

Increasing Access to Specialty Neuropsychiatric Care: An Evaluation of the Functional Neurological Disorders Clinic

Project Overview

Functional neurological disorders (FNDs) are the second most prevalent condition seen in neurology clinics, after headache^{1,2}. FNDs are classified as neurological conditions not consistent with another neurological disease or explanation and include symptoms such as non-epileptic seizures (NES), tremors, limb weaknesses, speech issues, and vision problems². FNDs are thought to be associated with psychosocial factors and psychological disorders such as trauma, depression, and anxiety. As such, this group of disorders remain highly misunderstood by clinicians and patients alike leading to patients being frequently shuffled around between specialists and often receiving inappropriate care².

To improve care for patients with FND, five multidisciplinary clinics consisting of neurologists and behavioral health professionals exist across the United States³. One of which was the Non-Epileptic Seizures (NES) Clinic at the University of Colorado Hospital at Anschutz Medical Campus, which was launched in 2016. Three years later, the clinic received supplemental funding to continue their program, changing their title to Functional Neurological Disorders (FND) Clinic.

Evaluation

Using patient data collected by the FND clinical team in FileMaker Pro, electronic health record (EHR) data, Colorado Medicaid claims data, team member interviews, external partner interviews, and patient interviews, we evaluated the reach and impact of the FND clinic on engagement, healthcare utilization, and patient satisfaction.

Program Elements

The FND clinic provides comprehensive management, albeit transitional, for patients dealing with FND and currently focuses solely on NES symptoms. Partly due to the influence of the COVID-19 pandemic, but also the needs of their population, who frequently face transportation issues, and to increase access to care across the state, the clinic decided in 2020 to transition to an almost exclusively telehealth model, only offering intakes in person. The current program model (Figure 1) consists of patients being diagnosed with NES through a video-electroencephalogram (V-EEG), referred to the clinic, the FND team determining if the patient is eligible for the treatment model based on their medical history, undergoing a neurology intake followed by a behavioral health intake, and then participating in up to two group therapy programs facilitated by behavioral health providers (hour-long weekly sessions that run for 6 weeks, followed by hour-long weekly sessions that run for 12 weeks). Patients are then referred out of the program to establish care with a community behavioral health provider.

