

IMPROVING QUALITY OF LIFE AND HEALTH EQUITY FOR PEOPLE LIVING WITH EPILEPSY THROUGH MULTI-SECTOR PARTNERSHIPS (EQOL) PROGRAM

Provider Survey: Summary of Key Findings

Prepared by:
Pamela Kelley, PhD
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Provider Survey: Background

- The provider survey was conducted in Year 4 as part of a larger evaluation of the Epilepsy Foundation New England (EFNE) EQOL program, a five-year initiative funded through a cooperative agreement between EFNE and the Centers for Disease Control and Prevention (CDC).
- The EQOL program aims to strengthen the health system and improve the quality of life (QOL) for people with epilepsy in New England through establishing EFNE Epilepsy Resource Rooms staffed by trained community health workers (CHWs) in participating hospitals/host sites to provide care management, education, support, resources, and referrals to epilepsy self-management programs and other community supports for health care providers to refer their patients with epilepsy.
- The purpose of the survey was to gain understanding of participating provider experiences with the program and to monitor progress towards key program outcomes.

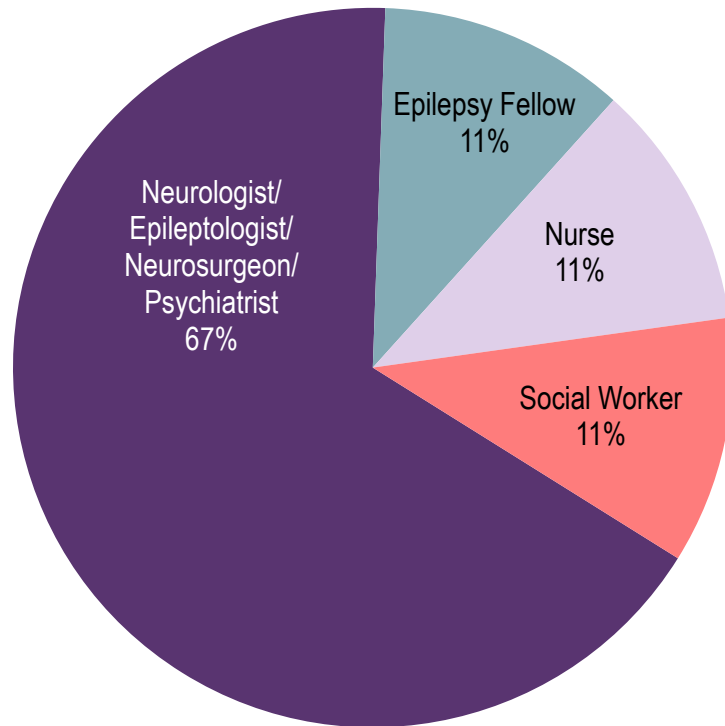


Survey Methods

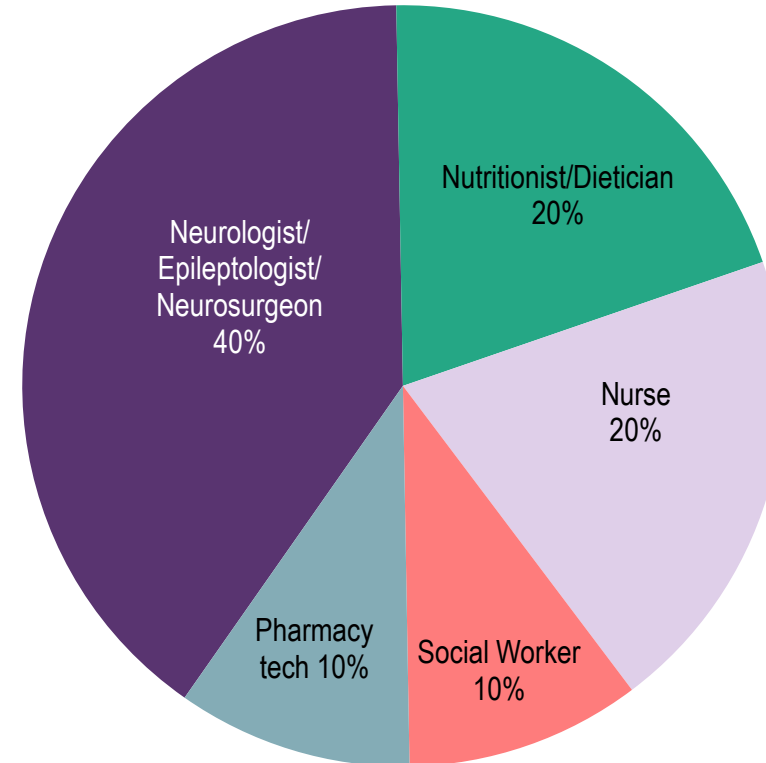
- The 13-item provider survey was developed collaboratively by the EQOL leadership team and the evaluation consultant.
- Guided by the program logic model, the survey was designed to collect quantitative and qualitative data pertaining to participating provider experiences with the program and program outcomes, with focus areas that included:
 - Referring patients to EFNE
 - Referral follow-up
 - Changes in patient care resulting from program participation
 - Changes in hospital capacity to monitor/ track clinical data for patients with epilepsy resulting from program participation
 - Provider suggestions to improve the program
- The survey was administered online (via Qualtrics) in Year 4 at the program's two host sites: Children's Neurodevelopment Center at Hasbro Children's (CNDC) and Mass General Brigham Epilepsy Service (MGB).
- Survey response rates were adequate at both sites:
 - MGB: Of 30 providers invited, 18 responded (60% response rate)
 - CNDC: Of 27 providers invited, 10 responded (37% response rate)
 - The higher response at MGB may be because the program started earlier there than at CNDC

