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# Michigan Pediatric Epilepsy Project

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## Intervention Change Package<sup>1</sup>

For a Learning Collaborative on Adoption and Implementation of Quality Improvement Practices to Improve Access to Quality Care for Children and Youth with Epilepsy in Michigan

The goal of the Michigan Pediatric Epilepsy Learning Collaborative is to **improve the quality, effectiveness, provision, and availability of health care delivered to children and youth with epilepsy (CYE)** particularly those in rural and underserved areas of Michigan. This project is part of the *Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy* initiative, funded by the U.S. Department of Health and Human Services, Maternal Child Health Services Branch through grant number H98MC26257.

This Learning Collaborative (“LC”) is focused on the adoption and implementation of best practices and evidence-based models related to comprehensive and coordinated care; telehealth/telemedicine; a framework to help youth successfully transition from the pediatric to adult system of health care; and outreach and education about epilepsy among stakeholders. This LC includes primary care and epilepsy specialty care sites that are committed to expanding access to quality care, assisting youth to successfully transition to adult care, and increase stakeholder and community members’ awareness and knowledge about epilepsy.

Participating sites are committed to testing meaningful changes that will help move them toward accomplishing this goal. These sites will share their adoption and adaptation successes and learnings in real time to further accelerate their achievement of improved outcomes. The Change Package that follows will serve as the foundation for this LC.

### ABOUT THIS CHANGE PACKAGE

This Change Package is comprised of the following elements: 1) Collaborative Mission; 2) Collaborative Philosophy, Principles, and Values; 3) Goals for the Collaborative; 4) The Challenge; and 5) the Summary Framework. The Summary Framework will help focus the work of participating sites in the LC through a diagram that depicts the relationship between the key components that must be addressed in this work and a summary that provides descriptions and strategies for achieving the success described in the Goals for the Collaborative. The strategies will serve as a launch pad for the small tests of change that sites will be conducting throughout this LC.

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<sup>1</sup> Markiewicz, J., Ebert, L., Ling, D., Amaya-Jackson, L., & Kisiel, C. (2006). Learning Collaborative Toolkit. Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.



## I. COLLABORATIVE MISSION

The mission for participating Project sites in this Collaborative is twofold:

- Improve capacity to deliver high-quality services and supports through the adoption and adaptation of evidence-based practice models; and
- Enhance understanding of diagnosis and treatment of epilepsy, levels of care, local and statewide resources, and successful transition to adult care across diverse settings, including project sites, non-project sites, and their local communities.

## II. COLLABORATIVE PHILOSOPHY, PRINCIPLES, AND VALUES

This Change Package is built upon nine (9) foundational principles. These principles express the overarching values guiding the work to adopt and implement evidence-based practices in the treatment of childhood epilepsy. They are interrelated and work together in a dynamic, synergistic way. The order does not reflect a judgment of each principle's respective worth or relevance. We believe that:

1. Much can be done to improve the lives of children and youth with epilepsy in rural and underserved areas of Michigan.
2. Children and youth with epilepsy who live in rural and underserved areas in Michigan need more options to access specialized epilepsy care and treatment.
3. Children and youth with epilepsy have the highest “parent-reported” need for care coordination<sup>2</sup> and care through a patient-centered medical home.
4. Health information technologies such as telehealth, telemedicine, and mHealth (delivery of health care services through a mobile communication device) serve as important tools in delivering chronic medical care for primary care providers and pediatric medical and surgical subspecialists.<sup>3</sup>
5. Early referral of children with uncontrolled seizures to a pediatric epilepsy surgery center for evaluation is critical to achieving optimal patient outcomes.<sup>4</sup>
6. Pediatric, specialty care, and case management providers have important roles in helping youth to successfully transition to adult health care providers.<sup>5</sup>
7. Coordinated and ongoing outreach and education directed at key stakeholder groups can increase understanding, empowerment, care management, and quality of life among

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<sup>2</sup> S.L. Toomey, A.T. Chien, M.N. Elliott, J. Ratner, and M.A. Schuster, “Disparities in unmet need for care coordination: The National Survey of Children’s Health,” *Pediatrics*, vol. 131, no. 2, pp. 217-224, 2013.

<sup>3</sup> B.L. Burke Jr., R. W. Hall, “Telemedicine: Pediatric Applications,” *Pediatrics*, vol. 136, no. 1, pp e293-e308, 2015.

<sup>4</sup> J.K. Cross, P. Jayakar, D. Nordli, et al. Proposed criteria for referral and evaluation of children for epilepsy surgery: recommendations of the Subcommittee for Pediatric Epilepsy Surgery. *Epilepsia* 2006; 47:952-9.

