

Special Report

Living Well II: A review of progress since 2003

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Abstract

Epilepsy as an issue for the public health community has a relatively short history in the United States. Not since the 1970s, when Congress established the Commission for the Control of Epilepsy and Its Consequences and the publication of its formal report, “Plan for Nationwide Action on Epilepsy,” has significant attention been paid to the public health implications of epilepsy. In fact, until the U.S. Congress established a small epilepsy program at the Centers for Disease Control and Prevention (CDC) 12 years ago, the condition was practically invisible at all levels of organized public health. Since then, two major conferences, and the recommendations arising from them, have generated a substantially increased level of activity in research, surveillance, and the production and distribution of public education materials, as well as a national initiative to improve access to care and to prevent epilepsy’s negative social impact. Even at the state level, long devoid of any attention to epilepsy in public health planning or provision of services, things are beginning to change, and new demonstration programs designed to identify and serve vulnerable populations with epilepsy are underway. This review highlights these activities, reflects a new and heightened level of attention to epilepsy, and speculates on what may lie ahead in the ongoing effort to give epilepsy greater visibility and higher priority in the public health arena.

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1. Living Well I

In 1994, the CDC’s Epilepsy Program, originally established in the Chronic Disease section of the agency and now housed in its National Center for Chronic Disease Prevention and Health Promotion, began with a modest annual budget of \$700,000. Shortly afterward, the program convened a series of meetings with leaders in the epilepsy medical and voluntary health communities to provide information on current issues and the needs of the nearly 3 million Americans living with epilepsy [1].

Three years later, the CDC’s Epilepsy Program, joined by the American Epilepsy Society (AES), the Epilepsy

Foundation, and the National Association of Epilepsy Centers (NAEC), sponsored the first Living Well with Epilepsy conference (Living Well I). It was the first major effort to shine a national spotlight on epilepsy since the nationwide hearings held by the Commission for the Control of Epilepsy and Its Consequences in 1977 [2].

The 3-day conference hosted epilepsy experts, consumers, and representatives of the medical, academic, public health, corporate, social advocacy, and voluntary communities to review the state of epilepsy management; identify unmet program, treatment, management, and advocacy needs; and draw up a series of recommendations to guide the public health agenda as well as to spur action on related fronts.

A major treatment theme emerged from this meeting: to “take seizures seriously; do it early and do it right the first time; be systematic, efficient, and effective; and empower

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the patient.” The phrase “no seizures, no side effects” was recommended as a guiding mantra for the medical community. Not only were early diagnosis and appropriate treatment of epilepsy held to be essential for seizure control and the reduction of medication side effects, but the patients’ right to be empowered to become self-advocates of their care through knowledge and resources was acknowledged. Other key recommendations urged greater attention to elimination of the stigma associated with epilepsy, especially among the young; increased research to improve care and provide more treatment options; reduction of associated disabilities; increased knowledge of epilepsy among the public; and strengthening of partnerships between segments of the community with the power to affect epilepsy care [3].

The 5 years that followed brought a series of studies, programs, and partnerships applying the basic functions of public health—assessment, policy development, and assurance—to epilepsy. Much of this activity was generated by the CDC, facilitated by the steady growth of the Epilepsy Program’s budget, which grew from \$4 million in 2000 to almost \$8 million in 2006.

Key achievements of the CDC Epilepsy Program in the years following the first Living Well conference included: collaboration with the Agency for Healthcare Research and Quality (AHRQ) to assess evidence linking elements of care to clinical outcomes in special populations; collaboration with the George Washington University Center for Health Services Research and Policy on development of health service purchasing specifications for epilepsy-related services; and a cooperative agreement with the Epilepsy Foundation to fight stigma through educational campaigns designed to improve awareness and understanding of epilepsy among teenagers. The CDC supported population-based epidemiological studies of epilepsy’s prevalence and incidence. It also supported surveys of health care needs in selected communities; studies of preventable causes of epilepsy such as traumatic brain injury and infections (e.g., cysticercosis); and evaluation of the incidence, prevalence, and patterns of care for epilepsy in a managed care setting.

