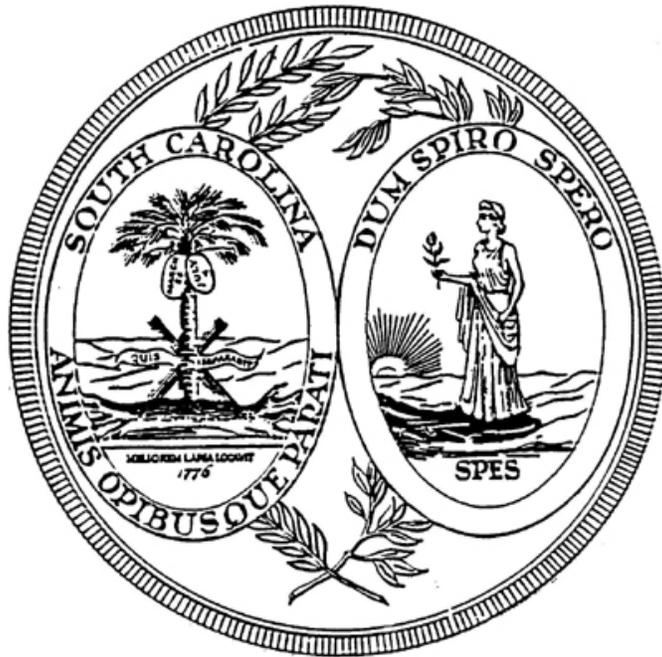


**REPORT OF THE  
STUDY COMMITTEE TO DEVELOP A  
STATEWIDE COMPREHENSIVE  
SERVICE DELIVERY SYSTEM  
FOR PERSONS WITH EPILEPSY**



**South Carolina  
Department of Health and Human Services  
July 1, 2008**

## Executive Summary

Persons with epilepsy (PWE) constitute a unique segment of our South Carolina population with multiple unmet needs. Their disabling medical condition prevents many of them from fulfilling normal educational programs, enjoying the social and economic rewards of society, obtaining and/or maintaining gainful employment, and experiencing satisfactory mental health. In a unanimous Joint Resolution by the 2007 SC General Assembly, our state government acknowledged that 2% of the state's population had ever had epilepsy, about 43,000 PWE in SC required continued treatment and more than half of the latter report limitation of their activities. It was also noted that the rate of psychological impairment for PWE was twice normal. The requirement for coordinated care and provision of diverse and needed services was recognized as necessary to enable all PWE to gain and maintain their highest possible quality of life and level of productivity.

The South Carolina Study Committee to Develop a Statewide Comprehensive Service Delivery System (Epilepsy Study Committee) for persons with epilepsy was convened in 2007 in accordance with the Joint Resolution (2007 Act 168). This Committee now provides its findings to the General Assembly. The bases of our findings include: 1) review of scientific literature, 2) review of state-based data on epilepsy, 3) statewide detailed surveys of about 100 persons (or parents of) with epilepsy, 4) statewide survey of 55 physicians, 5) survey of twenty state agencies/organizations which were perceived to provide services relevant to PWE, and 6) experiences of designated committee members and invited experts.

The Committee finds that most of the community and many service providers see the major disabling issue for epilepsy as the epileptic seizure. Yet, the most debilitating facets of this condition may be stigma and comorbidities (i.e., co-occurring medical conditions). Stigma permeates the public perception of epilepsy and results in social isolation, institutional segregation, and limitation. Also, in varying degrees, many PWE perceive themselves to be helpless, inferior and different. Patient and public education and quality treatment are the likely components for a resolution of stigma. Over 50% of PWE have comorbidities associated with epilepsy. These may include impaired cognition, depression and other psychological challenges, adverse effects of treatment, and social isolation imposed by stigma. A high level of awareness by treating physicians and service providers can appropriately direct PWE to services required to ameliorate some of these problems.

Most citizens in SC have typical and reasonable expectations for employment, education, recreation, and enjoyment of routine lifestyles and relationships. These goals, which are assumed for most of us, are not readily achieved by many PWE. Specifically, quality of life is notably diminished by the

occurrence of just one seizure per month. Current research indicates that nearly 20,000 adult South Carolinians with epilepsy are having at least one or more seizures every three months. With this frequency, PWE cannot legally operate a vehicle, may be encouraged to seek alternative educational or training systems, may fail to obtain or maintain gainful employment, yet would be ineligible for social security disability benefits, and be unable to obtain health insurance or life insurance at reasonable costs, if at all. Even those PWE with fewer seizures or no seizures may continue to endure repercussions of stigma, impaired cognition and/or mental health, high medical care costs, under employment, and trouble accessing services.

The impact of epilepsy extends beyond the PWE. Every mother, father, spouse, sister, brother, and even grandparents of the PWE realize first the physical and emotional effects of a seizure and then are often themselves subject to many of the same restrictions on social integration and other consequences imposed by epilepsy. They are hypersensitive to the reactions of others when a seizure occurs. It is a living, ever-present fear that envelopes everyone near that PWE. When seizures are poorly controlled, the effects are extended to include limitations or barriers for employment, transportation, healthcare access, and education. It is not unusual after the diagnosis of epilepsy for there to be job changes which result in insurance coverage changes and even loss of all insurance coverage. The consequences are felt by all in the family and the community as well.

The Committee has studied the cost of epilepsy. It is difficult to include all costs, but it found the estimated that the annual US direct cost and indirect cost range from \$12.5 (1995 dollars) to \$16 billion (1994 dollars) [1,2]. A restricted analysis of healthcare expenditures in SC shows annual Medicaid total expenditures for epilepsy as \$29.5 million (in 2006). Considering this to represent about 25% of the overall total, then SC expenditures for medical treatment is estimated at \$118 million. Indirect costs can be extrapolated using information from published studies and would suggest the indirect costs in SC are \$843 million annually, based on direct costs consisting of 14% of total cost [2]. Since costs are highest in PWE with continued seizures, expert care and efficient management of service delivery will affect savings for our state while improving quality of life for PWE.

The Committee has considered the multitude of services that would be beneficial for the resolution of the barriers for PWE. Our state agencies and private sector have the capabilities to provide essentially all of the diverse services. The real need is to bring specific services to bear on the individual PWE and his/her community. In some cases that will be the development by the school nurse and parent of an Individual Health Plan in order for teachers to know what to do when a seizure occurs in the classroom and to best understand the capabilities and limitations for that child. Vocational rehabilitation may be necessary for an adult who has been unable to reach full employment because of

work restrictions put in place secondary to the epilepsy. Advocacy with the employer can also yield positive results. Prompt treatment of depression by a clinician knowledgeable about epilepsy and associated behavioral disorders can avert dysfunctional moods and behaviors that can repress quality of life as well as impair educational and employment success. Education of first responders and police about the various presentations and first aid management of epileptic seizures may prevent inappropriate decisions and even incarceration for a potentially life threatening condition. It is proposed that a well trained case manager can successfully find and procure appropriate services from a pool of diverse providers and facilitate efficient care, promote best outcomes and increase quality of life.

This Committee has concluded that an effective and efficient system of service delivery based on case management practices will offer many solutions to the problems experienced by PWE. Initial contact for the presumptive patient and family is typically through a medical channel. If the diagnosis of epilepsy is established, the medical model remains a constant in the services system. Hence, it is appropriate to build a service delivery system with the epilepsy clinic as an integral interface for the PWE, the case manager, and community resources. The case manager will be knowledgeable about the needs of PWE and about the availability of diverse community resources and how to most efficiently utilize those services. A consortium of six SC Regional Epilepsy Clinics (RECs) will be established by offering the opportunity of participation to existing private and institutional neurological practices. A proposal for bid to participate will include stringent personnel and operational requirements. The bids will be competitive and clinics will not be funded by new state resources. A Comprehensive Epilepsy Program (CEP) with extensive diagnostic, therapeutic and service capabilities will function as the organizational head of the consortium of regional clinics. The CEP epilepsy clinic will also become one of the regional epilepsy clinics.

The epilepsy case manager (ECM) should reside in the same region as the PWE and thus have a direct link to the community and its resources. The specific strengths and weaknesses of the resources should be known, and if needed, modified through feedback. The ECM will be a part of the REC and have direct links to all professionals and staff to ensure clear and direct communications. The ECM will also function as a liaison and educator in the community. The Committee findings indicate that some agencies/organizations do not see epilepsy as a likely recipient for their services. Thus it is likely that when those services are requested or provided, they do not have any specificity. This circumstance would warrant intervention and enlightenment by the ECM. This should be a beneficial action for those agencies and enhance needs awareness, referrals, and appropriate delivery of services.

The REC consortium will promote the highest quality of medical services by fostering professional education, joint case conferences, rapid consultations

and uniformity of professional diagnostic and treatment protocols. Technological advances (such as Telemedicine) will enhance these activities. PWE who enter this system will become a part of a registry which will permit surveillance of quality of care and services, medical and non medical outcomes, healthcare expenditures, and delivery system costs and savings.

The CEP will consist of epileptologists, neurosurgeons, neuropsychologists, psychologists, epilepsy nurse practitioners, neuroradiologists, social workers, vocational rehabilitation counselors, clinical and basic neuroscientists and EEG technologists. There should also be affiliated psychiatrists who have special interest and expertise with epilepsy. Some of these personnel will also be a part of the attached REC. The CEP leadership role includes readily available physician-physician consultation, a teleconference network for all RECs and CEP, recurrent personnel training for support staff and service providers, development of continuing medical education activities, development of protocols, procurement of research grants, and advocacy through lay organizations. The clinical role of the CEP and its REC will include extensive diagnostic services and epilepsy surgery through referral by other RECs. Once evaluated and treated the majority of referral will be returned to their REC and community for continued medical follow up and community services. Other non medical consultations will be provided as needed as well. The highest level of comprehensive medical and non medical services in effect will be extended through all regions of SC.

The Committee envisions an advisory group that provides oversight for the initiation and maintenance of the epilepsy service delivery system and its surveillance. This group would include PWE, caregivers of PWE, educators, psychologists, epileptologists, epilepsy nurses, state service providers, social workers, community representatives, and SC legislative representatives. The advisory group would routinely review the surveillance data and surveys of PWE to make recommendations to the epilepsy service delivery system, state agencies, and state legislature.

The service delivery system proposed by this Committee is notable for its potential cost savings through use of existing private sector and state government resources. The quality of services will be enhanced through provider and PWE education and training. Public and service provider awareness will be increased with a resulting efficiency in referral/utilization of existing agency/organization resources. It is believed that there will be wide spread cost savings and improved quality of life for PWE by making available statewide skilled specialists in epilepsy. There should be travel reduction, reduction of individual antiepileptic drug prescription costs, increased employment and job retention, decreased disability, improved healthcare in the educational systems, and more efficient utilization of community healthcare resources (e.g. emergency department, emergency medical services, diagnostic studies). Limitation for new state resources and cost reductions has been a persistent caveat of this

Committee. A comprehensive services delivery system that efficiently bridges the PWE (through a case manager) with existing public and private community resources will work successfully to improve services and improved outcomes for those PWE in SC without creating substantial costs for the state.

Direct costs for the epilepsy service delivery system would include six case manager salaries and an administrative staff along with overhead costs for the administrative office and general supportive services. Specific support services would include technical personnel to keep the database operational. Funding for public, patient and agency education and awareness activities would be moderately substantial but bid out to competing organizations which have capabilities and experience with epilepsy. Medication payment issues will be a primary concern of the surveillance team. Should coverage be a significant issue, further review may be necessary to achieve best medical outcomes and care for PWE and their families. While indirect costs might include the increased use of already existing state and federal services, we expect that the resultant increase in education attainment, employment, and social involvement of PWE would more than offset the indirect costs. This should be enhanced by coordinated and comprehensive state-of-the-art epilepsy treatment.

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## I. Introduction

### A. 2007 Act 168

On June 6, 2007, Governor Mark Sanford signed Act 168 (House Bill 3135). This joint resolution is the first South Carolina legislation that specifically addresses concerns about the current situation for South Carolinians with epilepsy and a plan to improve their plight. Earlier attempts by advocates for persons with epilepsy (PWE) to develop legislation were not successful for a variety of reasons. Members of the Epilepsy Foundation of South Carolina obtained the support of Representatives J. E. Smith, Jr., L. Funderburk and W. Cotty to author and present a Joint Resolution (House Bill 3135) to critically analyze the situation of this unique and underserved population (see Appendix for bill in its entirety). This effort was supported by the results of two research projects at the Medical University of South Carolina (MUSC). The South Carolina Epidemiological Studies of Epilepsy & Seizure Disorders provided strong evidence for the SC lifetime prevalence of epilepsy being 2.0%. The South Carolina Health Outcomes Project for Epilepsy is identifying and quantifying the socioeconomic, employment, educational mental health and medical issues so important in the lives of people with epilepsy and their families.

As called for in the resolution, a committee of twelve members (see Appendix) was appointed August 2007 and had its first meeting on September 6, 2007. The Epilepsy Study Committee was given specific objectives:

- (1) provide a definition of epilepsy;
- (2) plan a statewide system that addresses the issues of prevention, identification, treatment, rehabilitation, and community integration of people with epilepsy and must include, but is not limited to:
  - (a) designation of a lead agency for each person with epilepsy, which shall assume primary responsibility for coordination of service delivery for that person;
  - (b) a case management system;
  - (c) medical care and long-term care monitoring;
  - (d) education;
  - (e) employment;
  - (f) housing;
  - (g) mental health;
  - (h) independent living services;
  - (i) access to and availability of treatment resources;
- (3) recommendations for the expansion of Medicare or Medicaid, or both, and other financial services to address the needs of the epilepsy population including families;
- (4) a data system in which epilepsy and seizure disorders can be identified from existing data sources to continually track and monitor the incidence and prevalence of epilepsy, including mortality and morbidity;

(5) recommendations for education programs to inform the public about epilepsy, its causes, prevention, employment, first responder treatment, and availability of treatment and services. The committee shall explore instituting more programs in the public schools, kindergarten through twelfth grade and institutions of higher learning, to promote awareness of epilepsy as a growing problem and shall explore incorporating epilepsy as part of the curriculum in medical schools;

(6) recommendations for policy and legislative changes that may be needed including, but not limited to, insurance, employment, prevention, motor vehicle driving, and public and personal safety practices.

The Committee and subcommittees were authorized to utilize the knowledge and expertise of any individual in another state agency, group, or association.

### B. What Is Epilepsy?

Epilepsy is the second most common neurological condition after stroke. It is defined as present in an individual who has had two or more unprovoked seizures. Estimates are that 86,000 South Carolinians currently have epilepsy. There are no socioeconomic classes, health conditions, racial, ethnic or age groups that do not experience the development of epilepsy. Medical data reveals underlying predicaments such as head trauma, prior nervous system infection, brain tumor, genetics, and cerebrovascular disease (stroke) as common causes. Yet, over one-half of cases have no clearly defined cause. It is predicted that there will be increases in the prevalence of epilepsy in South Carolina related to an aging population of retirees in our state (a wonderful place to retire) and the return of post-war veterans with head injuries (traumatic brain injury and extremity injuries being the two most common injuries in Iraq War survivors).

For many PWE there are no outward signs of this disabling condition. It has become apparent over time that multiple social, psychological, cognitive and behavioral problems are associated with epilepsy. These problems complicate all efforts at treatment, rehabilitation and some times simply day to day existence. These problems are not amenable to standard first-line medical treatments which can successfully ameliorate the most obvious manifestation of epilepsy, seizures. There is even recent information which now indicates that these associated biological, behavioral and neurological problems are intrinsic to the issue of epilepsy. Some of these factors are preexistent to the emergence of epileptic seizures. Physical issues are also associated with long term epilepsy, its seizures and its treatments. Specific problems with bone health, infertility, personal injury, skin and liver conditions, and cognition may occur in the course of this disorder. Mortality is increased two to three fold. Thus, looking at epilepsy simply as a problem of only epileptic seizures may yield erroneous and misleading conclusions.

Epilepsy is more than seizures. Indeed, there are many different types of epileptic seizures and conditions associated with seizures. As indicated above, there are many causes of seizures. The seizure is primarily a symptom of an underlying brain disorder. The constellation of the epileptic seizure type, the associated cause and the findings of various laboratory tests (EEG), genetic history, neurological examination and clinical course constitutes an epileptic syndrome. There are many types of epilepsies but only one type for any given individual. Given this complexity as well as the associated consequences of the condition, the International League Against Epilepsy offers a more inclusive definition of epilepsy as “a chronic condition of the brain characterized by an enduring propensity to generate epileptic seizures and by the neurobiological, cognitive, psychological and social consequences of this condition” [1]. This definition acknowledges the presence of psychological and social consequences of epilepsy. Many of these attendant phenomena are referred to as comorbidities. Medical or surgical treatment of the epileptic seizure is only half of the battle in the comprehensive care of PWE.

Continuing advances in medical treatments for epilepsy will not alone support or maintain the person with epilepsy in the mainstream of society. The most successful outcomes will occur with treatment interventions that include those services which deal with social, economic, cognitive, educational, vocational and behavioral needs. An enlightened public is also necessary in order for persons with epilepsy to enjoy full and unrestricted integration into today's society. These multifaceted services can be best obtained and administered through a comprehensive services delivery system.

### C. Stigma

*“I am fortunate in that my condition is currently controlled by medication. It has not always been this way. Persons with epilepsy are discriminated against by nearly everyone. The main problem is ignorance as we are often thought to be drug addicts or emotional wrecks. This is not so. I have experienced every form of humiliation and discrimination there is. But, for the last 15 years I have been seizure free and hopefully will remain so for the rest of life provided I can afford my medication.”*  
*PWE in Appalachia III Health District*

Stigma is a major problem for PWE. Stigma refers to a loss of status that originates from certain attributes which are thought undesirable, different, discrediting or dehumanizing. In the case of epilepsy, the attributes are the recurrent seizures. In antiquity, PWE were considered possessed, sinful and "afflicted". The medical community of the 19<sup>th</sup> and 20<sup>th</sup> centuries has attempted to link epilepsy to aggressive or criminal behavior, abnormal sexual activity, hereditary degeneration, and a specific epileptic personality. In more recent times, PWE have been dehumanized by legal and statutory discrimination including denial of access to public places, prohibition of marriage, annulment of

adoptions (child could be 'returned' if he or she developed epilepsy), forced sterilization (South Carolina and 29 other states), denial of immigration (Theodore Roosevelt and US Congress 1907), restriction from military service, lack of reasonable health and life insurance, limitation of driver licensing and more subtle discrimination for professional training and employment. Exorcism and root medicine as therapies for epilepsy are still sometimes practiced today. These negative markers perpetuate stigma.

Jacoby and Austin [2] have examined the stigma around epilepsy and point out that public attitudes, which have improved somewhat, are borne of a lack of understanding and knowledge. The same may be said for those rules and sanctions against PWE. The personal perception of stigma is felt by 14-51% of PWE. There is a clear relationship between felt stigma, seizure frequency, and degree of illness. Quality of life is subsequently affected by learned helplessness, depression and anxiety, impaired physical health status, increased somatic symptoms and other health problems, and compromised self esteem and life satisfaction.

There are salient avenues for improving the consequences of stigma. Recognition of epilepsy and sound education of PWE and the public are effective. Political or legislative steps must be pursued where there is institutional or vocational discrimination and/or unavailable services to allow continued participation in society. Where there are necessary precautions in life as with driving, counseling with a positive attitude should be undertaken, through physician, family, friends and support groups. Early epilepsy educational intervention at the time of diagnosis and increased education of the public will reduce chances for the development of stigma surrounding epilepsy

#### D. South Carolina Advocacy Medical History

Many efforts on behalf of PWE have preceded the Act 168 of the 2007 General Assembly. In the early 1960s, a chapter of the national Epilepsy Foundation was formed in Greenville, South Carolina. This was followed by an independent South Carolina low-country organization promoted by Dr. Capers Smith and some financially successful parents of adults and children with epilepsy. A major effort was undertaken to create a vocational rehabilitation program for PWE. While well-supported by small numbers, this group faded and after two or three years ended with the exit of Dr. Smith from Charleston.

A ground swell of interest developed in the state during the mid 1970s. The supportive and productive participants were mostly from Charleston, Columbia and Florence. This group created a state-wide nonprofit organization, the South Carolina Epilepsy Association (SCEA) with chapters in each of the cities. The SCEA successfully served educational needs for the public as well as for schools and patients. It was an information and referral resource for

physicians and their patients. Leadership ended up in Columbia and with waning participation by the Charleston and Florence chapters, the Midlands Chapter became the sustaining and surviving group. Subsequently, the Midlands Epilepsy Association (MEA) became an independent and successful unit funded largely by the United Way. This organization was quite successful in the 1980s and 1990s and provided many services which were for the most part limited to the midlands area of the state.

Later in the 1990s, the Epilepsy Foundation of South Carolina evolved from the MEA. It affiliated itself with the Epilepsy Foundation of America and extended its activities to include Greenville and Charleston. Today, this viable foundation is the public body which speaks for South Carolinians with epilepsy. It (EFSC) has been instrumental in laying the groundwork for Act 168 and for substantial portions of input which constitute the basis for this report. EFSC has been able to reach approximately 5000 PWE each year (about 6% of the epilepsy population) with limited resources.

#### E. Medical History in South Carolina

Medical resources in South Carolina specifically for PWE have evolved over the past forty years. These services are found where physicians have specific interest and training in the care and management of patients with epilepsy. Highlighting those developments in modern times likely began with the development of a Division of Neurology at the Medical College of South Carolina. In the 1960s that effort brought in Dr. Gilbert Young, a pediatric neurologist, and later Dr. Capers Smith who had a Medical College appointment as well as a private practice. Dr. Young was well recognized as an expert in treating children with epilepsy. He actively worked with the Crippled Children's Program now known as the Children's Rehabilitative Services (CRS), a department of SC Department of Health and Environmental Control. Dr. Smith, who suffered from posttraumatic epilepsy (sustained in World War II), was vitally interested in setting up a vocational rehabilitation program for PWE. He submitted an excellent grant proposal but it was not funded. Dr. Neil Marshall later joined the Medical College faculty and was an excellent manager of medical pharmacological treatments and also a master of teaching medical students about epilepsy. Notably, all of these physicians fully appreciated the necessity for comprehensive care and referred patients out to appropriate but limited state resources.

In the 1970s a Comprehensive Epilepsy Program was developed at MUSC. The South Carolina Vocational Rehabilitation Department already had an established liaison and epilepsy case counselor working full time with MUSC. It was a very natural and easy step for the Department of Neurology to join ranks with this agency. Additional funding for services for a social worker and an epilepsy nurse was obtained by grants through the newly created Developmental

Disabilities Council. Medical services were provided for adults by Dr. Braxton Wannamaker and for children by Dr. Lawrence Mauldin. Additional support through the federally funded Regional Medical Program was obtained and permitted the statewide training of EEG technicians. Neuropsychological services were made available through Dr. Sidney Denman. This program obtained a grant to support research as well as education of service providers throughout the southeastern US including social workers, nurses, teachers, etc. This program provided clinical services and consultation to the CRS clinic in Florence and to the residential institution at Ladson, SC. An epilepsy surgery program was formed with the MUSC Department of Neurosurgery (Dr. Christian Vera). The first temporal lobectomy was performed in 1976. Without sustaining staff and funds, the comprehensive epilepsy program phased out in the early 1980s.

New efforts in 2007 were started for comprehensive epilepsy services through a program at MUSC. Most recently, MUSC received designation as a Comprehensive Epilepsy Center in 2008 and has the ability to provide extensive diagnostic evaluation and therapeutic services for PWE. The University of South Carolina School of Medicine has both pediatric and adult specialists in epilepsy. Spartanburg Regional Healthcare System has a pediatric epileptologist. Consistent with nationwide training programs in epilepsy there are now growing numbers of neurologists in private practice with credentials to offer excellent medical care to PWE. Notably, neurological practices in Columbia, Florence, Greenville, Hilton Head, Myrtle Beach and Spartanburg among others have the capabilities for excellent medical services for PWE.

#### F. Legal

In South Carolina, state laws regarding “epileptics” can be found. Notably, as the second state in the nation to establish an institution for mental illness, the state of South Carolina in the 1820s provided that this institution admit “all idiots, lunatics and epileptics”. It is unknown when these demeaning terms were removed from the admission policies of the mental health system in South Carolina.

In 1935 the South Carolina General Assembly enacted a law for forced sterilization which included people with epilepsy. This law was finally repealed in 1985. South Carolina had been one of thirty states in the United States to have such laws. Sterilization was at the discretion of the superintendent of the State Hospital. In 2003 Governor James Hodges apologized to the South Carolina victims and their families. Mrs. Margaret Masse, former executive director of the MEA, was a staunch advocate for the repeal of this heinous law.