<sup>5</sup> American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. Clinical Report – Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. *Pediatrics*, vol. 128, no. 1, pp. 182-200, 2011.

children and youth with epilepsy and their families.<sup>6</sup>

8. Family engagement is an essential component of meaningful improvements in the quality of health care delivery and the health of the population.<sup>7</sup>
9. Collaboration among key stakeholders (e.g., public health, schools, healthcare, epilepsy centers, non-profits) will lead to improved delivery and coordination of community services.<sup>8</sup>

### III. GOALS OF THIS COLLABORATIVE

The Collaborative Goals fall into seven (7) best practice categories. The ultimate goal of this Collaborative is for each participating site to achieve measurable improvements in each of these categories. The seven categories for improvement include:

1. Care to children and youth with epilepsy (CYE) within a patient/family-centered medical home
2. Comprehensive and coordinated treatment and care plans for CYE patients
3. Transition infrastructure in the patient/family-centered medical home
4. Successful youth transition to adult health care providers
5. Access to specialized epilepsy care for CYE living in medically-underserved and rural areas
6. Telemedicine, telehealth, and mHealth as tools to expand services to CYE
7. Family involvement in all project activities

**Note:** *The suggested targets listed in the goal statement will likely need to be individualized by each clinic team in order to be useful, achievable targets for the above goals.*

### IV. THE CHALLENGE: BACKGROUND & NEED

In 2010, HRSA awarded \$1,057,409 to the Epilepsy Foundation to support a National Center of Excellence. An additional \$2,982,170 was awarded to grantees across the U.S. to support community-based program implementation aimed at improving access to care for children and youth with epilepsy. Michigan was one of these grantees, using funding to increase availability of quality health services for children and youth with epilepsy in medically underserved and rural areas using telehealth and the increased application of medical home coordination. These activities were continued with another three-year award in 2013. In 2016, HRSA awarded \$3.2 million to seven grantees, including Michigan, to implement quality improvement learning collaboratives designed to further advance access to quality health care for CYE.

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<sup>6</sup> IOM (Institute of Medicine). 2012. *Epilepsy across the spectrum: Promoting health and understanding*. Washington, DC: The National Academies Press.

<sup>7</sup> K.L. Carman, P. Dardess, M. Maurer, S. Sofaer, K. Adams, C. Bechtel and J. Sweeney, "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies," *Health Affairs*, 32: 2 (2013):223-231.

<sup>8</sup> IOM (Institute of Medicine). 2012. *Epilepsy across the spectrum: Promoting health and understanding*. Washington, DC: The National Academies Press.

In Michigan, approximately 22.4% of children enrolled in Children’s Special Health Care Services (CSHCS) live in rural areas.<sup>9</sup> Children with an epilepsy diagnosis comprise 10.12% of Michigan’s CSHCS total population of 33,082. Among these CYE, 76% rely on Medicaid for health care coverage compared to 66.6% of all Michigan CSHCS families, and 43% are also SSI (Supplement Security Income) recipients.<sup>10</sup>

In a January 2016 parent survey of Michigan’s CSHCS enrollees with epilepsy, parents expressed several challenges or barriers to their child’s care:<sup>11</sup>

- Distance to specialist appointments is a challenge. The majority of parents indicated they travel more than 30 minutes to get to their child’s epilepsy specialist, and 12% need to travel more than 2 hours.
- More than half of parents expressed interest in using telemedicine for some appointments with their child’s epilepsy specialist.
- Epilepsy action plans (“seizure action plans”) are underutilized as a strategy to get specialists, primary care providers, parents, and CYE “on the same page.”
- Many CYE are not progressing toward greater independence in their own care, and 38% of parents expressed interest in trainings around transition to adulthood for CYE.
- More than half of parents say their child does not have a medical home. These parents were more likely to not receive help with coordinating appointments and referrals, insurance and transportation questions, and school-related issues.
- Parents are interested in training, especially related to emotional health of CYE, being a sibling of a child with a chronic disease, being an advocate for CYE, care coordination/medical home, and becoming a parent mentor.

The Plan, Do, Study, Act (PDSA) process, which enables testing and implementation of small, rapid changes, has been demonstrated as an effective strategy to accomplish multiple goals across various sites.<sup>12</sup>

Through participation in this Learning Collaborative, sites will strive to implement quality improvement practices related to patient/family-centered medical home models, comprehensive and coordinated treatment and care plans, telemedicine (or telehealth or mHealth), transition, specialty care, and family involvement in their diverse settings.

## V. SUMMARY FRAMEWORK

While the Philosophy, Principles, and Values provide an overarching foundation for this work, the components describe what sites and staff at various levels must do to apply these principles. In this framework, there are three levels of components identified:

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<sup>9</sup> National Survey of Children’s Health, NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health website. Retrieved 04/06/16 from [www.childhealthdata.org](http://www.childhealthdata.org).

<sup>10</sup> 2015 Michigan Children’s Special Health Care Services Data Warehouse, retrieved October 2015.

<sup>11</sup> S. Clark, *Statewide Survey of Parents/Caregivers of Children and Youth with Epilepsy*, Child Health Evaluation and Research (CHEAR) Unit University of Michigan, May 2016.

<sup>12</sup> The W. Edwards Deming Institute. The Plan-Do-Study-Act (PDSA) Cycle. <https://deming.org/management-system/pdsacycle>. Accessed December 19, 2016.

- 1) Organizational readiness;
- 2) Clinical competence; and
- 3) Effective family and youth engagement.

An organization must have the capacity to implement a new evidence-based practice model, must have worked through organizational culture barriers to implementing evidence-based practice, and must have an infrastructure in place to sustain system-wide change. In order for this to happen, engagement must happen at all affected levels (See Figure 1).

Additionally, improved access to quality care for children and youth with epilepsy will be most successful when project partners have a strong understanding of Michigan’s system for comprehensive diagnostic and treatment services for individuals with intractable epilepsy; robust partnerships are established between primary care providers and epilepsy specialists; epilepsy action plans are utilized to their fullest potential; technology is leveraged to expand access and support care management; and families are engaged in meaningful involvement.

Figure 1