In 2000, the Living Well conference theme of “no seizures, no side effects” was echoed by a 2-day international scientific conference entitled “Curing Epilepsy: Focus on the Future.” From that meeting, cosponsored by the NINDS, the Epilepsy Foundation, AES, Citizens United for Research in Epilepsy (CURE) and the NAEC, emerged a call for benchmarks against which research progress could be measured. In 2002, NINDS produced benchmarks that could be applied to progress in the understanding of basic mechanisms, prevention, and treatment of epilepsy[4].

2. Living Well II

In 2002, five years after the first Living Well meeting, planning began for a second conference to review progress

made and to guide the future course of the public health agenda.

In 2003, Living Well with Epilepsy II (Living Well II), took place in Baltimore, MD. Like its predecessor, it was jointly sponsored by the CDC, the AES, the NAEC, and the Epilepsy Foundation, as well as by a new partner, the Association of State and Territorial Chronic Disease Program Directors (also known as the Chronic Disease Directors, or CDD). Once again, leading representatives of the epilepsy community attended: clinicians and scientists; specialists in the public health disciplines of prevention, epidemiology, health education, and health promotion; and other health care professionals, advocates, and people with epilepsy and their families. Living Well II was charged with identifying critical gaps in knowledge of the scientific basis for effective recognition, treatment, and prevention of epilepsy and its comorbid conditions (including effects on cognition and mood); and recommending strategies for removing barriers to optimal health and functioning for persons with seizures and epilepsy, including attitudinal barriers within society [5].

The recommendations of Living Well II were the result of the deliberations of four topic-specific workshops: early recognition, diagnosis, and treatment; epidemiology and surveillance; self-management; and the impact and outcome of epilepsy on quality of life. In each case, workshop participants were asked by the conference organizers to address key issues within each topic area.

Members of the early recognition, diagnosis, and treatment workshop were asked to promote policy development through identification of clinical issues and priority questions for clinical research. The epidemiology and surveillance group was tasked with assessment of epilepsy’s impact through examination of current data systems, surveillance and data collection, and identification of measurement gaps. Participants in the self-management workshop were asked to discuss ways of ensuring that people with epilepsy have the information and support they need to manage the condition and its treatment effectively, whereas the quality of life workshop had the responsibility of identifying issues that negatively affect the quality of life of people with epilepsy and to help ensure improvement through development of effective policies, programs, communication strategies, and interventions. The groups were not limited to their respective charges, however. Each was also asked to consider epilepsy in a broader context, to think of seizures as a spectrum of disorders with various causes and consequences that may, in turn, be affected by such issues as gender, age, and ethnicity.

Several key themes emerged from the Living Well II workshops. First came the call for improved patient access to epilepsy specialists and to comprehensive systems of care. Second, established criteria for quality care of epilepsy and its comorbid conditions were described as urgently needed. Third, substantial gaps were identified in current understanding of epilepsy’s consequences, especially in the areas of mental health and cognition. Furthermore,

the conference held that systems and models of care must foster empowerment and independence for people with epilepsy, and that surveillance systems must address certain critical issues, including the burden of disease, mortality risks, and more precise estimates of prevalence. Stigma, it was noted, remains a major barrier to good quality of life, and new research and communication techniques are required to combat it. Finally, public education was recognized as critical to improving seizure recognition and first-aid [5].

To what extent do these and other concerns arising from Living Well II differ from those of the first Living Well conference? Although many issues appear in both conference reports, there are some significant differences in tone and emphasis. One is Living Well II's sharpened focus on the burden of disease associated with epilepsy and the level of mortality associated with it, particularly among the young. Similarly, concerns about the rare but devastating syndromes of early childhood are reflected in the new priorities, with specific reference to early recognition and treatment.

