



DRRC Response - Social Determinants of Health Caucus – Request for Information

[Social Determinants of Health Caucus Website](#) (RFI Information/Questions Below)

Experience with SDOH Challenges

What specific SDOH challenges have you seen to have the most impact on health? What areas have changed most during the COVID-19 pandemic?

Social determinants of health (SDOH) encompass multiple levels of experience in daily life from social risk factors to structural and environmental factors (such as structural racism and poverty). People with disabilities face substantial challenges relating to each of these elements.

Congress has already recognized people with disabilities as a distinct minority group, subject to pervasive social stigma and institutional discrimination, and has passed significant civil rights law (e.g., the Americans with Disabilities Act, the Rehabilitation Act, and the Individuals with Disabilities Education Act) to protect this population. It should also help protect the health of people with disabilities by recognizing and addressing the disadvantages they encounter in terms of social determinants of health (i.e., socioeconomic status, employment, schooling, stable, affordable, and supportive housing, food security and access to quality nutrition, access to transportation, social support, and community resources). It is critical to recognize that while the SDOH relevant to people with disabilities and the broader population may cover the same categories, disability status often acts as a compounding factor, making an individual with a disability more likely to encounter additional discrimination and stigma because of their status as well as leading to more adverse health outcomes and comorbid conditions.

Pre-pandemic survey data (available in a report here: <https://bit.ly/3EiCwP7>) demonstrates that adults with disabilities, compared to those without disabilities, were much less likely to be employed, less likely to graduate from high school, more likely to live in poverty, and much more likely to be in fair or poor health. They also use health care more than their nondisabled counterparts and are much more likely to report difficulties in obtaining and paying for their health care. Clearly, disability status acts in much the same way as other social determinants and can have a compounding effect on the well-understood impact of more traditional, non-medical factors like stable housing, reliable transportation, and access to healthy foods. It is critical that disability be understood in this dual manner (as both a health outcome and a social determinant) and that people with disabilities be recognized as a population facing specific disparities in the Caucus' work and in all SDOH discussions.

In addition to the general consideration of disability as a social determinant, there are a number of issues that have had a disparate impact on people with disabilities, illnesses, injuries, and chronic conditions prior to and during the pandemic. For example:

- *People who lived in nursing homes during the pandemic, most of whom have significant disabilities, were far more likely to die from COVID. This was largely due to policy and economic decisions leading to inadequate staffing levels and poor management of long-term care institutions; outcomes that could have been avoided with prior investment in safer institutions and more extensive home- and community-based services.*
Additionally:
- *Lack of appropriate access to care for patients, including but not limited to rural areas, especially inpatient rehabilitation hospitals (IRFs) and other post-acute care (PAC) settings. When the appropriate PAC settings are not available, patients may be forced to utilize other, less appropriate PAC settings for their level of medical need or end up needing costly acute care due to worsening conditions or resultant secondary comorbidities.*
- *Lack of access to basic needs such as clean water, sanitation, and clean air, especially for underserved communities. The health impacts of these deficiencies are clear, and particularly impact individuals with disabilities, who often live in under-resourced areas.*
- *Health literacy issues, which are often more prevalent in underserved communities. Decreased health literacy, particularly with regards to COVID-19-related misinformation, leads to decreased health outcomes and can compound the effect of other social determinants.*

What types of gaps in care, programs, and services serve as a main barrier in addressing SDOH in the communities you serve? What approaches have your organization, community, Tribal organization, or state taken to address such challenges?

The federal government has a variety of programs that thus far inadequately and incompletely seek to address some of these SDOH – these programs need to be strengthened. A few existing programs particularly important to people with disabilities are cited here.

Medicaid Home- and Community-Based Services (HCBS): The Medicaid HCBS program is a fundamental federal-state support for people with disabilities. Consistent with the Americans with Disabilities Act (ADA) and the Supreme Court’s Olmstead decision, these programs prioritize “community integration” by focusing on “community inclusion,” “choice,” and “self-direction.” As stated in pending legislation (S. 3277, the HCBS Infrastructure Improvement Act), “HCBS play an outsized role in addressing the social determinants of health among older adults and people with disabilities, who require accessible housing, transportation, and access to reliable personal care to avert costly medical crises.” However, as reflected in the Better Care Better Jobs Act (S. 2210), Medicaid HCBS programs face chronic under-spending, staffing shortages, and long waiting lists in most states. Additionally, Black recipients of Medicaid HCBS, especially those with intellectual and developmental disabilities (I/DD) face significantly higher disparities than white recipients in COVID-19 vaccination rates, assignment of a behavioral support plan, barriers to community involvement, social isolation, unemployment, and lack of choice in health care provision and residential settings.