In remaining statutes in the SC Code relevant to the commitment of children in need of mental health treatment, specific reference is made to the fact that children in need of commitment for mental illness will not be excluded for “the presence of epilepsy, mental retardation, organic brain syndrome...” These

references while probably functionally innocuous, likely promulgate the stigmatization. How would this affect the child with psychosis following epileptic seizures?

State and federal laws, statutes, guidelines, etc. can protect and provide necessities for education, employment and health care of some PWE. The emphasis has continued to be for PWE who have the onset at a certain time in life and must also have intellectual disability. Many of the needed services can simply be withheld due to the age of onset of seizures. We do not know the exact proportion of PWE in SC whose epilepsy began after age 21. However, in MUSC's SC HOPE study (described later in report), 97% of adults participating were able to report a date of onset, and of those, 41% reported an onset of 22 years or later. Therefore, it is evident that a substantial portion of South Carolinians with epilepsy are excluded from many state services appropriate for their unique needs.

The legal inclusion of epilepsy in a diverse group of disabilities did permit limited protection from discrimination and provided subsequent rights for education and employment and a way of life appropriate for the individual's fully developed capabilities. Civil rights provisions for PWE were included under the Rehabilitation Act of 1973, particularly Section 504. The Americans with Disabilities Act (ADA) of 1990 also protected the civil rights of individuals with epilepsy. The 1975 Education of All Handicapped Children Act (EHA) has provided the standards for distribution of federal funds to states for special education and related services for disabled students to receive "a free, appropriate education in the least restrictive environment". This law was modified and reauthorized as the Individuals with Disabilities Education Improvement Act (IDEA) in 2004. These federal laws have been instrumental in improving the education, employment and the improved habilitation of many citizens with developmental disabilities. Unfortunately, the evolution of these laws restricted services for many individuals with epilepsy who do not fall under the guidelines of a "developmental disability" because of a qualification that the age of onset must be before 22 years and the required association with mental retardation (now termed "intellectual disability"). Many of the needed services not funded and are not provided due to these qualifiers. We do not know the exact proportion of PWE in SC whose epilepsy began after age 21. However, in the MUSC SC HOPE study (described later in report), 95% of adults (22 years and older) participating reported a date of onset, and of those, 39% reported an onset of 22 years or later. Therefore, it is evident that a substantial portion of South Carolinians with epilepsy are excluded from many state services appropriate for their unique needs.

G. Activities of the Study Committee to Develop a Statewide Comprehensive Service Delivery System for Persons with Epilepsy

The members of this Committee and additional volunteer advisors are listed in the Appendix.

The members began their undertaking with some preconceived ideas about what services were needed to enhance the lives of PWE. There were also ideas about the availability and implementation by state agencies and organizations. It was seen as very important to solicit the opinions and information from PWE and their families, agencies and organizations which provide services, businesses that employ PWE and physicians who provide medical services. The following activities were conducted:

1) To reach PWE

a. a website ([www.scepilepsyact168.com](http://www.scepilepsyact168.com)) was constructed and included the rationale and brief history for the Joint Resolution, a list of Committee members, a complete copy of Act 168, a 33 question online "Patient Survey" survey and a contact address

b. a live interactive statewide video-teleconference was held in November 2007; this 3 hour conference was generously supported by the SC Vocational Rehabilitation Department (SCVRD), VR counselors at 14 different SCVRD Area Offices served as hosts along with EFSC volunteers, and "Patient Surveys" were distributed, and

c. the teleconference and website were advertised for three weeks during October and November 2007 in major regional newspapers and ETV radio across SC

2) To reach service providers, the Committee developed and mailed surveys to 20 SC state agencies and organizations presumed to provide services relevant to PWE. These packets of "Agency Survey" were sent directly to the heads of the organizations with a letter of request and explanation, a copy of the Joint Resolution authorizing the request and the survey with detailed instructions.

3) To obtain information from physicians the Committee mailed a letter and brief questionnaire ("Physician Survey") to board certified pediatricians, family practitioners and neurologists. The survey was distributed randomly excepting designated areas so as to include different areas across the state..

4) Employers at various and different industries were personally contacted and surveyed in order to understand their SC experiences of employment and hiring practices as related to PWE.

5) The Committee created numerous subcommittees (see Appendix) and assigned members based on interest and expertise. Areas of concern that these subcommittees addressed included an epilepsy service delivery system,

education and public awareness, employment, medical cost and accessibility, transportation, mental health, long term care, and utilization of new technologies for information transfer. Various advisors were invited to participate. The analyses of the findings of these subcommittees, our personal and professional experiences and opinions, the survey results, and professional literature were assimilated into reports which are the bases for this final report.

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## II. Epidemiology

Researchers in the Department of Biostatistics, Bioinformatics, and Epidemiology, College of Nursing, Department of Pediatrics, and Department of Neurosciences at the Medical University of South Carolina (MUSC) have been investigating the epidemiology of epilepsy in SC. For three years (2003-2005) questions on epilepsy were included in the *SC Behavioral Risk Factor Surveillance System (SC BRFSS) survey*. This survey, conducted by the SC Department of Health and Environmental Control, is a random-digit-dialed telephone survey across the entire state of individuals 18 years and older. The main advantage of such a survey is that it should well-represent the non-institutionalized population of the state, and the data collected is weighted to reflect population demographics of sex, race, and age. The main drawback of such a survey is that the epilepsy information is not clinically-based, but rather self-reported. Across the three years, 19,769 persons in SC responded to the questions on epilepsy in the survey.

Two percent of individuals who participated in the SC BRFSS survey reported ever having been told by a physician that they had a seizure disorder or epilepsy, thus *the lifetime or ever prevalence of epilepsy in SC is 2%* [1]. One percent reported that they currently took medicine to control their seizure disorder or epilepsy and/or they had had one or more episodes of seizures in the preceding three months, so *the active prevalence of epilepsy in SC is 1%*. Similar prevalence has been seen in BRFSS surveys in Georgia and Tennessee, as well as in a national survey [2,3,5,10]. Forty-six percent of those with active epilepsy in SC reported a seizure within the past three months. This is surprisingly high, considering the BRFSS in California found 37% of persons with active epilepsy reported seizures in the past three months [4], and the BRFSS in Ohio found 31% [5].

The data was examined to determine who is most likely to have epilepsy. There were *no differences noted by sex or race*. Persons more likely to report ever having epilepsy were *those 45-59 years of age* compared to older persons, persons with a high school education or less compared to those with higher education, persons in the lowest household income level compared to those with higher income, and persons not employed compared to those employed or retired. Since this is a cross-sectional survey it is not possible to comment on whether there are causal relationships. In regard to access to health care, although persons with active epilepsy may be more prone to dental problems due to some antiepileptic medications, they were less likely than persons without epilepsy to have seen a dentist in the past year. There was no significant difference in percent of persons having a routine check-up in the past year or in percent with health care, but *38% of persons with active epilepsy reported they were unable to see a health care provider at some time in the previous year due to cost*, compared to 15% of those without epilepsy. When compared to respondents to the Ohio BRFSS, a similar proportion of persons without epilepsy

were unable to see a doctor when needed in the past year due to cost (13%), but only 11% of persons with epilepsy (PWE) reported this [5]. As to lifestyle behaviors, persons with active epilepsy were equally likely to be overweight or obese (67%) as those without epilepsy (62%), but less likely to be a heavy drinker. However, persons with active epilepsy were more likely to be a current smoker. Finally, only *27% of persons with active epilepsy reported meeting physical activity recommendations compared to 46% of those without epilepsy*. Yet, at our videoconference individuals from Charleston, Columbia, and Florence noted that they were not allowed to attend a gym because they had epilepsy. Clearly there is need for improvement in access to health care and preventive care through healthy lifestyle behaviors.

The SC BRFSS data has also shown that *persons with active epilepsy report significantly more mentally and physically unhealthy days and activity-limited days in the past month than persons without epilepsy* [6].

*Focus groups* were held in four areas throughout SC to ask persons with epilepsy about their experiences with medical and community care [7]. Forty-one people participated, who represented a total of 31 people with epilepsy (i.e., some participants had epilepsy, others were family members of people with epilepsy). Of the persons with epilepsy represented, 77% were over 21 years of age, 58% were male, and 65% were white, so while a small group, they represented fairly well the demographics of the state (69% over 21, 49% male, and 67% white in the year 2000 [8]).

In relation to health care, participants related difficulty finding assistance,, and reported multiple barriers to obtaining care. These included expense, lack of mental health care, complex treatments, lack of transportation, and difficulty obtaining disability benefits. As for community care, participants related the need for better vocational services (although also mentioning the helpfulness of some Vocational Rehabilitation counselors), the loneliness and isolation connected with epilepsy, loss of opportunity, dependency, employment difficulty, stigma, and medication side effects. Despite the known difficulties associated with obtaining and keeping employment in some cases of epilepsy, numerous obstacles for obtaining disability benefits were noted, including being diagnosed after 18 years of age, epilepsy itself not being considered a disability (i.e., only getting assistance if you have a child, if you file as mentally ill or as mentally retarded, etc.), unable to get assistance with disability filing until being turned down 3 times, and not qualifying for transportation assistance despite not being allowed to drive.

MUSC is currently conducting *a study which looks at the health outcomes of persons with epilepsy in SC*. It is being conducted by telephone interview with the person with epilepsy, or if they are unable to answer questions by telephone, a proxy individual may do the interview. In the latter case it is an abbreviated interview, skipping subjective questions. The study is not population-based, and

since it is not yet completed, has not been weighted to the SC population. The majority of participants were recruited from a university epilepsy clinic or a private neurology practice. However, it does cover a wide range of demographics. The findings reveal that of PWE approximately 64% are white and 31% black; 42% male, and 17% under age 18, 75% 18-64 years, and 8% 65 years and older (unfortunately, the elderly are under-represented). 54% report having had a seizure within the past 3 months, as compared to 46% of adults with active epilepsy responding to the SC BRFSS survey. Thus, participants in this study may reflect a higher proportion of intractable epilepsy than the general population of PWE in SC.

In addition, the adult participants had slightly larger proportions of higher education than the population of SC. Eighty-one percent of participants 25 years of age or older had at least a high school diploma compared to 76% of SC citizens (per the 2000 census), and 27% had at least a bachelor's degree compared to 20% of SC citizens [9], so those participating in this survey appear to be more educated than the general population of SC, as well as the overall population of PWE in SC. However, when asked if *epilepsy had prevented them from going as far in school as they would have liked*, 33% of the adults with epilepsy responded 'yes'. Of youth with epilepsy ages 11 to 17 years currently attending school in this study, 69% of parents/caregivers reported the youth were either currently getting extra help or going to classes for special needs, or the parent/caregiver felt they needed extra help.

Epilepsy had a dramatic effect on employment. *Approximately 1/3 of the adults interviewed were working, 1/3 were on disability, and the last 1/3 were retired, not working because of epilepsy or another medical condition, homemakers, students, or other.* Of those on disability, 70% were on disability due to epilepsy. *67% of adult participants had had at least one seizure in the past year.* When asked if they felt that epilepsy had ever kept them from getting the kind of job they would like to have, 51% of adults replied 'yes'.

Ninety-five percent of participants took antiepileptic medications during the previous year, *41% of whom reported side effects from the medication that bothered them.* Whether a person saw an epilepsy specialist or not appeared to make a difference in their care. Forty-five percent of adults seeing an epilepsy specialist reported their provider asked them about medication side effects versus 19% of those not seeing a specialist for their seizure care. Sixty-one percent of adults seeing an epilepsy specialist reported their provider asked them about their mood or behavior versus 44% of those not seeing an epilepsy specialist.

Stigma continues to be attached to epilepsy in SC. Sixty percent of adults responded 'agree' or 'strongly agree' to the statement, "In many people's minds, epilepsy attaches a stigma or label to me", and 38% of adults endorsed the statement, "I feel others are uncomfortable with me because of my epilepsy".

This data shows us that epilepsy is not an uncommon disorder and it affects many aspects of a person's life. Appropriate and affordable health care could decrease seizures, comorbid conditions, and medication side effects. Intervention in education and employment would enhance quality of life for persons with epilepsy. Interventions are needed for smoking cessation as well as physical activity appropriate for persons with epilepsy. Changes in disability that recognize the unique challenges of epilepsy, as well as assistance in filing could ease financial burdens when appropriate. Public education on epilepsy could decrease the lingering stigma attached to epilepsy.

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### III. Cost of epilepsy

*"I've lost my house, my car, and the right to engage in my profession, my family is close to financial devastation, and I'm pissed off."  
PWE in Trident Health District*

*"I've looked into insurance for myself, it would cost me at least 900.00 per month, since my child is 19 yrs old I cannot get Medicaid or even food stamps, because I work 35 [hrs] per week"  
PWE in Trident Health District*

Determining the cost of epilepsy is a difficult task. While there are a number of studies on this subject, there is little consensus on how best to quantify the cost. Among the difficulties in this task are variations in the definition of epilepsy and in case ascertainment between different studies, as well as the theoretical framework of the studies. Economic studies vary in their definition of direct and indirect costs, on inclusion of indirect costs, whether they use actual, average, or hypothetical costs, how well they are able to exclude costs due to concomitant illnesses, and how they value intangible costs such as quality of life. Direct costs are the cost of medical, non-medical, and patient- or family-related resources used to prevent, diagnose, treat, or rehabilitate persons with disease [1], although in reality it usually includes only physician visits, inpatient and emergency department visits, diagnostic or therapeutic procedures, laboratory tests, and antiepileptic medication costs. Rarely, nursing home or home health costs are included, and epilepsy-related medical costs that are not coded as epilepsy-related (i.e., injuries secondary to seizures, antiepileptic medication adverse events, dental costs secondary to antiepileptic medication side effects, ancillary health care needs as physical, occupational and/or speech therapy, etc.) are likely to be missed. Indirect costs are the cost of economic output that is lost because of the effects of an illness on a person's productivity on the job and at home [1]. When these are included, they usually only encompass work hours lost due to illness, underemployment, unemployment, and work hours lost by caregivers. Costs such as special education, vocational training, residential care, social support, transportation, and mortality are often not counted. Finally, there are the intangible costs of epilepsy, which are the psychosocial costs not related to resource use or productivity [1]. These are most difficult to put assign a cost, and are routinely left out of the economic studies of epilepsy.

Studies in the US have used a number of methods to assign costs to epilepsy. Some use data sets from an insurer and tally the actual cost per epilepsy patient [2-5], others use an expert panel of clinicians to assign average or hypothetical costs to a theoretical population [6-8], or finally, use of a national survey on medical expenditures [8]. Also important are the population included in the study. It may include only incident (newly diagnosed in a period of time) cases, prevalent cases (all cases during a period of time), or a subset of patients (such as those with refractory epilepsy).

These studies have reported total annual costs of epilepsy in the US as follows:

<b>Total costs</b>	<b>Costs considered</b>	<b>Reference</b>
\$2.4 billion (1995 dollars)	Direct only	[8]
\$10.1 billion (1992 dollars)	Direct only	[3]
\$12.5 billion (1995 dollars)	Direct & indirect	[2]
\$16 billion (1994 dollars)	Direct & indirect	[9]

Most studies commented that they felt their estimates were probably low due to either not capturing the entire population or not capturing all costs. Average annual per patient costs in the US have been reported as follows:

<b>Per patient costs</b>	<b>Costs considered</b>	<b>Other information</b>	<b>Reference</b>
\$1150 (1994 dollars)	Direct only		[9]
\$1335 (1995 dollars)	Direct only (claims related only to epilepsy)	Privately insured, so mostly employed, working age	[5]
\$2923 (1995 dollars)	Direct only (compared epilepsy pts to non-epilepsy pts and removed non-epilepsy-related costs)	Same as above	[5]
\$1490 (1995 dollars)	Direct only		[8]
\$2012 (1992 dollars)- Medicaid cost \$5047 (1992 dollars) – normative costs	Direct cost (claims related only to epilepsy)	Determined costs to Medicaid population as well as cost if not covered by Medicaid	[3]
\$9617 (1996 dollars)	Direct cost (all pt claims, not just those related to epilepsy)	Only included patients < 65 years, privately insured so unlikely to be disabled	[4]

Even when looking only at direct cost, there is obviously a wide range of estimates depending on the population and methods. Assignment of direct and indirect costs varied from an average of 14% direct for prevalent cases (and 16% for incident) in a mixed-severity population [2] to 25% direct for prevalent cases (and 33% for incident) for refractory cases [7].

Incident cases had higher costs in general than prevalent cases, since most testing usually occurs in the first year after diagnosis [2,7,8]. Since there is often a delay in diagnosis, costs of epilepsy prior to a diagnosis may be missed, especially if only cases with recurrent seizures are included in a study [1]. Refractory and more severe cases of epilepsy had higher costs than cases responsive to treatment, the latter of which make up the majority of cases. One study considered patients seen by generalists compared to those seen by epilepsy specialists. They reported an average annual direct cost per patient of \$1035 for those with a generalist and \$1902 for those seeing a specialist [8]. It was noted that the patient group seeing generalists had emergency department visit costs almost 6 times higher than the specialist group. The authors stated “Members of the physician panels emphasized the need for appropriate treatment immediately following the first unprovoked seizure. The ideal scenario would involve patients consulting a neurologist who specializes in epilepsy to begin a treatment regiment.” [8] They felt the usual scenario of waiting until the second or later seizure, and seeing a series of primary physicians prior to a specialist ultimately resulted in higher costs.

A summary report on the costs of epilepsy in children concluded that overall direct costs per year were higher in children than adults [10]. Other findings included utilizing rectal diazepam (to terminate breakthrough seizures) led to savings, reducing polypharmacy in children with multiple handicaps led to a reduction in the need for healthcare services as well as a reduction in seizure frequency, post-ketogenic diet costs were less than pre-diet costs, vagal nerve stimulators had a 2.3 year cost payback period, and post-surgical costs eventually dropped below pre-surgical costs [10].

Per the SC Department of Health and Human Services State Fiscal Year 2006 Annual Report, Medicaid covers approximately 25% of the citizens of the state [11]. We looked at Medicaid payments in 2006 for persons in SC with epilepsy, which we defined as having had a primary or secondary epilepsy or seizure diagnosis ICD-9-CM code (345.xx, 780.3, or 780.39) and a prescription for an antiepileptic drug during the year. There were 11,362 persons with epilepsy as defined above. This definition of epilepsy is a rough estimate— it could be missing individuals whose epilepsy has been treated by surgery, VNS, or ketogenic diet who are not taking antiepileptic drugs. It may also errantly include individuals with seizures but not epilepsy who are on an antiepileptic drug for something other than epilepsy. The total cost for inpatient and outpatient hospital visits, emergency department visits, physician office visits, and antiepileptic drug prescriptions was \$29,499,472. This total cost, and any other data unless otherwise noted, is minus extreme minimum or maximum values (the standard in health data related statistics is to remove values outside of plus/minus two standard deviations from the overall mean). The average expenditure is \$2596 per person. It should be noted that these costs are associated with visits in which seizures or epilepsy is listed as a discharge diagnosis, but the visit may have been for a condition other than epilepsy, so the

costs cannot all be attributed directly to epilepsy. The following are the average Medicaid expenditures for visits: \$5065 for inpatient hospital visit, \$114 for emergency department visit, \$97 for non-emergency department outpatient hospital visit, \$56 for physician office visit, and \$86 for antiepileptic drug prescription. The following are the average number of visits with a seizure- or epilepsy-related diagnosis code per epilepsy patient: 1.3 inpatient hospital visits, 1.6 emergency department visits, 1.7 non-emergency department outpatient hospital visits, and 1.9 physician office visits. There was an average of 10.1 antiepileptic drug prescriptions. The average expenditure by age group is \$2349 per patient in those under 18 years, \$2844 per patient in those 18-64 years, and \$1050 per patient in those 65 years and older. Below is a table of Medicaid costs, visits, and prescriptions (Rx) for all ages (see Appendix for analyses by age group).

2006 Medicaid Expenditures in SC for persons with a seizure or epilepsy diagnosis and an antiepileptic drug prescription

Type of Visit	Total Cost	Max Cost	Max Cost*	Mean Cost	S
<b>Inpatient Hospital</b>	\$16,317,981	\$38,844	\$462,198	\$5,065	
<b>Emergency Department</b>	\$661,017	\$172	\$779	\$114	
<b>Non-ED Outpatient Hospital</b>	\$836,639	\$803	\$14,650	\$97	
<b>Physician Office</b>	\$490,713	\$195	\$1,847	\$56	
<b>Antiepileptic Drug Prescriptions</b>	\$11,193,122	\$436	\$6,934	\$86	

\*Maximum prior to outlier removal

Type of Visit/Rx	Total Visits/Rx	Max Visits/Rxs	Max Visits/Rx*	Mean Visits	S
<b>Inpatient Hospital</b>	2738	3	13	1.3	
<b>Emergency Department</b>	4879	5	53	1.6	
<b>Non-ED Outpatient Hospital</b>	6967	5	38	1.7	
<b>Physician Office</b>	7600	5	58	1.9	
<b>Antiepileptic Drug Prescriptions</b>	110,747	32	136	10.1	

\*Maximum prior to outlier removal

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## IV. Surveys

### A. Survey for Persons with Epilepsy

A survey concerning living with epilepsy in SC was posted on the SC Epilepsy Act – 168 website. It asked for persons with epilepsy (PWE), family members of PWE, or others to fill out the anonymous survey. Most of the survey consisted of multiple choice or fill-in questions, with an open section for listing needed services, as well as comments, at the end. In addition, in November we held a videoconference for persons with epilepsy and their families. Vocational Rehabilitation linked 15 of their sites throughout the state, and individuals discussed epilepsy services in SC: what works and what doesn't work or is needed. Ninety-four individuals filled out surveys: sixty-two via the website, and thirty-two from the video conference. Some surveys may be referring to the same individual. At most, it is felt there are 9 surveys that could be duplicates (10%), but even in the few suspected to be duplicates, not all the responses are identical, so all surveys were included in the analyses. Note that some percents may sum to 99% or 101% due to rounding.

Forty-eight PWE (51%) reported for themselves, 37 individuals (39%) reported for their child (19 of these were adult children), and 9 individuals (10%) reported for a spouse or other family member. Most persons represented were adults, but 20% represented children with epilepsy, and 7% represented PWE 60 years or older. Urban areas were over-represented with 73%, whereas per the 2000 census, 60.5% of SC lived in urban areas [1]. Of those 18 years and older, the few individuals from isolated and small rural areas did not report that transportation was a problem. 39% (7 of 18) of those from a large rural area, and 50% (27 of 54) of those from an urban area reported that transportation was a problem.

Only 1 individual reported not currently being treated for epilepsy and had no seizures in the past year. 73 (78%) PWE were receiving treatment and had had seizures in the past year. This may not be representative of all individuals in SC with epilepsy (Begley et al. described a US population-based group in which 71% were controlled, however the group they studied consisted of either HMO-insured persons or persons living in one of the wealthiest counties in the US [2]). 40 (43%) go to a specialized epilepsy clinic for management of their epilepsy. 11% of children were using Children's Rehabilitative Services, 23 of PWE (24%) reported receiving Medicaid and 14 (15%) reported receiving Medicare. When asked how PWE located state services, 67 gave responses. Only 28% were referred by a professional (ie, doctor, nurse, lawyer, social worker, healthcare provider) and 7% referred by the Epilepsy Foundation. 99% were taking medication for epilepsy. 39 out of 89 (43%) reported difficulty obtaining their epilepsy medication, and 75% of them reported the expense of the medication was the problem. Respondents were asked how they pay for their medications. 46% self-paid, 48% had insurance that paid all or part, 27% used Medicaid, 10%

used Medicare, and 12% used a payment assistance program through their community, a drug company, the doctor's office, etc.

We asked those individuals between 18 and 65 years of age if they worked. 22 (36% of the 61 responses) said yes. Of the 39 not working, 7 (18%) reported trouble concentrating related to epilepsy, 16 (41%) reported too many seizures, and 9 (23%) reported no transportation related to their epilepsy (some individuals reported more than one reason). A total of 26 (67%) of those not working responded that it was due to reasons related to their epilepsy, which represented 43% of those aged 18-65 responding to the working question.

Forty-five percent (45%) of respondents had at some time applied for disability due to their epilepsy. 23% reported ever receiving social security disability benefits for epilepsy. 3% had ever received disability benefits for a condition other than epilepsy, and 14% had ever received supplemental disability income for their epilepsy. A total of 30% had ever received disability benefits related to their epilepsy.

Individuals were asked to list their level of education. For those 18 and older, 73 responded. 49% went to college or technical school, and 12% attended graduate school. 32% of PWE in the survey had received extra assistance in school for learning difficulties, 29% had been given an individual evaluation or testing for learning difficulties. 35 of 78 (45%) felt the SC educational system had not served their needs. When looking at those individuals of usual working age (18 to 65 years), 26 of the 39 individuals (67%) who reported not working had gone to college, technical, or graduate school.

