National
Multiple Sclerosis
Society

November 1, 2021

The Honorable Ron Wyden
Chairman
Senate Committee on Finance
221 Dirksen Bldg.
Washington DC 20510-3703

The Honorable Mike Crapo
Ranking Member
Senate Committee on Finance
239 Dirksen Bldg.
Washington DC 20510-1205

RE: NMSS Response to Senate Finance request for information on behavioral health needs and assessing factors contributing to gaps in care

Dear Chairman Wyden and Ranking Member Crapo:

The National Multiple Sclerosis Society (Society) applauds the Senate Finance Committee's focus and request for information (RFI) on improving access to timely, quality mental and behavioral health care and substance use disorder services. We appreciate the opportunity to respond to the RFI and offer information on the gaps in care and access challenges that people with multiple sclerosis (MS) experience, and provide recommendations on solutions and ideas to enhance behavioral health care on behalf of those living with MS.

MS is an unpredictable, often disabling disease of the central nervous system, which interrupts the flow of information within the brain and between the brain and the body. Symptoms range from numbness and tingling to blindness and paralysis. The progression, severity, and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS.

The Society works to cure MS while empowering people affected by MS to live their best lives. To fulfill this mission, we fund cutting-edge research, drive change through advocacy, facilitate professional education, collaborate with MS organizations around the world, and provide services designed to help people affected by MS move their lives forward. Additionally, we see our organization as a partner to the government in many critical areas. To date, the Society has invested $1 billion to accelerate the discovery, development, delivery of MS treatments and through the MS Navigator program, we provide direct and personalized support to connect people affected by MS to the information, resources and support they need to move their lives forward.

MS and its impact on mental and emotional health

In addition to the physical symptoms of MS, the disease may have profound impact on an individual's mental health and behavior, as well as the mental health of their family members and caregivers. People with MS may have difficulty adjusting to the diagnosis of a disorder that is unpredictable, has a fluctuating course, and carries a risk of progression over time to some level of physical disability[i]. Depression, anxiety and other mood and behavioral changes additionally are all common symptoms of MS, thought to be part of the disease process itself, and people with MS experience these disorders at higher rates than those observed in the general population.[ii] [iii]

Mental and behavioral health issues that are common in people with MS include:

- Depression is the most common mental health diagnosis in MS, with a lifetime risk for major depressive disorder of 50–60%[iv][v].
- Anxiety frequently occurs with depression. Compared to the general population, anxiety is three times more common for people living with MS.[vi]
- Suicidal ideation is about three times as common in MS compared to the general population.[vii]
- Adjustment disorder (approximately 24%) and bipolar disorder (13%) are also more common in people with MS.[viii]
- Pseudobulbar affect (PBA), involuntary laughing and/or crying often without consistent feelings, affects more than 10% of people with MS, particularly those with secondary progressive MS.[ix]
- People with MS are diagnosed with substance abuse disorder at three times the rate of the overall population.[x]

The direct causes of mood, emotional and behavior changes in people with MS are not well understood, and a variety of factors can contribute to these conditions. In addition to being challenging for an individual to manage, these conditions can also have an impact on the MS disease course. Demyelination and damage to nerve fibers in the brain can also result in emotional and mood changes**.** Depression can affect cognitive functioning in MS, including aspects like working memory, processing speed, learning and memory functions, abstract reasoning, and executive functioning[xi]. Additionally, substance abuse disorders have the potential to cause more neurologic damage to the central nervous system (which is already compromised due to MS)[xii], and may interact with any disease modifying therapy or other MS medication and is a significant factor in increased suicidal rates[xiii][xiv].

Strengthening Workforce

We appreciate the Committee's focus within the RFI on strategies to improve strengthening the mental and behavioral health workforce. Even prior to the COVID-19 pandemic, research has demonstrated an unmet need for mental health services among people living with MS.[xv] Pandemic-related stress and increased isolation has only exacerbated this need, and we applaud the Committee for seeking input from stakeholders how best Congress can address the barriers that contribute to the workforce issues that are present which create barriers to allowing people with MS to get the necessary care they need to live their best lives.

