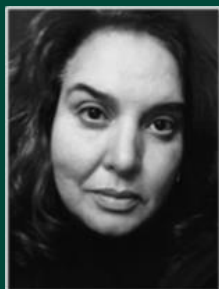




A Path to Equitable Care in Epilepsy



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Director, HOBSCOTCH Institute for Cognitive Health & Well-Being
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The Goal: Health Equity for People Impacted by Epilepsy

Reimagining care pathways and partnerships

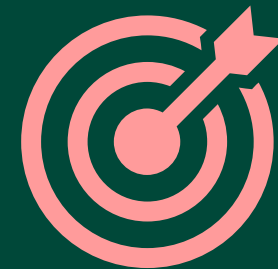
Ensuring a competent workforce

Mobilizing community partners

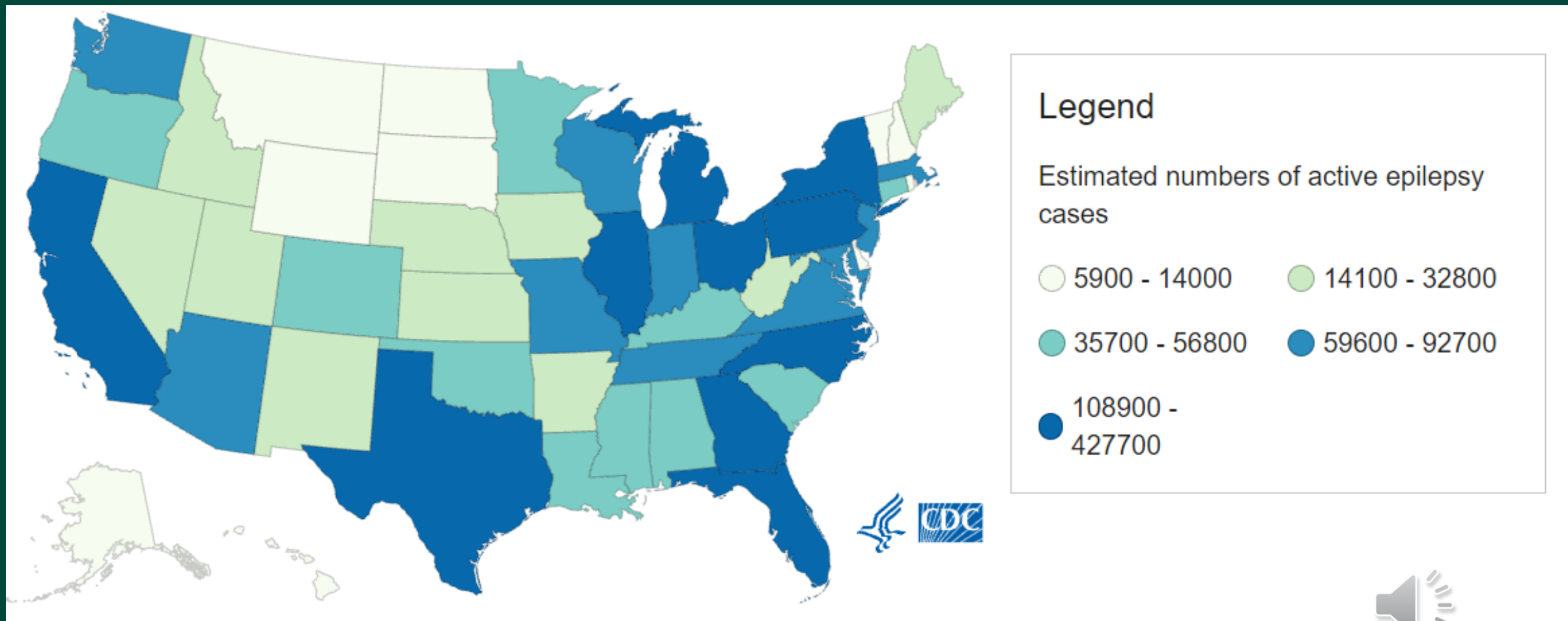
Reaching the most vulnerable populations

