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To: 2022 Special Committee on Intellectual and Developmental Disability Waiver Modernization

From: Leighann Thone, Research Analyst

Re: Navigator Roles

This memorandum provides information in response to a request regarding navigator roles and practices made during the October 13, 2022, meeting of the Special Committee on Intellectual and Developmental Disability Waiver Modernization.

Navigators

The U.S. Centers for Medicare & Medicaid Services (CMS) defines a navigator as “an individual or organization that’s trained and able to help consumers, small businesses, and their employees as they look for health coverage options through the Marketplace, including completing eligibility and enrollment forms. These individuals and organizations are required to be unbiased. Their services are free to consumers.”

Navigators help consumers prepare applications to establish eligibility and enroll in coverage through the Marketplaces and to qualify for an insurance affordability program. They also provide outreach and education to raise awareness about the Marketplace, and refer consumers to health insurance ombudsmen and consumer assistance programs when necessary. Navigators operate year-round, increasing awareness among uninsured people about the coverage options available to them, helping consumers find affordable coverage that meets their needs, and assisting consumers beyond the enrollment process to equip them with the tools and resources needed to utilize and maintain their health coverage all year. Navigators must complete comprehensive federal Navigator training, criminal background checks, and state training and registration (when applicable), prior to assisting consumers.

Each year, CMS makes grant awards to organizations that serve as navigators in states with federally facilitated marketplaces (FFMs). On August 26, 2022, CMS awarded \$98.9 million in Navigator grant awards to 59 organizations to continue serving as navigators in the 30 states

with FFM¹. These awards support the work of organizations that offer assistance to consumers navigating, shopping for, and enrolling in health insurance coverage for plan year 2023.

Kansas CMS Navigator Grants

Two organizations in Kansas received 2022 CMS Navigator Cooperative Agreement awards². Community Care Network of Kansas (formerly Kansas Association for the Medically Underserved) received an award in the amount of \$1,175,000 for statewide support of “underserved and diverse populations in every county that are susceptible to vulnerabilities due to inequities in resources and other barriers to health, such as insurance status, income, racism, geography, health professional shortages, or other economic and social determinants.”

Thrive Allen County was awarded \$1,681,510 to provide Navigator services to 52 Kansas counties with a target population of “LGBTQ+, vulnerable or underserved populations, seniors or individuals with disabilities, rural residents, and the farming community.” Subrecipients for this grant include Barber County United Coalition; Dickinson County Quality of Life Coalition; El Centro, Inc.; Project Access; Impact Ulysses; LiveWell Northwest Kansas; Mitchell County Regional Medical Foundation; Northeast Kansas Community Action Partnership; Southeast Kansas Community Action Program; Community Health Center of Southeast Kansas; Liberal Area Coalition for Families; and Grow Clay County.

Cover Kansas (getcoveredkansas.org) provides a directory of navigators in the state. The website is a project of Community Care Network of Kansas and is supported through an award from CMS.

Types of Navigators

Different terms can be ascribed to navigators; “specialist,” “peer support,” “family,” and “educator” are often used to help describe the role of navigator. A 2018 report by the Association of Maternal & Child Health Programs (AMCHP) lists patient navigators, parent navigators, nurse navigators, peer support specialists, and resource specialists as some of the titles that are given to individuals performing navigator roles.

While CMS defines navigators more in terms of assisting with health care options, eligibility, and enrollment, some navigator positions are more integrated into a patient’s treatment. Sarah Cannon Research Institute, a cancer treatment institute in Nashville, Tennessee, uses nurse navigators to coordinate care and provide consistency for patients who might see as many as eight different doctors during their treatment. Children’s National Hospital in Washington, D.C., utilizes a Parent Navigator Program to support parents and provide direction for children with chronic conditions and special health care needs.