Another emerging issue concerns mental health and epilepsy, with special attention to cognition and mood disorders. There is repeated emphasis on the importance of self-management and the recognition that many patients receive suboptimal care, often for years, before new drugs are substituted for ineffective ones or before referral to specialized care. The tendency of people to settle for subopti-

mal care and the various barriers, including those of access and cost, to specialized care for hard-to-control seizures were seen as major obstacles to effective management. In addition, Living Well II recommendations emphasized the need to be sensitive to cultural and ethnic influences on epilepsy care, a reflection of growing diversity in the United States and the implications of those developments for effective seizure management (Table 1).

The public health, medical, voluntary, and professional education communities concerned with epilepsy responded to the Living Well II recommendations by creating a Living Well II Task Force to encourage collaboration and a series of ongoing initiatives in research, public education, access to care, and professional education.

2.1. Research

Since 2003, the CDC has funded a series of research projects in response to Living Well II recommendations (Table 2). The areas of research include identification of underserved populations, incidence and prevalence of epilepsy, best practices in treatment, transitioning youth in pediatric care to adult care models, effective self-management tools, standards of care, primary prevention, and risk factors in minority populations (Table 3). In addition to its support of individual projects, the CDC has begun to promote broader collection of prevalence data through the Behavioral Risk Factor Surveillance System (BRFSS), which

Table 1
Priority Recommendations, Living Well II^a

Early recognition, diagnosis, and treatment

1. Support research to evaluate existing best practices and standards of care for persons with epilepsy
2. Improve understanding of seizures and epilepsy and best practices for epilepsy management, including referral to tertiary level of care, particularly for primary care providers
3. Improve early recognition and timely diagnosis of seizures and epilepsy, including rare forms of seizures
4. Improve access to optimal care for persons with epilepsy
5. Improve recognition and use of appropriate seizure first-aid
6. Enhance understanding of mortality in epilepsy among all audiences

Epidemiology and surveillance

1. Develop and enhance the capacity and infrastructure for surveillance and epidemiological studies of persons with epilepsy
2. Develop surveillance systems to examine health care utilization and resources for people with epilepsy
3. Expand research on mortality and epilepsy to increase understanding of the causes of death in epilepsy
4. Expand research on co-morbid conditions and epilepsy

Self-management

1. Enhance behavioral and social science research of people living with epilepsy and self-management of epilepsy
2. Facilitate the development and testing of self-management models that incorporate critical components for epilepsy
3. Ensure that programs recognize the spectrum of epilepsy and tailor content appropriate to people with well-controlled, refractory, and new-onset seizures
4. Promote self-management and self-determination principles and programs in the care of and services for people with epilepsy

Quality of life: Impact and outcomes

1. Improve the assessment and treatment of the mental health needs of people with epilepsy through professional education and research
2. Enhance resources and infrastructure necessary to improve access to social services and enhance quality of life of people with epilepsy
3. Improve understanding of risks and consequences of epilepsy and its treatment
4. Improve understanding of the impact of seizures and epilepsy on learning and cognition and ways to lessen and prevent these effects
5. Enhance efforts to combat stigma in epilepsy

Source. Ref. [5].

^a Each of the 19 recommendations listed above is supported by a series of specific actions designed to achieve the stated goal. A total of 71 action steps are detailed.