Respondents' Profession/Job Title

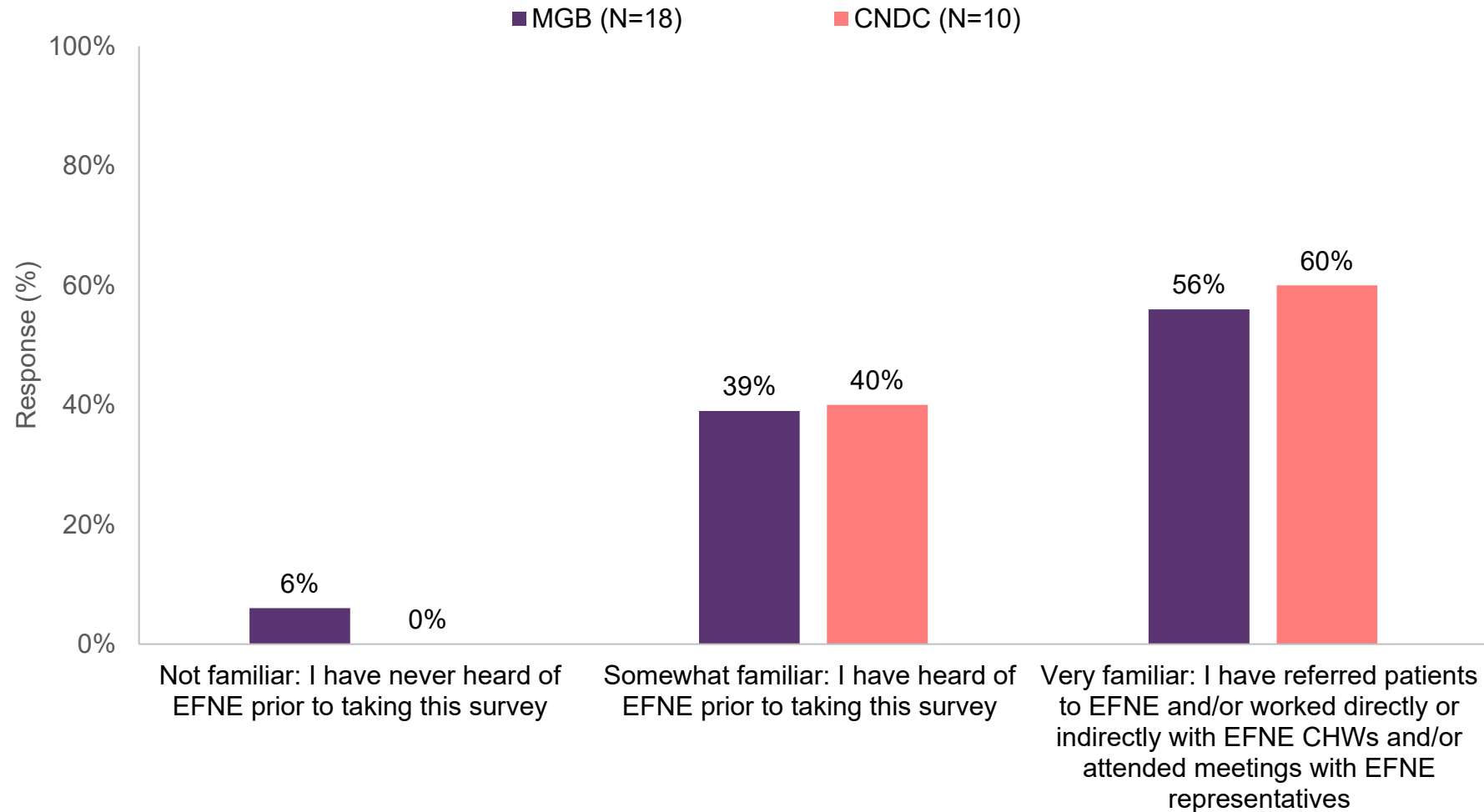
MGB
(N=18)