Medicaid and Housing: The Medicaid and CHIP Payment and Access Commission (MACPAC)'s June 2021 issue brief on "Medicaid's Role in Housing" states that "the relationship between housing and health is well established. Poor housing conditions can worsen health outcomes related to infectious and chronic disease, injury, and mental health... Medicaid and supportive housing programs serve many of the same individuals, yet collaboration between the two has been limited in the past. As states focus attention on addressing SDOH, however, Medicaid programs are increasingly collaborating with state and local housing authorities to assist beneficiaries in need of supportive housing." The National Academy for State Health Policy emphasizes this situation in a March 2021 report: "Housing is an essential social determinant of health. Evidence shows a strong association between access to safe, affordable, and stable housing and positive health outcomes."

Dual-Eligibles: Congress has authorized integrated programs, administered by the Centers for Medicare and Medicaid Services (CMS) Medicare and Medicaid Coordination Office (MMCO), for persons dually eligible for Medicare and Medicaid. An estimated 12 million persons dually eligible for these programs are typically low-income individuals, over the age of 65, who have a disability. As stated by the Alliance for Health Policy's July 2021 handbook, "They (persons dually eligible) often experience socioeconomic vulnerability and have various complex care needs, such as multiple chronic conditions, functional limitations, and behavioral health conditions. This group typically represents the highest need and highest cost beneficiaries of both programs." MMCO currently administers roughly a dozen demonstration programs that should be greatly expanded.

Non-Emergency Medical Transportation (NEMT): Congress recently required MACPAC and CMS to study the federal-state Medicaid response to NEMT needs. MACPAC's January 2021 report documents the failure of many states to adequately provide NEMT and offers best practices and policy ideas. Federal policy solutions are needed now to address these transportation needs.

Are there other federal policies that present challenges to addressing SDOH?

People with disabilities face additional burdens related to their disability which can have a ripple effect compounding other social determinants and increasing the overall negative impact on health. For example, federal health care payer policy (particularly the Centers for Medicare and Medicaid Services) will often explicitly not cover durable medical equipment, particularly mobility assistive equipment (MAE), if it is only used for mobility outside of the home. Almost all other health payers adopt this stance as a result. This can render many people with mobility impairments confined to their home, or without stable or affordable access to devices (such as manual wheelchairs, power wheelchairs, and mobility scooters) if they are intended for use outside of the home. Some individuals may be marginal ambulators in their home but need a device to get out into the community, limiting their ability to address other social determinants. For example, individuals may need a mobility device to access healthy food at a grocery store, travel to medical appointments, or move away from dangerous or violent situations. Without access to mobility equipment, they may be forced to rely on more costly alternatives, such as non-emergency medical transportation, or have to rely on family, friends, or caregivers, creating additional burden and stress. Addressing access to functional mobility within the community, in addition to within the home, would improve SDOH for many individuals.

Is there a unique role technology can play to alleviate specific challenges (e.g. referrals to community resources, telehealth consultations with community resource partners, etc.)? What are the barriers to using technology in this way?

During the pandemic, telehealth demonstrated itself as a viable option for people to access health services in a more reliable manner. For many people with disabilities, telehealth helped address significant access problems, such as difficulty traveling to appointments, inaccessible medical facilities, lack of distractions associated with unfamiliar settings (especially for individuals with cognitive impairments and intellectual/developmental disabilities), and more. Maintaining access to these services virtually as medically appropriate will go a long way towards addressing challenges faced by people with disabilities and other underserved populations.

However, telehealth is only limited to certain providers. During the public health emergency, physical, occupational, and speech therapists have had temporary privileges to provide telehealth services, but these exceptions are ending in several states and will expire under the Medicaid program at the close of the PHE. Losing access to therapy services via telehealth will put more hardship on people with disabilities who have found that these services can be provided successfully in a virtual environment.

Adequate access to therapy services increases the likelihood that people who face a variety of physical and psychosocial challenges can live safely and independently at home. Some of the greatest barriers to receiving these services are directly related to where a person lives in relation to clinical facilities and whether that person has adequate transportation options. This is an especially significant barrier to people with disabilities for whom even reasonably short journeys can be quite challenging. The rapid expansion of telehealth as a delivery mechanism for therapy and other rehabilitation services during the PHE has enabled providers to demonstrate the clear value of telehealth services provided alone or in conjunction with in-person services. Patient and provider reports indicate that telehealth has reduced delays in receiving care while making it easier to connect with beneficiary caregivers and enabling easier identification of home safety issues. This can be crucial in preventing falls or other injuries, quickly addressing functional decline, and avoiding costly emergency room visits and hospital admissions which, in turn, can reduce the cost of care. This increase in access to therapy via telehealth, however, is currently only temporary. Congressional action is needed to list physical, occupational, and speech therapists as approved Medicare telehealth providers, or, at minimum, to provide CMS with the authority to expand the types of providers (including therapists) who can offer telehealth to Medicare beneficiaries once the PHE ends. Otherwise, this new delivery mechanism will functionally end for many patients, a major setback for individuals with disabilities and other high-need individuals who have come to depend on this easier access to virtual care.