Table 2
CDC-supported research, 2006

<i>Unprovoked seizure and epilepsy in Washington Heights/Inwood, New York City: incidence, prevalence, and patterns of care.</i> Dale Hesdorffer, MPH, Ph.D., Columbia University
<i>Prevalence of epilepsy in minority inner city populations.</i> W. Allen Hauser, M.D., Columbia University
<i>Medical University of South Carolina epidemiological studies of epilepsy and seizure disorder.</i> Anbesaw Selassie, DrPH, Medical University of South Carolina
<i>Traumatic brain injury (TBI) follow-up registry and surveillance of TBI in the emergency department.</i> Anbesaw Selassie, DrPH, Medical University of South Carolina
<i>Population-based studies of the prevalence of cysticercosis in high-risk communities.</i> Victor C. W. Tsang, M.D., Centers for Disease Control and Prevention, National Center for Infectious Diseases, Division of Parasitic Diseases
<i>California Health Interview Survey: epilepsy and health-related quality of life (Interagency Agreement with the National Cancer Institute).</i> Point of contact: David Grant, Ph.D., UCLA Center for Health Policy Research
<i>Standards of care and evaluation in pediatric epilepsy.</i> Deirdre Caplin, Ph.D., University of Utah
<i>Improving self-management among persons with epilepsy.</i> Michael Pramuka, Ph.D., Western Psychiatric Institute and Clinic, University of Pittsburgh Medical School
<i>Promoting development and transition among youth with epilepsy.</i> Roy Martin, Ph.D., University of Alabama at Birmingham
<i>Examining epilepsy care using a multifaceted approach.</i> Lewis Kazis, Sc.D., Boston University School of Public Health
<i>Socioeconomic status, health care use, and outcomes in epilepsy.</i> Charles Begley, Ph.D., University of Texas at Houston School of Public Health
<i>South Carolina Health Outcomes Project on Epilepsy.</i> Principal Investigator: Anbesaw Selassie, DrPH, Medical University of South Carolina
<i>Examining the validity of community-based screening questions for assessing epilepsy.</i> Lewis Kazis, Sc.D., Boston University School of Public Health
<i>Use of computer technology to develop a theory-driven, interactive self-management program for adults with epilepsy.</i> Colleen DiIorio, Ph.D., R.N., Emory University School of Public Health
<i>Prevalence of epilepsy along the Arizona–Mexico border.</i> David Labiner, M.D., University of Arizona College of Medicine

Table 3
Selected Epilepsy Foundation Grants/Fellowships in Cognition and Mental Health, 2006

<i>Cognitive rehabilitation therapy and telerehabilitation in epilepsy patients.</i> Melody Lynn Snider, Ph.D., Emory University
<i>Integrative model of depression for people with temporal lobe epilepsy.</i> Eun-Jeong Lee, University of Wisconsin, Madison
<i>Working memory in children with epilepsy as assessed by functional imaging and neuropsychological studies.</i> Madison Mehalani Berl, Ph.D., Children's National Medical Center
<i>Functional role of seizure-generated neurons in cognitive impairment associated with epileptic activity.</i> Sebastian Jessberger, M.D., Salk Institute for Biological Studies
<i>Hippocampal subfield cell density and post-surgical memory change in temporal lobe epilepsy.</i> Bonnie C. Sachs, University of Florida
<i>Hyperspectral optical imaging of language processing in the epilepsy population.</i> Adam Olding Hebb, M.D., University of Minnesota
<i>The amygdala in depression and anxiety disorders in childhood complex partial epilepsy.</i> Melita Lori Daley, M.D., University of California, Los Angeles
<i>The role of cortisol dysregulation in depression and hippocampal dysfunction associated with temporal lobe epilepsy.</i> Robyn M. Busch, Ph.D., Cleveland Clinic Foundation
<i>Impact of executive functioning on depressive symptoms in temporal lobe epilepsy.</i> Jennifer Duncan Davis, Ph.D., Rhode Island Hospital
<i>Predictors of differential vulnerability to anxiety and depression in epilepsy: A diffusion tensor imaging study.</i> Jack J. Lin, M.D., University of California, Irvine

has resulted in the implementation of epilepsy-related questions in 19 states [6].

The Epilepsy Foundation's research program has also responded to Living Well II recommendations with special emphasis on issues related to cognition, memory, and mood.

Traditionally, the Foundation funds both scientific and clinical research, awarding grants on a competitive basis,

following National Institutes of Health protocols. Recent clinical work supported by the Foundation has included, among others, studies of certain rare but devastating disorders of early childhood, genetic factors involved in the development of seizures, and novel interventions in brain stimulation.

The Foundation has addressed the Living Well II recommendations by developing new programs of research

targeted to cognition, childhood quality of life, and aging. Similar issues are being studied with Foundation support through its behavioral science fellowship program. These fellowships provide support for young scientists in either research or practice settings. Beginning in 2008, the Foundation will expand its targeted research program to include initiatives for studying issues specific to women and reproductive health, youth, and catastrophic epilepsies, as well as research to develop effective models of care for people with epilepsy and seizures, all of which were primary issues addressed by Living Well II. In addition, the Epilepsy Research Foundation and others have increased funding for research into mortality and comorbid conditions in response to the conference report.

