

# Recommendations on Social Determinants of Health in Neurologic Disease

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*Neurology*® 2023;101:S17-S26. doi:10.1212/WNL.000000000207562

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## Abstract

Social determinants of health (SDOH) are increasingly recognized as important drivers of inequities in neurologic disease and outcomes. However, our understanding of the biopsychosocial mechanisms by which SDOH affect neurologic disease remains in its infancy. The most robust epidemiologic research has been on the associations between education, schooling, and place-based social determinants on cognition, dementia, and cerebrovascular disease later in life. Further research is needed to more deeply understand the complex interplay of SDOH on neurologic disease. Few SDOH screening tools have been validated in populations with neurologic disease. In addition, comparison across studies and populations is hampered by lack of standardized common data elements. Experiences of populations historically underrepresented in research should be centered in future research studies, and changes should be made in recruitment expectations and measurement choices. For research on inequities, it is critical to support and incentivize institutional infrastructure to foster meaningful engagement with populations affected by research. Finally, it remains to be seen whether individual-level health or behavioral interventions or place-level, systemic or policy interventions to reduce population burden will be most effective in reducing inequities in neurologic disease and outcomes. Although numerous clinical trials have focused on addressing downstream SDOH such as health literacy and health behaviors (e.g., medication adherence, physical activity, diet), few have addressed upstream, structural determinants which may have a more profound impact on addressing inequities in neurologic disease. Ultimately, further research is needed to determine which specific SDOH should be targeted and how, when, and by whom they should be addressed to improve neurologic outcomes.

## Introduction

It is increasingly recognized that social determinants of health (SDOH)—conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life—are principal drivers of inequities in health.<sup>1</sup> SDOH are fueled by fundamental, or structural, determinants of health: the social, economic, and political mechanisms that stratify people according to factors such as race/ethnicity, sex, income, education, and occupation.<sup>2</sup> These structural determinants operate through intermediate determinants (e.g., health care access, physical environment, community infrastructure, and sociocultural environment) and proximate factors (e.g., health-related behavior and knowledge, psychosocial factors) to shape health outcomes.<sup>2</sup>

There is mounting evidence that SDOH affect the incidence of neurologic disease and outcomes. For example, adverse individual SDOH, neighborhood socioeconomic status (SES), and living in

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Go to [Neurology.org/N](https://www.neurology.org/N) for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

The Article Processing Charge was funded by NIH/National Institute of Neurological Disorders and Stroke.

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## Glossary

ACE = adverse childhood experiences; NINDS = National Institute of Neurologic Diseases and Stroke; SDOH = social determinants of health; SES = socioeconomic status.

a state with poor public infrastructure are associated with stroke incidence.<sup>3,4</sup> Neighborhood measured and individually perceived disadvantage are associated with poorer cognitive function in middle-aged and older adults.<sup>5</sup>

Although SDOH screening has become more widespread in health care settings, little is known regarding optimal tools and timing for screening for SDOH in populations with neurologic disease. In addition, little is known about the complex biosocial mechanisms behind SDOHs' impact on neurologic disease. Despite known associations between SDOH and neurologic disease across the lifespan, it is unclear whether there are specific factors that are low hanging fruit for intervention. Elucidating the interactions between specific SDOH and neurologic disease and ascertaining whether addressing each SDOH alters the trajectory of outcomes will be key stepping stones to addressing inequities. Finally, data are lacking regarding optimal interventions and timing for addressing SDOH to affect neurologic risk and outcomes. Addressing these gaps in our understanding will be crucial for eliminating inequities in neurologic risk, care, and outcomes.

## Methods

The SDOH subgroup of the National Advisory Neurological Disorders and Stroke (NANDS) Council Working Group for Health Disparities and Inequities in Neurological Disorders performed a literature review related to the impact of SDOH on neurologic disease and interventions designed to either prevent the risk of neurologic disease or alter outcomes of neurologic disease; identified key research gaps; and developed priorities for subsequent research. These priorities were presented at the NINDS Health Disparities and Inequities in Neurological Disorders (HEADWAY) Workshop in September 2021, which assembled experts from various disciplines (e.g., epidemiology, clinical and health services researchers; implementation and behavioral scientists; community stakeholders, and patient advocates). The workshop recommendations were subsequently refined by the authors. The article is structured as follows: The first section describes key considerations regarding screening for SDOH; the second section delves into the body of literature exploring the associations of several key structural, intermediate, and proximate SDOH on neurologic disease; the third section provides a brief overview of types of interventions to address SDOH; and the final section describes the final set of recommendations.

