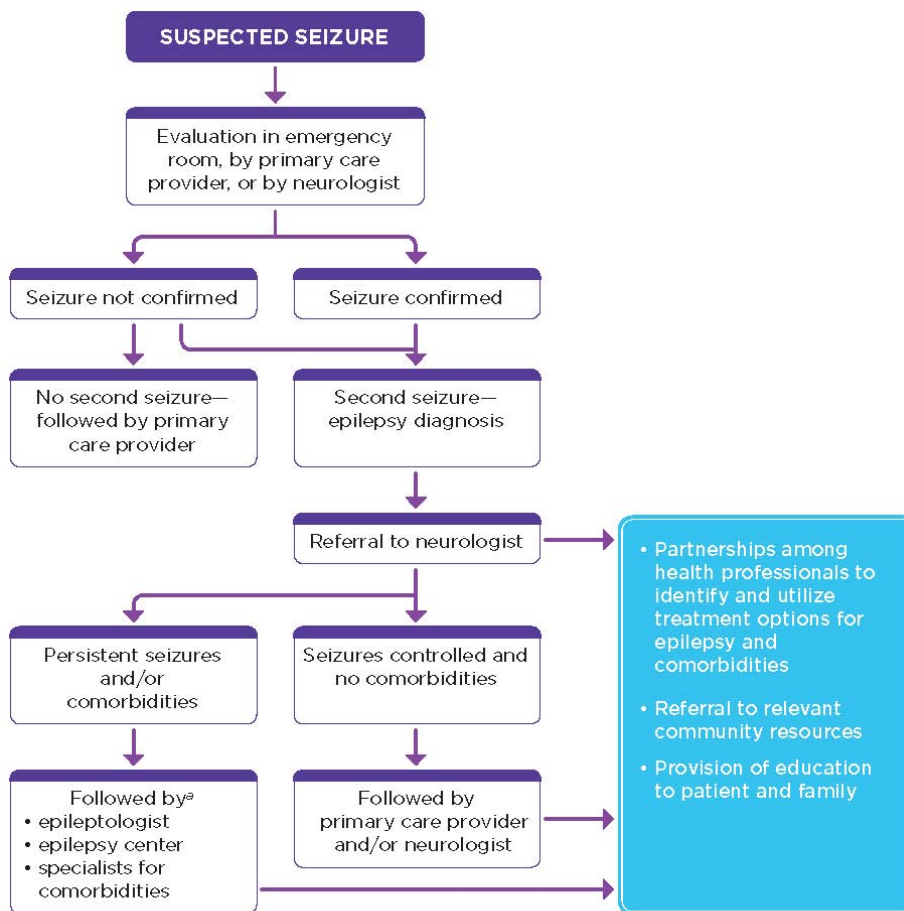


## Select Figures and Text Excerpts from *Epilepsy Across the Spectrum: Promoting Health and Understanding*<sup>1</sup>

The Institute of Medicine (IOM) examined the public health dimensions of the epilepsies with a focus on four areas: (1) public health surveillance and data collection and integration; (2) population and public health research; (3) health policy, health care, and human services; and (4) education for providers, people with epilepsy and their families, and the public. In the resulting report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*, the committee describes its vision for achieving a better understanding of the public health dimensions of the epilepsies and for promoting health and understanding.

### Treatment Pathways for Individuals with Epilepsy

One of the biggest challenges to improving access to care of people with epilepsy is ensuring timely, adequate care by the appropriate health care and human services providers. Figure 4-3 illustrates the committee’s view of the potential decision points for referrals to various providers and emphasizes that strong connections are needed with community resources throughout. In brief, the figure follows practice guidelines stipulating that epilepsy



care for patients who are diagnosed and have seizures that are easily controlled with medical therapy may continue treatment with a general neurologist or primary care provider. When the diagnosis is in question or when seizure control is not achieved, then the patient should be referred to an epilepsy specialist or center.

Because epilepsy is a spectrum of disorders that ranges broadly in severity, the care needs of individuals vary from the time of initial diagnosis to long-term management and from one individual to another. Clear clinical pathways should be laid out for people with epilepsy so that they are aware of their options, informed about available specialist care, and understand when to talk with the health care team about moving to another level of care. Another purpose in establishing clinical pathways is to move toward consistent protocols and accountability within and across institutions.

**FIGURE 4-3**  
Treatment pathway for individuals with epilepsy.

<sup>a</sup>When seizures become controlled, the patient can receive ongoing care from a primary care provider or neurologist, with care provided for comorbid health conditions as needed by specialists or primary care providers.