Individuals were asked how they usually traveled distances greater than two miles. For those 18 years and older, 28% were able to drive their vehicle, 65% relied on a family member to drive them (as well as friends, walking, taxis, or public transportation). Of note, only one respondent out of the 74 listed public transportation among their replies, and only two noted use of an agency transportation. 45% stated that transportation was a problem for them.

We asked if respondents currently exercise or have a healthy level of physical activity. 57 of 89 (64%) responded yes. Of those who responded no, 34% were afraid to exercise because of their epilepsy, and 19% could not exercise because of a condition other than epilepsy. Four individuals responded that depression, tiredness from medications, or lack of energy interfered with exercise.

Fifty-six percent (56%) reported they had been treated badly by others because of their epilepsy. Of the 45 responding as to whom had treated them badly, 29% reported family members had treated them badly, 53% reported friends, 38% reported school teachers, 56% of those over 17 years reported employers, 29% reported medical professionals, and 18% reported state

employees. 44% reported they felt they do not get enough social interaction. 28% of respondents did not feel well-informed about epilepsy, but 93% reported that those closest to them knew the first aid for epilepsy.

Sixty of 91 respondents (66%) said they had had depression or anxiety that interfered with their life. Unfortunately, due to a problem with our on-line survey, we were unable to get complete answers to all of our depression-related questions. Thus, we only have 24 responses to whether they had ever sought help or evaluation for the depression or anxiety. 16 of those 24 (67%) did not seek help for their depression/anxiety. However, a total of 31 individuals responded to the next question concerning why they had not sought help, so it appears that at least 35 of the 60 respondents (58%) who had experienced depression or anxiety did not seek help or evaluation.

We asked the open-ended question 'what services for epilepsy would benefit you?' The most commonly mentioned services involved financial help with medications and insurance (25, or 27%). The next most common service was transportation (22%). 15% wanted employment assistance. 12% wanted better medical care, 10% wanted more information about their epilepsy, and 10% wanted the public to be educated about epilepsy. Other services requested included support groups for epilepsy, information about epilepsy-related services, continuing education assistance, disability benefits, unspecified financial help, better education of teachers concerning epilepsy, social activities for people with epilepsy, daycare/school assistants/companions, more school services, psychological services, and affordable housing/group homes.

We also left a space for comments. Some of the comments received head the various portions of this report. The extended version of this report and a partial listing of comments are in the Appendix.

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## B. Videoconference

A videoconference was held November 14, 2007 in SC Vocational Rehabilitation Department regional offices throughout the state. It was advertised on the SC Epilepsy Act168 website, in newspapers throughout the

state, on ETV radio stations throughout the state, and by word-of-mouth. On the night of the teleconference, individuals attended in Aiken, Anderson, Berkley-Dorchester, Charleston, Conway, Florence, Greenville, Columbia, Laurens/Greenwood, Orangeburg, Spartanburg, and Sumter. Approximately sixty individuals participated. About half of these individuals filled out a questionnaire at the time of the videoconference. It is not known whether the others filled one out on-line.

Although many of their concerns may have been captured through the questionnaires, we wanted to highlight some of the issues that came up repeatedly during the videoconference. Greatly discussed was the high cost of antiepileptic medicines (participants from two different areas mentioned \$400/month), the high cost of medical care, and the high cost of obtaining insurance (\$600/month was cited). Particularly difficult is trying to insure an adult child who is unemployed (and perhaps unemployable/difficult to employ due to epilepsy). If someone does have employment-related insurance they feel trapped, unable to change jobs for fear of not getting insurance again. There is difficulty in obtaining disability, and additional financial hardship while waiting for approved disability to begin. Numerous individuals discussed losing their jobs due to epilepsy, and wanting to work. Businesses and employers often fear liability issues, and refuse persons with epilepsy as either employees or patrons. In the area of education, many of the parents had gone to schools themselves to educate the teachers, school nurses, and students about epilepsy, and emphasized the need for better education.

It was also mentioned a number of times that Emergency Medical Services (EMS) will insist on transporting a seizure patient, even if the patient and/or parent indicate they do not need transport. In at least one case, the insurance company would not pay the bill for one of these unwanted transports because they deemed it was not an emergency. EMS and also police were identified as needing better education. A large area of concern is the lack of opportunities for teen-age and young adults with epilepsy to socialize, work, and live away from home. Finally, the need for support groups and the need for transportation were raised at almost every site.

### C. Physician Survey

*“All of the good doctors don’t take Medicaid...Public school has failed children with epilepsy. It is not being acknowledged so teachers don’t know what to do or what accommodations need to be given. Parents don’t even know what services are available for children with epilepsy.”*  
*PWE in Waccamaw Health District*

*“Initial information given after initial diagnosis needs to be more thorough as to services available - not having to go to website, but having a person readily available at local level.”*

*Parent of PWE in Trident Health District*

A total of 55 physicians completed the surveys (please see Appendix for complete survey and detailed results). The response rate was 46% (22/47) for family practitioners (FP), 38% (8/22) for pediatricians, and 57% (25/44) for neurologists. Two envelopes were returned by the postal service from the FP group, two were returned from the pediatrician group, and one from the neurology group. Surveys were sent to physicians throughout the state. Zip codes were transformed to urban/rural listings using the Rural-Urban Commuting Area Codes data (RUCA, version 2.0, updated 11/13/07). The RUCAs are designed to define rural and urban based on the Census Bureau's definitions of Urbanized Areas and Urban Clusters, based on criteria including population density and population work commuting patterns. 67% of the physicians were in urban areas, 24% in large rural areas, and 9% in small rural areas.

Regarding whether the surveyed physicians regularly treat patients with epilepsy (PWE), 64% FP report they treat PWE, while 27% reported they did not. This does not follow the US medical belief that primary care practitioners are the “gatekeepers” for all patients, and infers that PWE do not have a primary care practitioner coordinating their care. There are also 1/4 to 2/3 of general health care providers who report diagnosing and evaluating PWE. There is an accepted statistic that about 2/3 of PWE are diagnosed and treated easily but these results infer that more are referred to specialists and that there may be more difficult epilepsy issues than previously thought. Another issue may also be that primary care providers do not have the time to assess for and coordinate the unique care issues of PWE.

Part of the survey queried physicians about which problems were typical for PWE. The neurology and pediatrician groups reported PWE having more issues with the known comorbidities than the FP. This may be a professional education issue and/or lack of understanding as it is well known that these typical comorbidities are not consistently assessed for by health care providers. Neurologists and pediatricians may inquire more about these than FP since neurologists are probably more aware of these issues and pediatricians assess more about school and developmental issues. All those surveyed reported issues with gaining or maintaining employment, although it is understandable that the pediatricians reported it less so due to their patient population age. Regarding the transportation law, since health care providers are not required to report epilepsy to the Department of Motor Vehicles, many health care providers may not inquire about transportation issues. Issues with access to medical care, paying for medical care and paying for medication are all strongly reported by neurologists and FP due to funding issues most adults experience. It is of concern that so many pediatricians reported these issues for children who can be

covered by Children's Rehabilitation Services if they are not eligible for Medicaid.

Physicians were surveyed about whether they were aware of organizations that may assist PWE. The results were of concern because general and specialized practitioners were not aware of common organizations that can provide assistance for PWE. The Epilepsy Foundation is a primary organization for PWE that can provide local and national resources as well as information about epilepsy, but very few of the health care providers were aware of this organization. Education about local, state and national resources appears to be needed.

Finally, the physicians were questioned about what they considered to be the most pressing service needs for PWE and their families. Each of the health care provider groups reported that paying for prescriptions was of concern and this is a national issue not only for PWE but all on medication due to cost issues. Another major issue was access to care. Access to care can be related to financial issues regarding insurance coverage and ability to pay for care. Also, in South Carolina, there has been no true coordinated epilepsy care for diagnosis and specialized evaluation until recently with the Medical University of South Carolina becoming a designated epilepsy center. Having an epilepsy center can also address the neurologists' concern of better ability to evaluate non-epileptic seizures (NES), which can be a comorbidity of epilepsy.

Of interest is that the pediatrician group reported concerns with obtaining comprehensive coordinated care, support for comorbid conditions, life planning issues, and patient education. The FP reported concerns with coordination of care issues like home laboratory draws for challenged PWE, patient education and life planning issues. Neurologists reported more community concerns noting lack of employer understanding, other employment issues, insurance/disability issues, lack of community awareness, and transportation issues. Both FP and neurologists reported concerns with compliance/adherence issues. All of these concerns point to the need for more coordinated care for PWE throughout the state to address all of these issues.

Overall, there appears to be a need for professional education of physicians about epilepsy services available in SC, common comorbidities of epilepsy and the importance of assessing for them, and the need to increase awareness about existing organizations that can offer support services and interventions to PWE and their families.

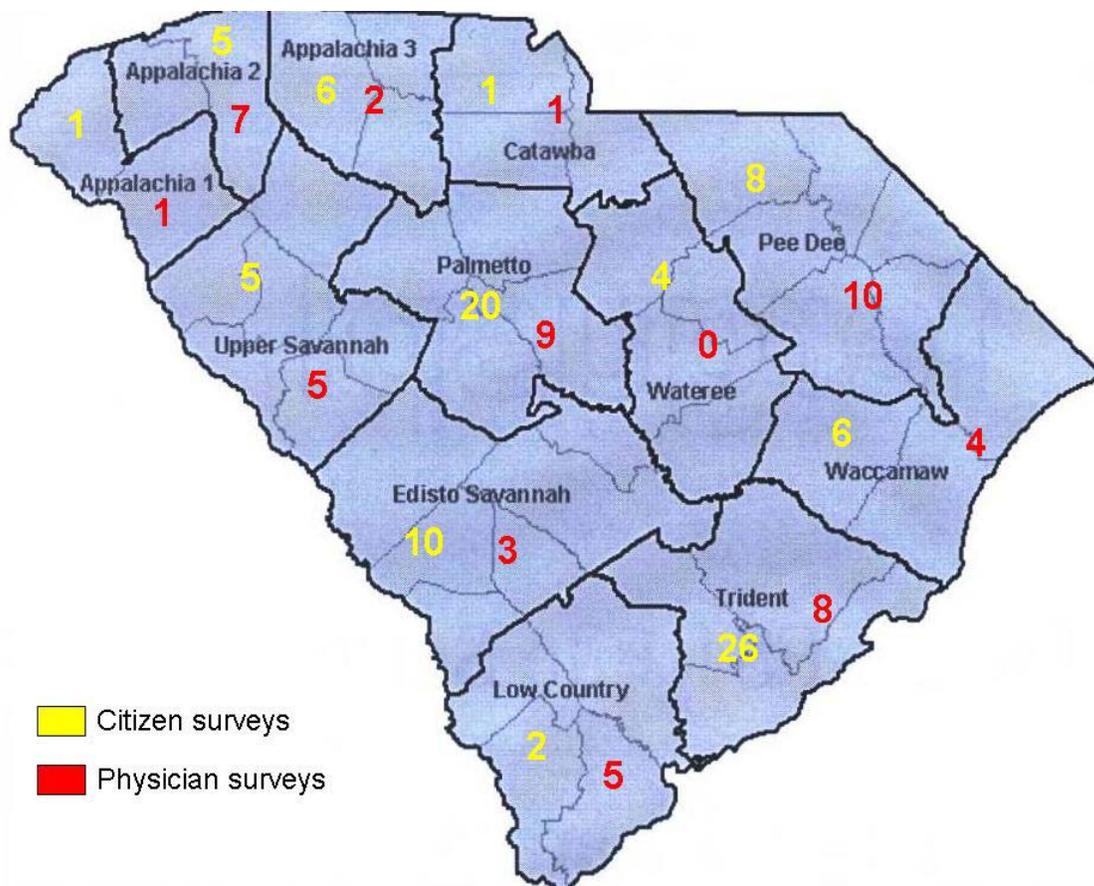


Figure 5. SC map of SCDHEC health districts and statewide distribution of those who responded to patient and physician surveys.

#### D. Survey of SC Agencies and Organizations

*“Too much idle time. The need for some type of employment and interaction with others is of great need. Also disability, as the outlook for fulltime, meaningful employment that could provide full support seems unlikely. Parents currently provide support. Have sought help from both Vocational Rehabilitation and Disabilities and Special Needs. Did not qualify for services from Disabilities and Special Needs and although having been to Vocational Rehabilitation and taken numerous tests provided by them and worked in their shelter program, no long term, meaningful help has occurred.”*  
 Parent of PWE in Waterlee Health District

*“The state of SC needs to offer healthcare assistance to children who are diagnosed with epilepsy independent of family income. Epilepsy has a huge effect on a child's life and their family. There are many state programs that are offered for other illnesses, injuries, birth defects (speech, hearing, etc). Epilepsy is not included.”*  
 Parent of PWE in Appalachia III Health District

The Committee considered that many state agencies and some not for profit organizations provide services for PWE. A survey tool was developed (see Appendix) to determine what services were being provided, its specificity to PWE, and how many PWE were provided these services. Twenty state agencies and organizations were chosen based on services they provided that were perceived to be of benefit to PWE. A deliberate decision was made to send the survey to the head of each organization in as much as the Committee did not know all available services or relevant individual(s) in those organizations. Further, the responsibility for the response remained with the lead person of the organization queried. Each survey was accompanied by a letter explaining our purpose, an instruction sheet and a copy of ACT 168 of 2007 which authorized the Committee to make such inquiries (see Appendix).

Ten of the twenty (50%) organizations responded. Seven of the 20 (35%) indicated that some services for PWE were provided (see Appendix). Services which directly impacted PWE were reported by only three organizations; Epilepsy Foundation of South Carolina (EFSC), SC Department of Health and Human Services (SCDHHS) and SC Vocational Rehabilitation Department (SCVRD). The SCDHHS supported services for 6146 PWE in 2005, 6137 PWE in 2006 and 6314 PWE in 2007. The SCVRD provided general and direct services for adults with epilepsy. This included 285 PWE in 2006, 301 in 2005 and 300 in 2004. The Epilepsy Foundation of South Carolina provided direct and indirect services for 4550 PWE in 2006 and 5136 in 2005.

Agencies providing general services for clients and that would also benefit PWE did not track PWE. There were four agencies that provided some teaching about epilepsy. There were no responses from either of the SC medical schools regarding teaching medical students or residents about epilepsy.

The limited number of respondents is disappointing. One might conclude that the survey had limitations and/or was misunderstood. Alternatively, the surveys may not have been sent to all of the appropriate agencies or individuals. Instead, our view is that there is a restricted focus on the problems of epilepsy. A number of agencies which must by law service this disabled, though unique, population either indicated no services for PWE or did not respond. Examples of non-responders include the SC Department of Education and the Protection and Advocacy Agency. The only organization which indicated a major role in epilepsy education was EFSC.

The Committee concluded that there are probably many available and pertinent services for PWE in South Carolina. However, access to those services is not only problematic for PWE but also likely not extended or communicated by existing agencies to this population in need.

E. Survey of Employers (see VII. Employment, page 41)

## V. Mental Health Care in Persons with Epilepsy

*“It would be great to have a support group like we use to have! The low country epilepsy support team and our meetings were fantastic. Then to have those and to have projects and funds and educate people about epilepsy was really made me feel good and I learned more constantly. That is one way of staying on top and knowing others that go through the same that I have to live through each and every day.”*  
*PWE in Trident Health District*

### A. Introduction

Epilepsy is a common disorder with a prevalence of 2% of the population in SC [1]. The term “epilepsy” is functionally more than just seizures. As a brain disorder it can include ongoing effects between seizures such as psychological, cognitive, and/or behavioral challenges. It is important to note that epilepsy treatments can also compound the challenges a PWE experiences. Therefore epilepsy management requires an interdisciplinary approach as it is a unique population with special needs. Depression, anxiety, attention and behavior issues occur commonly in 29-60% of PWE [2]. These problems along with breakthrough seizures and epilepsy treatments can all encumber the PWE’s well-being, leading to decrease quality of life. Additionally, the PWE and their family perceive stigma and may feel inadequate managing the seizures, further placing them at risk for maladjustment to their disorder and leading to psychiatric issues. As these issues have come to the forefront, the National Association of Epilepsy Centers in 2001 updated the Specialized Epilepsy Center Guidelines and emphasized the need for a systematic approach to epilepsy as a chronic illness.

Currently in SC there is no formal system for the assessment, evaluation and treatment of acute and/or chronic psychosocial issues in PWE. Our clinical experience suggests that psychiatrists, psychologists, and mental health counselors report lack of experience and comfort in treating the psychosocial issues in PWE. There is no state agency appointed to coordinate the psychosocial and developmental needs of PWE. In fact the majority of PWE with mental health issues continue to cope with the special issues of epilepsy without assessment, intervention or treatment in SC. As practitioners we are often confronted with difficulties when referring PWE for urgent, chronic and new mental health issues and finding that assessment and treatment is problematic. If a PWE with a mental health exacerbation could benefit from inpatient care to titrate medications and provide therapy in an acute situation, there is no practical mechanism for admission unless they have threatened to hurt someone or are suicidal. PWE in need of admission must be assessed at an emergency room of a local hospital or medical center to see if they qualify for an admission. The emergency room staff is burdened and likely ill equipped to deal with these situations, due to training and/or comfort level in assessing PWE. There are special issues in assessing the PWE as their problems are complex and

neurologically based. The PWE must be assessed for possible change in epilepsy, effects of treatment along with psychological and behavioral problems. If the PWE is not admitted for such acute issues, the PWE is then left at home awaiting treatment while the family attempts to cope with the situation. There have been incidents where family members of PWE with secondary mental health issues have been told to call the police for assistance. This is entirely inappropriate as it can further escalate an unstable and unmanageable problem.

## B. Evidence

Mental health conditions, particularly depression, have been more recently considered to be serious health problems that significantly impact all areas of life. For example, Healthy People 2010, with a primary goal to increase quality and years of healthy life highlights mental health as one of the 10 leading health indicators for this goal [3]. According to the World Health Organization, depression was the leading cause of disability as measured by years lived with disability and the fourth leading contributor to the global burden of disease in 2000 [4].

Comorbid depression for persons with epilepsy presents a double impact, and with both pathophysiological and psychosocial similarities between depression and epilepsy, this creates a complex picture [5]. Indeed, Ettinger et al [6] noted that depression, not seizure frequency, has been cited as the most important predictor of health-related quality of life in persons with epilepsy [7,8]. In response to Living Well with Epilepsy I and II, Epilepsy Foundation of America (EF) and the American Epilepsy Society have increased attention to comorbid mental health conditions in children and adults [9]. Gilliam [10] listed depression as the most common comorbid condition associated with epilepsy. The EF notes an average prevalence of 29% of major depressive disorder in PWE which is almost twice the rate in the general population. [2]. Multiple other studies have found depression to be more common in people with epilepsy than in the general population [11-13], Even subthreshold depressive symptoms not warranting a clinical diagnosis of depression can still significantly impair functioning [14,15]. In light of these findings, the EF stated in 2005 that systematic screening of mood disorders in people with epilepsy would help insure that patients receive indicated intervention [14]. The EF statement agrees with the national practice guidelines for recognition of depression, which recommends screening of high-risk groups, including those with possible physical causes of depression [16]. It also agrees with the US Preventive Services Task Force, which recommends screening adults for depression in clinical practices that have systems in place to assure accurate diagnosis, effective treatment, and follow up [17].

The impact of depression on persons with epilepsy cannot be underestimated; and despite a growing body of literature to support the importance of attending to depression in persons with epilepsy, it continues to be underdiagnosed and undertreated. Kanner [5] notes that while depression in

epilepsy may be an atypical presentation, one that does not mirror the DSM-IV diagnostic criteria, the most common reasons that it is not recognized is the failure of practitioners to ask their patients about it and the failure of patients to report symptoms. Studies of both adults [18,19] and children [6] with epilepsy have found that depression is often neither diagnosed nor treated, and Gilliam [10] reports that 80% of neurologists do not routinely screen for depression in patients with epilepsy. Poor accessibility and underutilization of mental health services by persons with epilepsy [20] may be explained by minimization of symptoms by the patient, conceptualization of depressive symptoms as “part of epilepsy,” physician lack of appreciation for the impact of mental health on quality of life, or physician unfamiliarity with evidence based interventions for depression [21,22]. Compounding the problem is the perception by physicians of increasingly stringent time frames for office medical evaluations [23,24], as well as lingering stigma. In fact, survey respondents in the UK ranked stress/depression first, followed by epilepsy, as the top two conditions that would cause them the greatest concern if they had to work with someone with either of these conditions [25]. In addition, there is an outdated belief among some practitioners that antidepressants may unduly lower the seizure threshold [26]. Treatment of depression can be cost effective. British economist Richard Layard has determined that if patients with depression and anxiety disorders were offered evidence based psychological therapies, the economic benefits would exceed the cost [27]. In addition, a US survey of PWE showed those with current symptoms of depression who were treated had significantly more medical visits than those treated patients not reporting current symptoms [28].

### C. Pertinent Research Findings in South Carolina

Investigators at the Medical University of South Carolina (MUSC) are performing epidemiological and behavioral investigations of PWE. Using SC Behavioral Risk Factor Surveillance System (BRFSS) data, researchers have found a prevalence of active epilepsy of 1%, and a prevalence of ever having epilepsy of 2% [1]. Compared to persons in SC without epilepsy, those with epilepsy reported significantly more mentally unhealthy days in the preceding month, which could indicate that PWE in SC are not receiving adequate mental health services.

In addition, a survey of individuals in SC with epilepsy was conducted to examine factors that may affect epilepsy outcome. The majority of participants were from a university epilepsy clinic or private practice, so they may not be representative of all individuals in SC. More than half reported having had a seizure within the last 3 months, compared to 46% of those with active epilepsy in the SC BRFSS. Preliminary findings from this current research show that about 40% of individuals aged 11 years and older have significant depressive symptoms (Center for Epidemiologic Studies Depression Scale [CES-D]). While almost 90% of youth (ages 11 through 17) had been asked by their epilepsy health care provider about their mood or behavior in the past year, only 55% of

adults had been asked. 47% of adults surveyed reported feeling down, depressed, worried, tense, or anxious, but only 22% reported seeing a health care practitioner or taking a medication for treatment. Correspondingly, 23% stated they felt they needed help for improving mood, or managing stress or emotional upsets, but had not received it. Of those who gave a reason why they hadn't received help, the most common reasons were 'didn't know where to get help', 'no one has offered', and 'need not recognized'. The youth sample was small (n=36), but 11% of the caregivers of youth reported that their child needed help for mood, or managing stress or emotional upsets, but had not received help, with half of these caregivers responding they didn't know where to get help.

In a related study with youth that comprehensively assessed depressive symptoms and psychosocial adjustment to epilepsy, 38% of youth reported having suicidal ideation. Results also showed that hopelessness mediated the relationship between attitudes towards epilepsy and depressive symptoms, suggesting that hopelessness is a target for psychological intervention. Further, in a clinical study, Wagner and Smith [29] found that few children with behavioral and emotional difficulties were referred to a psychologist onsite in the pediatric neurology clinic. Anecdotally, parents who did receive psychological intervention reported satisfaction with services provided. From these findings we can conclude there is a critical need for depression screening and facilitation of mental health resource utilization in youth and adults with epilepsy in South Carolina. It was noted that unrecognized and untreated depression in PWE is having a significant impact in SC. Important information from the SC Physician Survey found that 96% of neurologists, 36% family practitioners, and 100% of pediatricians noted behavioral or emotional disorders in the PWE they treat.

### Recommendations

1. Establish one comprehensive epilepsy program (CEP) and six regional epilepsy centers (REC) throughout the state that can provide specialized mental health evaluation and care for PWE. Provide training to neurologists and epileptologists to assess and start initial treatment for the PWE for anxiety and depression. If this initial intervention is not successful, then the PWE will be referred to the CEP psychiatrist or a psychiatrist with experience in epilepsy located closer to the PWE for further evaluation and treatment planning.
2. Establish a system of consistent referral relationships that are accessible and efficient between the CEP, Regional Epilepsy Clinics, emergency rooms/acute care centers, general neurologists and primary care practitioners for PWE.
3. Inform primary care practitioners and general neurologists about advances in epilepsy care and attendant psychosocial issues at least biennially (making use of available technology, e.g. podcasts, etc.).

4. Promote screening for psychosocial issues that coexist in epilepsy and use the same screening tools at all levels of care for the initial evaluation and repeat at least annually.
5. Provide an epilepsy self-management and self-determination empowerment model that is part of the intervention at the RECs to increase self-reliance, decrease maladjustment and the development of psychiatric disorders, decrease stigma and promote best outcomes for PWE and their families. (Consider using I-Chat for more accessible counseling of the family at home.)
6. Raise awareness of mental health care providers, vocational counselors and community advocates about epilepsy care and psychosocial issues at least biennially.
7. Educate teachers, school nurses, guidance counselors, and school administrators about epilepsy issues, including the mental health and learning issues that can coexist with epilepsy.
8. Create relationships, communication and referral processes between primary care practitioners/general neurologists, Mental Health Centers, SCVRD, Department of Education, RECs and CEP.
9. Continue increasing the integral involvement of the EFSC with all levels of medical care and the community. Encourage increased presence of the EFSC activities regarding patient and family support groups, community education, patient advocacy, social and fundraising events to continue increasing awareness and decreasing stigma in society.
10. Develop a respite care process for PWE and their families to provide relief support during periods of psychosocial difficulties.
11. Develop a state internet website where PWE and their families can gain information about epilepsy, epilepsy comorbidities, treatments and resources available at local, state and national levels. This could include chat rooms so PWE may share their experiences with, learn from, and empower each other.
12. Continue development and support of mental health parity.
13. Utilize state registry of PWE to monitor costs of mental health care.

