

Epilepsy Association

2012-14 Strategic Plan

Mission: *The Epilepsy Association is a not-for-profit corporation dedicated to helping people cope with and manage seizure disorders by improving their quality of life, while empowering individuals to reach their full potential within the community.*

Vision: *Our vision is that all people with epilepsy and seizure disorders will be accepted in our community and have a measurably improved quality of life.*

2012-2014 Strategic Plan

The purpose of the EA 2012-14 Strategic Plan is to define the focus and direction of the agency over the next three years

The Role of the Epilepsy Association

- Provide relevant services to those affected by epilepsy
- Raise awareness of epilepsy
- Raise funds to support agency services

EA has provided service since the early 1950's when the organization was founded as the Parents Crusade Against Epilepsy. Services have expanded and include:

- information and referral
- mental health case management
- support groups
- community and school based education

The Epilepsy Association is responsible for creating programming that is responsive to the needs of the epilepsy community, is effective and efficient in its administration and works to improve the quality of life for those individuals living with epilepsy.

Key Markets

Key markets and constituents for the Epilepsy Association include:

- Individuals who are living with epilepsy
- Individuals who are significant others/ spouses or family/close friends of individuals with epilepsy

Within the broader community:

- Schools/teachers, physicians and other healthcare providers
- Individual donors, grantmakers and other funders

In the eleven county geography of the Association there are between 31,855 and 63,710 individuals affected by epilepsy based on 2010 population estimates. www.census.gov

Strategic Environment

Approximately **1 to 2 percent** of the general population is affected by epilepsy, regardless of age, race, gender, or national origin. Two to three million Americans with epilepsy do not have complete seizure control; or experience control at the cost of debilitating side effects from medication. Two hundred thousand new cases are diagnosed annually which is nearly 4 times as many as will be diagnosed with HIV AIDS; and seizure related deaths will reach fifty thousand cases annually, which is more than will die from breast cancer.

The Epilepsy Association faces challenges. There is insufficient awareness of Epilepsy Association services. **The Association serves a variety of different audiences** with varying outreach requirements and there is low client volume relative to incidence and prevalence occurrence of the disorder. Consumers served are of an extremely compromised nature both medically and socioeconomically and they require specially trained staff who can provide effective interventions. There is increased competition for available funds to support programs and a depressed economic condition nationally and locally with high rates of unemployment which further strains available funding sources.

In the past decade in Ohio, **median wages declined** more than in any other state. The percentage of men who are working is the lowest in recorded history in Ohio and **long-term unemployment is higher than it's ever been in 60 years** of record keeping, both in Ohio and in the nation. Ohio was one of only 10 states to see the inflation-adjusted median wage decline from 2000 to 2010.

(The State of Working in Ohio 2011, a report from Policy Matters Ohio, Amy Hanauer Sept. 2011)

In the future there will be **fewer dollars available from the State of Ohio** and in the Cuyahoga County budget for health and human services.

The economic downturn has clearly affected nonprofit organizations and their employment practices, resulting in **organizational risk of overworking employees by using current staff to run new programs**. Human resource management is not a priority for most nonprofits and nearly 75% indicated that their organizations did not have any formal budget for recruiting employees and the majority had limited resources to staff management and HR in general.

(2010 Nonprofit Employment Trends Survey, Nonprofit HR Solutions and the Caster Family Center for Nonprofit and Philanthropic Research, 2010)

Most groups still use traditional fundraising and communication channels, and increasingly are using **new interactive channels**. The use of new channels is putting a big strain on organizations because total revenue has not grown significantly, yet costs for each communication channel has increased. Donors throughout the world want to see evidence that their money is being spent well and that nonprofits are being run as efficiently as possible.

Philanthropy Journal, November 4, 2010, Survey tracks fundraising trends

In 2010, United States **foundation giving was nearly unchanged** at an estimated \$45.7 billion almost matching giving in 2009.

