

Insights

Using Data Evaluation to Support Improvements in Epilepsy Care

As a special healthcare need, epilepsy can be difficult to treat because it doesn't affect every patient the same way. Seizures, a common epileptic symptom, vary in frequency, severity and type between people, which means that healthcare providers need to understand that range of outcomes to create treatment plans.

And because epilepsy affects a small portion of the population, expertise for treatment isn't always available. The Centers for Disease Control and Prevention estimated in 2013 that 2.9 million people in the United States, including, [460,000 children between ages 0 and 17](#), had epilepsy.

To help create a robust system of care and ensure that all patients have access to treatment, the American Academy of Pediatrics is conducting the Children and Youth with Epilepsy initiative, which NICHQ is supporting in the evaluation to create a data dashboard for quality improvement (QI) metrics. The goal of the QI initiative is to strengthen current resources and systems while also identifying gaps in systems.

One of the keys to making improvements is understanding the performance of current systems. As with other QI initiatives, [baseline measures and data](#) need to be collected to determine where there are areas for improvements and what elements are working well enough that they should be replicated across the healthcare delivery system.

The overall objectives are to bring expert level care to all people with epilepsy and improve the transition from pediatric to adult care for all patients. For the former, tools such as telehealth will be used to better connect children and families with expert providers like epileptologists and neurologists that otherwise would be inaccessible. For that latter goal, NICHQ will work with Got Transition, a key partner on this initiative, in implementing its strategies to ensure that the proper resources are being used to connect families with the appropriate health services and transition adolescents to adult care as they age out of the pediatric clinic.

"Evaluating the use of telehealth resources, transition plans for children with epilepsy and use of tools like Epilepsy/Seizure Action Plans will provide insight on how improvement plans should be shaped and how to address the underlying challenges to creating better health outcomes," says Sabrina Selk, ScD, NICHQ's associate director of applied research and evaluation.

The collaborative evaluation process will help other program stakeholders provide targeted technical assistance during the project, and ultimately inform the creation and implementation of strategies that lead to sustainable change in the long term. As data is accumulated and analyzed, stronger systems, tools and transitions can be developed so that every child with epilepsy can reach their optimal health.