The lack of qualified mental and behavioral health specialists is a driving factor which prevents people living with MS from accessing mental health services.[xvi] Many factors contribute to this workforce shortage, including an aging workforce; low salaries; a lack of resources; and fewer people entering the profession. These reasons contribute to the severe network adequacy challenges that are seen in the mental and behavioral health sector. We know that when networks are limited or there are no providers taking on new patients, people with MS are forced to wait or travel long distances for care, or ultimately forgo care altogether.

The Society encourages the Senate Finance Committee to work with colleagues on the Senate Health, Education, Labor, and Pensions (HELP) Committee and explore incentives to increase entrance and retention into the mental and behavioral health workforce, especially for those serving underserved populations in both rural and urban areas. We urge the Committee to explore H.R. 3150/S. 1578, the bipartisan Mental Health Professionals Workforce Shortage Loan Repayment Act, which would increase the availability of qualified providers working in underserved communities through a student loan repayment program for those mental health professionals who commit to working in underserved areas.

It is also critical that the Committee focus on increasing diversity in efforts to recruit and retain mental and behavioral health providers. The Society's Access to High Quality Healthcare Principles outline our priorities and commitment to expanding access to comprehensive, affordable health coverage. We believe that people with MS should have access to and receive high quality MS care regardless of their race, ethnicity, cultural background, socioeconomic status, sex, gender, sexual orientation, level of disability, age, geographic location, language and care setting that is culturally relevant, accounts for treatment and care preferences and differences in identity. With that principle in mind, it is imperative that diversity in the mental and behavioral health workforce reflect the diversity of people who live with MS, and this is the same for other chronic health conditions. A key learning from the Society's Black MS Experience Program Series was that people of color with MS want to see providers who look like them and understand their cultural and individual needs. To address this disparity, the Society offers cultural competence training and incorporates this training in all Society-funded fellowships to help train the next generation of researchers and providers. We applaud the steps the federal government has taken thus far towards diversifying the behavioral health workforce, such as the work of NIH's Scientific Workforce Diversity Office and UNITE Initiative and encourage the Senate Finance Committee to look at other measures to advance diversity and inclusion in the mental health workforce pipeline.

Increasing Integration, Coordination, and Access to Care

People with MS experience mental and behavioral health conditions like major depression and substance use disorder at three times the rates of the overall population[xvii]; yet many are unable to obtain the mental or behavioral health treatment they need. Reasons often cited for not being able to access treatment are network adequacy issues, the financial costs of care, stigma associated with mental health, social determinant of health factors, and the lack of comprehensive insurance coverage for mental health services. We applaud the Committee for focusing on strategies of improving integration and coordination of mental and behavioral health services into primary health care services and improving access.

The Society's Access to High Quality Health Care Principles align with the Committee's goal of integrating behavioral and mental health care. We urge the Committee to examine strategies that address current gaps in integrating the electronic health records from primary care and mental and behavioral care, while still protecting patient privacy. As the symptoms of mental health challenges can impact physical health and MS symptoms, we believe it is critical that health care providers have a full picture to assess an individual's overall health that includes mental and physical health care records. We also urge the Committee to ask the GAO to study how social determinants of health uniquely impact access to and utilization of mental health services. We believe that this study will help provide gaps that could be addressed by federal, state and local governments to meet the needs of their citizens and enhance physical and mental health.

We also know that even in areas where there is a more robust behavioral health workforce, people living with MS continue to face barriers in accessing mental health services due to lack of adequate insurance coverage for those services. The Society encourages the Senate Finance Committee to convene a stakeholder roundtable to explore barriers and potential policy solutions that would incentivize mental health providers to accept private insurance and to increase insurance coverage of mental health services more generally for individuals on Medicare and Medicaid, especially for people living with chronic conditions. The Society believes this type of roundtable discussion will help align incentives that patients need with provider needs to explore potential pathways forward. We urge the Committee to publish any findings and policy proposals in a whitepaper that would allow groups to build on progress made in the roundtable to enact policy solutions.

Additionally, we believe that a stakeholder roundtable will offer a venue in which key learnings and information can be shared to coordinate a federal response. We recommend that Congress consider a nationwide registry of crisis services that would be available for mental health providers, counselors, and other professionals to utilize to provide resources and connect individuals with the help they need. Society navigators currently utilize state resources from the Substance Abuse and Mental Health Services Administration, but a coordinated national resource would be beneficial for non-profits and other groups who often refer individuals to services.