Empowering people with epilepsy

Community Epilepsy Training
CHW Integration into Epilepsy Care
Telehealth Supported Epilepsy Self-Management



CDC: Epilepsy Disease Burden



Medical Challenges

- Delayed diagnosis/misdiagnosis
- >30 seizure types; for many, more than 1 type
- Complex treatment regimens
- 30%-50% uncontrolled seizures
- Medication side-effects
- Psychological and physical comorbidity
- Hidden disability/disclosure
- Challenging for patients to self-manage
- Injury and death



Social Challenges

- ↑ unemployment
- ↑ disability
- ↓ educational attainment
- ↑ low household income
- ↑ social isolation, stigma
- ↑ transportation restrictions
- ↑ inability to afford different types of care

ABOUT ½ of ADULTS WITH ACTIVE EPILEPSY and SEIZURES HAVE ANNUAL FAMILY INCOMES < THAN \$25,000 (NHIS 2103,2015)

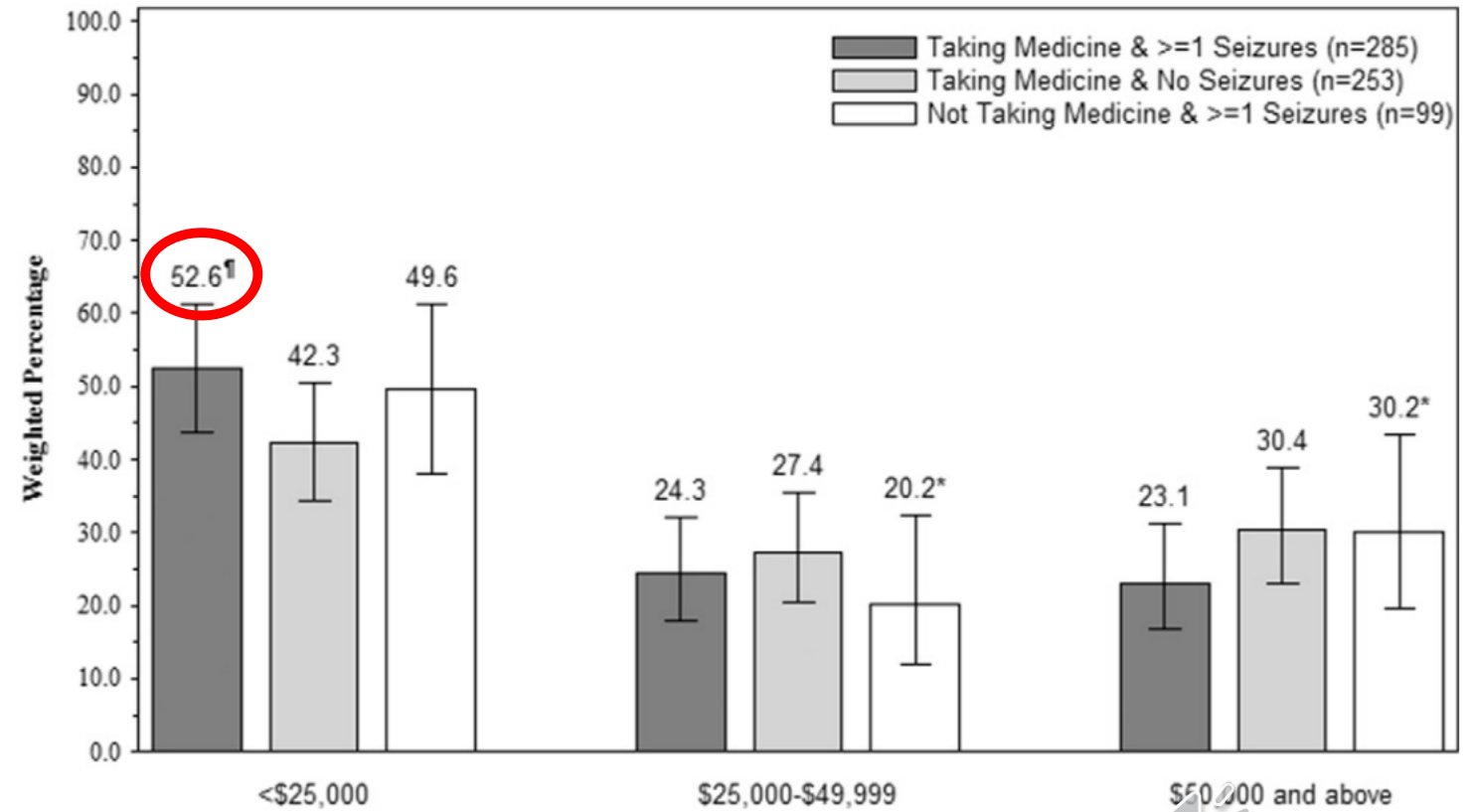


Table 1: Percent of Member Months and Costs for Select Episode Treatment Groups for Commercial Members from July 1, 2018 to June 30, 2019

**From IHPP New Hampshire Claims Report Suite*

Episode Treatment Group (ETG)	Percent of Member Months with Condition	PMPM Conditions Costs for Members with Condition	PMPM - All Costs for Members with Condition