### SDOH Screening

Adverse SDOH can be divided into *social risks* and *social needs*. Social risks are the “specific adverse social conditions associated

with poor health” measured at the individual level, whereas social needs are determined by individual preferences and priorities. For example, a social risk would be a positive screen for food insecurity, whereas a social need would be a request for food assistance. An individual can have multiple social risks and fewer social needs or vice versa. Assessments of social risk may be most important for epidemiology, risk adjustment for payment models, or the design and deployment of programs or policies to address social risks, whereas social needs may be most important for caring for individual patients. Identifying and addressing adverse SDOH may lead to positive outcomes; however, screening without the resources to respond can have potential negative consequences and ethical implications.

Unmet social needs are rarely identified without a structured screening mechanism. The NIH-funded PhenX (consensus measures for Phenotypes and eXposures) collates high-priority, well-established, broadly applicable measures to promote research collaboration and cross-study analysis. Although the PhenX toolkit includes SDOH, gaps in social needs assessment tools remain. Most SDOH screening tools have not been validated in neurologic populations.

There are numerous barriers to screening, the most significant of which are lack of resources and referral processes when social needs are uncovered. In fact, some argue that it is unethical to screen for SDOH without a clear plan of action for managing unmet social needs because this may create harm for the patient. Unlike screening for medical conditions, which can be addressed with medical interventions, addressing SDOH often relies on entities outside the medical system or changes to local, state, or federal policies or funding. Furthermore, availability and consistency of community safety net resources vary greatly by community; maintaining up-to-date partnerships and knowledge of community resources requires effort and funding. An alternate approach is to universally distribute up-to-date community resource information to providers.

Screening for SDOH has gained considerable uptake in the pediatric setting; family context and financial stability are commonly explored arenas. There are few incentives for US insurers to screen for and address SDOH, particularly for those among the highest risk: children on Medicaid. Most Medicaid insurers allow clients to switch insurers monthly; therefore, insurers have little incentive to screen for and minimize SDOH that may affect long-term outcomes. To complicate matters, children with the highest burden of SDOH are more likely to live in more than 1 household and/or be cared for by multiple caregivers; the SDOH for that child may need to be addressed in multiple settings.

Determining who is financially responsible for addressing SDOH identified by screening is a major barrier to widespread screening.

## Impact of Key Social Determinants of Health on Neurologic Conditions

### Place-Level Determinants

Place can be conceptualized at several geographic levels (e.g., country, state, county, city, neighborhood), each of which may influence neurologic diseases through different mechanisms and may be amenable to different types of interventions. Place of residence can influence neurologic risk and quality of life among people living with neurologic disease through exposure to toxins, social norms, infectious exposures, resources that affect feasibility of healthy behaviors, socioeconomic resources, chronic stressors, sources of resilience, and medical resources. These mechanisms reinforce one another and are variously relevant for primary, secondary, or tertiary prevention. Different mechanisms operate more powerfully at different geographic levels; for example, social norms around smoking behaviors may operate at state or larger geographic levels, while conditions regulated by city policies may operate at more local levels, and social resources such as churches or grocery stores vary at a neighborhood level. Because of these multiple mechanisms, place-level inequities can be seen as a window into the importance of modifiable social factors. Many place-level risk and resilience factors are highly modifiable. Place-level risk factors can be shaped by policies set at state, county, or local levels and by systems that are highly represented in a particular geography.

Major geographic differences in neurologic disease risk indicate modifiable, socially patterned risk factors. These are well-documented for stroke and dementia but less so for other neurologic diseases. Major research priorities involve identifying the mechanisms accounting for these geographic differences and evaluating effective strategies at structural, systems, and individual levels to reduce inequities.