Additionally, for many individuals, internet access is not readily available, especially to people with lower incomes. During the pandemic, assistive technology clinics like one at the University of Pittsburgh Medical Center have leveraged Assistive Technology Professional (ATP) suppliers to visit consumers in their homes, serving as “tele-helpers” and “tele-presenters” to assist with connection to clinicians, including therapists and physicians. Connecting assistive technology users with their clinicians during the pandemic has provided health care providers with important information about how individuals function within their

home and what barriers may need to be mitigated. However, many suppliers report they have to use personal cellular connections and data plans during these encounters due to a lack of stable Internet connectivity in the person's home.

Policymakers must realize that the Internet is not only necessary for telehealth, but also many more common activities of daily living that are often carried out using a smart phone or computer (such as ordering food and medications, operating smart appliances and security systems, ridesharing, banking, navigation, etc.). Access to broadband Internet and appropriate telehealth services should be considered a critical aspect of SDOH.

It is just as important that expansion of telehealth services does not come at the expense of in-person care, especially when the services needed by the patient are more effectively and efficiently provided in-person. Individuals with illnesses, injuries, disabilities, and chronic conditions often need the highest levels of medical care in order to maintain, regain, and/or improve their health and function. It is crucial that individuals remain able to access the most appropriate care in the most appropriate setting.

New regulations and legislation expanding telehealth must ensure that telehealth is utilized when clinically appropriate (including regarding the patient's non-medical needs) and that individuals who need in-person care do not face additional barriers to access as a result of telehealth adoption. When either virtual or in-person care is considered to be equivalently appropriate for the patient's clinical needs, reimbursement policies should not promote one over the other. The decision between virtual and in-person care should be made between the patient and their provider.

Improving Alignment

What potential do you see in pooling funding from different sources to achieve aligned goals in addressing SDOH? How could Congress and federal agencies provide state and communities with more guidance regarding how they can blend or braid funds?

We support the significant proposed budgetary increase for the Centers for Disease Control and Prevention's (CDC) SDOH program in Fiscal Year 2022. The proposed \$150 million increase will dramatically expand CDC's capabilities to address SDOH and improve health equity nationwide. Having a strong central body responsible for addressing SDOH issues will help coordinate activities across the country while helping distribute funds to state and local entities performing work on the ground in communities.

One broader issue is recognizing broadband Internet access as a public utility as well as a social determinant. The task of increasing broadband nationwide is a split responsibility across federal agencies, and coordination including health care stakeholders can lead to exponential improvements.

Are there any non-traditional partners that are critical to addressing SDOH that should be better aligned with the health sector to address SDOH across the continuum from birth through adulthood? What differences should be considered between non-health partners for adults' social needs vs children's social needs?

One way to help improve the current fragmented health care system is to expand the role of and provide additional health navigators to assist with care coordination for individual

patients across their health care journey. This can also help improve health literacy and a broader understanding of the intersection of social factors with health outcomes.

The Caucus should also work to promote and expand the role of community health workers and behavioral health peer specialists in the continuum of care, as well as outside of the typical health care system.

What opportunities exist to better collect, understand, leverage, and report SDOH data to link individuals to services to address their health and social needs and to empower communities to improve outcomes?

It is essential that Congress recognize its role in directing uniform demographic data collection that includes disability status. As Congress has continued to embrace public health data collection (including during a recent Energy & Commerce Committee hearing entitled, Empowered by Data), numerous bills reference and mandate collection of “race, ethnicity, age, sex, geographic region, and other relevant factors.” On behalf of the DRRC, we urge Congress to explicitly identify disability status as a standard demographic group in the legislative text for all future bills requiring health data collection.

Legislation currently under consideration in the House, including the Data to Save Moms Act (H.R. 925), the Social Determinants Accelerator Act (H.R. 2503), the CARING for Social Determinants Act (H.R. 3894), the Social Determinants of Health Data Analysis Act (H.R. 4026), and the Improving Social Determinants of Health Act (H.R. 379), among many others, would advance important policy to address SDOH issues. However, NONE of these bills include any mention of disability status, in the associated data collection requirements or otherwise. Including disability status as a required demographic category in legislative data collection requirements is a critical first step in ensuring that people with disabilities are not left behind in the SDOH conversation.