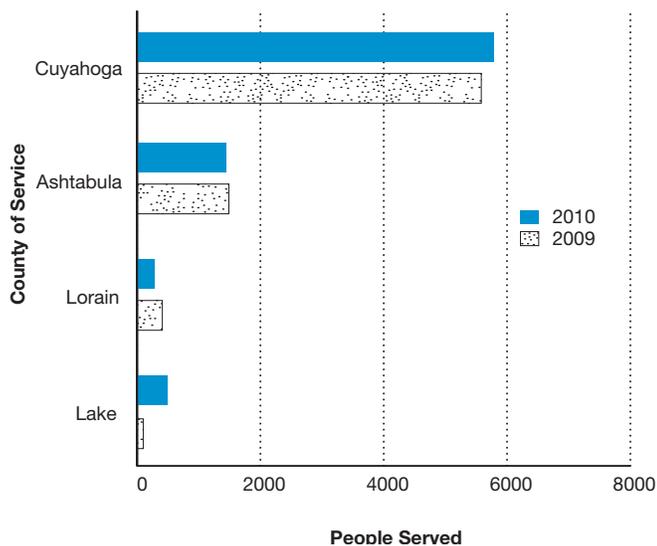
Foundation Growth and Giving Estimates, 2011 Edition, Foundation Center

Emerging Market Trends

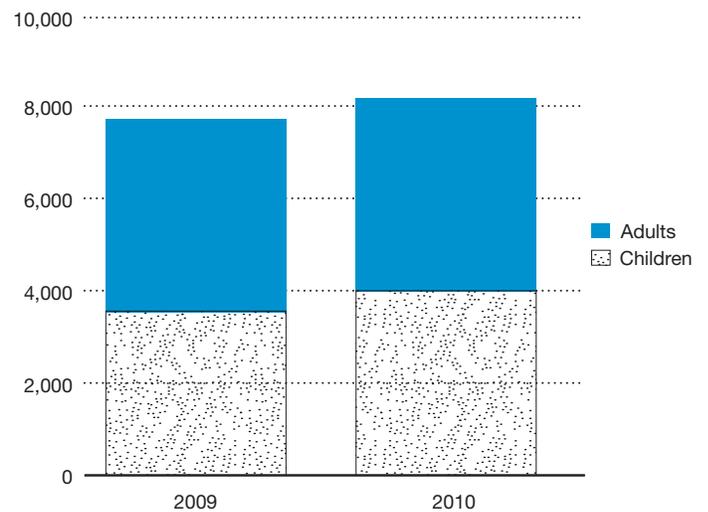
- The medical home and disease management models are an emerging market trend and will require EA to communicate about services in a way that shows a connection to that delivery model.
- Evidence-based practice models, as a basis for program design are becoming increasingly important as a means of proving the credibility of programming.
- The ability to provide data from standardized tools and link to agency interventions is increasingly important as a way to persuade donors to support services.
- Collaboration continues to be important as a tool to maximize agency resources.
- Use of social media as a way to build donors and communicate the agency message has benefits that should be examined.

Geographic Market

Includes Cuyahoga, Geauga, Lake, Lorain and parts of Ashland, Ashtabula, Erie, Huron, Medina, Richland and Trumbull counties



Comparison of Children versus Adults Served



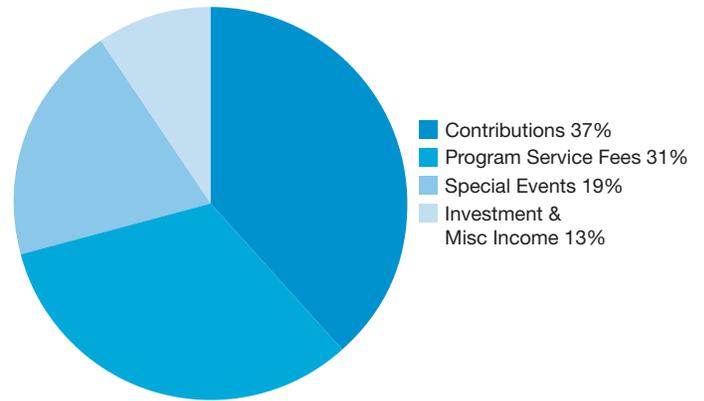
Strategic Emphasis

The Epilepsy Association 2012-2014 Strategic Plan is focused into three areas:

- **Program Services:** Creating and maintaining high quality, consumer focused, culturally competent services which meet the needs of those living with epilepsy and those around them.
- **Service Quality:** Effective and efficient agency operations functioning with well trained staff and integrated technology are expectations within the nonprofit market.
- **Market Awareness and Funding:** Awareness of epilepsy and agency services is central to building and strengthening the epilepsy community. Securing funding to support services is critical to the sustainability and long term viability of them.

