

Social Determinants of Health in People with Epilepsy

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INTRODUCTION

The purpose of this educational sheet is to provide a framework to increase understanding regarding the interaction between Social Determinants of Health (SDOH) and epilepsy management. This sheet is intended as a resource for healthcare providers, caregivers, individuals with epilepsy, and community members to highlight important factors which may pose as barriers or protective factors in supporting effective epilepsy care.

SDOH are the non-medical factors within the environments where individuals live that impact their health, well-being, ability to function, and their quality of life. There are five domains of SDOH including: Economic Stability, Education Access and Quality, Healthcare Access and Quality, Neighborhood and Built Environment, and Social and Community Context (Healthy People 2030). SDOH have a direct impact on health outcomes and are important in the context of epilepsy as they can influence who develops epilepsy (based on factors such as infection), how a person's epilepsy is managed, how it progresses, and how it affects their overall health and safety.

DIMENSIONS OF SOCIAL DETERMINANTS OF HEALTH:

Economic Stability:

Socioeconomic status and economic stability can impact an individual's ability to meet their basic needs and access necessities such as healthy food, housing, transportation, and healthcare. For an individual with epilepsy this may mean barriers to accessing timely medical care, affording medications, or maintaining aspects of wellness that are key for seizure management. Resources to help improve economic stability, such as programs that increase access to employment or public benefits, may aid in improving epilepsy management.

a. Considerations:

i. Explore Public Benefits Programs, including:

1. SSI (Supplemental Security Income) - <https://www.ssa.gov/ssi>
2. SNAP (Supplemental Nutrition Assistance Program) - <https://www.fns.usda.gov/snap/supplemental-nutrition-assistance-program>
3. Social Service Agency State locator - connect with information about public benefits programs in your state <https://www.usa.gov/state-social-services>

ii. Prescription assistance resources:

1. Patient Assistance Programs - <https://www.epilepsy.com/patient-assistance#973097505-992040283>
2. Good Rx - <https://www.goodrx.com/>
3. CostPlus Drugs - <https://www.costplusdrugs.com/>
4. Needy Meds - <https://www.needymeds.org/>
5. The Assistance Fund - <https://tafcares.org/>
6. Epilepsy Alliance America - <https://epilepsyallianceamerica.org/medication-cost-assistance/>

iii. Connect with the community: Community Action Agencies can provide assistance with applying for public benefits, accessing local food pantries, and emergency assistance. Find a CAA near you: <https://communityactionpartnership.com/find-a-cap/>

iv. Explore career/job training programs in your local area, many cities and towns have agencies to support access to employment.

1. <https://www.defeatingepilepsy.org/about/workforce-development/>
2. <https://www.prideindustries.com/work-with-pride/who-we-support/jobs-for-people-with-epilepsy>

v. If you are in a healthcare setting, explore opportunities for concrete resources to provide to patients such as gift cards to offset costs of groceries, gas, parking, medication etc.

Education Access and Quality:

Access to education and academic services can support improved health, wellbeing and longer life-expectancy. Educational access can improve health literacy as well as access to safe, stable employment. Individuals with epilepsy may be at increased risk for experiencing challenges with learning and accessing an educational curriculum and thus may require additional support, such as through the provision of Special Education or 504 Plan accommodations, to succeed. Additionally, it is widely known that inability to manage basic needs and the stress of living in poverty can impact brain development, further reinforcing the importance of access to quality education. With these factors in mind, it is important to note that educational and informational materials should be written to be at no higher than a 6th-grade reading level, provided in a person's preferred language, and available in multiple formats to accommodate learning needs (such as written vs audio visual resources).