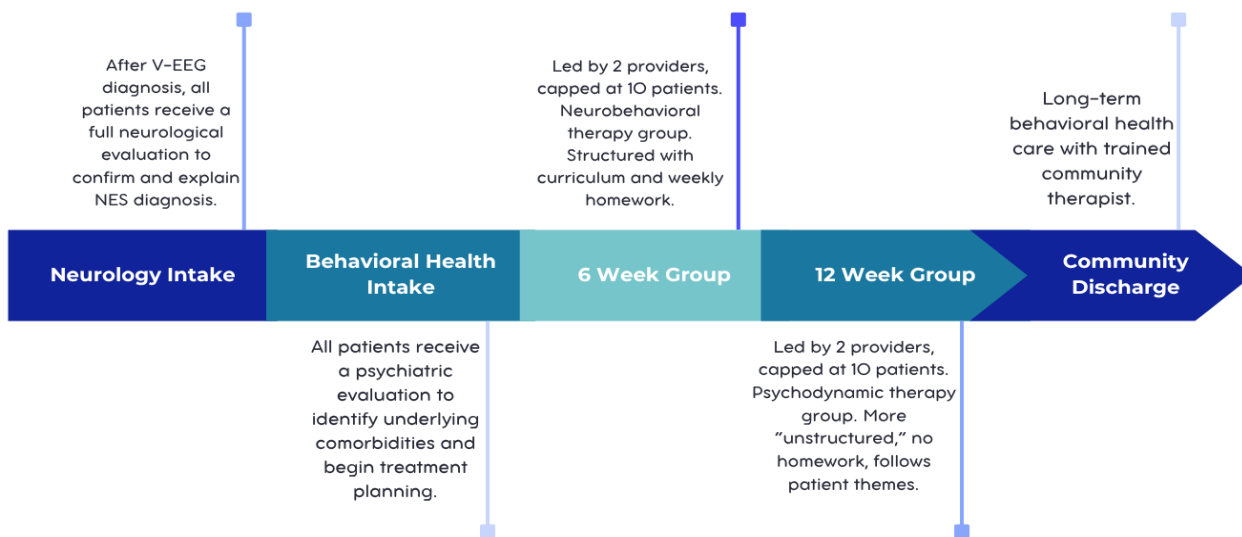


Figure 1. FND treatment program overview

1. Stone, J. & Carson, A. 2015. Functional Neurologic Disorders, *Continuum Journal*, 21(3): 818-837.
2. Barnett, C., Davis R., Mitchell C., & Tyson S. 2022. The Vicious Cycle of Functional Neurological Disorders: A Synthesis of Healthcare Professionals' Views on Working with Patients with Functional Neurological Disorder. *Disability and Rehabilitation*, 44(10):1802-1811.
3. FND Clinic Expansion Proposal. 2024. Accessed 7/2025.

QUANTITATIVE ANALYSIS

Methods Overview

The quantitative analysis characterizes the demographics and program engagement for Medicaid patients that had a scheduled FND neurology intake (e.g. were eligible for treatment with the FND clinic based on medical history) between April 2020 and April 2024. For patients with multiple scheduled neurology intakes, only their first attended neurology intake (and if none attended, first not attended) was used in the evaluation. Only patients with valid Medicaid IDs recorded in Epic were included in the analysis. To understand the impact of the program, patient healthcare utilization (e.g. inpatient and emergency room claim count and Colorado Department of Health Care Policy & Financing (HCPF) spend), as indicated by state Medicaid claims data, was analyzed 12 months before and after neurology intake using a Wilcoxon signed-rank test. Healthcare utilization 12 months before and following the scheduled neurology intake date between neurology intake attendees and non-attendees was analyzed using a Wilcoxon rank sum test.

Results

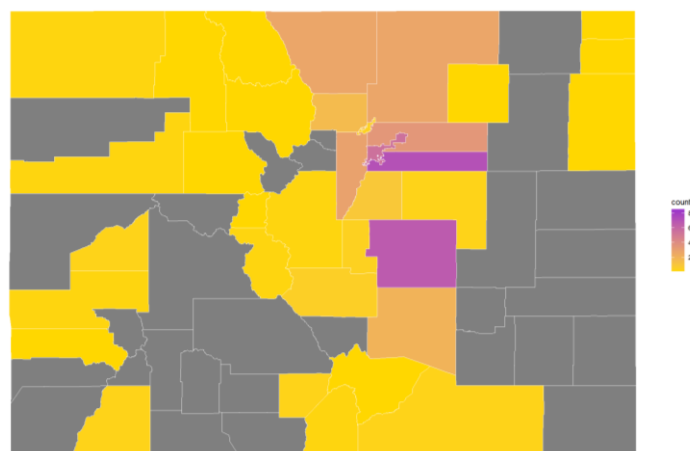
Over the four-year evaluation period, 478 Medicaid patients were deemed appropriate for FND care, had a valid Medicaid ID, and scheduled a FND neurology intake. Of those patients, 408 (85%) attended their scheduled neurology intake. Demographics were similar between patients that attended and patients that never attended their neurology intake, though a higher percentage of patients that attended the neurology intake were female than those that did not attend.