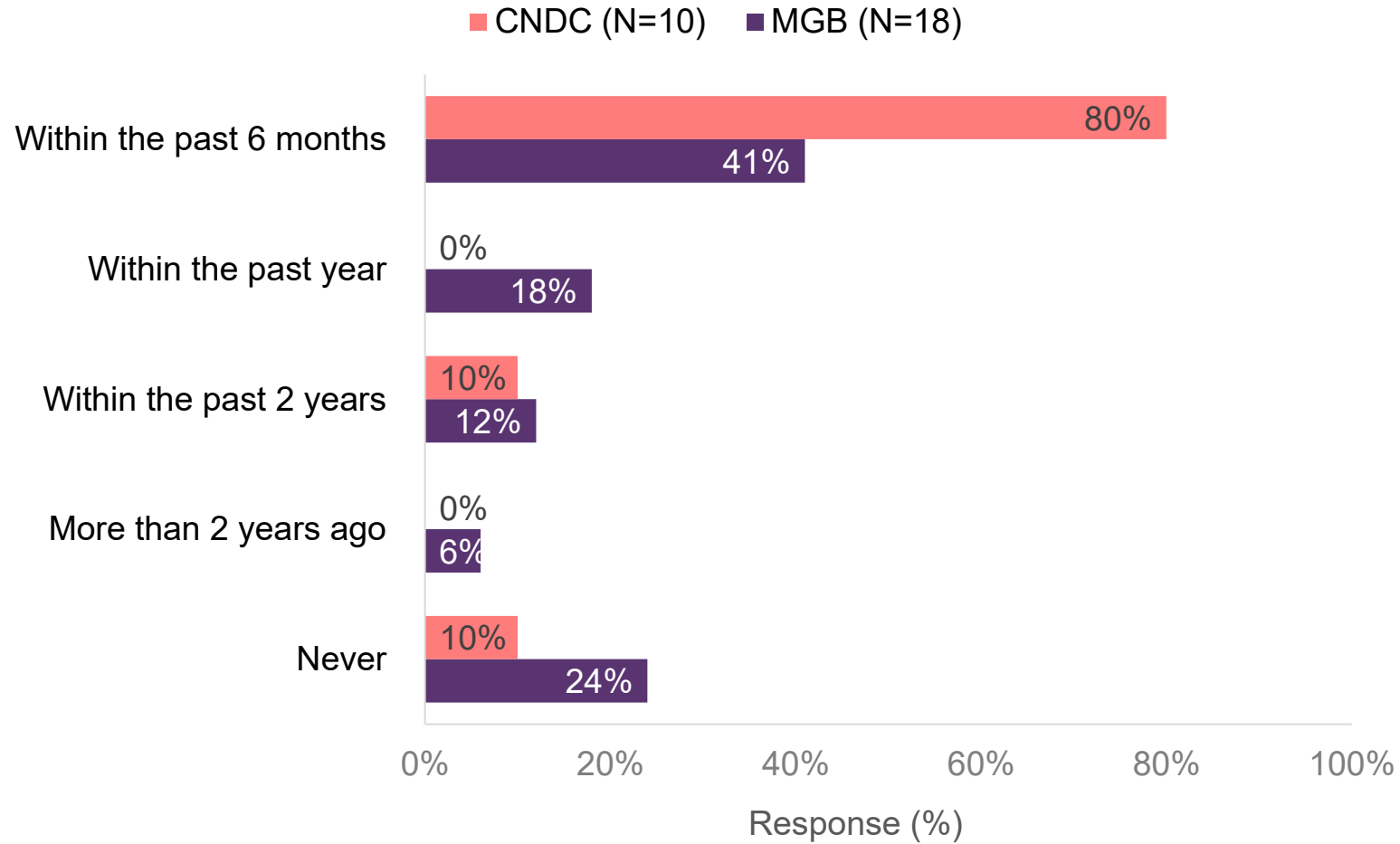
CNDC
(N=10)