a. Considerations

- i. Understand the legal rights of students with Epilepsy: <https://www.epilepsy.com/legal-help/legal-rights>
- ii. Familiarize yourself with academic support options: <https://www.parentcenterhub.org/accommodations/>
- iii. Connect with your state's Parent Center Network: <https://www.parentcenterhub.org/the-parent-center-network/>
- iv. Consider school personnel training resources:
 1. <https://www.cdc.gov/school-health-conditions/chronic/epilepsy.html>
 2. <https://learn.epilepsy.com/collections/seizure-safe-schools-courses>
 3. <https://learn.epilepsy.com/courses/school-personnel-OD-v3-1>
 4. <https://rutgerstraining.sph.rutgers.edu/Epilepsy/#/>
- v. Explore opportunities for Epilepsy related scholarships:
 1. UCB Family Epilepsy Scholarship <https://www.ucbepilepsyscholarship.com/>
 2. FACES Scholarship <https://bigfuture.collegeboard.org/scholarships/faces-college-scholarship>
 3. Charles L. Shor Epilepsy Opportunity Fund <https://epilepsywellness.com/scholarships/>
 4. List of epilepsy related scholarships for higher education (some location specific) <https://bigfuture.collegeboard.org/scholarship-search?sort=deadline-nearest-first&keyword=epilepsy>
 5. Check with your local Epilepsy Foundation chapter <https://www.epilepsy.com/local>

Health Care Access and Quality:

Individuals may face barriers to accessing health care services due to a number of challenges including: challenges affording health insurance, difficulty accessing a primary care provider, limitations in health literacy and ability to navigate health systems, and significant distance from where they live to needed providers. Individuals with epilepsy are vulnerable to experiencing barriers to accessing health care due to risk for economic instability, cognitive and learning challenges, behavioral health challenges, discrimination, and cultural factors. Supporting access to quality health care will aid people with epilepsy in managing their health.

a. Considerations

- i. Consider various learning styles and methods of communication and adapt treatment to meet individuals where they are at.
- ii. Connect with supportive programs such as the Managing Epilepsy Well Network <https://managingepilepsywell.org/>

- iii. Familiarize yourself with the health insurance options in your state such as via one's employer or the state marketplace and state medicaid programs, and the resources available to support individuals and families:
 1. Find your state's insurance marketplace - <https://www.healthcare.gov/marketplace-in-your-state/>
 2. For example, Kids Waivers provides information for available Medicaid waivers in each state - <https://www.kidswaivers.org/>
 3. Agencies such as community action agencies or hospital financial counseling offices can assist individuals with accessing health insurance.
- iv. Understand availability of state or community run programs that may provide case management or care coordination support to individuals or children and families:
 1. Patient Advocate Foundation: free case management support to individuals with chronic illnesses <https://www.patientadvocate.org/connect-with-services/>
 2. There is a National Center for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN): <https://www.aap.org/en/patient-care/national-center-for-a-system-of-services-for-children-and-youth-with-special-health-care-needs/>
 - a. Family 2 Family information networks may help find the CYSHCN programs in your state - <https://familyvoices.org/felsc/whataref2fs/>
 3. State Directory for agencies serving individuals with Developmental Disabilities <https://www.nasddd.org/state-agencies/>
 4. State Directory for agencies serving individuals with Substance Use and Behavioral Health needs <https://findtreatment.gov/state-agencies>
 5. Local chapters of agencies such as the ARC (<https://findtreatment.gov/state-agencies>) or the Epilepsy Foundation (<https://www.epilepsy.com/>) may also be able to offer healthcare navigation support or connection to local resources.
 6. Individuals can also sometimes request a case manager through insurance.

Neighborhood and Built Environment

For individuals living with epilepsy, the neighborhood and built environment play a critical role in shaping health outcomes and overall safety. In the epilepsy population, barriers like limited access to neurologists, poorly lit or uneven sidewalks, or lack of emergency services can significantly impact seizure management and personal safety. Particular consideration should be given to public transport access for those who are unable to drive. By improving neighborhood infrastructure and ensuring equitable access to supportive resources, we can help mitigate environmental risks and promote healthier, more secure lives for those affected by epilepsy.

