



## **Epilepsy Association of Calgary Program Needs / Service Gaps Assessment - Final Report**

### **Executive Summary**

#### *Purpose*

The program needs / service gaps assessment was carried out over a six-month period from October 2020 to March 2021. The goal was to confirm the Association's mandate of supports and education to improve the lives of people affected by epilepsy, and to identify priorities for future programming and services.

#### *Methodology*

Surveys were developed and sent to four specific stakeholder groups: current EAC program /services participants/clients, health care professionals serving people living with epilepsy, along with current or recent (active within the past three years) volunteers and donors. The approach incorporated a combination of surveys (online, mail or over the phone), focus groups, individual interviews, direct service observations, and two past needs assessments. Additionally, from mid-November 2020 through March, the Program Manager / Social Worker assumed responsibility for direct service, responding to client inquiries and community requests. This provided another opportunity to gather data and information from participants and community partners.

The project was completed in-house by the Association's Program Manager / Social Worker with additional support provided by the Executive Director. Louise Gagne, MSW RSW was hired in September, 2021 with the skills and experience in community and program development and program evaluation to facilitate the Association's needs and service gaps assessment.

An Interim Report (Appendix A) was prepared as input to the Board Strategy Retreats held February 6 and 20, 2021. The Final Report was presented to the Epilepsy Association of Calgary's Programs Committee on April 15, 2021 for recommendation to the Board of Directors at its meeting held May 4, 2021.

#### *Key Findings*

Four distinct client/participant groups emerged:

- Newly diagnosed individuals and families
- Adults who have lived with refractory epilepsy and require specific supports to manage various conditions including isolation, poverty, and often concurrent mental health diagnosis.
- Individuals who have been stable in their living with epilepsy and have new/emergent seizures patterns
- Families who have children with complex diagnosis that includes epilepsy



The themes emerging today support observations found in the earlier needs assessments and identify some new priorities for programs and services:

- Persistent stigmas / need to dispel myths to create a caring community where people with epilepsy feel physically, emotion and psychologically safe.
- Need for counselling and supports for people living with epilepsy, many of whom also live with concurrent mental health diagnosis (commonly anxiety and depression)
- Financial self-reliance and opportunities around employment- over 60% of persons living with epilepsy are either unemployed or underemployed, primary related to misunderstandings about epilepsy and general safety and liability.
- Collaboration with medical services to directly refer patients to EAC for information and education
- A full range of support groups, in person and on-line designed for specific age groups, (children and siblings, parents, caregivers, men and women's groups etc.)
- Communication in all forms- accessible and easy way to navigate website, connect to social media Instagram, emails, and print/ mail out material available to those who do not access technology.

Service delivery observations further include:

- Requests for service initiated by individuals almost always present with some degree of urgency. Callers have often reached crisis point – whether a new diagnosis, a driver's license revoked, an unexpected seizure, unanticipated side effects of medication or suicidal ideations – when they decide to seek help
- Requests from community providers are generally exploring our scope of service due to the lack of previous contact.

### *Recommendations*

A successful transition to needs-focused community programming requires the following shifts and enhancements:

- A swift and effective path of referral from the local medical clinic to community-based programs designed in such a way that clinicians and staff can explain the value of the Association's supports and services and the Association can introduce itself to newly diagnosed patients.
- Educational programming that empowers individuals and families to self-advocate and build their knowledge around epilepsy and connect with others who are also interested in learning
- Year-round educational program available for delivery in community
- A robust peer support program that includes one on one mentoring and support, groups and opportunities for social and recreational programs that create
- Investment in sourcing and stewarding partnerships with experts in complimentary fields like family counselling and employment services
- Cultivation and curation of resources and information empower the community with knowledge around epilepsy



### *Opportunity*

COVID-19 has created new options for program delivery- on line support, although in person meetings are still most preferred. Virtual program offerings open opportunities to explore collaborations with other Epilepsy Associations, for example Edmonton opened a six (6) month parent group open to all of Alberta; Epilepsy Toronto offers employment related workshops and yoga classes that are open to Calgary and southern Alberta. Similarly, our recent webinars were advertised in BC and Saskatchewan.

This is a unique time and opportunity for EAC to respond to expressed community needs, expand program offerings with specific personnel skills sets and invite collaborative initiatives with local, provincial, national, and international initiatives.