Place-level patterns in stroke exemplify the importance of geographic inequalities in neurologic disease. People who lived as children in a large region in the southeastern United States, dubbed the “Stroke Buckle,” embedded within the larger “Stroke Belt” have markedly elevated stroke rates throughout life.<sup>6</sup> The disparity can be observed in incidence, prevalence, and mortality outcomes but is primarily driven by incidence. Differences in stroke seem mirrored by inequity in dementia; birth or residence in the Stroke Belt increases dementia risk, likely driven by vascular dementia.<sup>7</sup> Individual-level SES predicts stroke and is geographically patterned, but mediation analyses indicate these differences—at least using conventional SES measures—are insufficient to explain the Stroke Belt. A plausible explanation is that more comprehensive SES measures, such as educational quality, economic instability, financial worry, or life course trajectories of SES, account for regional differences in stroke. Another explanation relates to the immediate and indirect

consequences of historical racism including slavery. Racially motivated divestment from community resources such as schools, health care, or social safety net systems may harm both Black and White residents.<sup>8</sup> In addition, Stroke Belt residence, especially in early life, may set in place health-harming behavioral patterns (e.g., limited physical activity). Social network influences may also be relevant: one’s spouse, closest friends, and relatives are often drawn from the same area of one’s lives in childhood. These processes may reinforce one another.

Some of the most compelling evidence on the importance of place arises from natural experiments in which large groups of people are displaced. In the wake of the 2011 Great East Japan Earthquake and Tsunami, many older adults were relocated. Older adults relocated with their social network in place had higher levels of subsequent social interactions and lower subsequent dementia rates than their counterparts relocated with strangers.<sup>9</sup>

Inequities in neurologic disease risk also prevail at smaller geographic levels. A key insight in the research on segregation and health is that residential segregation facilitates divestment from countless shared resources such as parks, sidewalks, high-quality schools, fire stations, grocery stores, medical resources, pharmacies, clean air, libraries, public transit, banks, and desirable employment opportunities. If disadvantaged individuals live in communities with almost no residents who are socially positioned to effectively lobby for community resources, such resources are at greater risk of being defunded or eliminated. Most US cities are markedly segregated along racial and socioeconomic lines. Much of contemporary segregation reflects historical practices such as redlining, discrimination that had a reinforcing effect over the years. Empirical evidence on neighborhood segregation and stroke or dementia outcomes has been mixed, with evidence showing some groups harmed and some helped.<sup>10,11</sup> This may partially reflect that racially integrated neighborhoods expose Black residents to higher likelihood of interpersonal racism. Overall, racial segregation has been linked to multiple mechanisms linked to stroke or dementia risk.<sup>12</sup>

Numerous other characteristics of neighborhoods, including the social, retail, and built environments, are also associated with incidence and outcomes related to stroke and cognition.<sup>13</sup> A major challenge has been identifying specific causal mechanisms. This difficulty may reflect the clustering of risk factors—for example, if places with poor resources to support physical activity also have higher exposure to air pollution and worse transit options to ensure access to high-quality medical care, it is difficult to disentangle this cluster of adversity. Another challenge is identifying emergent positive aspects of neighborhoods with dense networks of community members from historically excluded groups providing community identity, shared resources, and support to one another. These positive aspects—including shielding individuals from interpersonal racism and supporting positive social norms—may offset from negative consequences of systematic denial of metropolitan resources or targeting of the community for “negative amenities” such as sources of pollution.

Major research priorities involve identifying the mechanisms accounting for these geographic differences and evaluating effective strategies at structural, systems, and individual levels to reduce inequities. Place may be key to understanding the limited effects achieved by many individual-level interventions because such interventions cannot overcome the multiple constraints and patterns imposed by place. Thus, for interventions to have large effects on inequities, they must address patterns beyond the individual, considering the places where people live, work, and recreate to evaluate how those places shape risk.