All of these recommendations are consistent with the Living Well with Epilepsy II Report [2], which included participation from the following groups: American Epilepsy Society, The Centers for Disease Control and Prevention, Chronic Disease Directors, Epilepsy Foundation, and National Association of Epilepsy Centers.

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## VI. Employment

*“I was diagnosed at 40, I've had 2 jobs my entire life. My current job is a great job with well above average pay but I'm about to lose it due to my condition. I do not know how I will support my children and wife. I've worked since I was 13 supporting myself. I want to continue to take care of my family.  
PWE in Upper Savannah Health District”*

*“Unable to work as an RN - unemployable at this time - minimal retirement and no paycheck. 45% of our gross paycheck (my husband's retirement) goes toward medical bills.”  
PWE in Upper Savannah Health District*

### A. Introduction

Most people with epilepsy are able to work in the full range of jobs. Neither the condition itself nor the treatments for it will affect their ability to work. Unfortunately, epilepsy is often still stigmatized. People are reluctant to tell potential employers for fear of not being hired, not being promoted or given lesser duties. A concern for SC is that southern states are associated with higher rates of disability claims by PWE . West et al conducted a study on workplace discrimination and epilepsy in the US examining 5232 unduplicated records from 1992-2003 with an ADA Title I allegation basis of epilepsy [1]. The 5232 records represented 3% of all claims after data cleaning. 45.2% of the epilepsy claims involved workplaces in the South, although the South contains only 35.5% of the national population, and only 30.8% of families with a member with disabilities. About three-fourths of the epilepsy allegations were related to post-hire issues.

### B. Epilepsy Employee Population

According to the Epilepsy Foundation (EF) there are three million people with varying degrees of epilepsy in the US and we estimate 86,000 in SC. There are three employment levels for this population. The first group is the majority and consists of persons who are employed, have excellent seizure control, can drive, and function like any other employee. The second group has limited seizure control and may require a structured work environment with proper supervision in varying degrees. The third group is unable to work and should be on disability.

It should be noted that one issue unique to a chronic condition like epilepsy is its episodic nature. A PWE may have controlled seizures and be employed. Breakthrough seizures can occur related to a change in the disorder or their health, and the PWE loses their job. The PWE then applies for disability, which entails a long wait. Once they are reviewed, or even on disability, seizures

may become controlled again. The PWE is then refused or loses disability benefits. This may continue on, disrupting the PWE's self-esteem and self-worth, as well as the family's financial and emotional well-being and stability.

### C. Assessment of Salient Issues

#### (1) Unemployment and Underemployment of PWE

Our SC focus groups showed that PWE want to work, but face enormous challenges in acceptance by employers [2]. Another focus group study in Ohio and Kentucky noted that a factor important for maintaining a job was finding an employer who was supportive and knowledgeable concerning epilepsy [3].

When the employer is aware of an employee with epilepsy, steps can be taken to mitigate accidents or situations that may cause harm to others, if necessary. SCVRD can assist with this effort. Per the Equal Employment Opportunity Commission, "Some employers also fear hiring individuals with epilepsy because they are concerned about higher workplace insurance rates or believe that employees with epilepsy will use a lot of sick leave. Workplace insurance rates, however, are determined by how hazardous the type of work is and by an employer's overall claims record in the past, not by the physical condition of individual employees. There is no evidence that people with epilepsy are more prone to accidents on the job than anyone else. Finally, because medications usually can control seizures for most people, they do not need to take time off from work because of their epilepsy." [4].

#### (2) Estimated Financial Losses

Epilepsy and seizures affect over three million Americans of all ages at an estimated annual cost of \$15.5 billion in the US and approximately \$220 million in SC through direct and indirect costs. Data from the Behavioral Risk Factor Surveillance Survey has shown that individuals with epilepsy in SC are less likely to be employed than individuals without epilepsy. Our survey of individuals with epilepsy while not representative of all PWE in SC showed that in the more than half of adults 18-65 years who responded they were not working, 73% of whom replied it was due to reasons related to their epilepsy. Yet 68% of these individuals who were not working had gone to college, technical, or graduate school, meaning they are most likely well prepared for the work force and SC is not benefiting from their talent.

#### (3) Impact of Employment on Quality of Life

Employment serves a number of important functions, including providing a sense of self-worth, an identity and personal status. For all persons, being unemployed contributes to emotional and behavioral problems and for those with epilepsy, unemployment is a major source of stress and can increase the risks

for comorbidities such as anxiety and depression. Aside from personal satisfaction, health care benefits available from most employers are a factor in improved life quality. Full time employment may greatly reduce the financial burdens and comorbidities associated with epilepsy.

#### (4) Employer Survey (Local)

The committee spoke with four employers in the Midlands, a large international manufacturer, a local manufacturer, a large public utility, and a large South Carolina bank. None of them asked new employees if they have epilepsy. All four indicated that if they knew an employee or applicant had epilepsy or any other disability covered under the Americans with Disability Act (ADA) they would make accommodations if possible for the person.

The committee also spoke with two of our temporary employee providers. The smaller agency asks their temporary employees if they have any disabilities or medical problems that would affect their work. The larger agency, which is one of the largest in the US, does not ask their temporary employees any questions about disabilities and indicate this is due to privacy and ADA regulations.

### C. Existing Resources

#### (1) Private Industry

Most employers adhere to the ADA and would make appropriate accommodations for anyone if necessary. Normally employees with epilepsy will not need special accommodations, but if needed, most can be accomplished with little or no cost. An informative brochure for employers is 'Working Effectively with Employees who Have Epilepsy' [5].

#### (2) Government

Government agencies should be the leader in employment of people with epilepsy or other disabilities.

#### (3) ADA

The ADA is a federal law that prohibits discrimination against individuals with disabilities and ensures equal opportunity in employment for persons with disabilities. Currently the EF is promoting the ADA Restoration Act of 2007 to restore the original intent of the ADA and amend the definition of disabilities. To assist people with epilepsy to fight discrimination, the EF has the Jeanne A Carpenter Epilepsy Legal Defense Fund.

#### (4) Vocational Rehabilitation

SCVRD is the primary source of retraining those workers requiring a change in occupations after being diagnosed with epilepsy and which cannot be controlled. Smeets et al noted "Findings suggest that treatment for people with epilepsy should focus on coping skills training that emphasizes the acquisition of active, problem solving-oriented, and goal-directed coping skills that can assist the individual with epilepsy in pursuing personal, social, and vocational goals [6].

For the adult with epilepsy, vocational rehabilitation can be essential to gain or retain employment. This process is centered about skills of working as much as skills of a specific trade or profession. For the young PWE, school performance may have been marred by the interruption of school attendance and the effects of seizures as well as comorbidities. This younger PWE may require remedial education and training as well as consideration of lost chances to develop social skills. If the onset of epilepsy is later in life, the already working adult may require a job change or position change. This is often a shift downward in status and pay scale. Benefits as health insurance also may be lost. In each of these circumstance the role of rehabilitation counseling and training provides critical support services to bridge all opportunities for gainful employment.

The SCVRD has developed and utilizes a cost benefit analysis of their efforts in rehabilitation (personal communication, Linda Lieser, Assistant Commissioner). The well validated model allows economic analyses for various disabilities, ages, gender and referral source. In the case of epilepsy, there is a 16.9% rate of return on the invested rehabilitation cost. It is concluded that in SC, Vocational Rehabilitation is beneficial for PWE, SC state government, society and the SC taxpayer.

#### (5) Sheltered Workshop

For those who do not have good seizure control, the focus should be sheltered workshops which operate like any other business, except that the employees are adults whose physical or mental disabilities currently prevent them from competing for regular jobs.

#### (6) Social Security Disability

Social Security disability should be available for those with epilepsy who are unable to find suitable employment because of uncontrolled seizures and who cannot work in a "sheltered workshop" situation.

PWE, with few exceptions, have a strong desire to be employed and earn a living as everyone else. Unfortunately, the reality is that PWE experience excessive unemployment and underemployment and it is thought that seizure control, stigma of epilepsy and comorbidities contribute to this problem. There are times when Social Security disability benefits are the rational solution and

application should be pursued. In SC, the application (claim) is processed through the Disability Determination Services of SCVRD. This division has a good rate of clearing claims. In 2006 and 2007, 79,013 and 66,472 claims were cleared in 74 and 69 days, respectively, whereas the federal goal is 107 days. DDS does not track claims based on the impairment of epilepsy or the rate allowances or denials for this condition. At the suggestion of the DDS, the Office for Freedom of Information in the Social Security Administration was contacted to obtain additional information specifically regarding epilepsy. The number of SC disability claims primarily based on epilepsy were provided. In SC for 2006 and 2007, there were 863 and 821 initial level cases (first claim), respectively. The allowances were small at 53 (2006) and 69 (2007). Conversely, the rates of denial were 94% (2006) and 92% (2007).

It is not infrequent that PWE report difficulty obtaining necessary benefits in a timely fashion. The consequence of this process can be costly. There will be difficulty in obtaining medications and needed medical attention. The PWE has an option to appeal the claim and usually at that time legal counsel is hired at additional costs to the PWE. The usual scenario is that following two denials of the claim, the PWE and attorney appear before an administrative law judge. An average and costly period of two years may lapse before there is successful completion of the claim.

The difficulty in obtaining these crucial benefits for PWE rests at the local, state and federal levels. In prior discussions with the medical examiners for DDS reveal that a primary problem is poor medical documentation. It is necessary that PWE and the treating physician provide clear descriptions of the seizures and clear frequencies of seizure occurrence. Education of PWE and physicians would effect improvement of this component of the process. The SSA makes available its listing of impairments through its "Blue Book" [8]. The impairment listings related to epilepsy are antiquated and make clear communications difficult. Disability (by SSA) is related to seizure type and description, seizure frequency, response to therapies and compliance as determined by antiepileptic drug blood levels. Functional capacity and comorbidities do not appear to be considered. Indeed, these issues may be paramount to the disability. It is also thought that the age at time of application weighs into the equation; the younger the age, the higher probability for denial. A comprehensive service delivery system could ensure that the best possible claims and follow through could be accomplished. To make changes at the federal level would be more challenging.

Ideally, a system of SS disability benefits should not create difficult barriers. It would best for PWE to have a system which requires regular review (every 3 months) and incentives to return to work. There are programs which do some of this and these programs are reported in the SSA "Red Book".

## Recommendations

1. Educate employers about PWE through educational outreach that may include workshops, access to internet site with information about epilepsy, and mailings.
2. Educate the public, health care personnel, and public/private school settings about job training opportunities in SC through SCVRD
3. Transportation is a major issue for PWE and is addressed in that portion of the report.
4. For those PWE who have been on disability but then are able to return to work, inform them of the circumstances under which disability may be continued while working. The Social Security Administration has available on-line their 'Red Book', which summarizes employment supports for individuals with disabilities [7].
5. For those PWE unable to work, medical professionals should inform them of the process of applying for disability. This information should also be conveyed to PWE through EFSC educational activities. When processing claims are unsuccessful, PWE should contact the Governor's Office of Ombudsman ([www.oepp.sc.gov/ombudsman](http://www.oepp.sc.gov/ombudsman) or (803)734-5049) or South Carolina Protection and Advocacy ([www.protectionandadvocacy-sc.org](http://www.protectionandadvocacy-sc.org) ).

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## VII. Education

*“School teachers need more info on the disease and its process. Do not let them exclude these children! They just want to be normal and included in learning activities.”*  
*Parent of PWE in Trident Health District*

*“Problems with a child which had seizures: trying to give the child good self esteem because of embarrassment of seizures in school and public places. Meds cause difficulty in concentration and school work, which also led to poor self esteem. Battled depression because felt isolated due to embarrassment from seizures and inability to drive.”*  
*Parent of PWE in Waccamaw Health District*

Epilepsy is a unique and complicated neurological condition encompassing medical, cognitive, social, academic, psychological/psychiatric, and vocational factors. Epilepsy is often misunderstood by the general public and by families of persons with epilepsy (PWE) as well as healthcare and public service providers. Stigma about epilepsy is an enduring and troublesome problem. A multifaceted educational approach to these issues is necessary for the best outcome. The Committee determined that there must be 1) patient/family education about epilepsy, 2) education about epilepsy and its comorbidities for the educators in our school systems, 3) education about epilepsy for the public, 4) specific education/training for first responders, law enforcement and healthcare support staff and 5) detailed education for healthcare professionals in training and in practice.

### A. People with Epilepsy and their Families

While it is obvious that newly diagnosed PWE need education, individuals with long-standing epilepsy are also in need of education. In a survey of newly referred patients to the Ohio State University Medical Centers' Comprehensive Epilepsy Center, patients were shown to need more knowledge about epilepsy [1]. 30% believed epilepsy is a mental disorder or a disease that is contagious. 41% believed it is necessary to put an object in the mouth during a seizure to prevent tongue swallowing. 25% thought pregnant women should discontinue their antiepileptic drugs to prevent birth defects. 86% were not aware of Ohio's regulations concerning seizures and driving. 25% believed it is okay to drive if they double-up on medication, are not driving alone, or are able to pull over at the onset of a seizure. 53% did not know it is illegal for a potential employer to ask if they have epilepsy. The number of years with epilepsy did not correlate with correct scores.

In SC where there is a large proportion of African-Americans, it is important to note that there may be unique challenges. In a qualitative study in Kansas African-American women with epilepsy were interviewed [2]. Financial

limitations were the single most important barrier in accessing epilepsy treatment and adhering to medical treatment. Associated with low economic resources was lack of transportation. In addition, a general lack of knowledge about epilepsy was found in the African-American community. Half of the participants reported they did not initially seek help for their epilepsy because they did not understand the condition, and the seizures were initially very rare. Even established sources of social support, such as churches, were found to lack education about epilepsy, decreasing their effectiveness as support systems.

Experience has shown that at the onset of epilepsy PWE and their families can be expected to have many questions about cause and prognosis. Subsequently, the diagnostic studies and treatments raise inevitable questions and concerns by the PWE. The patient and their family can access a broad range of general information from various sources but specific information for that individual has to come from the treating healthcare provider. It is imperative that this information be given and thoroughly explained to facilitate the best medical, social, vocational and educational outcomes for each individual patient.

There are varying degrees of impact that epilepsy has on individuals. In those situations where seizures are controlled and epilepsy remains "hidden" there are still likely to be problems with mental health, cognition, behavior and education that prevent full assimilation into society. These individuals do not currently qualify for services and "fall between the cracks". They require patient education and empowerment to understand and seek needed care for the comorbid conditions of epilepsy.

#### Recommendations:

1. EFSC provides a toll free telephone number and a regularly updated website for information and referral services. All information will be regularly updated after critical review its Professional Advisory Board. This information will be specific to the PWE age and life stage.
2. EFSC will raise awareness among emergency departments and neurologists, pediatric and family practice offices as to the availability of . of resources from EFSC and their role in disseminating this information
3. EFSC will collaborate with the SC Nursing Association and the SC School Nurses Association to make nurses aware of EFSC resources for PWE.
4. Increase awareness among health care providers of the of the need to provide information to PWE who appear to have little or no apparent impact from epilepsy and live an independent life but who may have unrecognized comorbid conditions.

## B. School System

The realization that epilepsy is more than just seizures is a necessary step forward for the school system to fully educate children with epilepsy. There are sufficient public laws that bring to bear provisions for the education of all handicapped children (see Appendix for ADA, IDEA) The intermittent occurrence of seizures while at school requires safety precautions and appropriate first aid which is not stigmatizing. There must also be recognition that the after effects of a seizure in school or at home may impair cognition for an extended period (even 12 to 24 hours), but do not necessarily require the PWE to be sent home or to an emergency department. This is of course individualized. Also individualized are possible epilepsy comorbidities, which are not uncommon and include impairment of cognitive abilities, learning disorders, behavioral problems, social issues and/or adverse effects of required treatment medications. Individuals with epilepsy are at greater risk for cognitive and academic difficulties (30% compared to 11% of the general population receiving special education support). The prominence of these coexistent phenomena can range from absent or subtle to profound and even disruptive. For many individuals who do not have learning or intellectual disabilities as classified by current criteria used in the educational system, subtle but diffuse neurocognitive impairments may still impede learning. For example, children with epilepsy are more likely to display difficulties in memory, attention, and information processing domains. Sometimes changes in medical therapy and/or academic intervention can resolve these issues if the parent, school nurse or physician is apprised of the situation and appreciates the potential causes and remedies. However, for other children, these factors continue to impede learning and should be considered in post-secondary educational settings.

Children have less developed adaptive skills than adults and stigma in the educational setting can be especially detrimental to a child's self-esteem and well being. Stigma about epilepsy persists and creates an unhealthy milieu for PWE and the rest of society. Societal segregation, isolation, and objectification are all at work to create withdrawal and depression in PWE. These circumstances are not related to the frequency of seizures. In fact, the more impaired child is likely to create a situation of compassion than the child with seemingly "normal" functions and only the occasional seizure.

### Recommendations

1. Create a Comprehensive Epilepsy Services Delivery System that will advocate for children and adults in need of school education and will assist state agencies and non profit organizations in the development and implementation of training and planning in their delivery of appropriate services in the educational system.

2. All schools (from pre-school up to post-secondary) and childcare programs/personnel (private and public) should receive epilepsy education (see Appendix for specific details).through EFSC

3. Adoption of an Epilepsy Policy created by the SC Department of Education for inclusion into a Chronic Health Condition Policy or Plan for by all schools and child care programs. This would include practical guidance and key information to help schools provide effective and appropriate support (medical, behavioral, cognitive and educational) for students with epilepsy.

4. Integrate epilepsy education into all current professional training programs, for identified educators, including school psychologists (see Appendix) and childcare workers whether private or public.

5. Require yearly individual school conferences for any student with epilepsy, initiated by the educational team, including the students and their caregiver(s) to develop the Individualized Health Plan (IHP), Individualized Education Plan (IEP) or 504 Plan, and Emergency Care Plan. These school plans should be developed and reviewed annually only by those school nurses, school psychologists, or designees who have epilepsy specific training.

6. If an IEP or 504 Plan is not needed, provide a comprehensive list of all school services and programs appropriate for students with epilepsy each year.

7. School nurses and the EFSC will provide age level appropriate Epilepsy Awareness and First Aid Training for all students (age level appropriate) in the Health Education curriculum in elementary, middle and high schools (Grades 3rd, 7th, and 10<sup>th</sup>).

8. Provide information to students with epilepsy regarding the ADA's allowance for persons with documented needs to have accommodations such as additional time and/or alternate environment for test taking, provisions for audio or video taping lectures, copies of class lecture notes, etc., if recommended by former school or health care providers, or if new onset epilepsy.

9. As part of a Transition Plan in the IEP, secondary schools should inform students with epilepsy of the available resources for post-high school education and/or vocational issues. For PWE, this could involve accommodations related to the following areas: attention problems, anxiety, depression, and information processing. Transition Plans should also include a plan to integrate vocational and community access if pertinent.

10. The staff of the Comprehensive Epilepsy Service Delivery System should develop and implement training programs regarding psychological assessment issues specific to children and adults with epilepsy, designed for

school psychologists, SCVRD evaluators, private practice psychologists, disability determination psychologists and psychological/psychiatric therapists.

### C. Public Education

Employers' attitudes towards PWE obviously have a direct effect on obtaining and keeping a job. A recent UK survey showed almost half (44%) of employers viewed employees with epilepsy with a high level of concern and felt epilepsy could lead to work absenteeism and work-related accidents [3]. Other common concerns were fear that other employees would be uncomfortable witnessing a seizure, and employer liability insurance costs would be raised. It was noted by the authors that bringing employers actively into contact with PWE would likely have more impact than abstract educational initiatives. US workers showed similar anxiety in a survey in New York City which reported only about half felt very comfortable or somewhat comfortable talking about the illness with the coworker, sharing an office, working on a project, or eating lunch together, and only 30% were very comfortable with providing first aid to a coworker with epilepsy [4]. The 2002 HealthStyles Survey of the US population showed only about a quarter of respondents felt knowledgeable about epilepsy [5]. Even among those who knew someone with epilepsy, fewer than half felt knowledgeable about epilepsy, and only about half thought they knew what to do if someone had a seizure. About 83% of adults had not read or heard anything about epilepsy in the past year.

Young adults with epilepsy may not be aware of the educational and vocational choices and resources available in SC to assist with the education process. Adults with epilepsy may need education and training programs for employment through SCVRD. Intervention and assistance by SCVRD is sometimes required to remain successfully employed. Awareness of these programs must be promoted in order for PWE, especially those who are young adults, to utilize these services. Interaction of program staff and medical/psychological teams to address not only the epilepsy but also the comorbidities (learning difficulties specific to PWE, depression, etc) is essential for successful job training and placement.

### Recommendations

1. EFSC and case managers will encourage increased epilepsy awareness and education in the business community in order to eliminate fear, discrimination and stigma and to promote PWE as being qualified for many forms of employment.

2. EFSC, case managers and SCVRD staff will advise and educate industry/business human resource personnel on safety measures and their

individualization when hiring PWE and will advise and educate PWE on the same.

3. EFSC can provide industry/business with best information and practices for First Aid for seizures to eliminate false and incomplete information. (See addendum for specific details.)

4. EFSC and Regional Epilepsy Clinic physicians and nurses should provide information to public service providers (police, emergency medical services, firefighters, institutional and hospital healthcare support staff) on a recurrent biennial schedule.

5. EFSC and the Comprehensive Epilepsy Services Delivery Program should appropriate funding for public service programs specifically to educate about epilepsy in order to eliminate negative issues which perpetuate the stigma of this chronic health condition and stifle efforts of PWE to achieve a successful and productive life.

#### D. Healthcare Professionals

Competent healthcare providers obtain continuing medical education (CME) and continuing education units (CEU) as an ongoing activity. The primary limitation is time and timing. There are many professionals involved in the routine treatment plan for PWE and include neurologists, family practitioners, pediatricians, pharmacists, psychologists, psychiatrists, emergency physicians, nurses, neurophysiology technologists, dietitians, medical social workers and various laboratory technologists. There are many national and some state and local CME and CEU programs. Excepting neurology, these remote programs generally offer very little in terms of epilepsy education even though the providers above are often in the front line with PWE.

#### Recommendation

The Comprehensive Epilepsy Services Delivery Program should conduct periodic epilepsy programs at South Carolina regional and local levels with the support of EFSC. These programs must be in accordance with the standards of recognized educational certifying organizations and which provide professional educational credit. The Program can provide both remote teleconferences as well as personal presentations by staff.

For established publications and information about epilepsy, please see:

[www.efa.org](http://www.efa.org)

[www.efa.org/sc](http://www.efa.org/sc)

[www.epilepsy.com](http://www.epilepsy.com)

[www.nih.gov](http://www.nih.gov)

[www.cdc.gov](http://www.cdc.gov)

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## VIII. Transportation

*“It is difficult for any person with epilepsy or another disability with only SSI and the lack of other assistance in smaller towns. Without family a person is in serious trouble with epilepsy. Transportation is a huge problem.”*  
*Parent of PWE in Appalachia III Health District*

### A. Background

The current policy in SC regarding driving for persons with epilepsy (PWE) is they must be seizure free for at least six months. Currently, when PWE renew or reinstate their driver’s license, a medical form is completed by a physician. Once the forms are received, they are sent to a medical advisory board to determine whether the individual can continue to drive. The validity of decreasing the length of seizure free status of less than six months is not known.