a. Considerations

- i. Identifying and supporting access to the resources available in one's community may aid in mitigating the potential impacts one's environment may have on their health and wellbeing.
- ii. Provide education and information about managing seizure safety in the community, including utilizing tools such as medical ID bracelets, devices etc.
 1. <https://www.getmyid.com/>
- iii. Familiarize yourself with transportation resources:
 1. Some insurance plans (such as medicaid plans) can provide assistance with transportation to medical visits.
 2. Explore accessible and public transportation options through your community which often offer decreased rates for individuals with disabilities.
 3. Explore funding programs through community agencies ex:
 - a. Epilepsy Foundation Ride Share Program - <https://www.epilepsy.com/ride-share>
- iv. Familiarize yourself with State and Federal housing programs for assistance applying for housing assistance, emergency shelter access, and support related to housing conditions (pests, mold etc.):
 1. Housing and Urban Development state directory <https://www.hud.gov/states>

Social and Community Context

Social and community context refers to the relationships, networks, and support systems that surround an individual. For people living with epilepsy, these connections can be vital in managing the condition, navigating epilepsy related stigma and discrimination, and improving overall well-being. Access to supportive communities, peer networks, and understanding social environments can reduce stigma, enhance emotional resilience, and promote adherence to treatment plans. By fostering inclusive and informed social structures, we can empower individuals with epilepsy to lead safer, healthier lives. Supporting access to social and community support systems can aid in management of epilepsy and overall health.

a. Considerations

- i. Understand the impacts of epilepsy, including the stigma and feelings of isolation that may occur and the importance of educating the community, and one's support system, about epilepsy.
- ii. Connect with local disability advocacy organizations through connecting with:
 1. Local ARC chapter <https://thearc.org/find-a-chapter/>
 2. Local Epilepsy Foundation chapter <https://www.epilepsy.com/local>
- iii. Assist individuals in identifying their support system and connecting with additional social support as needed (such as connecting with a therapist, support group, or a supportive organization)
 1. Epilepsy Alliance- <https://epilepsyallianceamerica.org/programs-services/support-groups/>
 2. Epilepsy Foundation (find your local chapter to identify groups) - <https://www.epilepsy.com/local>
- iv. Consider the impacts of an individual's identity and cultural beliefs and how this may impact their epilepsy care and the importance of developing culturally informed materials and programs.

SDOH Screening Tools

Proactive screening for SDOH in a healthcare setting may be beneficial to identify barriers to care and support needs. The below list of tools that can be utilized for SDOH screening is meant as a resource, each tool may have its own advantages and disadvantages for use dependent upon population and setting.

- PRAPARE (Protocol for Responding to & Assessing Patients' Assets, Risks & Experiences) <https://prapare.org/>
- AHC HRSN (Accountable Health Communities Health-Related Social Needs Screening Tool) - <https://www.cms.gov/priorities/innovation/files/worksheets/ahcm-screeningtool.pdf>
- Health Leads Screening Toolkit - <https://healthleadsusa.org/news-resources/the-health-leads-screening-toolkit/>
- Epilepsy Needs Assessment Survey (ENAS) - <https://www.sciencedirect.com/science/article/pii/S2666459322000142>

Notable Articles

- AES/ILAE, American Epilepsy Society / International League Against Epilepsy–North America Joint Task Force. 2025. "Addressing epilepsy care disparities in the United States: a call to action." *Epilepsy Currents*. <https://pmc.ncbi.nlm.nih.gov/articles/PMC12149156/>
- Dorian M. Kusyk, Stephen Jaffee, Keith Lejeune, Emily Brignone, Yue Yin, Jenna Li, Alexander C. Whiting, The effects of social determinants of health on patients with epilepsy, *Epilepsy & Behavior*, Volume 168, 2025, 110419, ISSN 1525-5050, <https://doi.org/10.1016/j.yebeh.2025.110419>.
- Szaflarski M. Social determinants of health in epilepsy. *Epilepsy Behav.* 2014 Dec;41:283-9. doi: 10.1016/j.yebeh.2014.06.013. Epub 2014 Jul 4. PMID: 24998313.

Online Resources

- Exploring Epilepsy: Social Determinants of Health
<https://www.exploringepilepsytoday.com/professionals/social-determinants-of-health>
- Find Help: <https://www.findhelp.org/>
- Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. from <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>
- Unite Us through Pediatric Epilepsy Surgery Alliance:
<https://epilepsysurgeryalliance.org/about/programs-and-resources/connect-with-resources/#:~:text=If%20you're%20looking%20for,or%20finding%20a%20care%20provider.>