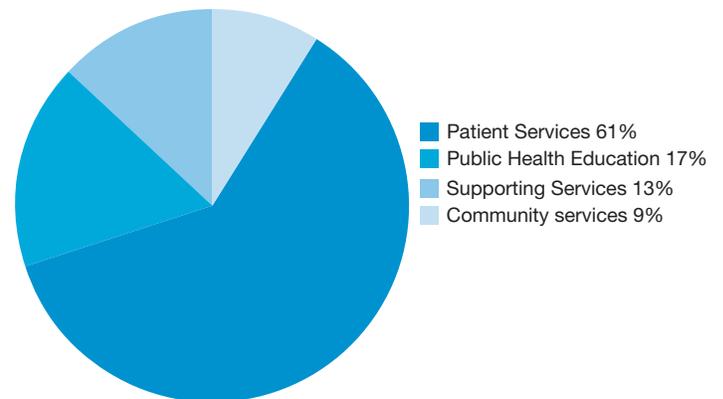
Operating Revenue Sources

2010 Data



Use of Program Funds

2010 Data



SWOT Analysis Summary

Internal Forces

Strengths

- Specialized programs that are highly individualized
- 86 cents out of every dollar goes to programs
- Nationally accredited by CARF and statewide by the Ohio Department of Mental Health
- Physical facility
- Collaborative administrative structure
- Active board of trustees
- Dedicated staff
- Long term leadership of the Executive Director

Weaknesses

- Low client volume relative to incidence and prevalence occurrence
- Insufficient awareness of Epilepsy Association services
- Limited staff resources
- Limited funds to enhance available staff resources

External Forces

Opportunities

- Use of new communication channels to increase awareness and usage of services
- Highlight evidence-based practice in communications
- Focus on outcomes
- National healthcare reform
- Emphasis on national epilepsy research
- Collaboration with organizations and institutions
- Client advocacy on state/federal level

Threats

- Depressed economic conditions nationally and locally with high rates of unemployment
- Increased competition for available funds to support programs
- Reduced funding for mental health services
- National healthcare reform

Strategic Emphasis

Program Service • Service Quality • Market Awareness and Funding

Program Service

Goals	Strategies
1 Deliver high quality, relevant services to individuals living with epilepsy as well as individuals in the broader community using evidence based practice models as the ideal standard	Provide services to meet basic needs
2 Utilize focused treatment approach using self reliance indicators	Collect and interpret current consumer data and refine treatment approach
3 Develop outreach programs for families and children	Conduct a needs assessment to guide program development for children and families in the community
	Integrate Be Smart About Epilepsy and Girl Scout curriculums into educational programs

Service Quality

Goals	Strategies
1 Maintain a superior work environment to support staff hiring and training initiatives	Assess program initiatives to determine areas where the Board of Trustees can provide expertise where knowledge gaps exist
2 Identify volunteer leadership with the talents and skills to help the agency	Develop technology solutions especially with regard to marketing awareness and funding strategies
3 Increase technologic capabilities of the organization consistent with plan goals	Assess administrative costs against industry standards to identify opportunities for growth in revenue or reduction in expense
4 Look for ways to reduce administrative expense	

Market Awareness and Funding

Goals	Strategies
1 Increase awareness	Use technology with current and new channels to develop and implement an integrated plan for communicating agency success stories
2 Sustain funding	Evaluate and appropriately continue special event offerings while managing a new event development process
3 Identify opportunities to raise new dollars	Cultivate relationships with donors which will recognize the differing needs of corporate, private and individual donors and will be expansive enough to include planned giving and major gifts relationship development
	Identify research related funding to access new sources of revenue

Conclusion

The Association is committed to the delivery of core services to assist those living with epilepsy through a financially responsible organization, accountable to the public.

We are certain that through increased communication of our story of success, there will be increased acceptance of those living with epilepsy and an interest in additional financial support of these critical services.