### B. Needs

Currently there are some public modes of transportation but many require much time investment on the part of the PWE as appointments must be made in advance, transportation is not always dignified, and PWE may have to spend extensive amounts of time in transport due to others’ needs for transportation. It is important to note that transportation is limited in all areas, especially, rural areas. Also, it is important to look at the needs of PWE with intractable epilepsy as public transportation may not be appropriate and/or PWE have been removed from transportation due to breakthrough seizures. It has also been difficult to have schools agree to bus attendants to assist bus drivers in transporting children with epilepsy to school. This reinforces the need for public education and awareness, as well as further review for systems of transportation for PWE. Considerations can be given for the following possible resources:

1. Identify a primary person and back up to assist with getting to and from employment, appointments, etc.
2. Coordinate transportation with others employed with the same company.
3. Some employers provide transportation, such as construction, landscaping, etc.
4. DHHS transportation, such as Tele-ride, senior citizen transport, human services buses
5. Regional Transit Authority (RTA) systems in the area.
6. Churches

## 7. Specific Programs as

- Scooter program in Allendale.
- McCormick Senior Center
- Coast Transportation – Horry County
- Chester Connector Van Service, Umbrella Services Van – Rock Hill, Red Rose Cab Service – Lancaster
- Bamberg Handyride Program
- Charleston Independent Transportation Network

### Recommendations

1. Voucher system to assist PWE who work and have had a seizure breakthrough to use for transportation. This will be less expensive than going on disability, unemployment, or losing their job. It could pay for public (i.e., bus, van) or private (i.e., taxi) transportation, or even for a neighbor or coworker to drive them.
  2. Provide training for drivers who transport PWE regarding epilepsy and first aid.
  3. Encourage the evolution of volunteer driving systems in the state, especially rural areas. These volunteer drivers will need seizure first aid training.
  4. As local and civic organizations address the transportation needs of PWE, liability issues must be reviewed to ensure that volunteers transporting will not be held liable if the PWE has a seizure or medical issue. In the event of a seizure, is the driver rendering aid covered by the SC Good Samaritan Law.
- Good Samaritan Law [Section 15-1-310]: Liability for emergency care rendered at scene of accident: Any person, who in good faith gratuitously renders emergency care at the scene of an accident or emergency to the victim thereof, shall not be liable for any civil damages for any personal injury as a result of any act or omission by such person in rendering the emergency care or as a result of any act or failure to act to provide or arrange for further medical treatment or care for the injured person, except acts or omissions amounting to gross negligence or willful or wanton misconduct. (<http://www.cprinstructor.com/SC-GS.htm>)
5. Mandatory reporting of PWE by physicians and health care practitioners will not be helpful and is not recommended. A study in Canada showed an equal accident rate between those with and without epilepsy, whether they lived in a mandatory reporting area or not [1]. Interestingly, females with

epilepsy had a lower accident rate than males without epilepsy, which the authors noted agreed with a number of previous studies.

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## IX. South Carolina Epilepsy Comprehensive Service Delivery System

*“Better hospital facilities and doctors. There are only 2 pediatric neurologists in Columbia, that I know of. We had to go to Charlotte for the ketogenic diet. Once our child became sick with an unrelated illness we were forced to quit because our Cola doc didn't know what to do and our Charlotte doc couldn't see him so they prescribed the wrong medication as well as medicine we couldn't get. It was a disaster.”*

*Parent of PWE in Palmetto Health District*

The duly constituted South Carolina Epilepsy Study Committee for a service delivery system has concluded that people with epilepsy are in need of and do deserve a comprehensive system of service delivery. The committee has surveyed PWE, various SC state agencies, and medical providers (pediatricians, family practitioners and neurologists). The results strongly confirm that PWE have many needs for services, and while many services are available in this state, PWE are unable to access many of them. The results suggest that some state agencies which have resources do not actively extend themselves to those PWE.

Disabled persons are not the same nor do they have identical needs. Epilepsy is one of a consistently neglected subgroup whose unique needs require special attention. Whereas visibly disabling conditions such as blindness, deafness, cerebral palsy, or paraplegia have needs for special support systems which are obvious, there are “hidden disabilities” as epilepsy. The manifestations of this condition sometimes appear mysterious and are often misunderstood. The primary symptom, an epileptic seizure, is intermittent with the individual being normal one minute and out of control the next. The underlying propensity for seizures to recur remains for the duration of life for many patients. The associated comorbidities and stigma are enduring and often times the most troubling problems as they affect all aspects of life even when seizures do not recur. The treatment for these associated phenomena is quite different from medical treatments and require expertise other than that of the epileptologist

Generally, the service areas of need for PWE are 1) medical access including payment for medical services and medications, 2) access to services covering coexisting conditions, such as receipt of and payment for psychological evaluation and treatment, 3) educational evaluation and appropriate supports and interventions, 4) vocational rehabilitation and employment, 5) transportation, and 6) create specific disability evaluation criteria for PWE.

On the basis of our standardized inquiries and reports from PWE, physicians, agencies and organizations this committee proposes that the state of South Carolina create a service delivery system that is comprehensive, responsive, efficient and effective. To this end, a South Carolina Epilepsy Service Delivery System should be designed around the service recipient, the PWE

(Figure 1), and include the following components; 1) a statewide Comprehensive Epilepsy Program (CEP) and affiliation of Regional Epilepsy Clinics (RECs), 2) a case management system, 3) a responsive, educated and trained network of designated state agency service providers, and 4) an educated body of private and public service organizations, institutions and citizens at large. This system can be referred to as " SUCCESS" (Statewide 'United' Comprehensive Care for Epilepsy Services System).

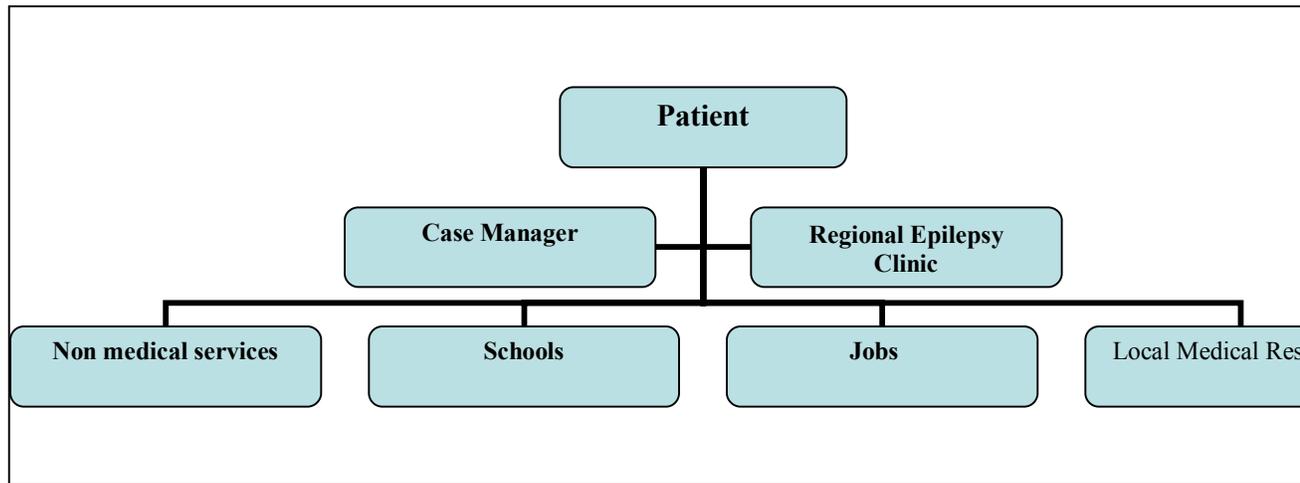


Figure 1. Relationship of the person with epilepsy to the community resources.

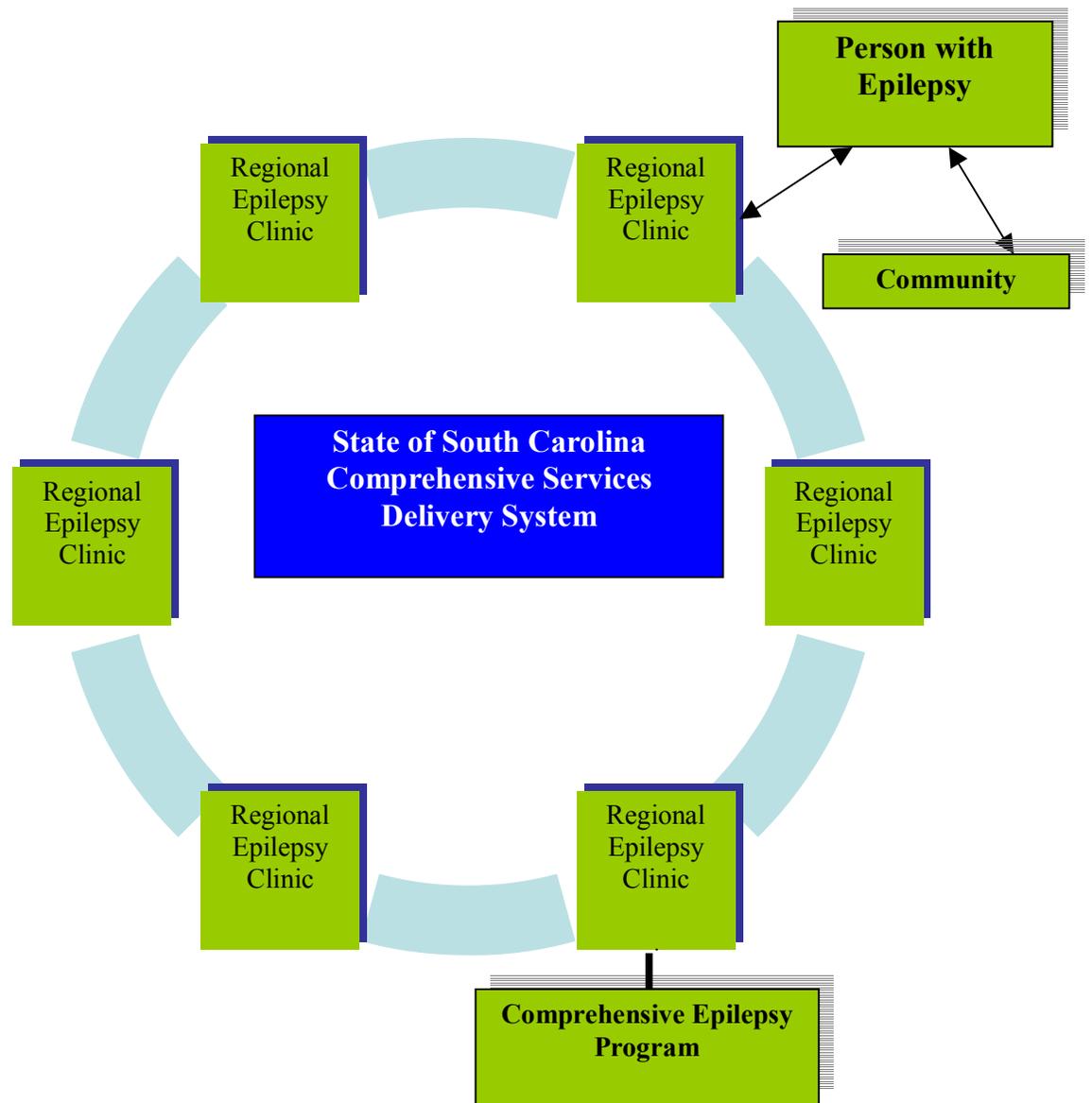


Figure 2. Schematic diagram of the epilepsy services delivery system for people with epilepsy in which the PWE and assigned case manager are interfacing with a Regional Epilepsy Clinic and local community services as having potential connections for statewide resources.

PWE generally enter the healthcare system before there is any necessity for other services. PWE also will remain in the healthcare system for a long period of time. Thus, it appears most practical that SUCCESS is based on a medical services platform. In the initial or first level of care the mandatory medical services will be given by first responders, emergency department physicians and /or the primary care physician (family medicine, internist or

pediatrician). In some circumstances the primary care providers will continue medical management, usually with a neurological consultation. The PWE and the family or the physician could avail themselves of further epilepsy information from the service delivery system by telephone, computer or mail. A second level of medical care is provided by the general neurologist upon referral. The community neurologist can call the Regional Epilepsy Clinic case manager (ECM) for advice or limited assistance regarding non-medical services. Should the neurologist find difficulty with seizure control, management of adverse events or excessive comorbidities, referral to the next or third level of care would be appropriate. Each REC has at least one ECM and provides the interdisciplinary services including medical, special neurodiagnostic services (EEG monitoring, MRI, SPECT), neuropsychological, and psychosocial services. At this level, the neurologist(s) have special interest and training in the field of epilepsy. The ECM, is well aware of the services in the community/region and forms a working bond with the PWE and their families for optimal utilization of services and efficient referrals to service providers.

Prior experience places the REC at the fore for diagnostic evaluation and treatment planning. RECs then provide access to specialty medical care, recognition of needs and available community resources. RECs are situated strategically across the state and will foster best utilization of area community resources by local community providers. A network of RECs can interact via the technology of today. Interactive medical consultation with other affiliated epilepsy medical service providers can occur regularly and without the PWE leaving the community. A REC can be created from area medical resources at minimal cost (and only minor change in medical practice) by incorporating existing neurological practices where there is a special and sustained interest in the care of PWE. A network of interacting RECs should enhance the level of professional provider activity and encourage earlier and improved diagnostics and treatment interventions.

The REC ECM will seek out appropriate community individuals who can provide clinical psychological services for assessment and basic treatment of emotional disorders associated with epilepsy, It is within this context that our report and subsequent recommendations for mental health assessment and care of the PWE and their family are made. (See appendix for suggestions to enact these recommendations.) Local social workers should also be identified for basic assessment of social needs. Those vocational rehabilitation counselors with special interest and training in epilepsy will be used as consultants.

A ECM will enhance the relationship between the REC, the patient and the community and will efficiently facilitate service delivery. This ECM will receive specialty training and education about epilepsy as well as knowledge about other community resources (schools, health care providers and resources, organization, transportation, housing and social services). ECM activities will be an integral part of a comprehensive treatment plan for each PWE in the REC

setting. The REC will typically provide medical services and links for additional supportive services in the community. PWE will enter this system through referral (pediatrician, family practice, local internists, neurologists, emergency departments) depending on case complexity, need for services or patient preference. For those instances when required therapy is more extensive and not available locally, the person with epilepsy will be referred to the REC affiliated with the CEC (i.e., neurosurgery, PET imaging, long term video monitoring, ketogenic diet, etc).

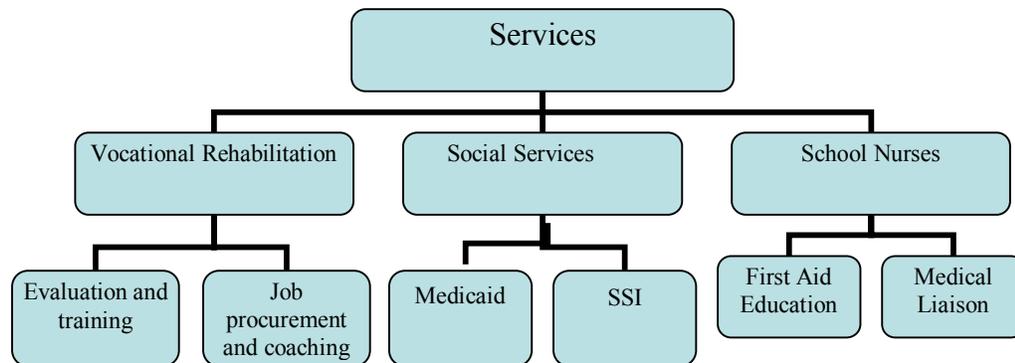


Figure 3. Non-medical community services are made accessible for the PWE through the assistance of the CM. The system allows integration with the medical team of the REC.

A Comprehensive Epilepsy Program (CEP) will be available for those problematic cases which require more advanced epilepsy assessment evaluation and treatment. Invasive EEG monitoring, epilepsy surgery, unique cases, extensive neuropsychological examination, special studies as MEG, PET scanning and functional MRI are available tools at this fourth level of care. Patients referred to the CEP from the community neurologist or the REC will return to their community with findings and recommendations for the physicians and ECM. The CEP will also serve as a consultant to the RECs for education, training and patient consultation via teleconference. Physicians at the first and second levels of care can also avail themselves of excellent training and continuing education.

A major finding of this Committee has been the paucity of available psychiatric treatment or psychosocial support by trained and interested mental health care providers knowledgeable about epilepsy. The SC Epilepsy Services Delivery System proposes to train its professional staff in the recognition, intervention and appropriate therapy of common psychiatric disorders and encourage treatment in the RECs. Additionally the CEP will seek out psychiatrists, psychologists, psychiatric nurses and social workers who have an expertise and willingness to provide evidence-based and effective services in a

timely manner.

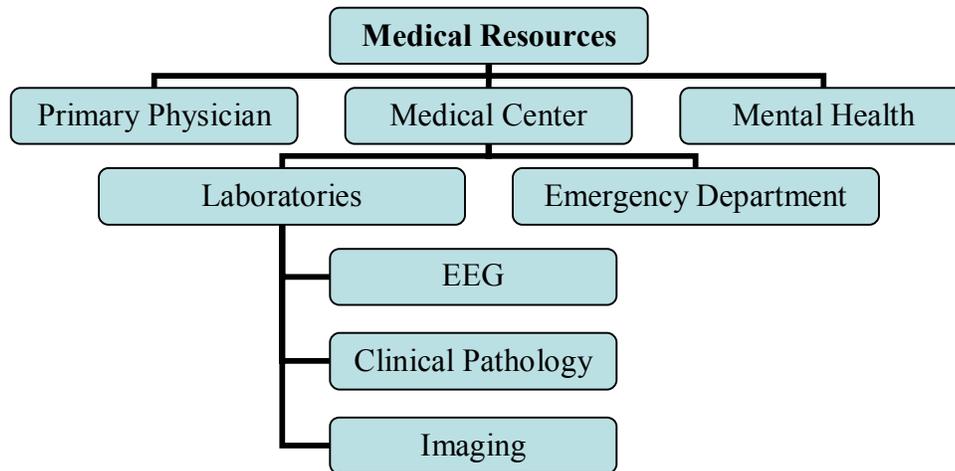


Figure 4. Medical resources in the community become an integral part of the overall treatment plan.

In some cases when epilepsy is well controlled, the number of visits to RECs could be reduced and primary care practitioners could provide interim follow-up medical services. Communication between REC staff, hospital and primary care staff must remain fluid and responsive at all times.

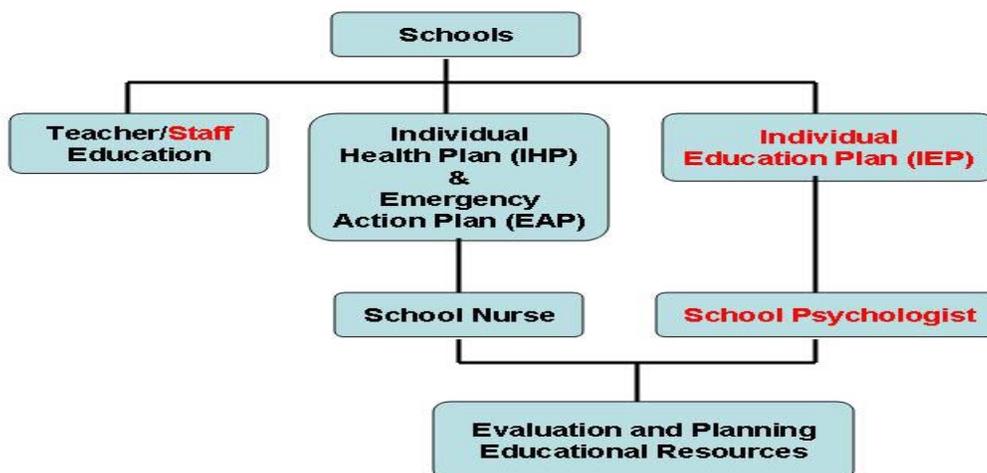


Figure 5. There are a number of integral providers and plans required to make successful facilitation of school performance for the child who is challenged with epilepsy and its consequences. The PWE and family will be assisted by the CM and REC medical team.

About 60% of PWE are able to be treated at the first and/or second levels. The remaining PWE require more specialized care. The above system maintains the PWE in their community and near its resources. Travel is minimized for families. Urgent care is administered by those most aware of the patient situation. There should also be cost savings for the PWE, the taxpayer, the healthcare system and the community. PWE will not be required to travel exceptional distances for medical care. Optimal health resources utilization can happen when the component RECs and CEP use uniform diagnostic protocols for CAT, MRI, EEG, intensive monitoring and interactive consultations via teleconferences. The community/regional services will be recognized and become more visible, better educated and more accessible (see section on Education). Outcomes, efficiencies, referrals and quality of service will be monitored externally (see section on Surveillance and Monitoring). By utilizing existing and proximate community resources including medical there is minimal or no cost for physicians, staff, offices, equipment or personnel. Limited allocations are anticipated for ECMs, a small administrative staff and educational activities. Existing community agency referrals and utilization will follow. The SC Epilepsy Study Committee believes that improved outcomes and quality of life for the PWE and their family will happen and will result in less healthcare and socioeconomic burdens. This is a unique system which beneficially engages the private sector with limited government funding and regulation.

The success of this system will rely on the interaction of community medical resources, REC activities and cooperative and immediate support from the CEC. The ECM role remains key for facilitation and patient advocacy. The ECM can also become an essential advocate and evaluator of system success and failures as well as assessing the need for other services not presently available.

## X. Long Term Care

*“My daughter has had 5 brain surgeries with no success. She is on 12 sedating meds which make her sleep 18 hrs a day. Life is passing her by. Her friends have moved on to college and jobs. My daughter is dying a double death, epilepsy and loneliness.”*

*Parent of PWE in Appalachia III Health District*

### A. Introduction

This subcommittee was formed to deal with the issue of long term care services for persons with epilepsy. For the purposes of this subcommittee, long term care is very broadly defined. A broad definition was needed in order to address the very broad spectrum of needs of South Carolinians with epilepsy for which no supports are currently available.

The prevalence of active epilepsy is about one percent. People with certain conditions are at a higher risk of developing epilepsy. The risk increases when someone has a condition such as: mental retardation, cerebral palsy, Alzheimer’s disease, cerebrovascular accident (CVA) / stroke, brain tumor, a metabolic disorder, or traumatic brain injury.

Of those who develop epilepsy, approximately 70% will achieve seizure control. The remaining 30% are considered to have refractory epilepsy which means that their seizures are not controlled. Whether controlled or not, some PWE will require support beyond their natural networks of family and community support; as well as the possibility of long term care services.

When epilepsy exists with another condition such as mental retardation, cerebral palsy, Alzheimer’s disease, etc., long term care services are often available through state and federally funded programs administered in South Carolina by the Department of Health and Human Services or the Department of Disabilities and Special Needs. The focus of this subcommittee was not to duplicate the services that are available. Instead, the focus is to identify service gaps or needed services for those who are not eligible for existing services.

### B. Services Spectrum

Most people, including PWE, have a natural support network on which they rely. This network often includes family, friends and others in the community in which they live. Through this natural support network needs are met and people are supported and assisted to live meaningful lives. Natural support networks provide support and assistance voluntarily.

While epilepsy is one of the leading neurological disorders in the US, it is not well understood and not well accepted in society. The stigma associated with

epilepsy often results in serious personal and societal consequences including the reduction of personal interactions, productivity, and self image. These consequences often result in the person with epilepsy having very limited natural support networks. When natural supports are limited or no longer exist, payment will be required to secure needed supports and assistance.

Long term care services for South Carolinians with epilepsy must cover a broad spectrum of services beginning with services aimed at helping people with epilepsy preserve their natural support networks and assist them to gain access to needed services (i.e., case management). This spectrum must also include services provided in the person's home that are aimed at supporting the person and his/her care giver to remain in his/her own home, and services to support the person when remaining at home is no longer an option and 24 hour support is needed.

### C. Case Management

Case management is the coordination of services to assure that people with epilepsy have access to a full array of needed community services, to include appropriate medical, social, educational and other needed services. This service includes the assessment of the person's resources, abilities and preferences in order to identify areas of need and the best services to meet those needs. Once identified, the person is assisted to connect with those services. When received, the services are monitored for effectiveness and to assure the person is satisfied with the service.

The goal of case management is to improve access to effective, cost efficient, community-based services thereby reducing the need for costly institutional or out-of-home care and making it possible for South Carolinians with epilepsy to continue to live as independently as possible in their homes and communities.

Providing case management services demands great skill, resourcefulness and perseverance. Therefore, it should be provided by professionals who have adequate and appropriate training. A clear understanding of epilepsy, the limitations/challenges associated with having epilepsy and an in-depth knowledge of a wide variety of resources is necessary. Due to these demands, case management salaries should be commensurate with the level of skill needed and should be comparable to similar jobs. Additionally, in order to be effective, a case management services system must be responsible to the needs of those served. In order to be responsive, caseloads must be manageable. It is recommended that the maximum CM to client ratio not exceed 1 to 40 in some situations ut the ratio for the ECM and out patient PWE may be considerably different..

### D. In-Home Supports

In-home supports are those services provided to or in support of someone with epilepsy that enable the person to continue to live as independently as possible. In-home supports may be used to support the person with epilepsy, provide relief to the person's primary caregiver or provide care in the absence of the caregiver. The services may include care, supervision, or assistance provided to the person with epilepsy. These services, when determined by a CM to be needed, can be provided by direct caregivers who are trained to provide the specific tasks needed by the person.