1 Kansas has an FFM. In an FFM, the U.S. Department of Health and Human Services performs all Marketplace functions, and consumers in FFM states apply for and enroll in coverage through healthcare.gov. Eighteen states use a state-based marketplace, in which the state is responsible for performing all marketplace functions for the individual market, and consumers apply for and enroll in coverage through websites maintained by each state. Three states (Arkansas, Oregon, and Virginia) are state-based marketplaces using the federal platform, in which the state is responsible for performing all marketplace functions for the individual market, but consumers use the federal healthcare.gov website for eligibility and enrollment.

2 cms.gov/files/document/2022-navigator-grant-recipients.pdf

Family Navigators

AMCHP reports that families of children and youth with special health care needs (CYSHCN) are often supported by family navigators, commonly funded through Title V Maternal and Child Health (MCH) Block Grants and community-based programs. Title V MCH Block Grants are provided through the Social Security Act and are administered by the Health Resources & Services Administration within the U.S. Department of Health and Human Services. AMCHP reports that 40 states had family navigation services for CYSHCN in 2018, including Kansas. The MCH Title V Needs Assessment: Priorities and Action Plan 2021-2025 report produced by the Kansas Department of Health and Environment (KDHE) Bureau of Family Health (BFH) found 45 total “Case Manager/Care Coordinator/Navigator” positions in the MCH workforce in Kansas for a total of 25.2 full-time equivalent employees as of July 1, 2019.

Kansas Navigator or Navigator-Like Title V MCH Block Grant Programs

KDHE’s 2021 report on Title V MCH Block Grant Programs³ provides an overview of programs the state provides with Title V grant funds. The following programs provide Navigator or Navigator-like services for children and families with special health care needs:

- **Holistic care coordination.** The Kansas Special Health Care Needs program provides holistic care coordination and helps families find, understand, and access services and resources within medical, school, and community systems to achieve optimal child/family health outcomes and empower and prepare parents to support their children. Eligibility for holistic care coordination services is expanding to those with medically eligible conditions, regardless of financial status or resources, and families of children three to five years of age who received early intervention through Part C/Infant Toddler Services.
- **Peer-to-Peer support network.** In partnership with the KDHE Bureau of Family Health Family Advisory Council, Title V moneys were used to launch a peer-to-peer support network, Supporting You⁴, to connect parents and caregivers of CYSHCN with peers who have like experiences, life circumstances, or both. The network is designed to help individuals connect with one another, share ideas and resources, and gain support. Two Kansas programs participate: the Kansas Special Health Care Needs program and the Kansas State School for the Deaf. The network is expected to expand in the future.
- **Family and Consumer Partnership Program.** Title V moneys are being used to build a formal partnership program with families through peer supports, family leadership, and advisory opportunities. This will serve as a framework for local and state Title V programs to assure families are engaged at the level they desire. Upon development of a resource toolkit, this Title V-supported program can offer technical assistance and opportunity to support partners with engaging families in planning, implementation, and evaluation of services, programs, and policy.
- **System navigation training for families.** System Navigation Training For Families is provided at locations across the state to help individuals and families

3 kdhe.ks.gov/DocumentCenter/View/5214/2021-Title-V-Executive-Summary-PDF

4 supportingyoukansas.org

learn how to navigate the systems of care. This free one-day training is offered to all families who have a loved one with a special health care need. Trainings are limited to a maximum of 25 participants and are conducted by individuals who also have children with special needs. Topics covered during these trainings include insurance, medical services, self-care, communicating with providers, Shared Plans of Care, transition, education, waivers, and available resources. Those wishing to participate in a training or to request one be conducted in their area may call 785-296-1312.

Navigator Programs in Other States

Delaware

Autism Delaware provides training to new family navigators. This consists of formal training on autism, state services, cultural competence, and working with families. In addition, new family navigators shadow experienced navigators for up to one year.

Prior to 2016, Delaware funded all family navigation through fundraising by Autism Delaware. Legislation enacted in 2016 allocates a minimum of \$100,000 per year for family navigation and parent education, which in 2018 covered “approximately 30 percent of the cost to provide family navigation statewide.”

