The Hospital for Sick Children – Epilepsy
ECHO Implementation Profile

"I see a seamless integration between GPs, pediatrics, community neurologists, and the specialist center level where patients were moving seamlessly between them, not getting stuck in silos. They're getting the right treatment. They're getting the best treatment they can. That knowledge is freely flowing between these different groups."

Project ECHO Ontario: Epilepsy Across the Lifespan, and two of its programs—the Children and Youth with Epilepsy ECHO and the Epilepsy Genetics ECHO—were included in a study led by Diffusion Associates and funded by the Robert Wood Johnson Foundation. The purpose of this study was to document and share how ECHO is adopted, implemented and sustained across ECHO hubs and programs in the United States and Canada. This study was separate from, but endorsed by, the ECHO Institute.

Trisha Calabrese, MPH, was a 2020 implementation fellow and worked with nine other fellows and Diffusion Associates that year in conducting this study. Calabrese wrote this site profile with Jim Dearing, PhD, professor at Michigan State University. Eva Serhal, PhD, another 2020 implementation fellow, and Dearing, conducted interviews from November-December 2020 which are the basis of this profile.

We begin this profile by sharing unique implementation insights from Project ECHO Ontario: Epilepsy Across the Lifespan.

ECHO Implementation Insights

Province Level Support

Project ECHO Ontario: Epilepsy Across the Lifespan was supported through evergreen funding from the Ontario Ministry of Health. In turn, this ECHO provided programs to meet the need of the Ontario Ministry of Health. This commitment and its success at attracting province-wide healthcare providers and delivering value illustrates the benefits of ECHO site leaders getting to know providence/state-level health authorities and showing them how ECHO programs can help achieve province- and state-level objectives.

Distributed and Shared Operation

Project ECHO Ontario served as a centralized hub, based at SickKids, for nine other hubs at nine regional hospitals, each offering epilepsy ECHOs in Ontario. A common set of didactics was used at each of the nine regional locations which also relied on some support from SickKids, although each site drew on their own experts and recruited their own participants. This distributed and shared approach to ECHO was seen as efficient and responsive to regional interests.

Lifespan Approach

The lifespan approach to a disease like epilepsy affects patients and their care providers. One interviewee made this point: "I'm an adult neurologist. I really found that the connection between adult neurology and pediatric neurology has strengthened through ECHO. That's important because these

kids, when they turn 18, they transition to the adult practice. In Ontario, we're very keen to support this transition from pediatric to adult care." ECHO has served to bridge this patient care transition by its different ECHO programs, linking the adult and pediatric providers which might not otherwise happen.

ECHO Model Adoption

Project ECHO Ontario: Epilepsy Across the Lifespan

In 2020, epilepsy was the second most common neurological condition in the province of Ontario. It impacted approximately 90,000 Ontarians and 6,000 new cases of epilepsy were diagnosed each year. Many individuals with epilepsy, when diagnosed appropriately, can be treated effectively with anti-epileptic drugs. In 2011, the Ontario Ministry of Health proposed a provincial strategy for epilepsy care and published findings from an expert panel resulting in the establishment of an alternate epilepsy network of district epilepsy care centers and regional epilepsy surgery centers of excellence. O. Carter Snead III, MD, pediatric epileptologist, and co-chair of the Ontario Epilepsy Implementation Task Force, led the creation of guidelines to improve epilepsy care in Ontario. He and Elizabeth Donner, MD, director of the Comprehensive Epilepsy Program at SickKids, had been examining and piloting various approaches to successfully implement the guidelines to improve the quality and consistency of epilepsy care, and to ensure that all Ontarians with epilepsy had timely access to treatment, including surgical care.

Project ECHO Ontario: Epilepsy Across the Lifespan served as the centralized lead hub, based at SickKids, for nine other hubs at nine regional hospitals, each offering epilepsy ECHOs in Ontario. They worked off a common set of didactics and with staff support from SickKids, but each hub was staffed with its own local experts and its own set of spoke providers. Epilepsy ECHO programs were administered out of the Institute of SickKids, which adopted an interprofessional approach that brought together educators from multiple disciplines and created new partnerships. The ECHO Ontario superhub provided support and training to the program staff. Each of the interdisciplinary teams included an epileptologist, nurse practitioner, pharmacist, social worker, and community agency representative connected with a provincial Comprehensive Epilepsy Program (CEP). Epilepsy programs at each of the nine hubs were funded by the Ontario Ministry of Health. Here we highlight two of those programs.

Children and Youth with Epilepsy ECHO

In 2017, the Ministry of Health encouraged Snead to apply for funding to support the launch of an ECHO program. The Ministry of Health began leveraging the ECHO Model in 2013 to address pain management and suggested ECHO as a model to build the capacity of frontline health care clinicians to treat patients with epilepsy. After receiving word of funding, Snead and Donner traveled to Albuquerque, New Mexico, to attend ECHO Institute immersion training. Project ECHO aligned with their goals of knowledge transfer and establishing a productive relationship with providers throughout Ontario. Initially cautioned by Sanjeev Arora, MD, the founder of Project ECHO, on the use of the ECHO methodology to address a niche condition like epilepsy, Snead and Donner partnered with the team at the American Academy of Pediatrics for guidance since that team had been running a successful epilepsy ECHO program. Collectively, with the education committee and a team of adult and pediatric epileptologists, the SickKids-led program had successfully run several iterations each over 15 weeks and evolved over time by modifying it based on learnings from previous sessions.