### Poverty and Economic Instability

Despite overall declines in US poverty rates, Black and Latinx people remain overrepresented among those living in poverty.<sup>14</sup> Poverty is a risk factor for the development of neurologic disease.<sup>15</sup> Children who grow up poor have increased risk for cognitive defects compared with their peers.<sup>16</sup> In adults, as poverty increases, so too does the risk for stroke,<sup>3</sup> cognitive deficits, and dementia.<sup>17</sup>

Socioeconomic status (SES) has an impact on health outcomes beyond income alone because SES encompasses an array of resources, such as money, knowledge, prestige, power, and beneficial social connections that protect health no matter what mechanisms are relevant at any given time.<sup>18</sup> The longstanding racial disparities in wealth in the United States are even larger than the corresponding disparities in income.<sup>19,20</sup> A recent study showed that wealth was more important than income in explaining Black-White disparities in cognition at older ages.<sup>20</sup>

Screening for poverty may occur at both the individual and community levels. Considering individual-level poverty, such as income or employment alone, without the broader family or community context may be myopic—the efforts of those that traditionally work inside of the home (women, students, differently abled, etc) may not be reflected in “household income,” and household income may not reflect how power is distributed among family members. Therefore, it is fruitful to consider many variables when exploring how poverty affects health in general and neurologic disease in particular. Future priorities include evaluating the impact of poverty and neighborhood disadvantage on neurologic disease and assessing the impact of policies and interventions addressing poverty on neurologic disease and outcomes.

### Schooling and Education

Pathways that link education and risk of neurologic disease and recovery from neurologic illness are complex and vary dramatically across subgroups. As a result, comprehensive measurement of educational experience for research on later life neurologic health and cognition should take into account formal and informal schooling, instructional time and content, possible critical periods, value of educational credential, and schools and schooling as individual, peer, family, and community-level resources. To inform interventions and policy, study design and analytic approaches should take into account the historical and

place-based context of schooling opportunities and structural racism and should distinguish influences of education from confounding by childhood socioeconomic conditions, early life cognitive abilities, and childhood health. Rigorous study designs should also consider the multiple, downstream mechanisms through which educational attainment or credential influence more proximal determinants of health, such as income and occupational complexity. Studies must be inclusively designed and adequately powered to determine whether neurologic “returns on education” are equivalent across socioeconomic status, sex, immigration status, racial and ethnic groupings, geographic region, or intersections of multiple sources of marginalization, oppression, and power.

A growing body of literature has documented the ways that education has been operationalized<sup>21</sup> and challenged the validity of “years of education” as an equivalent measure of educational experience across population subgroups and over time.<sup>22</sup> Historically informed measurement of education recognizes that because all aspects of schooling are affected by structural racism and economic inequality, educational attainment reflects dramatically different experiences across groups. Schooling should provide opportunities and competencies to students, and this requires investment in well-trained and supported faculty, safe facilities, and other resources. Because researchers rarely have access to direct, personalized assessment of these resources, school quality is usually measured using proxy variables. For research on aging and cognition, these proxies have included reading level in adulthood,<sup>23</sup> school segregation,<sup>24</sup> and historical administrative data at the state, county, or school level<sup>25</sup> and show that increased investment in schools is associated with better later life cognitive health. Major limitations and sources of error within many of these proxies is that they do not reflect that coursework, resources, and instructional methods are often grouped or segregated within schools using curricular tracking, and data linking requires retrospective reporting of early childhood school name and location.

Most previous research linking education with neurologic disease focuses on the association of more schooling with higher cognitive level,<sup>26</sup> less cognitive decline,<sup>27</sup> and lower dementia risk<sup>21,27</sup> among older adults. Studies that include in vivo or autopsy measures of brain structure or neuropathologic burden indicate that education is an activity that increases cognitive reserve or resilience against Alzheimer and cerebrovascular disease,<sup>28</sup> and the cognitive reserve hypothesis has also been examined in multiple sclerosis,<sup>29</sup> traumatic brain injury,<sup>30</sup> and HIV-associated neurocognitive function.<sup>31</sup>

Future research priorities include supporting representative samples with geographic reach to include variation in educational experiences; powering studies so it is possible to test heterogeneity of education effects across population subgroups; evaluating the external validity of effect sizes for social exposures; measuring and evaluating impacts of educational experience beyond years attained or credentials, to include



peer effects, quality of teacher preparation, classroom size, school quality, life course timing of educational experiences, and education of spouses and other network members; evaluating the links between education and biomarkers of neurologic disease; evaluating pathways of educational disparities in neurologic disease; fielding rigorous evaluations of investments in schools serving Black, Latinx, and indigenous children to determine whether they narrow disparities in neurologic disease; and evaluating long-term impacts of schooling, informal learning, and cognitively engaging activities on cumulative neurologic disease risk.