Iowa

Iowa’s Title V agency Child Health Specialty Clinics (CHSC) had a statewide network of family navigators composed of 28 parents of children with special health care needs. CHSC is overseen by the University of Iowa Division of Child and Community Health and is part of the Carver College of Medicine and the Stead Family Department of Pediatrics. CHSC developed a face-to-face training program for family navigators in 2009 and provides monthly continuing education based on MCH leadership competencies.

Several funding sources support the statewide Family Navigator Network. Foundationally, the Title V Block Grant supports family navigators working in regional centers. CHSC also receives funding from the Iowa Department of Education for family navigators working in Iowa’s early intervention program. Additional sources of funding include the Iowa Department of Human Services for family navigators serving in the Pediatric Integrated Health Home and Community Circle of Care locations administered by CHSC; the Iowa Department of Human Services for family navigators working in the Iowa waiver system; and the University of Iowa for a family navigator working in an interdepartmental autism center. Additional funding from Iowa’s Division of Mental Health and Disability supports workforce development by training family peer support specialists, including family navigators, across the state.

Missouri

Missouri’s ParentLink program, an outreach unit of the University of Missouri College of Education & Human Development, operates the ParentLink Navigators in the southeastern region of the state to help improve parents’ access to resources. Four navigators are housed in county health offices; each Navigator splits their time between two county offices, so the program serves a total of eight counties. The role of the navigator is to assist parents and

caregivers to connect with resources that relate to improving health and well-being, including physical and mental health resources, home visiting programs, developmental screenings, educational programs, legal services, housing, transportation supports, and job training. Resources might be on a prevention, intervention, or treatment level.

ParentLink also provides a WarmLine that connects callers to Family Support Specialists, individuals who hold master's degrees in human services fields. The WarmLine provides an access point to community services and information about other resources.

North Dakota

The North Dakota Center for Persons with Disabilities, the state's University Center for Excellence in Developmental Disabilities, is housed on the Minot State University campus. Within that center, the North Dakota Navigators employs nine certified navigators, six of which are assigned to specific regions of the state.

Rhode Island

Rhode Island manages a statewide navigator program under a contract with Health Source Rhode Island and the Executive Office of Health and Human Services. Every federally qualified health center and 11 community-based organizations throughout the state have navigators ready to help connect Rhode Islanders to health insurance. In addition, certified application counselors are located at several community organizations and are available to provide free and unbiased in-person enrollment assistance.

Virginia

Virginia's Center for Family Involvement (CFI) is housed within the Partnership for People with Disabilities (a University Center for Excellence in Developmental Disabilities) at Virginia Commonwealth University. The Family to Family Network is an initiative of CFI that uses a peer support model based on Parent to Parent USA evidence-based practices in matching families one-to-one using trained volunteer parents, grandparents, siblings, and self-advocates. Local networks coordinated by the Family to Family Network provide resource referrals on topics such as special education and early intervention services, health care and related financing (such as private insurance, TriCare and Medicaid), home and community-based Medicaid Waiver long-term-care services, disability services, and other community resources.

CFI also supports the Family Navigator program, which recruits and trains parents and primary caregivers who are supporting (or have supported) a family member with a developmental disability or special health care need. These family navigators provide support to individuals and families through the Family to Family Network, including helping families identify and obtain information, resources, services, and community supports, as well as providing assistance with using disability services and systems. Family navigators may also serve as family leaders in effecting public policy and systems change in their locality. Family navigators agree to volunteer approximately five hours a month.

Wisconsin

Since 2000, the Wisconsin Children and Youth with Special Health Care Needs (WI CYSHCN) Program (Title V) has supported a network of regional centers. Staff at five CYSHCN regional centers help families across the state navigate the care system for their children who have autism spectrum disorder/developmental disabilities and special health care needs. WI-CYSHCN regional center staff include professionals from disciplines such as social work as well as parents of CYSHCN. Additional Title V program-affiliated family navigation support is offered through the Family-to-Family Health Information Center (Family Voices of Wisconsin) and Parent to Parent of Wisconsin. In both agencies, parents of CYSHCN assist other parents through education, information, leadership development, and emotional support.