Table 1: Characteristics of Medicaid Patients Eligible for FND Clinic

	Neurology Intake Attendee (n=408)	Neurology Intake Non-Attendees (n=70)
<i>Race</i>		
White or Caucasian	289 (70.8%)	46 (65.7%)
Black or African American	35 (8.6%)	7 (10.0%)
Other	84 (20.6%)	17 (23.3%)
<i>Sex at Birth</i>		
Female	248 (60.8%)	32 (45.7%)
Male	63 (15.4%)	8 (11.4%)
Other	97 (23.8%)	30 (42.9%)
<i>Age</i>		
Mean of Age in Years (SD)	34.6 (11.4)	34.9 (12.1)
<i>Social Vulnerability Index (SVI) Score+</i>		
Mean of SVI Scores (SD)	.71 (.23)	.77 (.22)

Note: +[Social Vulnerability Index](#); SD=standard deviation

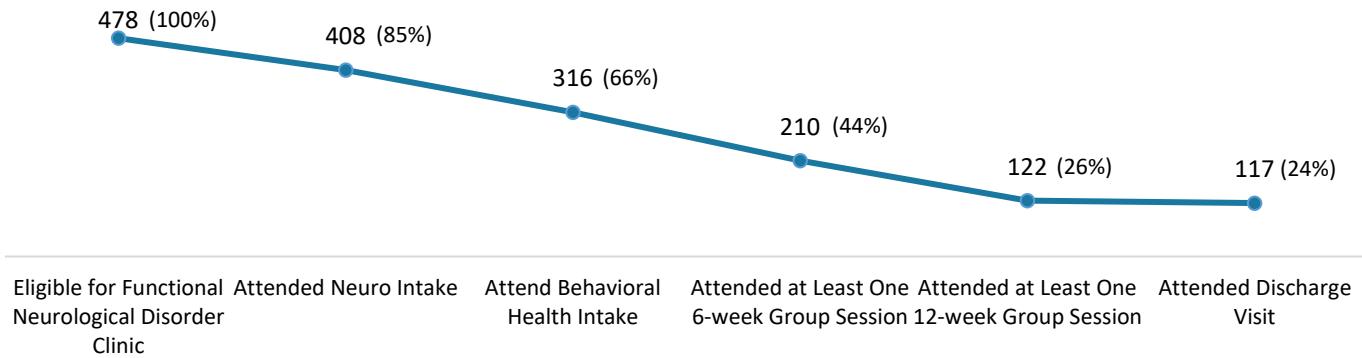
Of the 408 patients that started treatment, most were from urban areas (83%). By using telehealth, the FND clinic was able to serve patients from 35 of the 64 Colorado counties (Figure 2), including 8 frontier counties and 15 rural counties.



Note: Grey indicates count of 0

Figure 2. Visual of Colorado reach

Of the 408 Medicaid patients that were engaged with the FND clinic, 316 (77%) continued to the behavioral health intake, 210 continued to the six-week group therapy sessions (51%), and 122 (30%) made it to the final step of twelve-week group therapy.



Note: 106 patients that disengaged after behavioral health intake were offered personalized treatment plan based on shared decision making

Figure 3. Medicaid patients retained over course of treatment

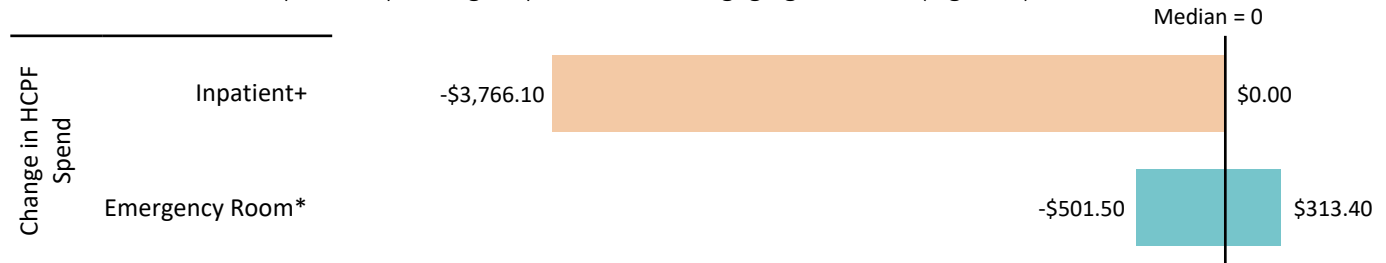
Of the 408 Medicaid patients, 198 had a change in inpatient claims and 344 had a change in emergency department claims. There was a statistically significant change in both inpatient (median = 0, Q1, Q3 = [-1.0, 0]) and emergency room (median = 0, Q1, Q3 = [-4.0, 2.0]) claim count for patients that attended their neurology intake, indicating a small reduction in the number of inpatient visits and modest reduction in emergency visits after engaging with FND (Figure 4).