### **Food Insecurity**

More than 10% of Americans are believed to be food insecure, and there are racial disparities—Black and Latinx households are more likely to be food insecure compared with the national average.<sup>32</sup> The relationship between food insecurity and chronic disease is cyclical—unreliable access to healthy, nutritious food, leading to greater challenges managing chronic diseases.<sup>33</sup> Studies have found associations between food insecurity and migraine headaches,<sup>34</sup> cognitive impairment,<sup>35</sup> and stroke.<sup>36</sup> Further research is needed to understand the association between food insecurity and neurologic disease and the extent to which addressing food insecurity alters neurologic outcomes.

### **Housing**

Housing is perhaps one of the most well researched SDOH.<sup>37</sup> Indicators of housing stability, such as homelessness and housing insecurity, are associated with poor physical and mental health outcomes.<sup>38</sup> Surprisingly, there is little research on the impact of housing insecurity on neurologic conditions. A recent study of veterans revealed that the prevalence of Alzheimer disease and related dementias was higher among housing insecure veterans than those who were stably housed.<sup>39</sup> Epidemiologic studies have shown that those who are homeless experience higher rates of cardiovascular events, including stroke, compared with the general population.<sup>40,41</sup> Despite the plethora of research on the association between housing and health in general, more research is needed to explore the relationship between housing and neurologic conditions and whether interventions aimed at addressing housing affect neurologic health.

### **Health Care**

Access to health care is the timely use of personal health services to achieve the best health outcomes and includes 4 components: coverage, service (i.e., having a usual source of care), timeliness, and workforce. Barriers to access include lack of health insurance or adequate coverage, linguistic barriers, disability, inability to travel or take time off work, and provider shortages. While the Affordable Care Act increased insurance among Americans, approximately 3 million potentially eligible people live in states that opted out of Medicaid expansion, perpetuating health disparities.<sup>1</sup> Working-age Native Americans and Alaska Natives, Native Hawaiians and Other Pacific Islanders, Black, and Hispanic people are more likely to be uninsured than White people.<sup>42</sup> Coverage also

includes out-of-pocket costs, which have risen considerably for neurologic medications, particularly for multiple sclerosis.<sup>43</sup> Higher out-of-pocket costs are associated with lower medication adherence among neuropathy, dementia, and patients with Parkinson disease.<sup>44</sup> Black, Hispanic, poor, uninsured, and low-educated Americans are less likely to have a neurologic visit than their counterparts.<sup>45</sup>

Tele-neurology overcomes some barriers to access, namely distance to provider, patient impaired mobility, cognitive function and driving ability, transportation, and time off from work. Acute telestroke has been at the forefront of tele-neurology,<sup>46</sup> providing timely acute stroke care and thrombolysis to hospitals with limited access to stroke specialists, and has been particularly important in delivering acute stroke care to rural areas. Telemedicine has expanded outside of stroke to include other neurologic conditions and accelerated during the COVID-19 pandemic.<sup>47</sup> However, this expansion has revealed a digital divide. Older adults, those with low socioeconomic status and minority race/ethnic populations, have lower digital access and use of telemedicine than their counterparts.<sup>48-50</sup> For the promise of tele-neurology to meet its potential, equality in digital access and digital literacy must be addressed.

Comprehensive health care includes access to a workforce and services that are responsive to the cultural beliefs and language of the population being served. Language barriers in health care are associated with decreased access to care, reduced follow-up, and decreased patient satisfaction.<sup>51</sup> Overall, patients report more satisfaction and rated their physicians as more participatory when receiving care from a provider of the same race<sup>52</sup>; whether this extends to neurologic patients is unknown. Cultural concordance is also important; individuals are more likely to hear and personalize messages and change attitudes and behaviors, if they believe the messenger faces similar concerns and pressures. Several randomized controlled trials to address inequities in stroke have used racially, ethnically, culturally, and linguistically concordant care team members and used culturally tailored materials, with variable results.<sup>53</sup>

Future research priorities include identifying neurologic disease-specific drivers of health care access, understanding how these affect outcomes among neurologic patients, and developing and testing interventions to enhance access to care for medically underserved populations.