Further, we urge the Committee to explore strategies to integrate behavioral health into primary care, which could help improve health outcomes, reduce stigma, lower treatment costs, and increase patient satisfaction with care. Anecdotally, people with MS have shared that a lack of knowledge about MS from health care providers (both mental health and primary health care providers) about the emotional and mental health impacts of MS add to the anxieties commonly experienced by people who are newly diagnosed. There are several evidence-based models for integrating primary and behavioral health care, and the Society encourages the Senate Finance Committee to explore opportunities to fund associated integration transition costs (e.g., provider education and training, staffing, physical changes to offices, etc.) for a variety of these models to allow for communities to select models that best fit their needs. We recommend the Committee explore innovative payment models that would allow licensed, credentialed mental health providers to provide mental health services to those with chronic health conditions.

There are additional strategies to support people with their mental health. For example, the Society developed a strategic partnership with Happy the App. Through this partnership, people affected by MS can access the 24/7 mobile based emotional support service from anywhere across the country. We have also developed a strategic partnership with eSupport Health. eSupport Health offers professionally led, online support groups for individuals and their families. Our experience has allowed us to step in and help bridge the gap to help meet the emotional/mental health of people affected by MS and believe this model could be scaled to better meet emotional and mental health needs of people across the country. We urge the Committee to work with their colleagues on the HELP Committee to authorize a grant program at SAMHSA for non-profit or other service organizations who provide funding for self-help groups, mental health referrals and educational resources for those they serve.

Across the country, many people living with MS – especially those with disabilities – rely on Medicaid programs for coverage. However, despite Medicaid being the largest payer of mental and behavioral health services, many people living with MS face extraordinarily long waitlists of services, leading some to seek care through emergency rooms or forego mental health care entirely. Additionally, some providers, like clinical social workers in private practice, are not eligible for Medicaid reimbursement and for psychologists and psychiatrists, the Medicaid reimbursement rate is so low that providers do not accept Medicaid patients, which worsen disparities and create additional barriers to people with MS receiving the coordinated care they need. We urge the Committee to explore solutions like the Medicaid Bump Act (S. 1727/H.R. 3450), which would incentivize Medicaid programs to increase state spending on coverage for mental health services.

Ensuring Parity

Mental health parity means that insurance benefits for mental health and substance use conditions are equal to coverage for other types of healthcare. Without parity, mental health treatment is covered at far lower levels in health insurance policies than other medical conditions. A lack of parity results in people being forced to navigate a confusing insurance system in the middle of a crisis. Early access to treatment that can prevent a more costly crisis down the road. In addition, denying adequate insurance coverage can exacerbate stigma against people with mental illness and substance use disorders.

Congress first addressed discriminatory insurance practices with the Mental Health Parity Act of 1996, which established the principle that there should not be disparities between mental and physical health benefits. This law was limited to employer health plans covering more than 50 employees and stipulated that mental health benefits already offered may not impose annual or lifetime caps on care.

Despite the MHPA of 1996, people seeking mental health services continue to face discrimination from insurers. While most employers complied with the law, many instituted new restrictions, and limits on mental health benefits far more than medical and surgical benefits (e.g., restricting the number of covered outpatient visits, higher cost-sharing requirements). In 2008, Congress passed the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act (MHPAEA) to curb the financial and non-financial ways that health plans limit access to mental health care. Additionally, passage of the Affordable Care Act (ACA) in 2010 significantly increased access to mental health services, especially for those in individual or small-group health plans. Because the previous federal parity laws did not apply to those plans, some insurers in those markets could screen patients for mental health history and use that information to deny coverage, exclude and cap mental health services, increase premiums/cost-sharing, and restrict access to drugs. The ACA addressed these issues by pairing coverage expansion with access to mental health care, mandating MHPAEA parity requirements to these state regulated plans, and including mental health as an essential health benefit.