The AES has incorporated research into the consequences of epilepsy and its comorbid conditions in its supported research program [7]. AES scientific meetings and other professional activities pay special attention to the Living Well II recommendations (see below). The National Institute of Neurological Disorders and Stroke (NINDS) continues to fund research (including large, multicenter clinical trials) related to the underlying mechanisms of epilepsy, genetics, epidemiology, comorbid conditions, stigma, and treatment. In the near future, the NINDS will sponsor workshops on models of epilepsy in aging and on identification and validation of epilepsy biomarkers. The NINDS has issued several initiatives relevant to epilepsy to encourage additional grant applications including collaborative research on mental and neurological disorders, brain disorders in the developing world, research across the life span, stigma, and reducing health disparities in the treatment of epilepsy [4].

2.2. Public education and awareness

To increase public education and awareness, the CDC responded to the recommendations of Living Well I by entering into a multiyear cooperative agreement with the Epilepsy Foundation, a not-for-profit, national voluntary health agency, based in the Washington, DC metropolitan area.

Founded 38 years ago, the Foundation is a major source of patient and family information and support. Thought leaders in medical and allied health communities specializing in epilepsy provide strategic guidance and program input to the Foundation and serve as members of its professional advisory board. The Foundation's mission is to "ensure that people with seizures are able to participate in all life experiences, and to prevent, control and cure epilepsy through research, education, advocacy and services." As already noted, it funds meritorious, epilepsy-related research grants and training fellowships and, through a network of 54 community-based Epilepsy Foundation affiliates, ensures that direct services are available in more than 100 communities nationwide. In addition, the Epilepsy Foundation conducts a variety of national and local public health education and awareness programs and leads efforts in the advocacy community to effect federal and state level

policy changes concerning access to medication and civil rights for persons with epilepsy [8].

In response to the Living Well I recommendations regarding the need for public education and measures to counteract the social stigma associated with epilepsy, the Foundation, as part of its cooperative agreement with the CDC Epilepsy Program, developed targeted educational materials and campaigns designed to increase awareness and acceptance of young people with epilepsy. The Foundation's "Entitled to Respect" campaign included a national teen survey regarding perceptions and attitudes toward epilepsy. This survey of 20,000 students found that 49% of young people were not sure whether seizures are contagious, and 67% would not know what to do if someone had a seizure. As a result, the Foundation developed media messages and teen-specific web site content. It also began funding community outreach grants to local Epilepsy Foundation affiliates with the distribution of educational materials designed to appeal to teens [9].

The following years' campaigns expanded the audience focus to include African-Americans and Hispanics. During this same period, the CDC Epilepsy Program developed "No Label Required: Teens Talk Straight About Epilepsy," a video and related materials designed to stimulate discussion among teens with epilepsy and help them answer questions about driving, dating, working, and disclosing their condition. This educational product was distributed through the Foundation's affiliate network and to public libraries nationwide.

The CDC Epilepsy Program also collaborated with the CDD on a project to examine the role of states in addressing public health issues related to lower-prevalence chronic conditions, using epilepsy as a model for the exercise. A report, *The Role of Public Health in Addressing Lower Prevalence Chronic Conditions: The Example of Epilepsy*, was published just prior to the Living Well II conference. It found that, with the exception of Florida and Texas, epilepsy was still not on the radar screen of state public health agencies [10].

The CDC and Epilepsy Foundation public education activities responded to Living Well II's recommendations by continuing their educational programs, but giving greater attention to underserved communities with increased outreach through national and local partnerships.