Further, mandating uniform demographic data collection, analysis, and public transparency will help better inform all SDOH and public health policies, including the COVID-19 response. It is quite likely that people with disabilities faced exacerbated disparities resulting from the COVID-19 pandemic, including higher rates of COVID-19 exposure, infection, serious symptoms, hospitalization, and death. They also may face significant barriers to vaccination or be at higher risk of developing “Long COVID.” But we do not know for sure, because the data simply has not been collected appropriately.

We do know that death rates among nursing home residents (nearly all of whom have significant disabilities) jumped by 32% in 2020. While most people with disabilities do not live in institutions, they do share many of the same COVID-19 risk factors. All people with disabilities, regardless of their living circumstances, require accessible and affordable health and support services, particularly in a public health crisis. Real-time data collection and disclosure of disability disparities in health and health care is the first step towards developing appropriate and just public health programs and policies to support this vulnerable population. It is well understood that racial and ethnic minorities and other underserved communities have also been hit disproportionately hard by the pandemic, and it stands to reason that the disability community has as well. However, the data is simply not sufficient in its current form to fully understand the impact of the pandemic and intersection of other social determinants within this population. Disability rates also vary by race and ethnicity, as well as

by age, gender, and geographic area. Understanding these intersectional relationships will be critical to building a more resilient and responsive public health system for all Americans.

Under Executive Order 13985, President Biden made it a goal for the federal government to advance equity and support for underserved communities, including people with disabilities. This Order also established an Interagency Working Group on Equitable Data. We believe that mandating and standardizing the collection of disability status data regarding the COVID-19 pandemic and public health efforts more broadly would be an important first step towards fulfilling the mission of this Working Group, and we encourage the Caucus and Congress to work with the Administration to achieve these goals.

What are the key challenges related to the exchange of SDOH data between health care and public health organizations and social service organizations? How do these challenges vary across social needs (i.e., housing, food, etc.)? What tools, resources, or policies might assist in addressing such challenges?

In addition to the need for collecting standardized disability status data, it is important to require collection of social factors and SDOH data (including through the use of Z-codes) in electronic health records. Compliance with these requirements should be mandatory for participation in alternative payment models. Building reliable repositories of this data will help researchers and policymakers understand and examine the relative importance of different factors in risk adjustment and/or stratification for public reporting, as well as identifying which SDOH are conceivable responsive targets to health care and policy interventions and which may be less effectively addressed by existing processes.

Best Practices and Opportunities

What are some programs/emergency flexibilities your organization leveraged to better address SDOH during the pandemic (i.e., emergency funding, emergency waivers, etc.)? Of the changes made, which would you like to see continued post-COVID?

Telehealth was further validated due to the pandemic, but action is needed to ensure it remains available, especially for high-risk/high-needs populations, especially individuals with disabilities who face higher barriers to accessing health care and specialty services. Congressional and Administration policy (as well as private payers' policies) must be more flexible with regards to telehealth, and balance the need for mitigating waste, fraud, and abuse with ensuring access is not hindered for those who can benefit from virtual care.

As Congress considers telehealth expansion (especially in Medicare) post-pandemic, it is important to ensure that access to different types of telehealth care, payment parity, and access to audio-only telehealth, as well as physical, occupational, and speech therapy services, is protected, especially for patients facing additional burdens to accessing health care generally.

In addition, there are several emergency waivers that, if extended permanently, would help provide improved access to care, especially for underserved populations.

- *The “60% rule” for inpatient rehabilitation facilities, which governs the types of patients who can receive IRF care. Expanding this rule to include additional conditions (such as cardiac & pulmonary issues, cancer rehabilitation, and “Long COVID” symptoms) would help more patients who can succeed in IRFs to access this care.*

- *The “three-hour rule” for IRFs – expanding this rule would ensure that more types of skilled therapy are available to IRF patients with injuries, chronic conditions, and disabilities, such as neuropsychology, recreational therapy, and respiratory therapy.*
- *As stated above, the current waivers allowing broad access to telehealth should be extended, allowing a wide range of providers to offer virtual care to patients in their home as is medically appropriate. Extensions of these waivers should ensure that access to in-person care is not inadvertently limited with the proliferation of telehealth.*

Which innovative state, local, and/or private sector programs or practices addressing SDOH should Congress look into further that could potentially be leveraged more widely across other settings? Are there particular models or pilots that seek to address SDOH that could be successful in other areas, particularly rural, tribal or underserved communities?