Unfortunately, some states do not actively enforce federal laws for parity for health insurance plans under their purview. According to a 2018 report, produced in collaboration with Morehouse School of Medicine, The Kennedy Forum and Well Being Trust, 32 states received a failing grade for behavioral health parity. The Society urges the Committee to pursue legislation that requires Medicaid Care Management Organizations (CMOs) to submit data to demonstrate compliance, set targets for improvement, and enforce parity provisions. We believe CMS should have the authority to withhold funds if these data points are not submitted and analyzed in a timely manner and if data shows a lack of parity enforcement.

Additionally, we urge the Committee to pursue legislation that would incentivize states to require insurers to submit an annual report to the relevant state agency demonstrating that medical necessity criteria and nonquantitative treatment limitations (NQTL) for mental health and substance use disorder benefits are comparable to medical and surgical benefits.

State agencies frequently state that there is a lack of resources and personnel available to analyze data needed for parity enforcement and we urge the Committee to examine the feasibility of grants that states could apply for to address these resource needs. States also face the challenge of making it easy for consumers and providers to report suspected parity violations online and conducting public education about how consumers and providers can report violations. Meaningful enforcement of parity laws requires regular market conduct exams for parity compliance, including nonquantitative treatment limitations (NQTLs) such as prior authorization, reimbursement rates, and denials based on medical necessity, utilizing best practice tools recently available to states (e.g., through the National Association of Insurance Commissioners). We believe that any grants from CMS or other federal agencies to address these resources should require states to data on outcomes for evaluation and return on investment to be determined. Additionally, we urge the Committee to solicit a GAO review of mental health parity laws and enforcement mechanisms at the state level and make recommendations on how enforcement can be improved to ensure mental health parity and improve access.

Expanding Telehealth

For people living with MS, a rare silver lining to the COVID-19 pandemic has been improved access to telehealth and tele-mental health services because of the decisive action taken by Congress and CMS to expand access to telehealth. The Society believes expanded access to these services are a core component to achieving health equity and has allowed those with MS located in underserved communities or areas where there is a provider shortage to access critically needed, evidence-based services. We urge the Committee to permanently allow this expanded access to telehealth and tele-mental health services.

Despite these benefits, people living with MS who are Medicare and Medicaid beneficiaries have concerns that their access to telehealth will be curtailed when flexibilities in telehealth are lifted with the current public health emergency. Many on commercial plans are already seeing a reduction in telehealth flexibilities, and those on Medicare are concerned that they too will lose access to their mental health providers. The Society urges the Senate Finance Committee to make federal telehealth coverage flexibilities permanent and include coverage for audio-only services – an important step towards equity for rural communities without reliable access to broadband, as well as those with disabilities or low technological literacy for whom videoconferencing isn’t accessible. Additionally, we encourage the Committee to remove unnecessary barriers such as the requirement that Medicare beneficiaries receiving mental health care via telehealth have at least one in-person visit every 6 months, and to incorporate telehealth for mental health services as a core part of care for beneficiaries. The bills listed below touch on many parts of our recommendations and we urge the Committee to utilize them as a framework to guide their discussions in this area:

- The Telehealth Modernization Act (S. 368), to build upon the expanded telehealth access allowed in the current public health emergency and expand what kind of healthcare providers and facilities provide telehealth services;
- Protecting Access to Post-COVID-19 Telehealth Act (H.R. 366), to require a study on the use of telehealth during the pandemic to inform future telehealth policies, including cost, uptake rates, health outcomes and racial and geographic disparities;
- The CONNECT for Health Act (S. 1512), to permanently remove various restrictions (including unnecessary originating site restrictions, which keep

people from being able to access telehealth in their homes) on Medicare coverage of telehealth services;

- The Telemental Health Care Access Act (S. 2061), to remove the requirement that Medicare beneficiaries receiving telemental health services have at least one in-person visit every 6 months;
- The Telehealth Coverage and Payment Parity Act (H.R. 4480), to require private insurance plans to cover telemental health services on equal terms and reimburse at equal rates as in-person services;
- The Permanency for Audio-Only Telehealth Act (H.R. 3447), to continue to allow Medicare to cover mental and behavioral health services furnished via audio-only telehealth.

Thank you for the opportunity to respond to the request for information. If you or your staff have any questions, please contact Leslie Ritter, Associate Vice President of Federal Government Relations at Leslie.Ritter@nmss.org.

Sincerely,

Bari Talente

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