The Epilepsy Foundation created outreach partnerships with the Hispanic Radio Network, local affiliates of the National Council of La Raza, and the Community Health Workers (Promotoras) National Network. In 2003, 20 Epilepsy Foundation affiliates received CDC support to develop partnerships with other local organizations to provide services or outreach to Hispanic communities, African-Americans, and people living in rural areas. A campaign of outreach to African-American women included recruitment of a celebrity spokesperson, a multifaceted media outreach, a national contest linked to the campaign theme, and a variety of educational events in partnership with African-American churches and beauty salons in major metropolitan areas.

Continuing its focus on improved awareness, understanding, and appropriate response to epilepsy in the school environment, the Foundation, with CDC support, developed “Seizures and You: Take Charge of the Facts” (Take Charge), a classroom curriculum designed to educate teenagers about epilepsy and seizure first-aid. Take Charge included a video on the nature of seizures and appropriate first-aid, and a classroom facilitator guide. Following completion of the Take Charge training conducted by the Epilepsy Foundation, the following changes in perception were noted: 89% of teens indicated that they believed that seizures are not contagious, and 86% would know what to do if someone had a seizure. Another 63% were sure that epilepsy is not a mental illness, and 55% would date a person with epilepsy. To improve the management of seizures in the schools, the Foundation, in collaboration with the National Association of School Nurses, developed “Managing Students with Seizures: A Training for School Nurses” on appropriate seizure management and response. The Foundation also began working with its affiliates on “You Are Not Alone: Parenting Your Teen with Epilepsy,” a CDC-developed tool kit designed to help parents deal with the complex issues involved with the experience of epilepsy during the adolescent years. The CDC is currently supporting a pilot test of a parent workshop with the tool kit as its centerpiece.

In response to the Living Well II conference’s attention to the fact that seniors are this nation’s fastest growing population [5], the Epilepsy Foundation has implemented an initiative targeting seniors. It aims to address the growing prevalence of epilepsy in this age group through a public awareness program for seniors and their caregivers and to train physicians in the diagnosis and treatment of epilepsy in this population.

The CDC Epilepsy Program has also announced a new partnership with the American Society on Aging and the Journalists’ Exchange on Aging to develop and disseminate information on epilepsy [6].

The Living Well II recommendations emphasize the importance of training first responders in appropriate response to seizures. The Epilepsy Foundation is currently revising its police training curriculum (“Take Another Look: Police Response to Epilepsy and Seizures”) and is developing a new training program for first responders. Further expansion of the first responders curriculum, with an additional module for such groups as mass transit workers, is planned. Development of online training will follow.

Finally, Living Well II’s focus on epilepsy as a serious health condition and its groundbreaking attention to mental health and mortality issues are reflected in the Foundation’s mood disorders initiative and its future plans to develop a variety of new educational materials on SUDEP (sudden unexpected death in epilepsy). These materials will provide family education on SUDEP and guidance for physicians on how to raise the issue with families and patients, as well as bereavement support.

2.3. Improving access to care systems

A major emphasis in the report of the Living Well II conference was the lack of public health systems to drive improved access to specialized comprehensive care for individuals whose epilepsy does not respond well to care at the primary level and who live in rural or otherwise underserved areas. In fact, despite successes at the federal level in raising the profile of epilepsy as a public health priority, similar progress at the state level has remained an elusive goal.

In the spring of 2004, however, the U.S. Department of Health and Human Services (HHS)’s Health Resources and Services Administration (HRSA) announced the availability of funds under its first epilepsy program, “Awareness and Access to Care for Children and Youth with Epilepsy” (Awareness and Access). The funds would support 3-year demonstration project grants to “improve access to comprehensive, coordinated health care and related services for children and youth with epilepsy residing in medically underserved areas; to implement a Learning Collaborative model for testing care improvement models; and to provide public education outreach regarding epilepsy and these projects in the demonstration states” [11].

In September 2004, HRSA awarded six demonstration project grants, totaling \$2.9 million. The program was to be administered through HRSA’s Maternal and Child Health Bureau (MCHB), an agency established by Congress as part of the Children’s Health Act of 2000 [12]. The new demonstration grants focus on improving access to care for children with epilepsy in medically underserved areas of California, Washington, DC, Oregon, West Virginia, and Wisconsin. In addition, the Epilepsy Foundation was funded to support three additional demonstration sites in New Jersey, Mississippi, and the Greater Chicago area.