### **Health Literacy**

Limited health literacy is more common among older populations, racially/ethnically minoritized groups, people living in poverty, and persons with lower education.<sup>54</sup> A survey of neurology clinic patients found that 20% had low health literacy.<sup>55</sup> Low health literacy is associated with lower medication adherence and higher emergency services utilization and health care costs.<sup>55,56</sup>

While the association between health literacy and health outcomes is well-established, whether health literacy is an independent determinant of health or a mediating or moderating

variable is less well understood. Evidence from 8 European countries suggests that health literacy is an independent, direct determinant of self-reported health.<sup>57</sup> Numerous stroke literacy interventions have aimed to improve stroke preparedness in the community.<sup>53</sup> In addition, multicomponent secondary prevention interventions have addressed stroke literacy and self-management skills among individuals with previous strokes, with mixed results.<sup>53,58</sup>

### Psychosocial

There is compelling evidence that early traumatic experiences affect health, behavior, and quality of life across the lifespan. The seminal adverse childhood experiences (ACE) study found a dose-response relationship between exposure to abuse and household dysfunction in childhood and adult morbidity and mortality.<sup>59</sup> Children with increased ACEs had worse overall adult health, were more likely to have executive functioning deficits, and had increased likelihood of stroke.<sup>60</sup> The proposed mechanism for ACEs' impact on health is a complex interplay between stress and allostatic load on the body.<sup>61</sup> When stress exceeds "typical" limits and becomes toxic stress, physiologic adaptations (or allostasis) occur as a part of a hormonal cascade, including increasing heart rate and blood pressure.<sup>62</sup> Over time, a high allostatic load and prolonged toxic stress can contribute to multisystem organ damage, including in the nervous system.<sup>62</sup> Another proposed mechanism is "weathering", whereby traumatic experiences hasten the aging process and contribute to health disparities by accelerating disease development at earlier ages in certain populations.<sup>63</sup> The conventional ACEs were collected from a homogenous, largely White and middle-income or upper-income population. The expanded ACEs includes community-level and society-level factors that affect health, including exposure to violence and discrimination, living in unsafe neighborhoods, experiencing bullying, and living in foster care.<sup>64</sup>

The effect of exposure to trauma on neurologic disease remains unclear. There are suggestive associations that people who survive trauma, especially if they develop post-traumatic stress disorder, are at elevated risk of stroke.<sup>65</sup> The causal direction remains uncertain, and research has been hampered by insufficient prospective data with long follow-up. Relatedly, it is important to understand whether treatment of post-traumatic stress disorder alleviates risk of neurologic disease.

Social support and integration may influence neurologic disease incidence and are likely especially relevant to prognosis, quality of life, and long-term outcomes. Various dimensions of social integration are linked to incidence of stroke and dementia and prognosis after stroke, and social ties shape access to timely care.<sup>66,67</sup> Social ties likely influence depression, offset stress, affect physiology, improve access to resources, establish autonomy, and enable achievement of goals in the wake of disabling events such as stroke.

Depression is a major determinant of quality of life and survival among people living with neurologic disease. Up to 50% of individuals with multiple sclerosis, a third of stroke survivors,

and a third of neurology outpatients experience depression or elevated depressive symptoms.<sup>68-70</sup> Depression may be due to cognitive assessments of limitations attributable to disease or to biological processes directly linked to disease etiology.<sup>69,71</sup> Optimal tools for diagnosing and managing depression among individuals with neurologic disease are needed.

Stress, discrimination, and stigma related to minority status—including interpersonal and structural racism—are potentially important causes of neurologic disease and likely mechanisms for other exposures discussed in this report.

Future research priorities include supporting training of researchers with expertise in psychosocial risk factors and quantitative and qualitative methods to understand psychosocial drivers of health inequities; evaluating causation of psychosocial risk factors for incidence of neurologic diseases by identifying quasiexperiments, leveraging longitudinal data, or triangulation of methods; establishing whether modifying psychosocial risk factors and social connectedness reduces neurologic risk or improves outcomes; incorporating measures of trauma, life course exposure to racism, and discrimination into major cohorts to determine how they affect neurologic disease; and conducting pragmatic, adaptive randomized controlled trials to identify optimal treatment paradigms for depression among individuals living with neurologic disease.