Anxiety disorder or phobias	6.59%	\$53	\$607
Asthma	4.55%	\$70	\$768
Attention deficit disorder	2.27%	\$43	\$402
Diabetes	6.57%	\$98	\$795
Epilepsy	0.51%	\$208	\$1,703
Hypertension	15.30%	\$42	\$750
Mood disorder, depressed	7.34%	\$103	\$795
Obesity	6.81%	\$55	\$783
Other drug dependence	2.43%	\$69	\$1,051



Study Sample (n = 1284)
422 family practitioners
432 internists
233 pediatricians
197 nurse practitioners

**at least 1% practice patients with epilepsy*



Contents lists available at [ScienceDirect](#)

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



From the US Centers for Disease Control and Prevention

When and why US primary care providers do and do not refer their patients with new-onset seizures or existing epilepsy or seizure disorders to neurologists—2018 DocStyles



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- PCPs refer patients with *new-onset seizures*
- 40% of PCPs did not refer if patient unresponsive to treatment
- less than one third of all practitioners consulted seizure treatment guidelines

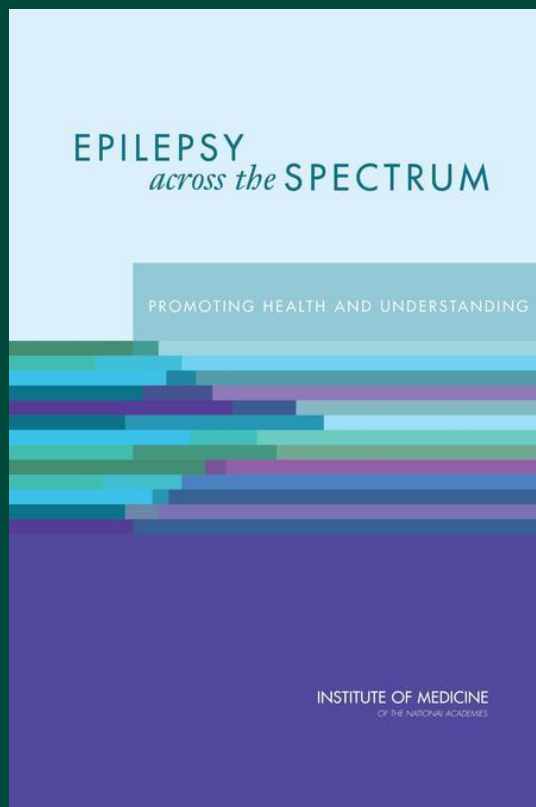
** prompt appointments, communication with PCP, patient's insurance, referral back to PCP may facilitate referrals*