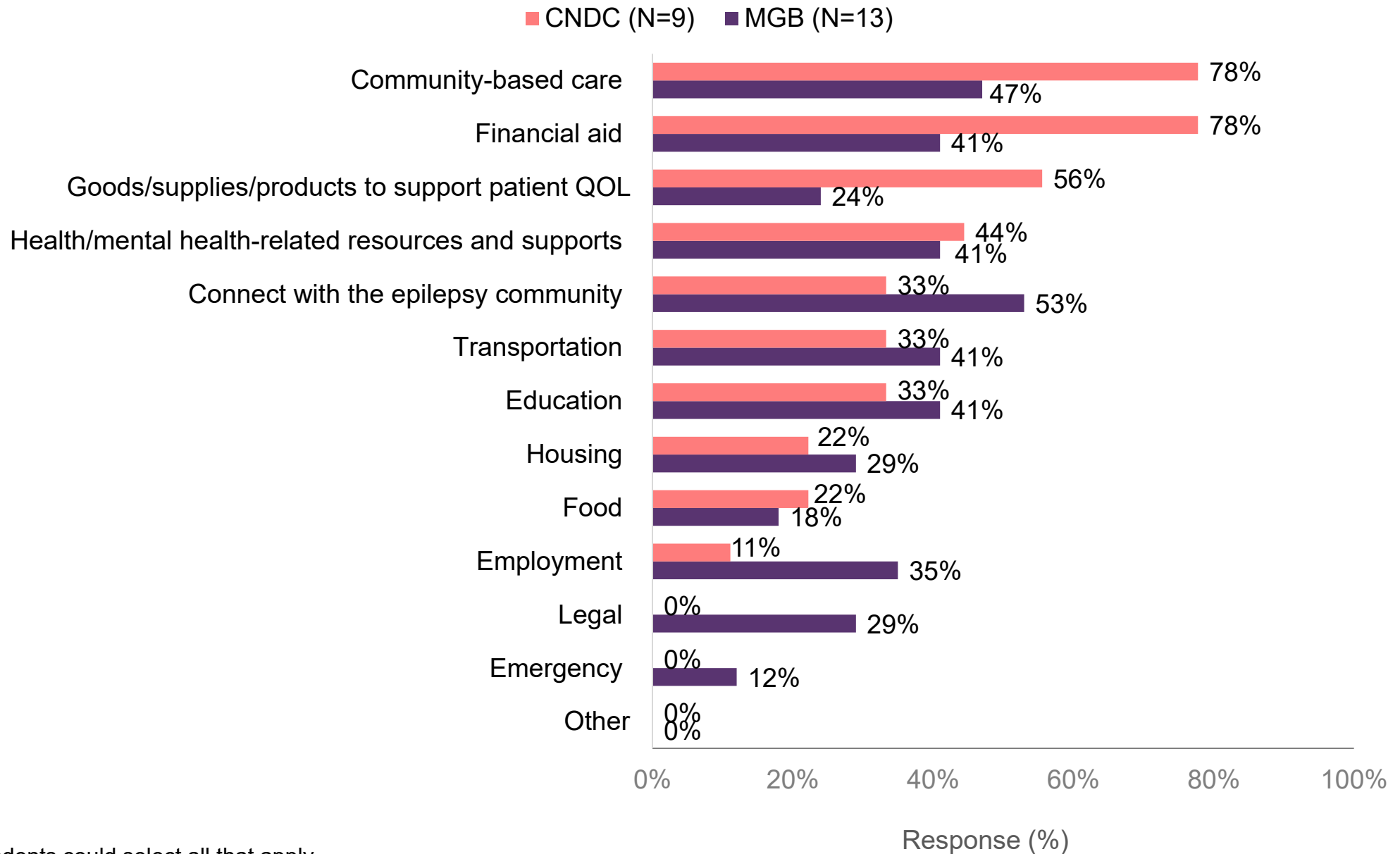
Providers' Familiarity with EFNE Services



Last Time Provider Referred a Patient to EFNE



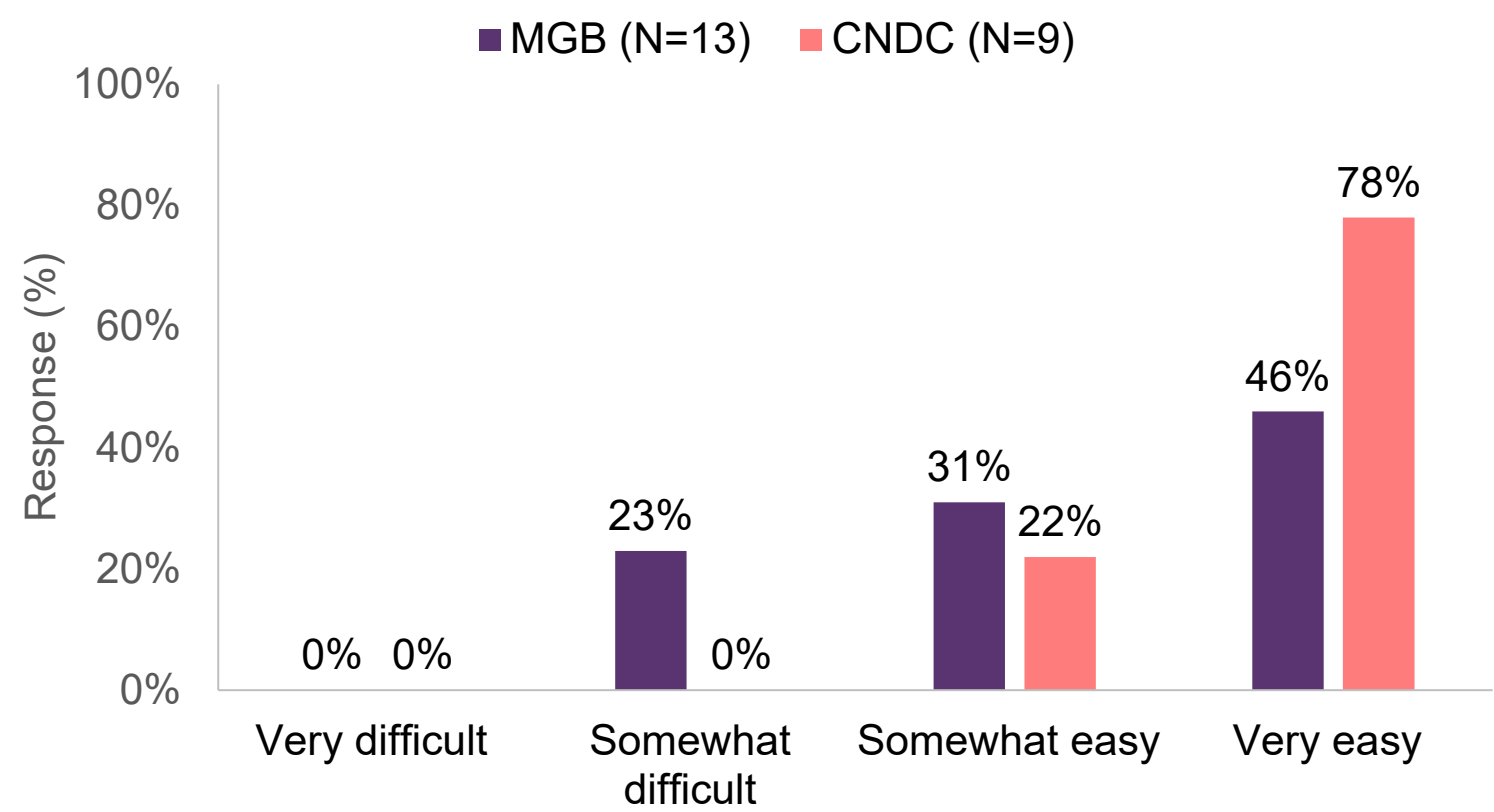
Providers' Reasons for Referring Patients to EFNE