Despite regional differences, the HRSA grants have a number of features in common, including the building of cooperative relationships between the medical community, the families, and the voluntary sector within a public health framework. All focus on enhancing dialogue and collaboration between families and their health care providers. Enhancement of the degree to which parents are regarded as a valued and integral part of a child’s health care team is an explicit goal, and all the programs are working to help parents become more empowered, stronger advocates for better care for their children, as recommended by Living Well II. As a group, the Awareness and Access programs funded through HRSA are committed to improving communitywide interventions and models of care that reduce the waiting time associated with referrals to specialists and specially trained primary care physicians. Again, these activities respond directly to Living Well II’s call for improved access to specialized care.

The programs also emphasize increased and culturally sensitive communications in support of children and empowerment of their family caregivers. Included are sys-

tematic development of care tools such as individualized, written care plans; home medication lists; individualized school support plans; and written plans to support the transition to adult care for the older child. In addition, the Awareness and Access grantees are adding to the resources available to patients, providers, and the community through conferences and workshops; cable television programming; health care provider educational tools; community mobilization tool kits; media materials; public service advertising; enhanced web site content; and new patient support tools such as Spanish-language *fotonovelas*.

Public awareness efforts to support these projects and spread the impact of the work being done in the demonstration states are being coordinated by the Epilepsy Foundation. The Epilepsy Foundation provides educational materials to all eight program sites and has been working on expansion of its existing materials in Spanish. It also provides updates on treatment management and other advances in epilepsy through a variety of media, including newsletters, electronic media, conference calls, brochures and in-service training. In addition, the National Epilepsy Library and Consumer Information Services of the Foundation's Epilepsy Resource Center expanded to include online access to scientific abstracts and educational materials.

Additionally, HRSA funded the National Initiative for Children's Healthcare Quality to promote improvement in epilepsy care and services through an effective learning collaborative model. Under this program, each demonstration program features a commitment to the Medical Home model of care for children with epilepsy in medically underserved areas.

A *medical home*, as defined by the American Academy of Pediatrics, is not a physical entity, but rather an approach to providing comprehensive primary care. In a medical home, children's medical care should be accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective [13]. HRSA's Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs, further defines the concept as an arrangement by which a pediatric clinician works in partnership with the family/patient to ensure that all of the medical and nonmedical needs of the patient are met. Through such a partnership, the pediatric clinician can help the family and/or the patient gain access to and coordinate specialty care, educational services, out-of-home care, and family support, and access other public and private community services that are important to the overall health of the child or young person with epilepsy [14,15].

Each HRSA project involves a marked degree of inter-agency, interinstitutional collaboration and partnership between the medical and community service providers, including the voluntary sector. This three-tiered approach is designed to coordinate, test, and educate, calling on local and national systems of public and professional education, to promote greater community awareness regarding epilepsy. The HRSA approach is also designed to implement

strategies to measure and record the impact of systemic changes—all leading to the timely and appropriate diagnosis and treatment of epilepsy in children residing in medically underserved areas.

2.4. Professional education programs

In addition to the substantial commitments described above on the part of HRSA, the CDC, the Epilepsy Foundation, and the participating organizations already involved in responding to the recommendations of Living Well I and II, there have been other significant responses on the part of epilepsy's community of care. One of these has been the establishment of a Living Well II task force representing the American Epilepsy Society, the Epilepsy Foundation, the CDC, the National Association of Epilepsy Centers, and the National Institute of Neurological Disorders and Stroke that has as a major goal to monitor progress made toward Living Well II recommendations.