Telehealth and affordable broadband Internet access are hugely important and influential on SDOH. For people with disabilities in particular, policymakers should place more emphasis on accessible software and hardware, as many applications and technologies that are becoming more prevalent are difficult or impossible for people with disabilities and older individuals to use effectively. When it comes to development of electronic strategies to address SDOH, especially those replacing contemporary and conventional processes, enforcement of Section 504 of the Rehabilitation Act must be paramount.

Given the evidence base about the importance of the early years in influencing lifelong health trajectories, what are the most promising opportunities for addressing SDOH and promoting equity for children and families? What could Congress do to accelerate progress in addressing SDOH for the pediatric population?

Children with disabilities can be impacted by social determinants in the same ways that adults are, and in many cases the impact of SDOH on pediatric disability populations will be exacerbated and compounded. Several of these factors include:

Economic Stability

Food insecurity: Children with special needs may receive nutrition via gastrointestinal tubes and the costs for these can be prohibitive. While less options are available, due to tolerance issues, these may not work for some patients, exacerbating financial instability for children and their families.

Housing instability: Functional decline and/or impairment in children with disabilities may result in a need for more accessible housing; these are often less easily available/obtainable and more expensive, limiting families’ ability to access stable housing to meet their children’s needs.

Poverty: The medical costs associated with meeting the needs of a child with disabilities (physical, behavioral, intellectual, developmental, or otherwise) are typically much greater than the average child, exacerbating financial issues for the parent(s).

Education

Early childhood education and development: While early intervention (EI) programs exist throughout the country, some facilities are not aware of or do not sufficiently utilize these

services. With limited access to EI and limited care coordinators (many of whom are over-worked), some children do not receive the benefit of all the services that should be available to them.

Language and literacy: Parental language and literacy barriers limit access to available services for children with special needs.

Health and Health Care

Access to health care: Transportation limitation (access to public/private transportation, inability to afford fuel, etc.) may impact families' ability to take a child with disabilities to (likely frequent) medical appointments. This can be compounded if, for example, a child requires a wheelchair or has a mobility impairment, further decreasing the availability of accessible transportation options.

Health literacy: Families with limited education and/or limited medical experience or background may have difficulty understanding the complex and often cooccurring medical issues children with disabilities may face. Proactive care coordination can help families navigate complex medical care with multiple physicians and care providers.

Neighborhood and Built Environment

Children with disabilities may have impaired immune systems or compromised respiratory systems, so poor environmental conditions may have an increased impact and result in additional hospitalizations and decline in health/independence.

Transformative Actions

Alternative payment models help to measure health care based on its outcomes, rather than its services. What opportunities exist to expand SDOH interventions in outcome-based alternative payment models and bundled payment models?

Currently, many of the services available to keep people living in their homes are fragmented in various silos, often with competing funding methods. SDOH components should be recognized, included, and packaged as performance outcomes for organizations that are awarded contracts for value-based care and other alternative payment models, including Accountable Care Organizations (ACOs). ACOs, especially those serving Medicare/Medicaid beneficiaries, must be accountable for outcomes as well as reducing costs. Alternative payment models and value-based payment models should be required to account for SDOH variables in the risk standardization models and/or through stratified analyses with explicit incentives for vulnerable populations. The National Quality Forum has issued significant best practices and guidance for developing and testing risk adjustment models, which can be critical for standardizing such measures across payment models.

Open Forum

Is there any other information you would like to share?

The Disability and Rehabilitation Research Coalition (DRRC) is a coalition of national non-profit organizations committed to improving the science of medical rehabilitation, disability, and independent living. The DRRC seeks to maximize the return on the federal investment in the field with the goal of improving the ability of Americans with disabilities to live and function as independently as possible. The coalition plays a leadership role in increasing and

leveraging federal resources devote to research in these fields. For additional details on the DRRC's mission and work, including past correspondence with Congress and the Administration on disability research issues, please visit our website at www.drcc-coalition.org.

As the SDOH Caucus continues to develop its agenda in Congress to address issues around social determinants, we stand ready to serve as a resource for the Caucus to answer any disability-related questions that may arise and provide technical expertise on behalf of the field. If we can be of any assistance, please do not hesitate to contact the DRRC coordinators, Peter Thomas, Bobby Silverstein, and Joe Nahra, at 202-466-6550 or by email at Peter.Thomas@powerslaw.com, Bobby.Silverstein@powerslaw.com, and Joseph.Nahra@powerslaw.com.