Note: + p<.001; ~ p<.01

Figure 4. Interquartile range (Q1-Q3) of change in claim count for Medicaid patients after engaging with FND

There was a statistically significant change in both inpatient (median = 0, Q1, Q3 = [-\$3766.10, 0]) and emergency room (median = 0, Q1, Q3 = [-\$501.50, \$313.40]) HCPF spend for those that attended their neurology intake, indicating a modest reduction in the HCPF inpatient spending on patients after engaging with FND (Figure 5).



Note: + p<.001; * p<.05

Figure 5. Interquartile range (Q1-Q3) of change in HCPF spending for Medicaid patients after engaging with FND

Of the 70 Medicaid patients that did not attend their neurology intake, 42 had a change in inpatient claims and 60 had a change in emergency department claims. There was not a statistically significant change in inpatient claim count, inpatient HCPF spend, or emergency room HCPF spend between those that attended their neurology intake and those that did not. There was a statistically significant change in emergency room claim count for those that attended their neurology intake (median = 0, QR= [-4.0, 2.0]) versus those that did not attend their neurology intake (median = -2.0, QR = [-7.0, .8]), indicating a modestly higher reduction in emergency room visits for those that did not attend their neurology intake.

QUALITATIVE FEEDBACK FROM FND TEAM MEMBERS

Methodology

Interviews were conducted with seven current team members including the program director, assistant director, psychiatrist, program manager, clinic coordinator, social worker, and a physician’s assistant. Responses were thematically analyzed into two domains: successes and challenges.

Project Successes

Though the clinic is transitional, serving as more of a “launching pad” for patients to obtain needed tools and to get established with an individual therapist, one of the biggest successes of this program is how the clinic has been able to create a medical home for its patients to obtain direct access to specialty care.

As the FND clinic director shared, the existence of the clinic itself fulfills a huge gap in care for these patients and allows for a wide spectrum of patients, to get “actual appropriate care.” The FND clinic also improves access by providing primarily telehealth services, which for their patient population is vital, as many of their patients cannot drive due to frequent non-epileptic seizures. Further, members of the FND team feel their model improves access to other specialty care clinics; by keeping their patients from filling time slots in the epilepsy or other neurology departments, they are opening up those visits for other patients. Additionally, the specialized group therapy model not only increases the volume of patients able to be seen but provides, “a huge reduction in shame and social isolation.” Patients can feel heard not only by a medical team but by other patients who are experiencing similar situations to them.

“[Patients] leave our clinic with a more established plan than when they came in...”

Education of community providers is also perceived to be a success, as it not only helps divert care, so patients are being sent to the clinic when appropriate, but it also allows patients to have access to behavioral health care providers who understand their condition and overall improves the partner network of the clinic. The clinic also ensures that their patients understand their diagnosis as much as possible, providing as much education as they can throughout the treatment process. Finally, while symptom reduction and improvement are common for the clinic, both the clinic and its patients focus more on quality-of-life outcomes. Like many other chronic disease models, improving a patients functionality is a priority, whether that may be focusing on being able to drive or work again or even improving familial relationships. As one team member shared, “They might not stop having seizures, but... eventually most patients get to a point of acceptance and other things click back into function of their life.”