As the national professional association committed to the improvement of the scientific understanding and treatment of epilepsy, AES has also incorporated additional Living Well recommendations into its current Strategic Plan, specifically: to enhance research into the consequences and comorbid conditions associated with epilepsy; to enhance professional education on seizures and epilepsy, particularly that geared to primary care providers and health care professionals in training; to focus epilepsy education programs on those components, skills, and strategies that promote self-management and self-determination; and to improve understanding of seizures and epilepsy and best practices for epilepsy management, including referral to tertiary-level care, particularly for primary care providers. AES has also established a practice standards task force to address Living Well recommendations and has held state-of-the-art conferences for professionals on the front lines of diagnosis and treatment. AES's annual scientific meetings have featured major symposia on comorbid conditions in pediatric epilepsy and cognitive comorbid conditions across the life span, both of which are key issues in the Living Well II recommendations. The organization's TeleConsult programs for professionals also cover several topics of concern to Living Well II, including assessment of the cognitive effects and outcomes of antiepileptic drugs, behavioral and cognitive comorbid conditions in pediatric epilepsy, and mood disorders in children with epilepsy [15,16].

The Epilepsy Foundation, in addition to its leadership role in many of the CDC and HRSA projects, has adopted the spirit of Living Well II as a guide to its own current and future activities. Living Well II concerns figure prominently in the strategies of the Foundation's new Strategic Plan for 2006–2010. Goals in the plan include: reducing the treatment gap between what can be done and what gets done; improving how people with epilepsy are perceived, accepted, and valued in society; and promoting a global research agenda that will result in new treatment options, including

research into comorbid conditions such as mood disorders and cognitive issues that complicate living well. The Foundation's future activities will focus across the life span of persons affected by epilepsy, with continued emphasis on teens, seniors, the medically underserved, and diverse communities [8].

The Foundation's strategic plan calls for continued outreach to ethnic and racial minority populations. Media outreach and public awareness/education efforts will continue to target African-American and Latino/Hispanic populations by providing technical assistance to affiliates and working with national partner organizations representing these populations.

3. Conclusion

The response of the epilepsy community to the recommendations of Living Well I and II is both far reaching and still a work in progress. There have been many solid accomplishments in the 3 years since Living Well II. The CDC is responding to the report's call for incidence and prevalence studies and greater attention to self-management as a positive treatment strategy while continuing, with the Epilepsy Foundation, to address individual and community educational needs and improved understanding of response to seizures by the public and professionals. The HRSA program is giving epilepsy a higher profile at the state level in medically underserved communities while focusing on empowerment of families, implementing comprehensive, coordinated care through improved access to specialists, and establishing a medical home for every child.

Looking ahead, both the Epilepsy Foundation and the American Epilepsy Society have incorporated selected Living Well II recommendations into their strategic plans for the next 5 years. Both agencies' plans refer to the need for increased attention to comorbid conditions, mortality, patient empowerment and effective self-management, the development of best practices, and timely referral to specialist care. Another outcome with promise for the future is the data to be collected from the inclusion of epilepsy-related questions in the BRFSS questionnaires in 19 states resulting from the grass roots efforts of Foundation affiliates and subsequent analysis by CDC. When all those data are in, the estimated prevalence of epilepsy will be more firmly established than ever—and it may hold some surprises. As noted above, it can be argued that Living Well II's emphasis on the burden of epilepsy is beginning, in subtle ways, to change the community's approach to epilepsy, and that, too, will affect the future.

Still to be addressed, however, are key recommendations that include developing consensus criteria among professionals in the epilepsy community on the warning signs of seizures and epilepsy. Equally necessary are identification of risk factors related to mortality and morbidity through surveillance and other studies and the creation of registries of

autopsy findings and brain bank resources. It is imperative that standards of care for treating mental health and cognition problems for persons with epilepsy, particularly with respect to the assessment and care of children, be established. A final much needed area of study is the development of a valid and reliable method of identifying and addressing stigma in academic and workplace settings.

Inevitably, a review of this type fails to do justice to all the program activities that have been undertaken by committed organizations as a result of Living Well II, and no doubt many important ones either have been omitted or have not received the attention they deserve. The authors acknowledge the vast contribution of all members of the epilepsy community in improving the quality of life for everyone touched by epilepsy and seizures.

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