Limitations of Traditional Clinic and Referral Models and Treatment Algorithms

- recognizing limitations is required for progress in equitable and timely epilepsy care
opportunity for improvement exists
- new model(s): integration of CHWs as non-medical providers of care
- acknowledges CHWs can be trained to provide an important set of skills and expertise that have been effective in other disease states (e.g., hypertension, asthma)
- targeting a workforce of CHWs with access to patients in their rural and diverse communities makes sense





The 2012 Institute of Medicine's Report on Epilepsy noted nontraditional health providers, including CHWs offer untapped opportunities for improving outcomes in epilepsy.

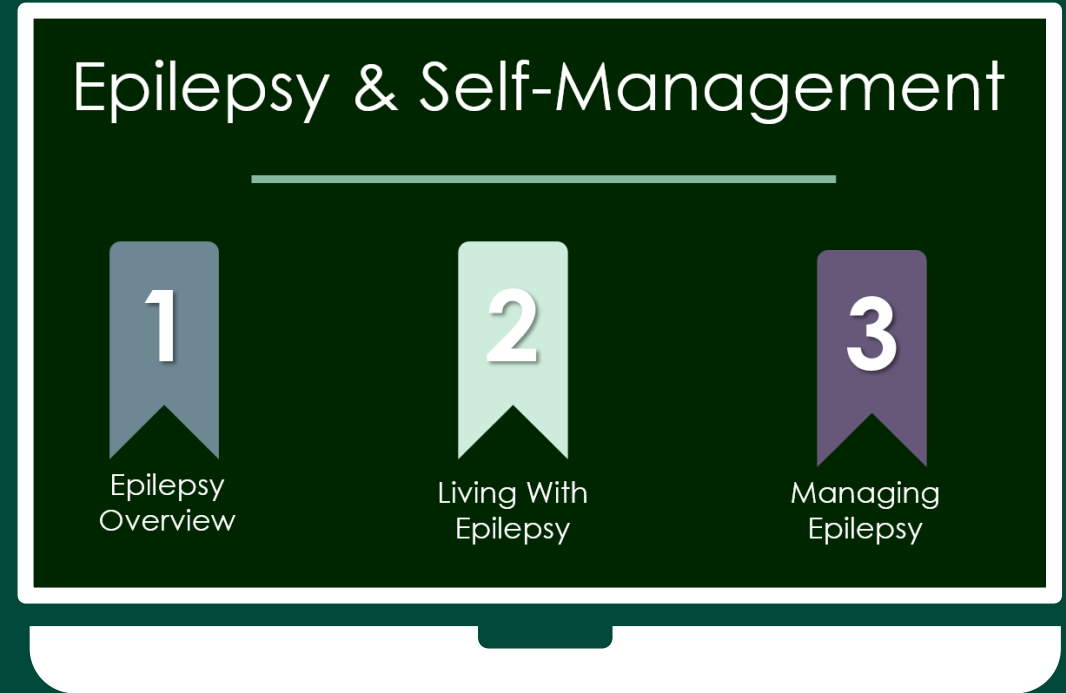
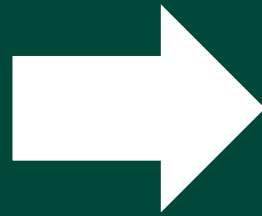
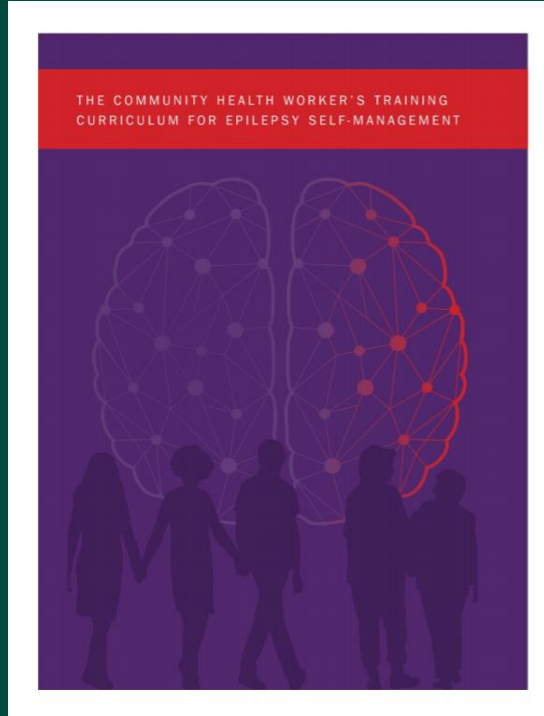