Note: Respondents could select all that apply.

Analysis sample included those respondents who reported they had referred any patients to EFNE.

Ease or Difficulty Referring a Patient/Patients to EFNE



Note: Analysis sample included those respondents who reported they had referred any patients to EFNE.

Reported Reasons Why It Was Difficult to Refer Patients to EFNE (Open-Ended) N=3*

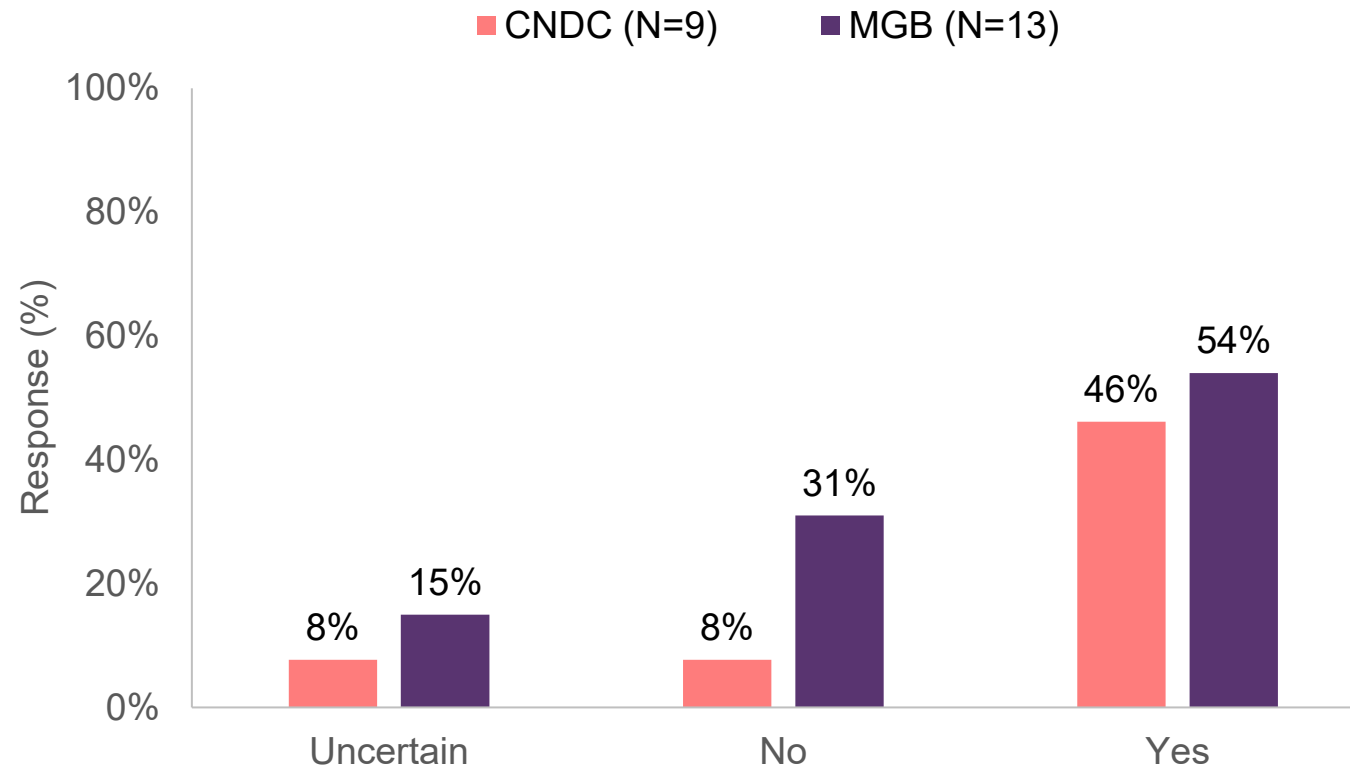
“Accessing EFNE and navigating the site, we have very little time during physician visits.”

“Patients have told me that they did not get responses. This may be due to the nature of requests: employment, transportation, support.”