#### E. Out-of-home Care

When the combination of natural and paid supports is no longer sufficient for someone with epilepsy to continue to live in their own home, out of home services will be needed. Out-of-home services include 24 hour on-site care and supervision. These services would typically be provided in congregate settings. However, these settings could vary from a multi-unit apartment-like complex with direct caregivers on the premises 24 hours a day to a group home setting with direct caregivers in the home 24 hours a day.

#### Recommendations

1. Better inform PWE, their families and health care providers of the available in-home supports.
2. Better inform PWE, their families and health care providers of available respite care opportunities.
3. Encourage a formal case management system for PWE, especially those who are experiencing serious co-morbidities and/or refractory seizures.
4. Increase awareness of the process of families being able to will their house to the state of SC with the provision that it would house their PWE as well as other individuals with epilepsy who need full time care.
5. Better inform PWE, their families and health care providers of available out-of-home care services.

## XI. Technology

### A. Integrated Technology System

The Technology Committee has considered how the new and ever increasing advances in technology could efficiently facilitate the provision of services to PWE. There were broad areas of consideration including 1) access to services, basic information about available resources and services and how to obtain them; 2) registration for surveillance and monitoring as pertains to public health and system organization and accountability in regard to results, costs, needs assessment; 3) patient/client, family and public education as well as professional education; 4) utilization of long distance conferencing among professionals which should limit patient referral and travel in a substantially rural state; and, 5) empowerment of PWE by personal education and health information portability.

#### Recommendations

1. Public websites - specific for epilepsy and South Carolina
2. Create a Registry and database – SC Office of Research and Statistics (ORS) or SC Department of Health and Environmental Control (DHEC)
3. Utilization of Video-teleconference where capabilities already exist to link RECs and CEP for statewide continuity of care, professional consultation and education.
4. Portable – memory stick (USB flash drive)/portable computer or hard drive

There are several currently available technical approaches at this time. Each method has specifically defined uses and restrictions for access. Those technologies dealing with personal health information must be HIPAA compliant (Health Insurance Portability and Accountability Act of 1996..

1. The publicly available websites which are proposed include that of the SC state government which contains sites for many state agencies with referring links, the University of South Carolina Center for Developmental Disabilities, a portion of the lead agency site or an independent such as Epilepsy Foundation of South Carolina, and privately funded sites as [www.scepilepsyact168.com](http://www.scepilepsyact168.com). Any of these sites will maintain general and detailed information about epilepsy, available services and resources specific to epilepsy and SC, and pertinent announcements. This site would be accessible to anyone.

Basic epilepsy education information

Access by public

Education materials

Announcements for drug/device/surgical investigations

Announcements for research studies

Announcements for relevant legislation (local, state or federal)

2. A central database for patient registry is essential for public health surveillance and monitoring. This database would be accessible only to personnel of the SC ORS and SC DHEC. De-identified data will be available for research conducted by other *bona fide* research institutions.

## State Registry of PWE

Access by authorized professionals onlyAccess by ORS and SCDHEC unlimitedAccess by SUCCESS researches for de-identified data

Surveillance

Monitoring

Costs analysis

Research

3. Closed circuit video-teleconference systems exist and permit telemedicine consultation, Statewide 'United' Comprehensive Care for Epilepsy Services System (SUCCESS) case conferences, and SUCCESS professional education courses, seminars or lectures for physicians and staff nurses, counselors and service providers. Access is limited to professionals and staff only.

## Closed circuit video-teleconference system

Access by professionals only

Telemedicine consultation

Statewide "United" Comprehensive Care for Epilepsy Services System (SUCCESS) case conferences

Statewide SUCCESS professional education

4. Lastly, PWE can be empowered by maintaining limited health information within small data systems such as portable memory devices or USB flash drives or portable hard drives. This single unit can contain educational material, limited health information, directions for emergencies, contacts for emergencies, and relevant contacts in their system of care. Ideally, there will be availability for medical and educational updates at each medical office visit. Only the PWE and specifically designated individuals will have access. There are companies who specifically market USB flash drives and programs specifically for medical use.

## Restricted and portable Electronic Medical Records (EMR)

Access by patient or physician only

Identification

Epilepsy category

Seizure type(s)

List of medical diagnoses

Results of relevant medical laboratory studies

Current medications

Prior medication/surgical treatments

Medication adverse event history including allergies

Current physician(s) and emergency contacts

Primary and legally responsible other

## XII. Prevention

While the causes of some cases of epilepsy are known, the majority (approximately two-thirds) are not [1]. Among known causes common in developed countries are the following: congenital malformations in the brain, birth asphyxia, cerebral hemorrhage at birth, gene defects that lead to disorders associated with epilepsy, infections in the brain or that spread to the brain, traumatic brain injury, tumors (benign, primary, or metastatic), stroke (ischemic or hemorrhagic), neurosurgery, and degenerative neurologic diseases. Some of these known causes can be prevented.

### Recommendations

1. Equitable, affordable, quality health care. Sixteen percent of the citizens of SC are without health care [2]. 11% of SC children do not have health care [3]. Disparities in rates of insurance also exist: almost one-third of citizens earning below \$25,000 are without insurance [4].
2. Promotion of pre-natal and perinatal care to enhance healthy brain development and prevent brain trauma before and during birth. SC is 4<sup>th</sup> highest in the nation for percent of low birth weight babies, and 3<sup>rd</sup> in the nation for infant mortality rate [4]. Part of this issue may be due to lack of access to care in underserved areas, as well as outreach to African-American, Hispanic, and very poor populations.
3. Child abuse prevention measures to reduce traumatic brain injury in children. SC is 13<sup>th</sup> in the nation for child fatalities due to child neglect and/or abuse [5].
4. Thorough immunization to prevent neurological side effects of preventable diseases. Only 79% of 19-35 month old children in SC are vaccinated [4].
5. Treatment for cardiovascular risk factors such as high blood pressure in order to prevent stroke. SC has the highest rate of stroke deaths in the country [4]. Stroke may lead to epilepsy. The Stroke Council of the American Heart Association lists well-documented, modifiable risk factors for stroke [7]. A study in Maryland noted the strong effects of these risk factors on stroke even in young adults (18-44 years), and in both blacks and whites [8].
6. Early recognition and treatment of depression. Three studies have reported depression as a possible risk factor for seizures or epilepsy [9-11]. Epilepsy-related suicide rate is higher than in the normal population. When ranked from the highest, SC is the 35<sup>th</sup> state in state mental health agency per capita expenditures [12].

7. Safety education and enforcement to prevent traumatic brain injury. This should include vehicle, recreational, sports, and work safety. . In California, the year after a helmet law was enacted motorcycle fatal and nonfatal traumatic brain injuries fell approximately 30%, and the severity of the head injuries decreased [13]. SC is 4<sup>th</sup> highest in mileage fatality rate, but only 73% of drivers use seat belts [14].

While at this time only some cases of epilepsy can be prevented, SC has room for improvement in multiple areas that would result not only in fewer cases of epilepsy, but also prevent many other injuries and medical conditions with the potential to greatly reduce quality of life, increase medical and disability costs and/or result in premature death.

Secondary prevention is necessary for those persons who develop epilepsy. Epilepsy can be accompanied by mood disorders, learning disorders, adverse drug side effects, psychosocial effects of stigma, poor seizure control, injuries from seizures, lack of independence, forced inactivity due to seizures or fear of seizures, etc. Throughout the report, we attempt to address ways to prevent these secondary complications of epilepsy, thus reducing the burden of epilepsy and increasing quality of life.

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### XIII. Surveillance and Monitoring

#### A. The Need for Statewide Epilepsy Follow-up Registry

Epilepsy is a significant public health problem in SC. According to the 2003-2005 data from the Behavioral Risk Factor Surveillance System, there are about 86,000 SC residents (2%) with a lifetime history of epilepsy, of which 43,000 are active epilepsy patients requiring regular clinical attention. It is estimated that there are at least 1,200 (0.03%) state residents who develop epilepsy every year. Based on the annualized incidence rate of 0.03% and accounting for a 1.7% annual mortality rate among persons with epilepsy, there will be at least 71,000 active epilepsy patients in SC by the end of 2011. Further, preliminary data analysis from the SC Health Outcome Project on Epilepsy (SCHOPE) indicates that 35% of adults reported disability that precludes employment. Extrapolation from this estimate indicates at least 25,000 persons with epilepsy will remain unemployed due to disability associated with epilepsy.

The BRFSS also showed that among adult South Carolinians ages 18 to 64 years without epilepsy, 70.2% are employed and 13.3% are out of work or are unable to work. However, among those who have ever had epilepsy, 44.8% are employed and 38.4% are out of work or are unable to work. And if you look at just those with active epilepsy, only 29.1% are employed and 50.0% are out of work or are unable to work. Applying the numbers for lifetime epilepsy to working age adults in 2006, there would have been approximately 21,000 PWE in SC out of work or unable to work in 2006. However, due to the lack of a follow-up registry, South Carolina has not been able to document the extent to which PWE remain unable to establish and maintain productive employment and full participation in the larger community. It also follows that with substantial unemployment there will be a high probability of failure to maintain adequate health insurance and preclude other health and social disparities.

The breakdown of epilepsy surveillance data by diagnosis codes over 3 year period (2001-2003) indicates a cumulative increase of severe forms of epilepsy. However, little is known about the quality of their lives, unmet needs, and to what extent they use the medical, social, and community resources in South Carolina. We also have little understanding regarding the extent to which impediments to health care access contribute to secondary conditions such as depression, systemic diseases, and sudden unexplained death.

SC offers an environment conducive to develop and maintain an efficient epilepsy follow-up registry. There is a well-developed, statewide, and legally mandated hospital and emergency discharge system that captures all cases of epilepsy managed in the nonfederal hospitals and emergency departments. The state has also a reporting system for state residents whose primary payer is Medicaid, Medicare, and the State Health Plan. By including physician offices that will be organized under the RECs, the epilepsy follow-up registry could be maintained as a natural extension of the existing reporting system to document

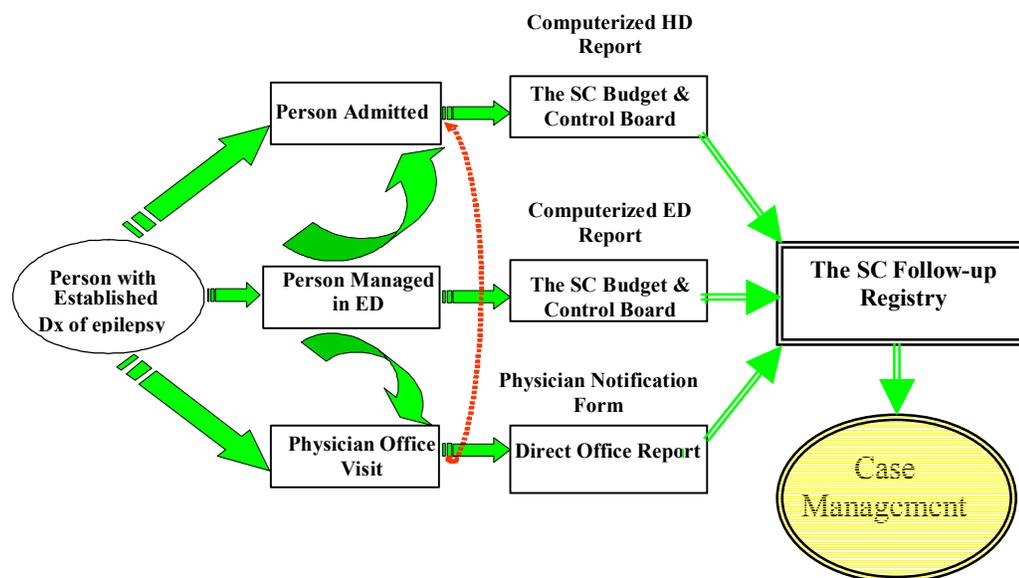
the full range of outcomes and needs of persons with epilepsy.

An epilepsy follow-up registry will benefit the service activities of the various state agencies and organizations that provide services in various capacities. The activities of the registry address these objectives:

1. To identify and document the specific outcomes of epilepsy
2. To monitor patterns of medical care
3. To determine risk factors for specific sequelae and identify risk groups for such complications.
4. To determine service utilization and barriers to services.
5. To determine the public health impact and societal costs using economic analysis methodology
6. To design rational measures for the prevention of secondary conditions attributable to epilepsy
7. To provide ongoing database for the delivery of comprehensive epilepsy care

### ***METHODS OF CASE ASCERTAINMENT AND DATA SOURCES***

Figure 1. Data System for the SC Epilepsy Follow-up Registry



Cases of epilepsy are ascertained from existing data sources, primarily hospitals and clinics participating in the comprehensive epilepsy program that will be reporting persons with epilepsy to the registry upon their agreement. The data set items are acquired in two stages. The first stage involves acquisition of data from the referring clinics; the second stage involves a brief interview with a PWE (Figure 1). This system will entirely depend on existing sources of data which are completely accessible. Each of these sources is briefly described below.

*(1) The Statewide Hospital Discharge Data Set (SHDDS)*

The Office of Research and Statistical Services of the South Carolina Budget and Control Board receives copies of patient billing related data quarterly from all nonfederal and federal hospitals (UB-92 report). Thus, the SHDDS is population-based for all hospitalized discharges in the state of South Carolina. The database includes ICD-9-CM diagnosis codes, external causes of injury codes, unique identifiers, acute care charges, and discharge disposition in addition to demographics and places of residence. The data set is 100% complete and 99% accurate with the exception of the 5th digit of the diagnosis codes. Upon patients' consent being given to the REC physicians, personal identifiers such as names, residential address, and contact information could be released.

*(2) The Statewide Emergency Department Visit Data Set (SEDVDS)*

The Office of Research and Statistical Services of the South Carolina Budget and Control Board has acquired population-based data from all hospitals in SC quarterly since 1995. All self-standing and hospital-based emergency departments are required to report. The data set has a high level of completeness, with 95% completeness for E-codes recorded in the first half of 1997.

*(3) Physician Office Visits (POV)*

Although physician offices are required to report to Medicare, Medicaid, and the State Health Plan of those persons under these payers, the reporting format and the data elements are based on the practice patterns of the offices. At a minimum, these practices could provide demographics, diagnoses, and payer information on either an electronic medium or hard copy. Factors influencing physician office compliance to such reporting may need to be explored.

*(4) Follow-up Information (FUI)*

After consenting to be included in the register, PWE will be requested to complete a short survey to provide additional information and validate information acquired from other data sources. At a minimum, information will be sought to assist case managers on service needs and access parameters (the 5 As—availability, acceptability, affordability, appropriateness, accessibility) to meet their individual needs. The registry will also serve as feedback to providers to ensure the receipt of recommended procedures, treatment, further referrals, and annualized case summary as collated by case managers.

The primary output of the registry is individualized information on each PWE to provide the evidence for person-centered service delivery. This will be facilitated through case management activities tailored towards a Home and

Community Based Service (HCBS) program to provide assistance within the homes of individuals with functionally limiting epilepsy. To this effect, a specialized waiver programs might be implemented to prevent worsening of epilepsy due to inadequate care and management.

#### XIV. Lead Agency

The Committee found it perplexing to identify a specific potential lead agency to organize, fund, staff, manage and sustain the comprehensive service delivery system which we have proposed. The complicating issues have to do with the stated missions, focus and activities of our SC agencies. As an example, the SC Vocational Rehabilitation Department (SCVRD) has great interest and expertise in vocational rehabilitation primarily of adults and older adolescents that have epilepsy. There is a statewide network of community offices and rehabilitation facilities that could support staff. Yet, there is no allocation for children. Those PWE who have continuing problems with seizure control may not be eligible for rehabilitation where community employment is the ultimate goal. Family education about this specific medical condition (epilepsy) is not in the expertise of SCVRD and would require re-orientation and substantial resource investment. Similar rationale applies to all of the state agencies and it is difficult to conclude that there exists a "best fit" Lead Agency.

Also, the model for the system is unique in that it requires the equitable integration of private medical staff, physicians, and offices with SC state supported personnel and services and with public volunteer and advocacy groups. This model will encourage efficiencies for provision of services and cost savings while posing interesting organizational, communication and management issues. Flexibility and cooperation will be required to have a successful result.

This Committee has discussed the results of our findings and our proposed comprehensive service delivery system with key leaders in several state agencies. Those state agencies which could potentially organize and administer a comprehensive services delivery system for PWE included the SC VRD, SC Department of Disabilities and Special Needs (SCDDSN), SC Health and Human Services (SCHHS) and SC Department of Health and Environmental Control (SCDHEC). SCDDSN has extensive experience with case management. SCVRD has prior experience and specific interest in working directly with rehabilitation of epilepsy clients. SCHHS provides financial services annually to about 6000 PWE and is keenly aware of the distribution of those expenditures. SCDHEC has multiple strong branches including pediatric clinical services, epidemiological surveillance, and statewide health facilities that could enhance our proposed system. Every agency can provide one or more, but not all, of the services required to fulfill the concept of comprehensive service delivery. Each organization while willing to assist in the delivery system recognizes its potential difficulties in trying to manage all aspects of the entire program and believes that reorganization or a new organization would be necessitated.

In as much as there are many diverse needs and service providers, we have discussed that this system might function best under an intradisciplinary authority, a commission or a coalition of agency representatives. Such a

multifaceted body could provide strength through multiple areas of expertise yet might be encumbered by the breadth of the task or by the lack of flexibility.

At this time, the Committee believes that the best approach for selection of a Lead Agency will require further examination and the wisdom of the SC General Assembly.

## XV. Financial Considerations

The Committee has concluded that the most appropriate funding sources for the proposed Comprehensive Service Delivery System should be generated through the development of a Medicaid Waiver Program. This would insure needed services for persons with epilepsy who have low income as well as those who are more fortunate. Many of the supporting services are available and can be provided through referrals to existing state agencies. Advocacy groups will play a major role in personal, family, and public education and also, counseling. Medical services will be provided independently through established community medical practices and medical university practices which will be unified as a consortium of epilepsy clinics. These services will not require direct appropriations. Epilepsy case managers will require administrative costs, travel and communication systems. The consortium of regional epilepsy clinics will require internal and external communications support. Surveillance and monitoring will be and integral for establishing quality control at all points, cost benefit analyses and public health trends which, heretofore, have not been ascertained.

This unique model of a service delivery system that combines public, state government and private sector effort is being proposed. It will include means for accountability at all levels to assure that the highest quality services are delivered in an efficient and cost effective manner for all South Carolinians with epilepsy and their families.

## GLOSSARY

absence seizures – brief seizures with staring of usually 10 seconds or less duration of and of sudden onset and cessation. The patient may stare but remains motionless and unresponsive and is unaware of the surroundings. A unique EEG pattern is seen with and without the occurrence of a seizure. These seizures may occur multiple times per day without treatment but are typically well controlled with medical therapy. The condition associated with these seizures is called absence epilepsy and usually occurs between 5 and 12 years of age.

ADA - Americans with Disabilities Act- prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress.

antiepileptic drug – a medication effective in the control of seizures. These medications are given orally and continuously to prevent seizures. Some antiepileptic drugs (AEDs) are given intravenously to immediately stop rapidly recurring seizures.

chronic health condition – a health condition that is lifelong with possible intermittent acute exacerbations as well as comorbidities that can affect quality of life

comorbidity – a condition which is regularly associated with another medical condition

complex partial seizures – These seizures consist of impaired consciousness, staring and, not uncommonly, automatic simple repetitive movements as rubbing, patting and head turning. The seizure is of slow onset and slow recovery lasting 30 seconds to three minutes. Some confusion and fatigue may persist afterwards for 15 to 60 minutes. This is one of the most common types of seizures and is an indication of abnormality in the temporal or frontal lobe of the brain.

developmental disability - is a term used to describe life-long disabilities attributable to mental and/or physical impairments or combination of mental and physical impairments, manifested prior to age twenty-two. The term is used most commonly in the United States to refer to disabilities affecting daily functioning in three or more of the following areas: 1) capacity for independent living, 2) economic self-sufficiency, 3) learning, 4) mobility, 5) receptive and expressive language, 6) self-care, and 7) self-direction

CRIPA – The Civil Rights of Institutionalized Persons Act (1980) authorizes the US Attorney General to investigate conditions of confinement at State and local

government institutions such as prisons, jails, pretrial detention centers, juvenile correctional facilities, publicly operated nursing homes, and institutions for people with psychiatric or developmental disabilities. Its purpose is to allow the Attorney General to uncover and correct widespread deficiencies that seriously jeopardize the health and safety of residents of institutions. The Attorney General does not have authority under CRIPA to investigate isolated incidents or to represent individual institutionalized persons.

disability - a condition or function judged to be significantly impaired/distorted relative to the usual standard or spectrum of an individual of their group. The term is often used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic disease. This usage has been described by some disabled people as being associated with a medical model of disability. (Wikipedia)

duty of care - Duty of care may be considered a formalization of the implicit responsibilities held by an individual towards another individual within society. It is not a requirement that a duty of care be defined by law, though it will often develop through the jurisprudence of common law. For example, doctors will be held to reasonable standards for members of their profession, rather than those of the general public in cases related to their fields. (Wikipedia)

EEG – initials for electroencephalography. This is a study conducted by measuring small electrical potentials of the brain through electrodes attached to the scalp. In many people with epilepsy, the potentials are abnormal and have distinct characteristics.

epilepsy – is a symptom of a variety of pathological processes in the brain. A diagnosis of epilepsy is given when an individual has two or more unprovoked seizures. There are many types of seizures and categories of epilepsy. Specialists now talk in terms of the epilepsies and epileptic syndromes. The term epilepsy is derived from Greek meaning to be seized by forces from without.

grand mal seizure or epilepsy – an out dated term. See tonic-clonic seizure.

IDEA - The Individuals with Disabilities Education Improvement Act (IDEA) (formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975, amended in 1997 and reauthorized as IDEA in 2004) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs.

IEP - IDEA requires public school systems to develop appropriate Individualized Education Programs (IEPs) for each child. The specific special education and

related services outlined in each IEP reflect the individualized needs of each student.

IHP – individual health plan is used by the school system to provide a health care plan for those students with health care needs

MRI – magnetic resonance image – frequently used in the diagnostic testing of the brain for causes of epilepsy. This test demonstrates the anatomy of the brain and discloses structural abnormalities.

myoclonic seizures – a brief seizure of rapid muscular jerking, frequently of the upper extremities, which can be symmetrical or asymmetrical. Consciousness is not altered. A common type of epilepsy with prominent myoclonic seizures is juvenile myoclonic epilepsy which begins typically in teenage years.

petit mal seizures – an out dated term that has been used synonymously with absence seizures and incorrectly with complex partial seizures of other seizures of brief duration

psychomotor seizure – a type of seizure also known as temporal lobe seizure and now termed complex partial seizure. This seizure is characterized by a loss of awareness and the evolution of automatic simplistic motor movements as rubbing, patting, repetitive swallowing, etc., followed by drowsiness and confusion over a period of two to five minutes.

quality of life - is the degree of well-being felt by an individual or group of people. There are now research techniques which are used to measure, quantify and analyze quality of life. Thus, the impact of epilepsy and comorbidities on quality of life (QOL) can be studied. Hence, reference to the QOL is no longer a euphemistic expression.

Rehabilitation Act –The Rehabilitation Act (1973) prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in title I of the Americans with Disabilities Act.

Section 504- a part of the Rehabilitation Act - Section 504 states that "no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under" any program or activity that either receives Federal financial assistance or is conducted by any Executive agency or the United States Postal Service.

seizure – a clinical manifestation of excessive and disorderly excitatory brain cell discharges. The different manifestations of seizures are dependent on the site where the discharges originate, the degree of excessive discharges, the path(s) and rapidity of spread and a few other factors. In some instances, the PWE may experience an aura or warning at the beginning of a seizure. The following seizure is referred to as the ictal phase and that period which follows the termination and before full recovery is the postictal phase.

simple partial seizure - a seizure that originates from one area of the brain and includes no alteration in consciousness as well as possible physical symptoms that are motoric and/or sensory in nature depending upon which area of the brain is involved. Many times older children and adults experience a pre-ictal symptom (warning) that a seizure is about to occur. -

stigma - Stigma refers to the loss of status that arises from being in possession of an attribute, for example a health condition, that has been culturally defined as “undesirably different” and so as “deeply discrediting” (Goffman, 1963).

Jacoby A, Austin JK. *Epilepsia*, 48(Suppl. 9):6–9, 2007

syndrome – a consistent constellation of several recognizable features and clinical signs. In epilepsy, the term refers to a disorder in which there are similar seizure types, clinical findings, EEG results, pathology and prognosis for course and/or treatment outcome.

tonic-clonic seizure – This seizure is associated with a loss of consciousness and, if standing, a fall. The person has excessive muscular rigidity and extended posture. This is followed in about 30 seconds by bilateral rhythmic jerking of all extremities for 1 to 3 minutes and finally cessation and body relaxation (flaccidity). The individual may lose control of bladder and bowel. Sleep, lethargy and confusion may persist for 30 minutes to 24 hours. The out dated term for this seizure is grand mal.