Project Challenges and Areas for Improvement

The team has had to balance competing priorities and needs of the academic setting with patient care, as well as sustainability concerns. The team has faced bandwidth issues over the past couple of years, with one team member taking on the bulk of care coordination work while also balancing clinical care. Additionally, due to limited resources, the FND clinic has focused only on NES and the team has had to turn patients away who do not have NES but have other symptoms of FND. The team has faced a few interpersonal issues with turnover and team unity, much of which improved when the associate director came on board, but some communication issues are still prevalent. Patient challenges, including lost-to-follow-up (LTFU), patient resistance to their diagnosis, and patients feeling skeptical of group therapy treatment remain for the team.

“Our goal is to continue to expand and not turn anyone away ideally.”

The team is looking to improve their program and the challenges they face including the bandwidth issues with more funding, as the team will be able to hire more personnel such as a nurse navigator and more behavioral health providers. With more providers, they will also be able to serve more of the FND community with the goal of expanding into movement disorders faced by FND patients. The team has also discussed implementing a tiered system to help with LTFU and patient resistance and one group session that is in-person for patients

who may want that option. Eventually, the team hopes to expand to be able to serve a wider spectrum of FND patients, including improving transitions of care between the children’s hospital to adult care at the FND clinic.

QUALIATIVE FEEDBACK FROM PARTNERS AND PATIENTS

Methodology

Twelve partners of the FND clinic were outreached to explore the needs and challenges FND patients face and insights into the FND clinic at UCH. Seven partners participated in interviews for a 58% response rate. This included 2 hospital collaborators: the UCH Neurology Outpatient Medical Director and the UCH Epilepsy Division Chief, and 5 community partners: a prior physician’s assistant, an individual from SK Life Sciences, the FND Hope Organization Executive Director, the Children’s Hospital Colorado NES Clinic Psychiatrist, and the director of an upcoming documentary about the clinic.

Patients were also outreached to explore their experiences with the team, satisfaction with services offered, and any suggestions for improvements to the program that may make their experience more beneficial. 14 patients were outreached via email to see if they would be interested in participating in an interview. 5 patients participated in an interview for a 36% response rate.

Partner Feedback

Partners shared that as education grows in the FND space, so does collaboration, and the FND clinic is no exception with its multidisciplinary spectrum of providers. Partners expressed that they hope the FND clinic can continue to expand, especially into other FND areas, like movement disorders. In general, partners believe more education is needed to combat the resistance and skepticism still surrounding FND in healthcare and increase the range of providers who understand FND. However, more resources are needed for both providers and patients including tangible educational materials and online resources. As one partner highlighted, “I think there's a lot of misunderstanding about this diagnosis. There are not a lot of good resources...And so, [clinicians] may not even give the patient a good understanding of what's going on.”

“This [clinic] is doing it right because they’re really providing not only a resource for the patients, but a resource for the clinicians...”

Patient Feedback

““It has honestly truly changed my life. So much for the better... Not only have I been able to get to the end of the tunnel. I'm in the sunlight again.”

FND patients felt the program greatly improved their quality of life, praising the program for allowing them to connect with others who “are having the same struggles.” Patients felt that, especially in the longer 12-week sessions, they were able to open up to each other, provide advice, and form strong connections. As one patient shared, “finding a group that actually understands you, because they’re going through the same thing, that was amazing.” As another shared, “It was just such a relief, just to know I wasn’t alone.” Patients also lauded the FND team for being caring, personable, and extremely supportive,

constantly available to help and answer any questions they may have. They also enjoyed the structure of the program, from being able to learn more about their diagnosis, to quickly getting scheduled for therapy sessions, the telehealth option of the sessions, and even getting referred to community therapists so they can continue their treatment.