Community Epilepsy Training

- Community Health Workers
- Primary Care Multi-Level Providers
- Behavioral Health Providers



Community Training



Centers for Disease Control and Prevention, 2017, *The Community Health Worker's Training Curriculum for Epilepsy Self-Management*, Managing Epilepsy Well Network, (managingepilepsywell.org)

2020 PILOT VIRTUAL TRAINING




Community Health Worker
Health Services Supervisor
Program Coordinator, Health Service
Hospital based CHW
Clinical Coordinator
Family Support Coordinator
Public Health Nurse Coordinator
Special Education Nurse
Intake and Health Care Coordinator
Family Services Coordinator
Non-Profit Resource Coordinator
Educational Advocate
Non-Profit based Peer Navigator
Hospital Patient Navigator
Director Patient and Family Advocacy
Social Worker

Lamprey Health Care
New Hampshire Family Voices
Epilepsy Foundation New England
Waypoint Child and Family Services
North Country Health Consortium
University of Massachusetts Medical Center
Department of Health & Human Services
New Hampshire Partners in Health
Amoskeag Health
Elliot Hospital
Federally Qualified Health Center
Primary Care Practice
New Hampshire Northern Human Services
New Hampshire Public Schools
New Hampshire DHHS
DHMC Community Health Workers
University of NH School of Nursing



Post Training Feedback: Key Takeaways

Combined data from participants who completed a training session and post training evaluation indicated

- 100% felt (*strongly agreed or agreed*)
 - the presentation of training materials was effective
 - the information in the training was important
 - the objectives of the session were achieved
- 98% of participants felt (*strongly agreed or agreed*) their knowledge on epilepsy and self-management had increased
- 100% of participants responded they would recommend this training to others
- Post training evaluation comments indicated interest in ongoing epilepsy training 

What we are learning...next steps...

- broad spectrum of trainees (n=204) with varied educational backgrounds
- workplace settings desiring online accessible epilepsy education
- early results indicate high user satisfaction with educational content and the ability to reach CHWs serving vulnerable populations
- virtual trainings are a cost-effective way to provide education for CHWs, multilevel primary and behavioral care providers to aid in improving outcomes for people with epilepsy
- additional implementation and evaluation studies ongoing



Expanding Efforts with Regional Community Partners



CHW Integration in the Epilepsy Clinic

A Model for Community Health Worker Integration into Epilepsy Clinical Care Settings Informed by Clinical Provider and Patient Readiness



CHW Clinical Provider and Patient Readiness Summary of Proposed Work

- regional assessment of provider and patient readiness for integrating a CHW into epilepsy center teams using digital survey and key informant interview methodology
- examines multidisciplinary clinician awareness of CHWs and perceptions of their benefit
- parallel patient feedback contributes meaningful experienced viewpoints from where to begin defining CHW roles, training and supervision in epilepsy care setting
- provide insight for development of a transferable model of clinical-community linked epilepsy care