## APPENDIX

ACT 168

Acknowledgements

Surveys

- Sample of patient survey

- Sample of letters to neurologists requesting completion of survey

- Sample of survey for physicians

- Sample of letter requesting completion of agency/institutional survey

- Sample of instructions for completion of agency/institutional survey

- Sample of survey for educational institutions

Mental Health

**ACT 168**

**A JOINT RESOLUTION TO ESTABLISH A STUDY COMMITTEE TO DEVELOP A STATEWIDE COMPREHENSIVE SERVICE DELIVERY SYSTEM FOR PERSONS WITH EPILEPSY IN THIS STATE AND TO PROVIDE FOR THE MEMBERSHIP, DUTIES, AND RESPONSIBILITIES OF THE STUDY COMMITTEE.**

Whereas, the identification and planning of systems to provide service delivery for persons with epilepsy is vital; and

Whereas, the treatment, the education, and the training of the public and professional service providers, and the treatment and rehabilitation of persons with epilepsy is an investment that benefits all of society; and

Whereas, the goal of a comprehensive epilepsy program is to improve the health and welfare of persons with epilepsy by assisting them in the attainment of optimum physical, psychological, and social potential in order to enhance their quality of life and to enable them to engage in a useful and productive life; and

Whereas, various studies have been conducted that provide data on the needs of persons with epilepsy, and specifically in South Carolina this data shows that 2.2% or 90,000 individuals have had epilepsy sometime in their lifetime and 1.1% or 44,000 have epilepsy requiring treatment; and

Whereas, the prevalence of epilepsy is expected to increase with the aging population and the return of head-injured veterans; and

Whereas, 64% of those adults with active epilepsy are disabled; and

Whereas, the rate of psychological impairment in people with active epilepsy is twice the rate of impairment in those people who do not have epilepsy; and

Whereas, it is imperative to coordinate care providers in order to provide the diverse and needed resources for persons with epilepsy to enable these persons to maintain or regain their highest quality of life and level of productivity possible. Now, therefore,

Be it enacted by the General Assembly of the State of South Carolina:

**Study Committee on Service Delivery for Persons with Epilepsy; created**

SECTION 1. (A) There is created the Study Committee on Service Delivery for Persons with Epilepsy. This committee shall review the multifaceted needs of

persons with epilepsy in this State and the available resources to meet these needs and shall develop a statewide comprehensive plan for the delivery of multifaceted services to persons with epilepsy.

(B) The committee is composed of:

- (1) one member of the public at large to be appointed by the Governor;
- (2) one member of the Senate to be appointed by the President Pro

Tempore of the Senate;

(3) one member of the House of Representatives to be appointed by the Speaker of the House;

(4) one representative from each of the following state agencies:

- (a) the Department of Health and Environmental Control;
- (b) the Department of Health and Human Services;
- (c) the Department of Disabilities and Special Needs;
- (d) the Department of Vocational Rehabilitation;

(5) one representative from each of the following to be appointed by the Governor:

(a) the Epilepsy Foundation of South Carolina, upon the recommendation of the foundation's board;

(b) a community-based neurological practitioner, upon the recommendation of the South Carolina Medical Association;

(c) a nurse practitioner, upon the recommendation of the South Carolina Nurses Association;

(d) one adult consumer, upon the recommendation of the Epilepsy Foundation of South Carolina; and

(e) one member who is the parent of a pediatric consumer, upon the recommendation of the Epilepsy Foundation of South Carolina.

(C) The at-large public member appointed by the Governor shall serve as chairman.

(D) Vacancies occurring on the committee must be filled in the same manner as the original appointment.

(E) The Department of Health and Human Services shall provide and coordinate staffing for the study committee.

(F) Members of the study committee will serve without mileage, per diem, and subsistence.

### **Study committee, duties and responsibilities**

SECTION 2. (A) The committee shall develop a specific plan for a coordinated approach to service delivery for persons with epilepsy, using the resources of both the public and private sectors. The plan must include, but is not limited to:

(1) a definition of epilepsy;

(2) a statewide system that addresses the issues of prevention, identification, treatment, rehabilitation, and community integration of people with epilepsy and must include, but is not limited to:

(a) designation of a lead agency for each person with epilepsy, which shall assume primary responsibility for coordination of service delivery for that person;

- (b) a case management system;
  - (c) medical care and long-term care monitoring;
  - (d) education;
  - (e) employment;
  - (f) housing;
  - (g) mental health;
  - (h) independent living services;
  - (i) access to and availability of treatment resources;
- (3) recommendations for the expansion of Medicare or Medicaid, or both, and other financial services to address the needs of the epilepsy population, including families;
- (4) a data system in which epilepsy and seizure disorders can be identified from existing data sources to continually track and monitor the incidence and prevalence of epilepsy, including mortality and morbidity;
- (5) recommendations for education programs to inform the public about epilepsy, its causes, prevention, employment, first responder treatment, and availability of treatment and services. The committee shall explore instituting more programs in the public schools, kindergarten through twelfth grade and institutions of higher learning, to promote awareness of epilepsy as a growing problem and shall explore incorporating epilepsy as part of the curriculum in medical schools;
- (6) recommendations for policy and legislative changes that may be needed including, but not limited to, insurance, employment, prevention, motor vehicle driving, and public and personal safety practices.
- (B) In carrying out its responsibilities under this joint resolution, the chairman may appoint subcommittees as he or she considers appropriate. The committee and subcommittees may utilize the knowledge and expertise of any individual in another state agency, group, or association.
- (C) The committee shall submit its report to the General Assembly before July 1, 2008, at which time the Study Committee on Service Delivery for Persons with Epilepsy is abolished.

### **Time effective**

SECTION 3. This joint resolution takes effect upon approval by the Governor.

Ratified the 31<sup>st</sup> day of May, 2007.

Approved the 6<sup>th</sup> day of June, 2007.

## ACKNOWLEDGEMENTS

### **Survey Responders**

South Carolinians with Epilepsy

South Carolina family practitioners, pediatricians and neurologists

South Carolina businesses

State of South Carolina agencies

Epilepsy Foundation of South Carolina

### **Lead Agency**

South Carolina Department of Health and Human Services  
Emma Forkner, Director

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**MEDICAID COST DATA**

Type of Visit	Total Cost				Maximum Cost			
	All Ages	<18 yrs	18-64 yrs	65+ yrs	All Ages*	<18 yrs	18-64 yrs	65+ yrs
Inpatient Hospital	\$16,317,981	\$3,564,734	\$12,217,764	\$535,483	\$38,844	\$37,580	\$38,844	\$33,9
Emergency Department	\$661,017	\$179,783	\$477,569	\$3,665	\$172	\$172	\$166	\$115
Non-ED Outpatient Hospital	\$836,639	\$333,892	\$490,290	\$12,457	\$803	\$787	\$803	\$57
Physician Office	\$490,713	\$112,579	\$373,123	\$5,010	\$195	\$191	\$195	\$12
Antiepileptic Drug Prescriptions	\$11,193,122	\$3,810,995	\$7,279,130	\$102,998	\$436	\$436	\$436	\$43

\*Maximum prior to outlier removal

Type of Visit	Mean Cost				Std Dev			
	All Ages	<18 yrs	18-64 yrs	65+ yrs	All Ages	<18 yrs	18-64 yrs	65+ yrs
Inpatient Hospital	\$5,065	\$4,811	\$5,312	\$2,958	5960	6379	5965	4859
Emergency Department	\$114	\$114	\$115	\$108	7	8	6	18
Non-ED Outpatient Hospital	\$97	\$94	\$99	\$95	144	139	147	129
Physician Office	\$56	\$61	\$55	\$27	34	32	35	30
Antiepileptic Drug Prescriptions	\$86	\$106	\$81	\$20	103	103	104	39

Type of Visit/Rx	Total Visits/Rxs				Maximum Visits/Rxs			
	All Ages	<18 yrs	18-64 yrs	65+ yrs	All Ages*	<18 yrs	18-64 yrs	65+ yrs
Inpatient Hospital	2738	638	1927	173	3	3	3	3
Emergency Department	4879	1442	3380	57	5	5	5	2
Non-ED Outpatient Hospital	6967	2900	3956	111	5	5	5	5
Physician Office	7600	1635	5782	183	5	5	5	5
Antiepileptic Drug Prescriptions	110,747	31556	74198	4993	32	32	32	30

\*Maximum prior to outlier removal

**MEDICAID COST DATA**

Type of Visit/Rx	Mean Visits/Rxs			Std Dev		
	All Ages	<18 yrs	18-64 yrs	All Ages	<18 yrs	18-64 yrs
Inpatient Hospital	1.3	1.3	1.3	0.6	0.6	0.6
Emergency Department	1.6	1.6	1.6	1.0	0.9	1.0
Non-ED Outpatient Hospital	1.7	1.8	1.7	1.0	1.0	1.0
Physician Office	1.9	1.7	1.9	1.1	1.1	1.1
Antiepileptic Drug Prescriptions	10.1	9.7	10.5	7.5	7.4	7.7
Antiepileptic Drug Prescriptions	10.1	9.7	10.5	7.5	7.4	7.7
			65+ yrs			65+ yrs
			1.1			0.4
			1.1			0.3
			1.4			0.8
			1.5			0.8
			7.4			5.9
			7.4			5.9

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 NOTES FROM VIDEOCONFERENCE

**Notes from Charleston group prior to conference beginning:**

People with epilepsy (PWE) encounter discrimination at work. Also encounter discrimination trying to get work. Perceived that Voc Rehab is not aligning themselves with large companies willing to hire PWE.

EMS is called when having a seizure, and PWE does not want to go to emergency dept. EMS tells PWE that they have to go to emergency dept. [Gigi noted that PWE should always wear medical ID tag, and can ask physician or nurse to write them a letter that they can carry with them concerning this.]

Some of public knows epilepsy only as grand mal seizures.

Family wants to keep epilepsy quiet. One PWE found out 3 deceased relatives had had epilepsy that she never knew about. Another found out her cousin had epilepsy, only after she mentioned her epilepsy to him.

Some individuals use the word 'fits' to deny epilepsy. One PWE knows a 20 y/o who has 'fits' and has never had a medical work-up.

Cost of epilepsy is 'unbelievable' for diagnostic tests, medications.

One PWE travels 500 miles to stay with a 'good doctor'. Not knowing the ins and outs of using the health care system, how to get a second opinion. Unable to get rehired although an experienced nurse. Epilepsy 'robs' things from you. In high school was thrown out of all physical activity and Regents classes (preparatory for a NY Regents diploma) and put into business curriculum.

School nurse thought young boy was faking grand mal seizures.

People hide epilepsy.

Number of individual's related story of having stable epilepsy for years, then suddenly it became worse. 'Never know when the bottom will drop out.' Would be helpful to have support group, there is none in Charleston.

Not being able to get around, leads to depression and anxiety.

Hurtful not to have transportation. Family telling you not to drive. Once PWE pulled over to have a seizure, and law officials took person to jail.

**Videoconference Notes**

**Aiken:** Cost of medication is a concern. Need more support groups. Individuals with epilepsy should sponsor support groups. Don't hide that you have epilepsy. From age 21 to 28 years, individual has not been able to be on mother's insurance; disabled but has taken long time to get disability; paying \$399/month for medications, hasn't gotten Medicaid, which would be helpful to have in the interim before disability.

**Anderson:** Availability of services, affordability of meds, difficulty affording insurance. There are neurologists in Anderson, but cost too much.

**Beaufort:** no one

**Berkley-Dorchester:** Daughter unemployed denied patient assistance because lives with mother, \$400/month for meds, \$600/month for health insurance. Mother pays these, but even with insurance, copay & meds difficult to cover.

Need better education for teachers and school nurses who are apparently unaware of epilepsy.

Need more support groups in the lowcountry.

19 year old son will age out of insurance soon.

Need discount on public transportation.

Getting life insurance an issue once epilepsy is diagnosed.

**Charleston:** Discrimination in jobs after being hired.

Diagnosed at 12 y/o, free from seizures from ages 28 to 58, then began again.

Now doesn't know how to access assistance. Diagnostic tests cost 40-50% of their gross income. Now unemployable. Was restricted from any gym activity until 30 y/o. Did not return to college until 38.

Depression is horrendous. Can't drive. Discrimination on the job. EMS has not allowed right to refuse transport, then often insurance won't pay for the ambulance because it wasn't an emergency.

**Conway:** Parent of 8 y/o. No support groups in Horry County, could come from county level. Life and health insurance are issues. Parent may not be able to change jobs because of this. Parent went to school each year and read a book about epilepsy to the class – she has had to educate the teachers and children. Other children become accepting of epilepsy. Teachers need to know about both the personal and educational effects of epilepsy. She would be willing to assist in educating teachers.

**Florence:** Her adult daughter has a long post-ictal period and EMS wants to insist on taking her to hospital. They want to see a power-of-attorney document. Need group home for persons with refractory seizures that will provide supervision, help with meds, and care for individuals who have seizures without auras.

Relies on friend for transportation.

25 y/o with epilepsy graduated from College of Charleston & was headed to MUSC medical school. Now finds transportation difficult.

Happy about Dr. Edwards putting together Epilepsy Center at MUSC.

**Greenville:** Lack of transportation, insurance issues, medical debt, need for bilingual forms.

**Columbia:** Need more pediatric specialists so don't have to travel to MUSC, need pediatric epilepsy center other than just in Charleston. Sometimes was driving to Charleston every 2 weeks for epilepsy appointments. Cost of medicine, insurance seems to cover less and less. Afraid to change jobs due to insurance. One person said 'we will owe people the rest of our lives'. Having to pay for brand name meds when the meds are new ones. Need support groups in all areas for adults, children, and teens, especially since feelings change. Need first diagnosis support. Epilepsy Foundation helped. Where do you get information initially?

Teen son will soon need specific type of job, not just moving widgets around, but has seizures at certain times of day, so will need that accommodation. Things especially difficult if people have less education and finances. Public needs knowledge. One parent has educated school nurses and teachers, but son no longer wants her teaching the other students about epilepsy.

EMTs are a problem. Workplace will insist employee go to hospital after a seizure. Store personnel are not knowledgeable.

Teen will need transportation and housing.

Suggested individuals who want support groups go to a hospital and ask them to start one.

Mentioned place in VA specifically for children with epilepsy. Children can stay there year round if necessary. Helped him as a child.

Need support in general. Include staff who have epilepsy at Epilepsy Foundation. Include this requirement in State Bill. Wants to exclude parents of children with epilepsy at this point. Banned from gym after seizure. Lost his teaching job until a senator intervened. Educate school parents. EMS a problem. Has VNS and no insurance, would cost \$400 to have the VNS read. 71 y/o sibling with epilepsy can't get long term health insurance. Neurologists don't want to deal with depression issues. No transportation. Cannot get into assisted living.

Include education for PWE in Bill. Has to get time off from work to help spouse with epilepsy.

**Laurens & Greenwood:** No public transportation. Trouble getting disability. Lost jobs due to seizures. Need help with medical costs. Need support groups. Wants to be able to work parttime to offset costs of meds.

Daughter in college and is going to be a teacher – epilepsy should be taught in educational training programs so private school teachers will be included.

**Marlboro:** no one

**Orangeburg:** Employers are unaware how to handle seizures. Lost two jobs secondary to seizures. Need transportation, need 'buddy', need people in authority to be aware of epilepsy, need interim help with medication costs prior to receiving disability, need housing, need to educate police, hospitals, etc, about people with disabilities in general.

**Rock Hill:** no one

**Spartanburg:** Cannot get cutting edge medical care with Medicaid, especially in rural areas. If you have a primary insurance, Medicare doesn't help. Medicare alone doesn't cover some needed services. Need social opportunities and better quality of life, especially as teens become adults. Teens need to be able to get out of house and work. Dilemma of losing benefits if you work, but it is difficult to get benefits back if you lose work. Once parents are gone, Medicaid will be insufficient to take care of child. Daughter unable to attend school but homebound program was inadequate, so had to hire own tutors. More internet-based courses would help. Need people in mental health who understand epilepsy and antiepileptic medications. Insurance not covering all medications.

**Sumter:** PWE lost job with school district, lost insurance, wants to work, misses his job. He can't get disability. He is on food stamps. Works day jobs to try to get some income. Lives alone. On Medicaid. Wants help to get his job back. Epilepsy Foundation needs bigger presence in Sumter, should educate individuals and businesses. Some in public know nothing about epilepsy.

**Aiken:** Children with epilepsy don't always get the extra educational help they need.

**Orangeburg:** Timely diagnosis is needed. Tests expensive.

**Conway:** Does Epilepsy Foundation work with lawyers for estate planning, etc? Need to plan for children as they become adults.

MUSC has program for children with special needs. May need power-of-attorney, etc. Asked if there was a lawyer in Columbia that specializes in this area?

Held back in school because of seizures. Told individuals with epilepsy cannot learn, but he's been in masters-level classes. Cautions to be careful about power-of-attorney – don't take away an individual's rights if not necessary.

**Florence:** People are afraid of liability second to falls (for example, her daughter isn't allowed to work out at the gym). Could something helping with this be put into the Bill?

**Laurens:** When applying for disability the forms don't apply to epilepsy, due to the intermittent nature of seizures. Difficult to be deemed eligible.

**Charleston:** Only healthy people with epilepsy could come out to meeting. Isolation is a problem.

An individual asked about special computer screens for people with epilepsy. Peter Zalka from Vocational Rehabilitation in Charleston encouraged people to reach out to the VR Engineering Department for special computer screens or other unique needs. They often consult with individuals even if they are not VR clients. He said VR will help individuals both with finding employment as well as retaining employment if epilepsy is a problem at work.

## RESULTS OF PATIENT SURVEYS

A survey concerning living with epilepsy in SC was posted on the SC Epilepsy Act – 168 website. It asked for persons with epilepsy (PWE), family members of PWE, or others to fill out the anonymous survey. Most of the survey consisted of multiple choice or fill-in questions, with an open section for listing needed services, as well as comments, at the end. In addition, in November we held a videoconference for persons with epilepsy and their families. Vocational Rehabilitation linked 15 of their sites throughout the state, and individuals discussed epilepsy services in SC: what works and what doesn't work or is needed. Ninety-four individuals filled out surveys: sixty-two via the website, and thirty-two from the video conference. Some surveys may be referring to the same individual. At most, it is felt there are 9 surveys that could be duplicates (10%), but even in the suspect ones, not all the responses are identical, so all surveys were included in the analyses.

Note that some percents may sum to 99% or 101% due to rounding.

Reporting individual: 48 (51%) reported for themselves, 37 (39%) reported for their child (19 of these were adult children), and 9 (10%) reported for a spouse or other family member.

Age: 18 (20%) were under 18 years, 31 (34%) were 18 to 29 years, 22 (24%) were 30 to 44 years, 14 (15%) were 45 to 59 years, and 6 (7%) were 60 years or older.

Residence: Transformed zip codes to urban/rural listings using Rural-Urban Commuting Area Codes data (RUCA, version 2.0, updated 11/13/07). The RUCAs are designed to define rural and urban based on the Census Bureau's definitions of Urbanized Areas and Urban Clusters, based on criteria including population density and population work commuting patterns.

Isolated = 3 = 3%

Small rural = 2 = 2%

Large rural = 20 = 21%

Urban = 69 = 73%

(Per the 2000 census, 60.5% of SC lived in urban areas [1])

Of those 18 years and older, the few individuals from the isolated and small rural areas did not report that transportation was a problem. 39% (7 of 18) of those from a large rural area, and 50% (27 of 54) of those from an urban area reported that transportation was a problem.

Epilepsy treatment: 92 responses. Only 1 individual reported no current treatment and no seizures in the past year. 18 (19%) were receiving treatment and had no seizures in the past year. 73 (78%) were receiving treatment and had had seizures in the past year. 6 (6%) had ever been on the ketogenic diet. 21 (22%) reported ever having had a vagus nerve stimulator (VNS). 15 (16%) reported ever having epilepsy surgery.

Medical services: 93 responses. 42 (45%) see a family doctor for epilepsy, 8 of those under 18 (44%) see a pediatrician, 839 (89%) see a neurologist, 7 (8%) see an epileptologist, 10 (11%) see a psychiatrist or psychologist, 10 (11%) go to a free or reduced cost health clinic, 40 (43%) go to a specialized epilepsy clinic, and 36 (39%) go to an emergency room (although some noted that this was not by choice).

State services related to epilepsy: 17 (18%) reported using Vocational Rehabilitation, 4 (4%) reported using the Department of Mental Health, 2 (11% of children) reported using Children's Rehabilitative Services, 23 (24%) reported receiving Medicaid, 14 (15%) reported receiving Medicare, 3 (3%) reported using Protection & Advocacy, 5 (5%) reported using the Department of Disability and Special Needs, 0 reported using the Department of Health and Environmental Control, 1 (1%) reported using the Department of Health and Human Services, 3 (3%) reported using the Department of Education services, 11 (12%) reported using the Department of Social Services, 12 (13%) reported receiving food stamps, 2 (2%) reported receiving transportation assistance, and 3 (3%) reported receiving housing assistance.

When asked how they located these services, 67 gave responses. 16 (24%) self-referred, 8 (12%) were told by a friend where to go, 19 (28%) were referred by a professional (i.e., doctor, nurse, lawyer, social worker, healthcare provider), 4 (6%) were referred by a community source (i.e., church, action agency, school, daycare center, another state agency), 5 (7%) were referred by the Epilepsy Foundation, 13 (19%) were told by a friend or family member where to go, and 9 (13%) found information from another source.

9 (10%) individuals reported a non-state agency had assisted them with epilepsy services. These included the Epilepsy Foundation (1), the national Epilepsy Foundation (1), a hospital support group (1), an art & play therapy center (1), the Medical College of GA (1), SSI (1), and a prescription assistance program at the Medical University of South Carolina (1).

Epilepsy medication: 90 individuals responded to the medication question. 89 (99%) were taking medication for epilepsy. 39 out of 89 (43%) reported difficulty obtaining their epilepsy medication. Problems with obtaining epilepsy medication included the following: transportation (8, or 20%), money (30, or 75%), pharmacist changes the medication to generic (4, or 10%), and insurance not covering medication (11, or 28%). None responded that they had a problem with the doctor not calling in the medication.

Fifteen out of 82 individuals (18%) reported they sometimes had to go without their epilepsy medication because of the problems listed above.

Respondents were asked how they pay for their medications. 42 of the 92 responded (46%) self-pay, 44 (48%) had insurance that paid all or part, 25 (27%) used Medicaid payment, 9 (10%) used Medicare payment, and 11 (12%) used a payment assistance program through their community, a drug company, the

doctor's office, etc. Of the 42 who responded self-pay, 16 (17% of the 92 responding) listed no insurance.

Employment and disability benefits: We asked those individuals between 18 and 65 years of age if they worked. 22 (36% of the 61 responses) said yes. Of the 39 not working, 7 (18%) reported trouble concentrating related to epilepsy, 16 (41%) reported too many seizures, and 9 (23%) reported no transportation related to their epilepsy (some individuals reported more than one reason). A total of 26 (67%) of those not working responded that it was due to reasons related to their epilepsy, which was 43% of those aged 18-65 responding to the working question.

42 respondents (45%) had at some time applied for disability due to their epilepsy. 17 (44%) had applied once, 16 (41%) had applied twice, and 6 (15%) had applied 3 or more times. 22 (23%) reported ever receiving social security disability benefits for epilepsy. Of the 12 who answered how many months the process required, for 2 (17%) the process took less than a year, for 5 (42%) the process took one year, and for the remaining 5 (42%) the process took more than one year. Three respondents (3%) had ever received disability benefits for a condition other than epilepsy. Lastly, 13 respondents (14%) had ever received supplemental disability income for their epilepsy. A total of 28 (30%) had ever received disability benefits related to their epilepsy.

Education: Individuals were asked to list their level of education. For those 18 and older, 73 responded. 3 (4%) had only attended grade school, 25 (34%) attended high school, 36 (49%) went to college or technical school, and 9 (12%) attended graduate school. 29 of 92 (32%) had received extra assistance in school for learning difficulties. 26 of 91 (29%) had been given an individual evaluation or testing for learning difficulties. 35 of 78 (45%) felt the SC educational system had not served their needs. When looking at those individuals of usual working age (18 to 65 years), 26 of the 39 individuals (67%) who reported not working had gone to college, technical, or graduate school.

Transportation: Individuals were asked how they usually traveled distances greater than two miles. For those 18 years and older, 74 responded. 21 (28%) were able to drive their vehicle. 48 (65%) relied on a family member to drive them (as well as friends, walking, taxis, or public transportation). Six (8%) neither drove nor had a family member driving them, but relied on other forms of transportation. Of note, only one respondent out of the 74 listed public transportation among their replies, and only two noted use of an agency transportation.