Epilepsy and Genetics ECHO

In 2019, Lyssa Boisse Lomax, MD, adult epileptologist at Kingston Health Sciences and Kevin Jones, MD, paediatric epileptologist at McMaster Children's Hospital, heard about ECHO program and saw it as an opportunity to launch an epilepsy and genetics program to help provincial providers. They both attended the immersion training in Albuquerque.

The Epilepsy and Genetics ECHO ran for one hour each week over five weeks and covered specialized topics such as testing and gene panel selection. Each session included a 10-minute didactic followed by case presentations. The faculty focused on generating discussion among participants. This program averaged 45-50 participants during its first cycle and included many neurologists. The program was developed as a result of recurring requests from participants about genetics. This series was used to help educate individuals on how to best order epilepsy panels.

For both programs—Children and Youth with Epilepsy and Epilepsy Genetics—the structure of each series was highly organized. Each began with didactics and proceeded into presentations by spoke participants and discussion. Each ECHO was supported by a core team at SickKids. Content was informed by a needs assessment during the planning. Provincial guidelines were also used to shape the curricula. Didactic Power Point slides were available on the website and attendees can earn continuing medical education credit for each program.

ECHO Model Implementation

The ECHO Model seeks to build a learning community where "all teach, all learn." This is done by leveraging technology, by sharing best practices, though case-based learning, and using data. We asked respondents to tell us what "all teach, all learn" meant to them. Respondents emphasized that mutual respect was an important pre-condition to learning and that they had changed their own care practices as a result of ECHO involvement.

"There's no one expert," said an interviewee. "I learn more from our pediatricians than I do from our hub team sometimes, because the pediatricians see people in the front line, and they have different perspectives. I think it's a case of we're all able to teach each other, because we have diverse understanding of our patients."

Another interviewee said that "I have to understand where they're [participants] coming from. If I ask myself, 'Why aren't they ordering retests on the MRIs?' well, it may be because they don't have access to them, or don't know how to order them. So, I'm understanding and learning from their point of view, in addition to teaching them a fact, or understanding a pathway, or simplifying a pathway for them."

This hub offered multiple epilepsy programs and during any given week there were one to two pediatric epilepsy ECHOs and one to two adult epilepsy ECHO programs available. For each program, the same didactic was offered at each of the hubs; however, they were run on different days and times so that participants could attend a session that fit their schedule.

Factors Influencing Implementation

Studies of program implementation identify context factors that can shape how a program was implemented. Such factors include leaders or champions, state and federal policies, funding, partnerships or collaborations, staffing, internal structures and processes, and monitoring for quality and fidelity. Not all of these factors play a role in how ECHO was implemented here or elsewhere.

Below, we identify factors that were emphasized by interviewees.

Funding

Project ECHO Ontario: Epilepsy Across the Lifespan was supported through evergreen funding from the Ontario Ministry of Health. SickKids received approximately $700,000 Canadian from the Ministry of Health to operate the program. Some of this funding supported a centralized staff responsible for coordinating and managing the programs for each of hospitals. Monies were also provided to each hospital to support its epilepsy ECHO hub. Continued funding and support from the Ministry were necessary to continue this ambitious effort across Ontario.

Policies

The Ministry of Health requested the development and implementation of the Epilepsy and Genetics ECHO. It was also commonly requested by spoke providers from across Ontario who took part in some of the more remedial epilepsy ECHOs.

Organizational Staffing

Respondents reported that the SickKids epilepsy hub was an organized and structured system with tiers of executive committees and subcommittees. This structure was necessarily complicated by SickKids being a lead hub with nine other hubs, each offering epilepsy ECHOs. For each program session, faculty and administrative staff were present, with the former attending to fidelity to the ECHO Model and the precepts of "all teach, all learn." At the start of each session, the facilitator read a script, which included language about fostering a positive learning environment by asking questions and making comments so that everyone could learn from each other. Standardized curricula were used, with the opportunity to include variation as needed, and cases were discussed. A multi-method evaluation was also conducted to monitor session feedback as well as pre- and post-program changes.

ECHO Vision and Sustainability

All respondents agreed that this hub and its programs would be considered successful if all Ontarians with epilepsy had better care, improved access to care, and every patient was treated appropriately. The team recognized this required systemic change; however, they felt that ECHO was helping to break down many barriers and silos.

When we asked each interviewee about their vision for the future, they each mentioned that reaching the rural and remote areas of Ontario and building cultural competency was key. In the future, the team would like to reach additional under-resourced areas, including areas with limited broadband. They were also interested in rigorous research to monitor progress as well as ECHOs' effectiveness at changing practice.

One respondent summed up a vision described by many; “You see the collaborations and the potential for growth. I've seen more and more of it. I see a seamless integration between GPs, pediatrics, community neurologists, and the specialist center level where patients were moving seamlessly between them, not getting stuck in silos. They're getting the right treatment. They're getting the best treatment they can. That knowledge is freely flowing between these different groups.”

Respondents

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