“I didn't know the proper contact.”

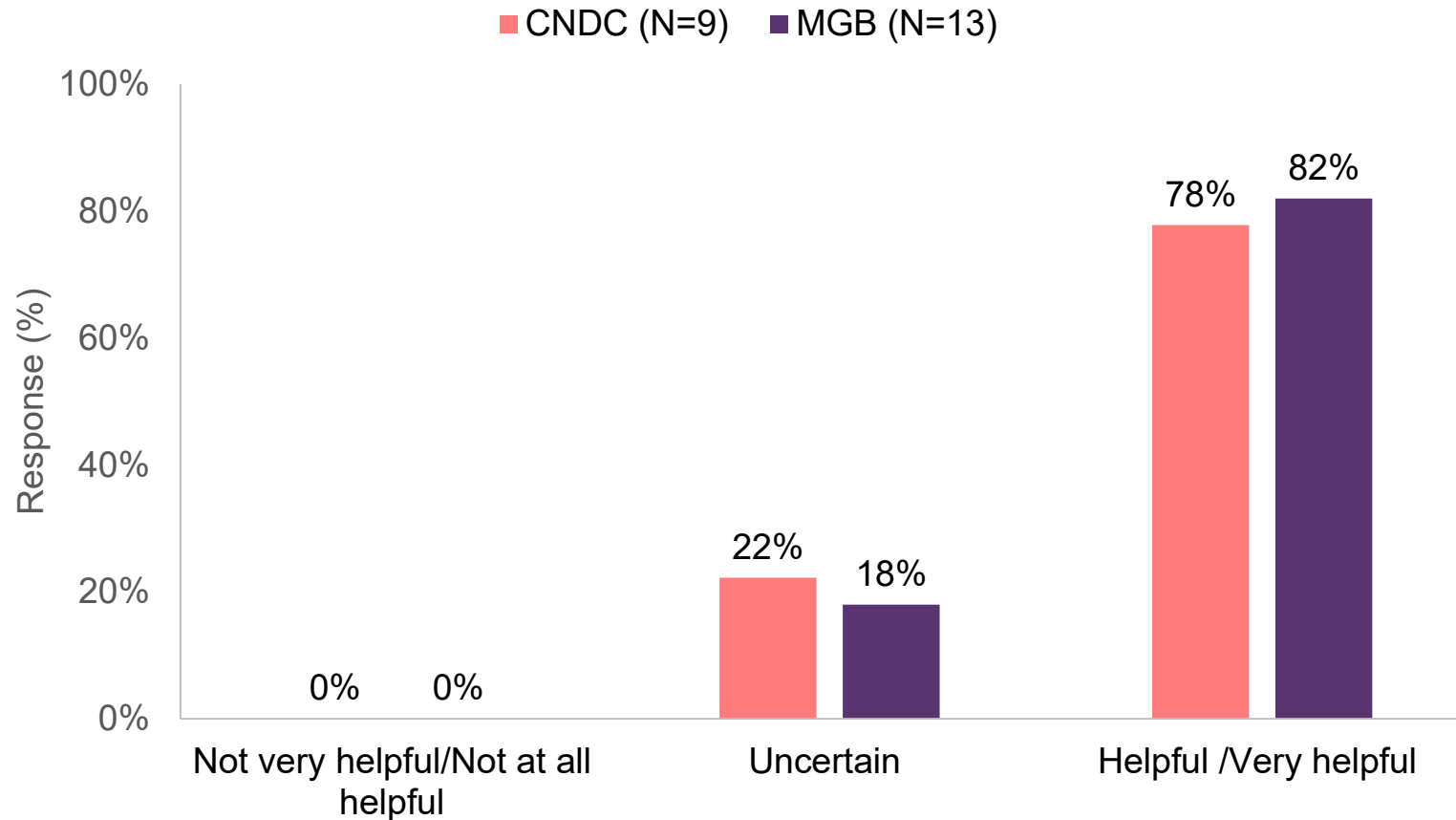
Note: Analysis sample included respondents who reported it was “Somewhat Difficult” to refer a patient to EFNE (N=3).

Providers Who Reported They Received Follow Up Information from EFNE About Patient Status (i.e., whether the patient was successfully connected with needed services)



Note: Analysis sample included those respondents who reported they had referred any patients to EFNE.