Patients also described a few challenges and recommendations for improvement. Some patients described differences in expectations and misunderstandings regarding the structure of the program. For instance, one patient thought the program would be able to get them off seizure medications and was disappointed when that did not happen. Another felt that in general, the group therapy sessions just did not help as much as individual therapy and other therapeutic techniques and felt overwhelmed by the imbalance in gender representation among patients. Overall, patients felt there could be more guidance in the group therapy sessions, as it would be very open-ended sometimes leading some patients to go off on tangents which wasn’t beneficial to other patients. Some recommend prompts or icebreakers to help with each session, incorporating the guided meditation from the 6-week sessions into the 12-week sessions, and a moderator to keep patients more on track.

EVALUATION SUMMARY

Based on the FileMaker Pro and EHR data, the FND clinic engages a large percentage of eligible Medicaid patients in the neurology intake, though loss-to-follow up throughout the program is high. Using the telehealth model, the FND team has been able to reach most Colorado counties, including most of the rural counties in the state and a third of the frontier counties. State Medicaid claims data indicate a reduction in healthcare utilization and HCPF spending for those who engage with the FND program, though not a significantly higher reduction than those who did not engage in treatment. Feedback from team members, clinic partners, and patients demonstrate high satisfaction with the program.

RECOMMENDATIONS TO THE PROJECT TEAM

While the data available trends toward positive outcomes, there were some limitations of the data capture processes. Additionally, themes from conversations with team members and patients indicate areas for program improvement. Below are our recommendations for your consideration.

While the percentage of patients who initially engaged with the program is high, the number of patients needing individual treatment plans and those lost-to-follow-up over the course of treatment is high, with **only 30% of Medicaid patients making it to the final stage (12-week group) of intended treatment**. One byproduct of this was too small of a patient sample to do healthcare utilization analyses for just graduated patients.

Recommendation 1: Consider shortening the length of treatment, if clinically appropriate. Eight months of weekly sessions may feel long and overwhelming for patients that are new to therapy. Consider clearly outlining what the group sessions will entail and the goal of each step of treatment to ensure expectations are well understood (e.g. goal is not to get off medications). Consider developing a loss-to-follow-up re-engagement process or a tiered referral system, as suggested by some team members. Consider adding a branch to the clinic for individual treatment and tracking outcomes of those patients. With improved tracking and increased numbers of graduated patients, consider a follow-up evaluation to compare outcomes of graduated students with those that need alternate care or disengage.

Data capture in Epic was difficult to extract and analyze. When paired with FileMaker Pro data collected by the FND team, **inconsistencies were uncovered between the two data sources**, including incorrect medical record numbers (MRNs), dates and types of service. Similarly, some fields in Epic carried title artifacts from old sessions.

Recommendation 2: Consider minimizing the amount of manual data capture done by team, as it increases the possibility of data error. Instead, work with an Epic builder to design EHR-based tools that can record measures and data of interest. Work to rename encounter types to more meaningfully reflect the encounter that is happening (e.g. 6-week group, session 1) to allow for improved tracking of engagement through program. Consider using flowsheets if encounter-level changes are not possible to increase the number of discreet data fields and minimize the number of open-text fields used.

Based on patient feedback, **some group therapy sessions felt unfocused** and led to patients using the session as a space to vent rather than feeling like a collective treatment session. Additionally, some male patients felt uncomfortable participating in primarily female-attended sessions, as they felt their life experiences were different.

Recommendation 3: Consider developing a more structured protocol for group therapy sessions. Though open dialogue is important, consider working in more collaborative prompts or activities. If possible, consider offering male-only sessions for patients who may feel reluctant to engage in female-dominated group.

Due to lowered capacity from team turnover and a small team, some team members had to adopt the role responsibilities of other team members, leading to **increased team member burden**. Both team members and partners felt FND was unable to reach a larger number of patients due to low team capacity.

Recommendation 4: Consider expanding the team with additional clerical or administrative roles, as well as additional clinical roles. This would not only allow for reduced team member burden but open up the possibility to expand services offered.