted canes, walkers, powered scooters and powered wheelchairs; access to home adaptive equipment including ramps, shower chairs/bars, and emergency contact.

The American Academy of Neurology (AAN), Core Curriculum for Managing Patients with MS can be used as a template for the necessary medical knowledge, including testing of objective knowledge with pre-and-post testing, with a specific focus on the management of MS-related symptoms (as opposed to the diagnosis and disease modifying treatment of MS). Modules can be created with an on-line curriculum that can be completed by motivated HCPs.

#### **Recommendation 1**

Partner with the AAN to identify physicians and HCPs in Illinois who treat MS to administer surveys to identify training needs specific to management of MS-related symptoms.

#### **Recommendation 2**

Create a training module for physicians and HCPs for the care of patients with MS.

#### **Recommendation 3**

Identify knowledgeable professionals in Illinois for MS subspecialty care (physiatry, urology, etc).

#### **Recommendation 4**

Partner with the Illinois MS Society to create a shared website for physicians and HCPs with services relevant to patients with MS (i.e., transportation and social work services, etc.).

#### **Recommendation 5**

Provide education through continuing education provisions to licensed practitioners in Illinois.

### **Recommendation 6**

Support more Illinois rehabilitation therapists becoming certified MS rehabilitation therapists through the Consortium of MS Centers: [http://www.mscares.org/?about\\_mscs](http://www.mscares.org/?about_mscs)

### **Recommendation 7**

Collaborate with universities which have HCP programs to develop and implement student therapy clinics for people with MS in Illinois.

### C. Access to Educational Programming

Gathering information about MS as a disease, MS treatments, and ways to live well with MS is important throughout the course of the disease. Many evidence-based educational programs for persons with MS and their families exist, such as programs for fall prevention and fatigue management, as well as programs for families and caregivers of people with MS. While these programs have many positive outcomes such as increased confidence in managing MS, reduction in the severity and impact of symptoms, improved quality of life; and have the potentials to reduce costs by reducing injury, hospitalizations and institutionalization, the availability and accessibility of such programs is limited.<sup>52,53,54</sup>

### **Recommendation 1**

Provide funding to MS agencies to support the dissemination of existing high-quality, evidence-based educational programs for people with MS and their families or caregivers.

### **Recommendation 2**

Provide funding to support the development and evaluation of educational programs for people with MS and their families or caregivers.

## **IV. Recommendations for Statewide Policy Change**

The MS Task Force recommends the following statewide policy initiatives to address the needs of persons with MS, their families and care givers; and persons with disabilities.

- The Illinois Income Tax Act (35 ILCS 5/224) should be amended to create an income tax credit for taxpayers who purchase a new accessible residence, or retrofit an existing residence, to improve accessibility and provide universal visibility for persons with disabilities. The tax credit may not exceed \$2,500 and the total amount of tax credits granted for a fiscal year shall not exceed \$2,000,000. The tax credit should be exempt from the Act's automatic sunset provision.
- The Illinois Income Tax Act (35 ILCS 5/208) should be amended to create a tax credit for residential real estate property taxes, if the tax payer qualifies for the disabled persons' homestead exemption under the Property Tax Code. The taxpayer would be entitled to a credit equal to 10% (instead of 5%) of real estate property



taxes paid by the taxpayer during the taxable year on the qualifying property. The tax credit may not be carried forward or back and may not reduce the taxpayer's liability to less than zero. The tax credit should be exempt from the Act's automatic sunset provision.

- The Illinois Insurance Code (215 ILCS 5/356z.8) should be amended to allow medically necessary preventative physical therapy without any treatment limitation or calendar year maximum, or no fewer than 110 visits per year for insured persons who are diagnosed with MS. Additionally, "preventative physical therapy" should include physical and occupational therapy prescribed by a physician licensed to practice medicine.

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## **Acknowledgements**

The MS Report of Recommendations was prepared by the members of the MS Task Force and partners from public health, MS organizations, academic institutions and persons affected by MS.

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