Helpfulness of EFNE Services at Improving Care for Patients with Epilepsy

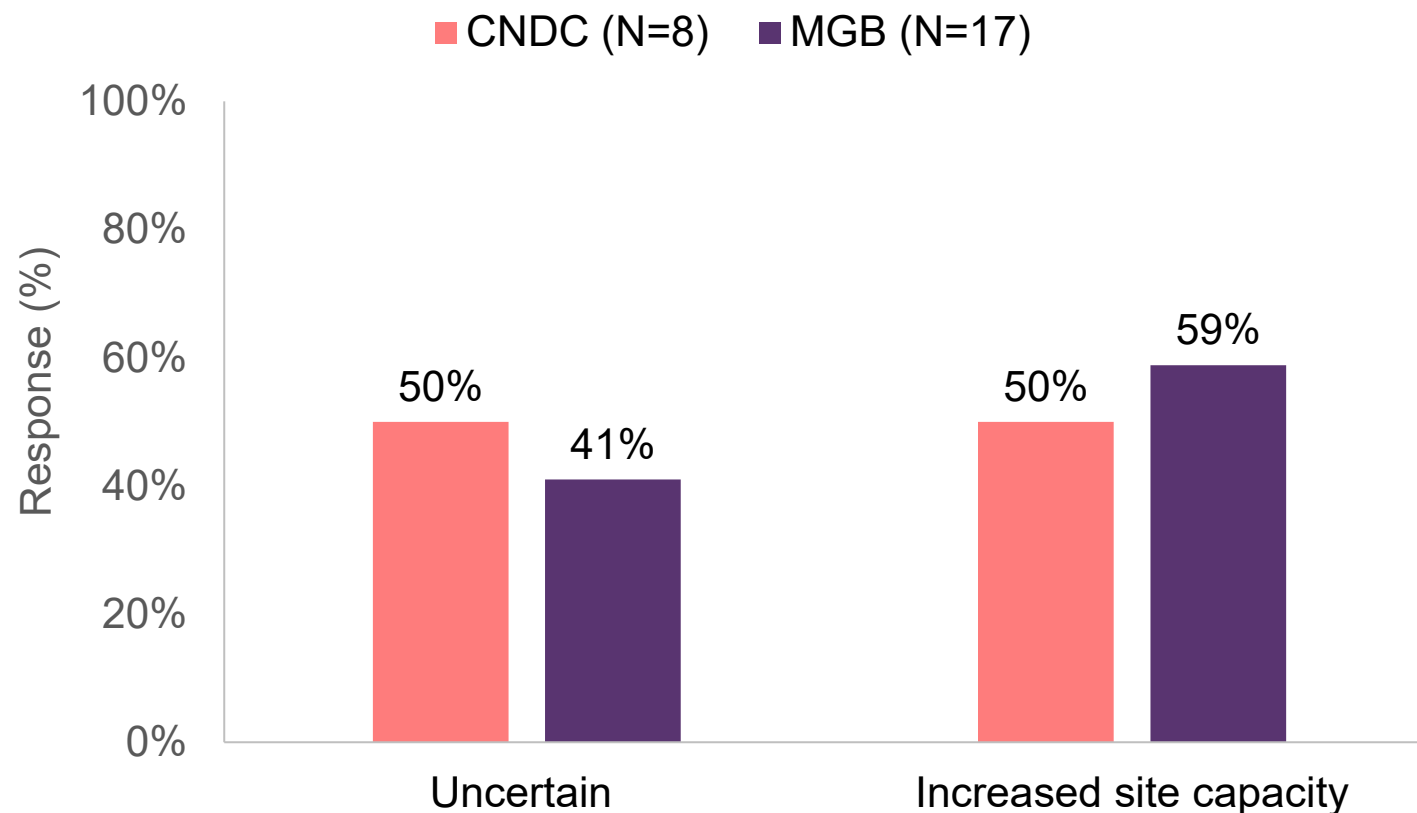


Note: Analysis sample included those respondents who reported they had referred any patients to EFNE.

Reported Ways EFNE Services Have Been Helpful or Not Helpful (Open-Ended) Example Responses (MGB and CNDC)

- *Families find the services helpful. I wish we could find a way for EVERY patient with epilepsy to know about EFNE and the services available.*
- *These services help our patients tremendously.*
- *There are many useful resources, particularly group activities.*
- *Online info is very helpful. I have heard of patients benefiting and have mentioned to patients they may reach out to EFNE.*
- *I have referred nearly 10 patients and [EFNE CHWs] and I am in regular communication and they are lovely and so helpful. Very responsive. My patients say they are hearing from EFNE in a timely fashion so that's great too!*
- *Good educational and epilepsy community resources for patients.*
- *For several years, we have not had social workers or other patient support services, and EFNE was a lifeline for us. The programs they run for our patients and for the children in our community are unique, and vital. We are so thankful for their work.*
- *EFNE is fantastic! They helped many of my pregnant patients to get housing, legal advice and financial/social support. Their help is immense, and I would not be able to offer the same level of care without their support!*
- *EFNE is amazing, but it would be better if they had even more resources (which means we need more donations to EFNE!)*
- *Most recently I referred a patient to the EFNE for help with transportation costs (Uber vouchers). Not sure if this was successful or not.*
- *I should have followed up with EFNE services to follow up how referred family did with EFNE service. A brief update message might have helped to close the loop.*

Providers' Who Reported EFNE Increased their Site Capacity to Monitor/Track Clinical Data for Patients with Epilepsy



Note: Open-ended responses to a survey question that asked, “In what ways, if any, has EFNE increased the capacity of MGB/CNDC to monitor/track clinical data for patients with epilepsy (e.g., support with seizure journals; depression screening; PROMs; etc.)?” were coded as follows: 1) Increased site capacity: the response included one or more ways EFNE helped increase their site capacity; and 2) Uncertain: the response indicated uncertainty or “N/A” (there were no responses that indicated EFNE services had not helped to increase their site capacity).