## Types of Interventions to Address SDOH

*Social needs–informed care* involves modifications to traditional medical care to account for patients' social circumstances (e.g., transportation, after hours clinics, interpreter services). More innovative approaches include using point-of-care testing to avoid follow-up visits and teleneurology. *Social needs–informed care* does not address the underlying social risks that adversely affect patients' health. *Social needs–targeted care* addresses patients' social needs directly (e.g., linking patients with transportation, food, income assistance, or housing support). While these approaches may improve patients' health, they have little impact on population health.

To enhance population health, policy changes at federal and state levels, partnerships between health care systems and other sectors and services, and community-based approaches may be necessary. At the state and federal level, policies that fundamentally influence the structural social and economic conditions shaping health for individuals within those communities may have a profound impact. For example, qualitative and meta-analytical data suggest that education is related to better cognitive health throughout the life course and may reduce disparities.<sup>72-75</sup>

At the health care system level, health care organizations can collaborate with other services and sectors (e.g., local governments, housing agencies, schools, food banks, and community-based organizations). Community-based approaches include using health care systems' financial resources to improve

community conditions indirectly through grants to community-based organizations or direct investments (e.g., Kaiser Permanente’s \$200 million commitment to address housing and homelessness). Alternatively, hospitals can facilitate or catalyze “accountable communities for health.” As is the case with social risk–informed and social risk–targeted care, little rigorously collected evidence illustrates whether and how community-level engagement strategies contribute to improvements in health in general and neurologic disease in particular.

Most neurologic research addressing SDOH have focused on downstream factors such as health literacy and health behaviors,<sup>53,58</sup> but few have robustly addressed upstream, more fundamental determinants such as housing, neighborhood environment, food security, or employment. Further research is needed to determine which specific SDOH should be targeted and how, when, and by whom they should be addressed to improve neurologic outcomes.

## Future Research Priorities

The priorities are categorized into 3 groups: screening, epidemiology, and interventions (Table 1). Future research priorities relevant to screening include validating SDOH screening tools in neurologic populations, expanding the PhenX toolkit, encouraging collection of SDOH using accepted standardized common data elements, determining how and when to screen

for social risks and needs among neurologic populations, and ensuring that social needs are addressed when identified.

With regard to epidemiologic priorities, key priorities include training a workforce with skills and competencies to lead rigorous research on the multilevel drivers of inequities; evaluating the effects of SDOH on neurologic disease, using representative samples with oversampling of racial/ethnic minorities, powering studies to test heterogeneity of effects across subpopulations, using adaptive recruitment designs, and incorporating known information about differential mortality and loss to follow-up among previously excluded populations; and evaluating external validity of effect estimates for exposures previously derived in specialized or convenience samples.

For intervention research, key gaps include determining optimal interventions on the individual-level vs place-level, systemic, or policy interventions to address population burden and inequities in neurologic disease; creating and evaluating neighborhood resources; developing and testing multilevel, multidisciplinary interventions; and supporting infrastructure for community engaged research. Thought should be given to which effects to measure and how to determine causality in interventions addressing SDOH, where the effects may be seen years after an intervention or policy change and may be confounded by numerous factors. Given the complexity of multilevel, multidisciplinary interventions performed in health care and community