34 (45%) stated that transportation was a problem for them. When asked to record where they had difficulty going, 25 (74%) had trouble getting to the grocery store, 26 (76%) had trouble getting to social activities, 26 (76%) had trouble getting to the doctor, 19 (56%) had trouble getting to the pharmacy, 13 (38%) had trouble getting to work, 11 (32%) had trouble getting to school, and 9 (26%) had trouble getting to state service agencies.

Exercise: We asked if respondents currently exercise or have a healthy level of physical activity. 57 of 89 (64%) responded yes. Of those who responded no, 4 (13%) did not like exercise, 6 (19%) did not have the time, 2 (6%) were told by their doctor not to exercise because of their epilepsy, 11 (34%) were afraid to exercise because of their epilepsy, and 6 (19%) could not exercise because of a condition other than epilepsy. Four individuals responded that depression, tiredness from medications, or lack of energy interfered with exercise.

Stigma: 49 of 87 respondents (56%) reported they had had people treat them badly because of their epilepsy. Of the 45 responding as to whom had treated them badly, 13 (29%) reported family members, 24 (53%) reported friends, 17 (38%) reported school teachers, 20 (56% of those over 17 years reporting) reported employers, 13 (29%) reported medical professionals, and 8 (18%) reported state employees. The latter included upper level school district personnel (1), the Department of Juvenile Justice (1), Department of Social Services (2), Medicaid (1), SC Supreme Court (2), Office of Disciplinary Counsel (1), and Social Security (1).

Social interaction: 39 of 88 respondents (44%) reported they felt they do not get enough social interaction. Among those reporting enough social interaction, 40 (98%) socialize with family, 37 (90%) socialize with friends, 7 (17%) socialize through employment, 20 (49%) socialize through social groups (i.e., church, volunteering, clubs, etc), and 2 (5%) socialize through on-line groups.

Epilepsy knowledge: 25 of 90 respondents (28%) did not feel well-informed about epilepsy. The most common sources where people learned the most about epilepsy included their doctor's office, doctor or nurse (52, 59%), the internet (24, 27%), books, pamphlets, or videos 17 (19%), and the Epilepsy Foundation (13, 15%). 86 of 92 respondents (93%) reported that those closest to them knew the first aid for epilepsy.

Depression: 60 of 91 respondents (66%) said they had had depression or anxiety that interfered with their life. Unfortunately, due to a problem with our on-line survey, we were unable to get complete answers to all of our depression-related questions. Thus, we only have 24 responses to whether they had ever sought help or evaluation for the depression or anxiety. 16 of those 24 (67%) did not seek help for their depression/anxiety. However, a total of 31 individuals responded to the next question concerning why they had not sought help, so it appears that at least 35 of the 60 respondents (58%) who had experienced depression or anxiety did not seek help or evaluation. Of the 31 respondents who gave reasons for not seeking help for their depression/anxiety, 14 (45%) considered the problem not that severe, 8 (26%) could not afford treatment, 5 (16%) did not want a mental illness label, and 5 (16%) could not find a suitable professional for help.

What services for epilepsy would benefit you? We asked this open-ended question on the survey, and have categorized the results as follows.

Financial help with medications and insurance: 25 (27%)

Transportation: 21 (22%)

Employment assistance: 14 (15%)

Better medical care: 11 (12%)

More information about their epilepsy: 9 (10%)

Educate the public about epilepsy: 9 (10%)

Support groups for epilepsy: 8 (9%)

Information about epilepsy-related services: 7 (7%)

Other services mentioned included continuing education assistance, disability benefits, unspecified financial help, better education of teachers concerning epilepsy, social activities for people with epilepsy, daycare/school assistants/companions, more school services, psychological services, and affordable housing/group homes.

Selected comments: We invited people to add comments. Following are some of them.

“My daughter has had 5 brain surgeries with no success. She is on 12 sedating meds which make her sleep 18 hrs a day. Life is passing her by. Her friends have moved on to college and jobs. My daughter is dying a double death, epilepsy and loneliness.”

“Better hospital facilities and doctors. There are only 2 pediatric neurologists in Columbia, that I know of. We had to go to Charlotte for the ketogenic diet. Once our child became sick with an unrelated illness we were forced to quit because our Cola doc didn't know what to do and our Charlotte doc couldn't see him so they prescribed the wrong medication as well as medicine we couldn't get. It was a disaster.”

“All of the good doctors don't take Medicaid...Public school has failed children with epilepsy. It is not being acknowledged so teachers don't know what to do or what accommodations need to be given. Parents don't even know what services are available for children with epilepsy. “

“Initial information given after initial diagnosis needs to be more thorough as to services available - not having to go to website, but having a person readily available at local level.”

“School teachers need more info on the disease and its process. Do not let them exclude these children! They just want to be normal and included in learning activities.”

“Unable to work as an RN - unemployable at this time - minimal retirement and no paycheck. 45% of our gross paycheck (my husband's retirement) goes toward medical bills.”

“Problems with a child which had seizures: trying to give the child good self esteem because of embarrassment of seizures in school and public places. Meds cause difficulty in concentration and school work, which also led to poor self esteem. Battled depression because felt isolated due to embarrassment from seizures and inability to drive.”

“Too much idle time. The need for some type of employment and interaction with others is of great need. Also disability, as the outlook for fulltime, meaningful employment that could provide full support seems unlikely. Parents currently provide support. Have sought help from both Vocational Rehabilitation and Disabilities and Special Needs. Did not qualify for services from Disabilities and Special Needs and although having been to Vocational Rehabilitation and taken numerous tests provided by them and worked in their shelter program, no long term, meaningful help has occurred.”

“It is difficult for any person with epilepsy or another disability with only SSI and the lack of other assistance in smaller towns. Without family a person is in serious trouble with epilepsy. Transportation is a huge problem.”

“The fear is with me always, what if it happens again? Will I hurt someone? Or hurt myself worse? Who will take care of my wife? It is not overwhelming, but it is there and always will be to some degree.”

“I've lost my house, my car, and the right to engage in my profession, my family is close to financial devastation, and I'm pissed off.”

“Could there be a way to make all information and therapies for epilepsy more cohesive and placed where caregivers and/or patients could easily access such information and aid?”

“It would be great to have a support group like we use to have! The low country epilepsy support team and our meetings were fantastic. Then to have those and to have projects and funds and educate people about epilepsy was really made me feel good and I learned more constantly. That is one way of staying on top and knowing others that go through the same that I have to live through each and every day.”

“The state of SC needs to offer healthcare assistance to children who are diagnosed with epilepsy independent of family income. Epilepsy has a huge effect on a child's life and their family. There are many state programs that are offered for other illnesses, injuries, birth defects (speech, hearing, etc). Epilepsy is not included.”

“I am fortunate in that my condition is currently controlled by medication. It has not always been this way. Persons with epilepsy are discriminated against by nearly everyone. The main problem is ignorance as we are often thought to be drug addicts or emotional wrecks. This is not so. I have experienced every form of humiliation and discrimination there is. But, for the last 15 years I have been seizure free and hopefully will remain so for the rest of life provided I can afford my medication.”

“I've looked into insurance for myself, it would cost me at least 900.00 per month, since my child is 19 yrs old I can not get Medicaid or even food stamps, because I work 35 per week.”

“I was diagnosed at 40, I've had 2 jobs my entire life. My current job is a great job with well above average pay but I'm about to lose it due to my condition. I do not know how I will support my children and wife. I've worked since I was 13 supporting myself. I want to continue to take care of my family.”

### **References**

- [1] Urban and rural population in South Carolina. South Carolina Office of Research and Statistics. [Online]. [updated 2002; cited 2008 Apr 16]. Available from:  
[http://www.sccommunityprofiles.org/scpages/sc\\_urban.asp?COUNTYID=47](http://www.sccommunityprofiles.org/scpages/sc_urban.asp?COUNTYID=47)

PHYSICIAN SURVEYS

**Sample of letters to neurologists requesting completion of survey**

February 11, 2008

Dr. John R. Absher  
274-A Commonwealth Dr  
Greenville, SC 29615-4813

Dear Dr. Absher:

South Carolina has a sincere interest in the health and well being of persons with epilepsy. In 2007 the SC General Assembly passed a Resolution (Act 168) to create a committee to study those services available and needed for people with epilepsy. The committee will propose a plan for comprehensive delivery of those services. A report of these findings and recommendations to the General Assembly will be made to the General Assembly by July 2008.

The medical care and needs of people with epilepsy (PWE) are many. It is our hope that you will assist us in determining the services that your patients and families with epilepsy need.

A quick survey is attached and will assist the committee in assessing the needs of PWE. We are asking neurologists, pediatricians and family practitioners/internists who treat PWE to participate. All information will be treated with confidentiality, and will be de-identified for the analysis. We value your time and expertise to provide such essential information and do not expect the survey to take more than 10 minutes of your time.

We will call your office staff to make sure that the survey was received. Your help is immensely appreciated and valued. If you have any questions, please call me at (803)707-0006.

Thank you. Please return by February 29, 2008.

Sincerely yours,

Braxton Wannamaker, MD  
Chair, Epilepsy Study Committee

**Sample of survey for physicians****EPILEPSY SURVEY**

Please answer the following questions about needs for services for patients and families with epilepsy in South Carolina from your perspective as a physician:

1. Do you regularly treat patients with epilepsy?

No

Yes

for diagnosis and evaluation

for follow up

refer to others

(Answer all that are applicable)

2. Do your patients have notable difficulties with any of the following?

school performance

behavior or emotional disorders

gaining or maintaining employment

transportation

access to medical care

paying for medical care

paying for medication

3. Are you aware of and refer to organizations which assist people with epilepsy?

No

Yes

Please specify which you use or refer to

Epilepsy Foundation

Children's Rehabilitation Services

SC Vocational Rehabilitation Department

Developmental Disabilities Program

Other, specify \_\_\_\_\_

Other, specify \_\_\_\_\_

Please indicate to this committee what you see as the most pressing service needs for patients with epilepsy and their families:

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Thank you

Please return to:  
Braxton B. Wannamaker, MD  
PO Box 1165  
Orangeburg, SC 29116-1165

Results of Physician Surveys:

**Do you regularly treat patients with epilepsy (PWE)?**

**FP report:**

64% do treat patients with epilepsy, 27% do not, and 9% did not answer the question

23% diagnose and evaluate persons with epilepsy, 77% did not answer

77% follow-up patients with epilepsy, 23% did not answer

27% refer to others, 73% did not answer

**Neurologists report:**

100% treat patients with epilepsy

96% diagnose and evaluate persons with epilepsy, 4% did not answer

96% follow-up patients with epilepsy, 4% did not answer

60% refer to others, 40% did not answer

**Pediatricians report:**

100% treat patients with epilepsy

37 ½ % diagnose and evaluate persons with epilepsy, 62 ½ % did not answer

50% follow-up patients with epilepsy, 50% did not answer

75% refer to others, 25% did not answer

**Do your patients have notable difficulties with any of the following?**

**Family Practitioners report:**

School performance: 36% acknowledged, 64 % did not answer

Behavior or emotional disorders: 36% acknowledged, 64% did not answer

Gaining or maintain employment: 55% acknowledged, 45% did not answer

Transportation: 45% acknowledged, 55% did not answer

Access to medical care: 41% acknowledged, 59% did not answer

Paying for medical care: 55% acknowledged, 45% did not answer

Paying for medication: 45% acknowledged, 55% did not answer

**Neurologists report:**

School performance: 68% acknowledged; 32% did not answer

Behavior or emotional disorders: 96% acknowledged, 4% did not answer

Gaining or maintain employment: 96% acknowledged, 4% did not answer

Transportation: 96% acknowledged, 4% did not answer

Access to medical care: 64% acknowledged, 36% did not answer

Paying for medical care: 84% acknowledged, 16% did not answer

Paying for medication: 96% acknowledged, 4% did not answer

**Pediatricians report:**

School performance: 100% acknowledged

Behavior or emotional disorders: 100% acknowledged

Gaining or maintain employment: 25% acknowledged, 75% did not answer

Transportation: 50% acknowledged, 50% did not answer

Access to medical care: 62 ½ % acknowledged, 37 ½ % did not answer

Paying for medical care: 37 ½ % acknowledged, 62 ½ % did not answer

Paying for medication: 37 ½ % acknowledged, 62 ½ % did not answer

**Are you aware of and refer to organizations which assist people with epilepsy?**

**Family Practitioners report:**

55% are aware of organizations, 32% are not, 14% did not answer

Epilepsy Foundation: 18% were aware, 82% did not answer

Children's Rehabilitation Services: 14% were aware, 82% did not answer

SC Vocational Rehabilitation Department: 41% were aware, 59% did not answer

Developmental Disabilities Program: 18% were aware, 82% did not answer

Other: Kiffin Penry Fund, Medicaid

**Neurologists report:**

84% are aware of organizations, 8% are not, 8% did not answer

Epilepsy Foundation: 52% were aware, 48% did not answer

Children's Rehabilitation Services: 12% were aware, 88% did not answer

SC Vocational Rehabilitation Department: 84% were aware, 16% did not answer

Developmental Disabilities Program: 16% were aware, 84% did not answer

Other: Medicaid, Pharmaceutical Companies

**Pediatricians report:**

100% are aware of organizations

Epilepsy Foundation: 25% were aware, 75% did not answer

Children's Rehabilitation Services: 75% were aware, 25% did not answer

SC Vocational Rehabilitation Department: 75% were aware, 25% did not answer

Developmental Disabilities Program: 62 ½ % were aware, 37 ½ % did not answer

Other: Family Connection

**Please indicate to this committee what you see as the most pressing service needs for patients with epilepsy and their families:**

**Family Practitioners report:**

Access to care (4.5%)

Home nursing for lab draws for patients with problems like CP (4.5%)

Lifelong epilepsy care issues (4.5%)

Non-practicing MD (4.5%)

Patient education (4.5%)

Compliance issues (9%)

Pay for prescriptions (18.2%)

**Neurologists report:**

Access to treatment (4%)

Community awareness (4%)

Compliance (4%)

Employers lack of understanding (4%)

Improved evaluation of NES (4%)

Job retraining (4%)

Reasonable insurance coverage (4%)

Working with epilepsy vs. rushing for disability (4%)

Insurance/government rules re: RX/TX (8%)

Transportation (8%)

Employment (12%)

Pay for treatment (16%)

Access to care (28%)

Pay for prescriptions (51%)

**Pediatricians report:**

Comprehensive coordinated care (12.5%)

Lifelong epilepsy care issues (transition) (12.5%)

Pay for prescriptions (12.5%)

Support for comorbid conditions (12.5%)

Access to care (25%)

Patient education (25%)

## AGENCY SURVEY

**Sample of letter requesting completion of agency/institutional survey**

January 15, 2008

Mr. John H. Magill, Director  
South Carolina Department of Mental Health  
Administration Building  
2414 Bull Street,  
PO Box 485  
Columbia, South Carolina 29202

Re: SC Epilepsy Study Committee Inquiry

Dear Mr. Magill:

The South Carolina Epilepsy Study Committee is requesting information about any services or activities that impact people with epilepsy, direct or indirect, which are provided by your institution. The Epilepsy Study Committee which was constituted in response to the 2007 Act 168 of the South Carolina General Assembly is charged with obtaining pertinent information about available services. Submission of our Committee report and its recommendations must occur by July 2008.

A survey form is attached. This form will yield responses that will be more or less uniform and can be collated with responses from other institutions. However, no limitation of your responses is intended and extended responses or comments could be helpful and bring additional insights to our Committee. If your institution has various departments, divisions, programs, etc which independently provide services, it will be appropriate to disseminate inquiry forms for each.

Please request electronic forms, if desired, through my e-mail [bwanna@pol.net](mailto:bwanna@pol.net).

Please do not hesitate to contact me (803-707-0006) or Dr. Pamela Ferguson (843-876-1130) if there questions. In addition to the inquiry form, I have attached a copy of the 2007 Act which authorizes our activities.

The Committee requests your response by March 1, 2008.

Sincerely yours,

Braxton B. Wannamaker, MD

## **Sample of instructions for completion of agency/institutional survey**

### **INSTRUCTIONS for SC EPILEPSY STUDY COMMITTEE INQUIRY**

#### **1. Who should complete.**

This inquiry is intended for any agency, institution, organization, program or board that provides services which regularly and specifically impact persons with epilepsy. You may be a local, state, or federal government body or possibly a non-profit organization.

For example, agencies as South Carolina Department of Health and Environmental Control provide some indirect services that impact all of us. This agency also provides direct services that specifically impact children with epilepsy (Children's Rehabilitative Services). It is the latter specific services that are relevant to this inquiry.

If you do not provide any services relevant to people with epilepsy, please indicate in Question #1 and return the Inquiry form.

#### **2. Multiple responses.**

Large agencies or institutions are asked to determine which part(s) of their organization provide the relevant services and forward a copy of this inquiry and instructions. For example, the University of South Carolina has several relevant colleges/schools (which likely have multiple relevant departments) as Medicine (Neurology, Psychiatry, Pharmacology) Nursing, Public Health (Epidemiology) and Arts and Sciences (Psychology).

#### **3. Services defined.**

Direct services specifically impacting people with epilepsy are considered, but not limited to, medical and psychological evaluations and treatments, provision and dispensing medications, transportation, vocational rehabilitation, first responder and public service personnel and support groups. Indirect services are considered teaching/education of healthcare providers, first responder and public service personnel training, public sector health information, licensing and regulatory activities (examples, Protection and Advocacy, Department of Motor Vehicles, Insurance Commission, Disability Determination, Health and Human Services) and research related to epilepsy.

#### **4. Period for consideration.**

Please consider only those services which are currently provided or have been provided during the period 2004-2007.

### **5. Information**

Should you require any further information please contact Braxton Wannamaker, MD at 803-707-0006 ([bwanna@pol.net](mailto:bwanna@pol.net)) or Pamela Ferguson, PhD at 843-876-1130 ([ferguspl@musc.edu](mailto:ferguspl@musc.edu)).

### **6. Return Inquires**

Inquires should be returned directly to the following address:

Braxton B. Wannamaker, MD  
State of South Carolina Epilepsy Study Committee  
P.O. Box 1165  
Orangeburg, SC 29116

Thank You!

**Sample of survey from for educational institutions****SC EPILEPSY STUDY COMMITTEE INQUIRY**

Agency name: \_\_\_\_\_  
 Department, if applicable: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Phone: \_\_\_\_\_  
 Contact person name: \_\_\_\_\_  
 Cell: \_\_\_\_\_  
 E-mail: \_\_\_\_\_

Agency Type of Service Provider:

Education\_\_\_,Medical\_\_\_,Nursing\_\_\_,Pharmacy\_\_\_,Mental Health\_\_\_,Public  
 service (police, EMS, fire)\_\_\_,Research\_\_\_,Vocational Rehabilitation\_\_\_,Public  
 Health\_\_\_,Human/Social Services\_\_\_,Other\_\_\_(specify)\_\_\_\_\_

Does your agency provide services to assist persons with epilepsy (PWE)?  
 YES\_\_\_ NO\_\_\_

Is your agency mandated by federal or state law to provide services specifically  
 for PWE?  
 YES\_\_\_ NO\_\_\_

Does your agency provide specific services for PWE, and/or their families?  
 YES\_\_\_ NO\_\_\_

What are the specific services which you provide for PWE?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

What criteria are used to determine if an individual is eligible for services? What  
 criteria are used to terminate services?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

How many PWE were provided services by your agency in each of the following  
 years?

2004 \_\_\_\_\_

2005 \_\_\_\_\_

2006 \_\_\_\_\_

Where are services provided?

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What fees for services are charged?

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What payers are accepted?

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Approximate number of clients turned away per year due to inability to pay: \_\_\_\_\_

Approximate number of potential clients on waiting list at any given time due to lack of state resources: \_\_\_\_\_

Can benefits of services be measured and how?

NO \_\_\_\_\_

YES \_\_\_\_\_

How? \_\_\_\_\_

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Is transportation available/supplied for your services?

YES \_\_\_\_\_

NO \_\_\_\_\_

Are there non-state agencies (either federal, private for profit, or private non-profit) to which you refer clients?

YES \_\_\_\_\_

NO \_\_\_\_\_

Does your organization plan in the future to serve persons with epilepsy?

YES \_\_\_\_\_

NO \_\_\_\_\_

Regarding your services for PWE, could your organization benefit in its planning for, or current provision of, those services from consultation with epilepsy professionals?

NO \_\_\_\_\_

YES \_\_\_\_\_

How? \_\_\_\_\_

#### EDUCATIONAL INSTITUTIONS

Education regarding epilepsy:

In what formal classes do you teach about epilepsy? \_\_\_\_\_

\_\_\_\_\_

Do you cover the physical, psychological, and social aspects of epilepsy? \_\_\_\_\_

\_\_\_\_\_

Do you have any informal sessions, open to everyone on campus, that teach about epilepsy? \_\_\_\_\_

\_\_\_\_\_

Services for persons with epilepsy:

What accommodations do you provide for persons with epilepsy who attend your institution? \_\_\_\_\_

\_\_\_\_\_

What educational resources and/or supports do you provide for persons with epilepsy who attend your institution (e.g., office for students with disabilities)?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Agency survey results**

	AGENCY	Responded	Type of Institution	Services impacting PWE*	
				General	Specific
1	Claflin University	0	Education		
2	Clemson University	0	Education		
3	Client Assistance Program Office of the Governor	0			
4	College of Charleston	x	Education	x	0
5	Epilepsy Foundation of SC Medical University of South Carolina	x	Volunteer	x	x
6	College of Nursing Protection and Advocacy Agency	x	Education Human Services	x	0
7	SC Department of Disabilities and Special Needs	0	Human Services		
8	SC Department of Education	x	Services	0	0
9	SC Department of Health and Environmental Control	x	Education	0	0
10	SC Department of Health and Human Services	0	Public Health Human Services		
11	SC Department of Insurance	x	Services	x	x
12	SC Department of Mental Health	0	Administrative Medical		
13	SC Developmental Disabilities Council	0	Medical Administrative		
14	SC Disability Determination Division (SCVRD)	0	Human Services		
15	SC State University	x	Services	0	0
16	SC Technical College System	0	Education		
17	SC Vocational Rehabilitation Department	0	Education		
18	SC Department of Social Services	x	Vocational Human Services	x	x
19	University of South Carolina	x	Services	0	0
20	College of Pharmacy Student Health Center	x	Education Health	x	0

\*Services impacting people with epilepsy: 1) general services such as teaching about epilepsy, referral services, advocacy; 2) specific services as patient education, healthcare, direct training.

**Response of Agencies/Institutions for Request of Information**

<b>AGENCY</b>	<b>Type of Institution</b>	<b>General</b>	<b>Specific</b>	<b>Number served*</b>	<b>Could benefit from education</b>	<b>Teaches about epilepsy</b>
College of Charleston	Education	x	0	3	x	n/a
Epilepsy Foundation of SC	Volunteer	x	x	5000	x	x
Medical University of South Carolina College of Nursing	Education	x	0		0	x
SC Department of Disabilities and Special Needs	Human Services	x	0		x	
SC Department of Education	Education	0	0			
SC Department of Health and Human Services	Human Services	x	x	6200	n/a	
SC Disability Determination Division (SCVRD)	Human Services	0	0	n/a	0	
SC Vocational Rehabilitation Department	Vocational Rehab	x	x	300	x	x
SC Department of Social Services	Human Services	0	0	n/a	n/a	
University of South Carolina College of Pharmacy Student Health Center	Education Health	0 x	0 0	n/a n/a	n/a n/a	x 0

\* Approximate annual number

## MENTAL HEALTH

Possible plans of psychosocial intervention:

A. Mental health practitioners trained in epilepsy and affiliated with by the Comprehensive Epilepsy Program (CEP) will provide consultation to second, third and fourth levels of care for PWE around the state. The second and third levels will be expected to begin evaluation and therapeutic intervention for the PWE. When the initial intervention fails, the PWE can be referred to the CEP for further evaluation.

The CEP will also provide a specialized clinic for medication management and comprehensive treatment planning for therapy needs, e.g. short- vs. long-term therapy, inpatient hospitalization, etc. The psychosocial staff of the CEP will include an adult psychologist, child psychologist, neuropsychologist, and advanced practice nurses specially trained in mental health and psychiatric illness with further training in epilepsy to provide therapy and medication management as part of the interdisciplinary team caring for the PWE. This team will provide education for the lay community as well as professional community regarding psychiatric co morbidities and treatment issues in the PWE and their families.

B. Mental health practitioners specially trained in epilepsy comorbidities will be identified and affiliated with CEP and/or RECs to provide consultation statewide to all practitioners regarding medication intervention and therapy care plans for PWE with psychosocial comorbidities in need of treatment.

C. Existing situation: Referral for psychiatric evaluation by the specialist or primary care practitioner. If this plan is chosen it would require increased communication between the epilepsy care practitioners and mental health providers, as well as initial and annual training for mental health providers. Current services would need expansion.