Addressing Social Determinants of Health in the Neurology Clinic

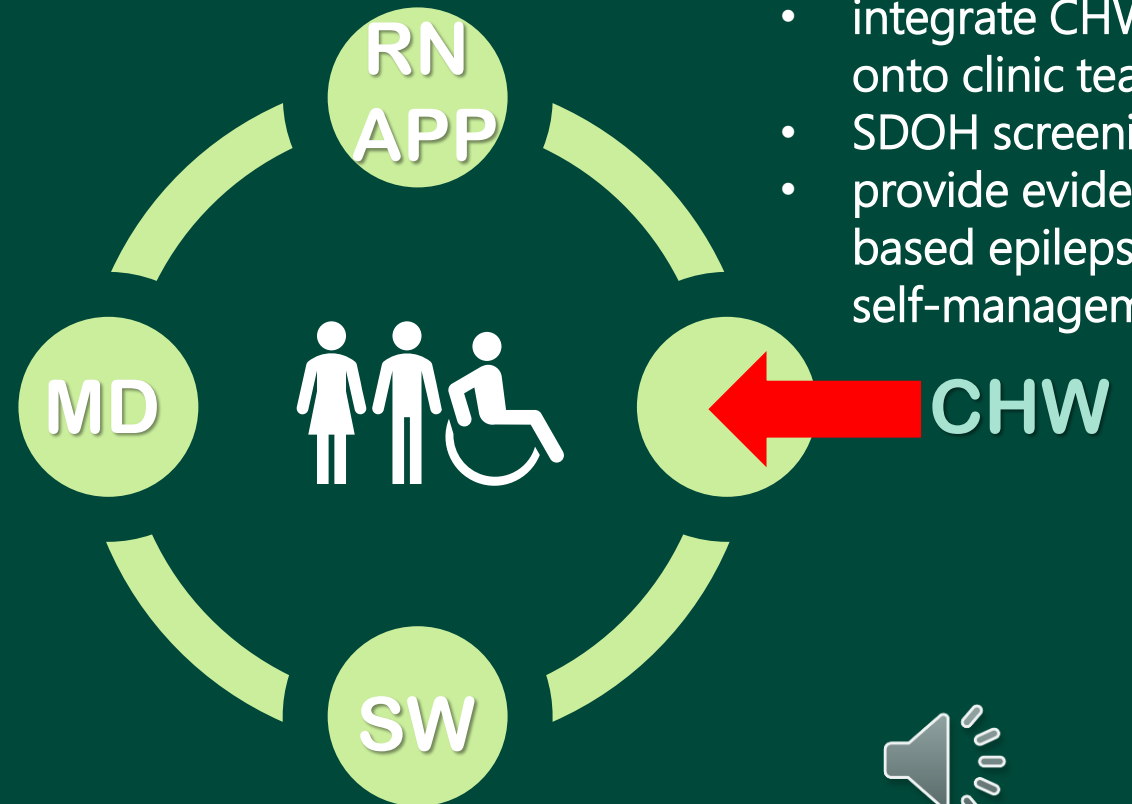
Addressing Social Determinants of Health in the Neurology Clinic



Clinic Integration of a Community Health Worker to Address SDoH for Patients with Neurologic Disease



improve
quality of care
and access




- integrate CHW onto clinic team
- SDOH screening
- provide evidence based epilepsy self-management



Referral to community supports, local and state resources

- Improved access to highest level of epilepsy care
- Timely referral for drug resistant epilepsy
- Referral to telehealth accessible ESM programs



 CHW at epilepsy centers integrated to assist patients address SDoH and deliver ESM

CHW are located in diverse clinical settings,
(primary care, FQHCs, behavioral health, community health clinics)

CHW are located in community epilepsy serving organizations

 Epilepsy center CHW integration model informed by both clinicians and patients

Building a Competent Workforce

TRAINING



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Thank you

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