Reported Ways EFNE has Increased Site Capacity to Monitor/Track Clinical Data for Patients with Epilepsy (Open-Ended)

Key Themes (MGB and CNDC)

- **Helping/Monitoring pregnant patients with epilepsy:**
 - Keeping track of medication levels
 - Reminding patients when they are due for lab/medical appointments
 - Scheduling appointments and rescheduling missed appointments
 - Reminding providers about communications with other specialties that need to happen at this vulnerable time in a woman's life for optimal care
 - Emotional support for patients experiencing increased anxiety and depression at this time
- **PROMs** [Patient Reported Outcome Measures]
- **Depression Screening**
- **Helping patients and families feel supported/Support with patient care, collecting data, connecting with community**
- **Helping patients with functional seizures**
- **Epilepsy Learning Healthcare System (ELHS)**
- **Epsy app** is helpful
- **Connecting patients and families with local resources**, including behavioral supports
- **Increasing patient engagement** with their diagnosis and providing more feedback to the clinic
- Uncertain/Not Sure/Have not seen this yet

Provider Suggestions for How EFNE Might Do More to Increase their Site's Capacity to Monitor/Track Clinical Data for Patients with Epilepsy (Open-Ended)

Example responses (MGB and CNDC)

- *It would be good to know that the patients with depression are being helped. This could be determined by giving them a depression screening tool that is monitored over the course of their treatment.*
- *It may help to have community coordinators/liaisons*
- *Setting up booths at clinic*
- *Increase awareness of what resources are available.*
- *Communicate/educate providers on clinical data tracking resources.*
- *I am pleased with how much they are doing; help from our institution to ensure faster onboarding would be essential as many weeks are lost initially.*
- *Continue to educate patients and expand on the programs beyond Boston, and to patients from diverse backgrounds. Health literacy education would be a huge help.*
- *More chart review and potentially coming in for the first part of follow up visits.*
- *It would be interesting if the CHW can provide information to the families of way[s] to track seizures, side effects, etc.*
- *It would be great if there is any update information if the families got access to the resources they needed.*
- *Unsure/N/A/No suggestions*

Providers' Suggested Improvements to Make EFNE Services More Helpful and/or Better Integrated into their Site Workflow (Open-Ended)

Example responses (MGB and CNDC)

- *Brochures with services and contact info made available in clinic.*
- *1) Faster onboarding of EFNE CHWs; 2) Physical presence/ads in clinic to raise awareness for our providers and patients; 3) Allotted space in clinic.*
- *It would be great if the EFNE community health workers could be more present in our clinics, and we have been working on this.*
- *Work with our social worker to ensure that she is up-to-date on services that are available. She will be seeing many of our patients and should be connected with the EFNE.*
- *Community liaisons would be helpful to help connect patients with the EFNE resources.*
- *An order into Epic would be very helpful to streamline visits in which I identify patients who would be helped by EFNE re: resources.*
- *Have EFNE attend some of our epilepsy conferences.*
- *I think the flow is going well as is. More established parameters on what they are able to be utilized for. There was a lot of uncertainty in the beginning.*
- *More awareness.*
- *I am hopeful that once we have 2 rooms for neurologists, the CHW can join [the] huddle and can meet with all the families with epilepsy.*
- *Consistent referral system (EPIC? Email?) and brief report system.*
- *Unsure.*

Providers' Additional Comments (Open-ended)

Individual Responses (MGB and CNDC)

"Keep doing the amazing work you are doing. We really hope the support you offer for our health system can continue with the sponsored staff you have given us. Thank you."

"Thank you for the regional talks/education that you sponsor, I took part in the General Neurology Conference 2024 as a presenter and love the outreach to community providers!"

"I am SO grateful for all you do! Thank you so much for your fantastic help with our patients!"

"EFNE is a fantastic service and members [CHWs] have been available to come and assess patients within the EMU [Epilepsy Monitoring Unit] (when they are available in-house certain days of the week). Our EMU patients benefit from being connected for the first time with EFNE and learning more about the organization and how to engage with services"

"Having the community health workers working with us and our patients has been so wonderful!!!!!"

"I am very thankful for the collaboration and the opportunity to have CHWs in the clinic. I am looking forward to the next year and seeing this collaboration grow."

"Amazing events"

"I can't thank you enough for the help we get from EFNS. Now we can offer more to the families to meet their needs."

Conclusion

- Providers report that EFNE services are highly valued and helpful for patients with epilepsy, offering essential resources, care management, and support.
- Referral processes are generally easy, though a few providers noted challenges related to communication and clinic workflow.
- EFNE services have improved site capacity for tracking clinical data, supporting patient care, and addressing social needs, especially for patients with complex needs.
- Providers highlighted the positive impact of the program's community health workers and expressed gratitude for the collaboration and resources EFNE provides.
- Suggestions for improvement include increased awareness; enhanced communication and follow-up; more integration into clinic workflows; and coordination with electronic health records (EHR) and other referral tracking systems.
- Overall, providers appreciate EFNE's ongoing support and look forward to continued partnership and program growth.



THANK YOU!