**Table 1** Future Research Priorities

Topic	Future research priorities
<b>SDOH screening</b>	<ul style="list-style-type: none"> <li>• Expand the PhenX toolkit to include more diverse social needs</li> <li>• Encourage collection of SDOH using accepted standardized common data elements</li> <li>• Validate SDOH screening tools in neurologic populations</li> <li>• Determine how and when to screen for social risks and social needs among neurologic populations</li> <li>• Ensure that research funding includes dollars allocated for provision of resources for health-related social needs identified.</li> </ul>
<b>Epidemiologic research</b>	<ul style="list-style-type: none"> <li>• Train a workforce with the skills and competencies to lead rigorous quantitative and qualitative research on the multilevel (e.g., spatial, structural, policy, community, family, and individual) drivers of health inequities.</li> <li>• Evaluate the effects of SDOH - including ACEs, access to and quality of care, health literacy, English proficiency, variation in educational experiences, poverty, food insecurity, housing, health care access, place-level determinants, psychosocial factors, and life course exposures to racism and discrimination - on neurologic disease. <ul style="list-style-type: none"> <li>◦ Use representative samples, with substantial oversampling of racial/ethnic minorities</li> <li>◦ Power studies to test heterogeneity of effects across population subgroups</li> <li>◦ Use adaptive recruitment designs powered to support evaluation of effects among minority groups and evaluation of drivers of inequality</li> <li>◦ Incorporate known information about differential mortality and loss to follow-up among traditionally excluded populations</li> </ul> </li> <li>• Evaluate external validity of effect estimates for clinical, behavioral, and social exposures, previously derived in specialized or convenience samples to representative populations or specialized high-need populations, recognizing the potential influence of modifiers such as education or other social resources.</li> </ul>
<b>Intervention research</b>	<ul style="list-style-type: none"> <li>• Evaluate the potential impact of individual-level health or behavioral interventions vs place-level, systemic, or policy-level interventions to reduce population burden and inequities in neurologic diseases.</li> <li>• Create and evaluate neighborhood resources that provide financial, psychosocial, and medical support, and have low individual administrative burden, to people living with neurologic disease and their caregivers to improve quality of life.</li> <li>• Develop targeted, multilevel, multidisciplinary intervention strategies to reduce social inequities in neurologic diseases and test them using novel approaches, such as pragmatic, adaptive, and effectiveness-implementation hybrid designs. Strategies would consider the following: <ul style="list-style-type: none"> <li>◦ Structural factors (e.g., food insecurity, housing, pollution, neighborhood safety, and cohesion)</li> <li>◦ Psychosocial risk factors and sources of resilience</li> <li>◦ Health behaviors and knowledge</li> <li>◦ Policies that shape health relevant behaviors (e.g., regulation of salt supplements, food taxes)</li> <li>◦ Health care access/quality factors and policies</li> </ul> </li> <li>• Support and incentivize institutional infrastructure to foster meaningful engagement with populations affected by research to ensure the perspectives, priorities, and insights of individuals most directly affected by the research are represented and incorporated into study design.</li> </ul>

## TAKE-HOME POINTS

- Elucidating the interactions between specific SDOH and neurologic disease and ascertaining whether addressing each SDOH alters the trajectory of outcomes will be key stepping stones to addressing inequities.
- Future research priorities relevant to screening include validating SDOH screening tools in neurologic populations; encouraging collection of SDOH using common data elements; determining how and when to screen for social risks and needs; and ensuring social needs are addressed when identified.
- Key epidemiologic priorities include training a workforce with skills and competencies to lead rigorous research on the multilevel drivers of inequities; evaluating effects of SDOH on neurologic disease, using representative samples with oversampling of racial/ethnic minorities; powering studies to test heterogeneity of effects across subpopulations; using adaptive recruitment designs; incorporating known information about differential mortality and loss to follow-up among previously excluded populations; and evaluating external validity of effect estimates for exposures previously derived in specialized or convenience samples.
- For intervention research, key priorities include determining optimal interventions on the individual-level vs place-level, systemic, or policy interventions to address population burden and inequities; creating and evaluating neighborhood resources; developing and testing multilevel, multidisciplinary interventions; and supporting infrastructure for community engaged research.

settings, the traditional randomized controlled trial, suitable for drug efficacy studies, should likely be de-emphasized in favor of designs that take into account real-world situations and variability (e.g., pragmatic, adaptive, and effectiveness-implementation hybrid designs).

### Acknowledgment

The authors would like to sincerely thank Dr. Erica L. Littlejohn for her valuable contributions.

### Study Funding

The authors report no targeted funding.

### Disclosure

The authors report no relevant disclosures. Go to [Neurology.org/N](https://www.neurology.org/N) for full disclosures.

## Publication History

Received by *Neurology* August 5, 2022. Accepted in final form May 9, 2023. Submitted and externally peer reviewed. The handling editor was Editor-in-Chief José Merino, MD, MPhil, FAAN.

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*Neurology* 2023;101;S17-S26

DOI 10.1212/WNL.0000000000207562

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