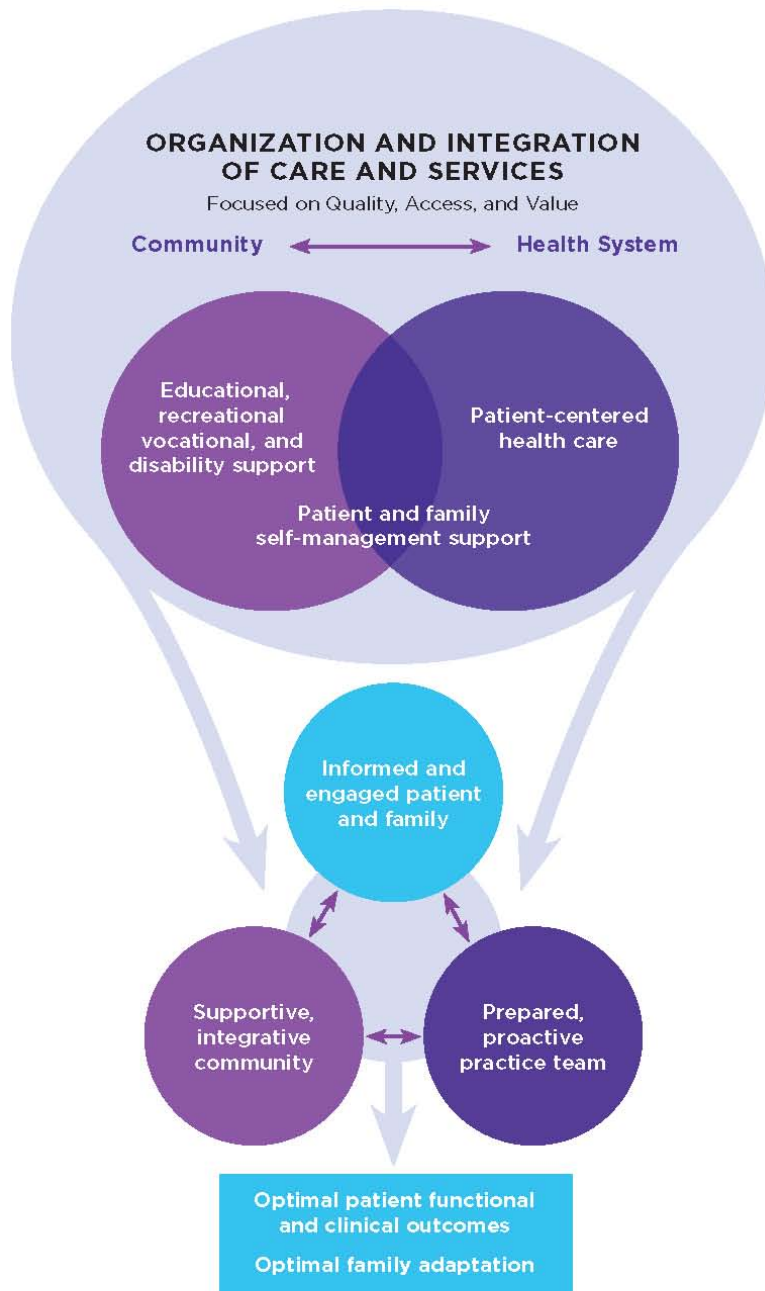
<sup>1</sup> References can be found in the full text of the report, which is available at [www.iom.edu/epilepsy](http://www.iom.edu/epilepsy).

## The Epilepsy Care Model

Epilepsy is a complex disorder that requires the active involvement of the individual with epilepsy, family and friends, and other caregivers; the time and expertise of many health care providers; and the knowledge and skills of varied community services providers.

The model of epilepsy care developed by the committee illustrates the emphasis placed on an integrated and collaborative approach to health care and community services. The model necessitates that community and health care systems are organized to provide access to and delivery of education and services that support self-management by the person with epilepsy and his or her family. Harmonization among services is essential to achieve high-quality outcomes. Because the majority of health decisions are made by the individual with epilepsy within the context of his or her family and community, patients must have the education, skills, and tools to manage their epilepsy appropriately day-to-day.

The main focus of this model is on the individual with epilepsy and his or her family—not the health care system—with efforts made to identify patient needs, recommend services, remove barriers to treatment, and facilitate care, including co-management of comorbid health problems when appropriate. Collaboration among care team members is critical to ensure that patients' needs are being met. The model should be the basis for accreditation, certification, guideline development, performance evaluation activities, and initiatives in epilepsy care.



**FIGURE 4-5**  
Epilepsy care model.

SOURCE: Adapted from Wagner, 1998. Reprinted with permission from the American College of Physicians.

**TABLE 6-1**  
Spectrum of Potential Epilepsy-Related Needs and Community Services

Types of Needs	Community Services
Information needs about the disorder, treatments, and health services (Chapter 7)	<ul style="list-style-type: none"> <li>• Nonprofit organization websites with general information about epilepsy (e.g., epilepsyfoundation.org; epilepsy.com)</li> <li>• Nonprofit organization websites with information specific to an epilepsy syndrome (e.g., dravet.org; tsalliance.org)</li> <li>• Federal and state websites and information resources</li> <li>• Health care providers, including community health workers</li> <li>• Case managers and social workers</li> </ul>
Information needs about local community services	<ul style="list-style-type: none"> <li>• State and local Epilepsy Foundation affiliates<sup>a</sup></li> <li>• Nonprofit organizations</li> <li>• Social workers, case managers</li> </ul>
Help in coping with the disorder and the associated comorbidities and challenges	<ul style="list-style-type: none"> <li>• Support groups</li> <li>• Self-management programs</li> <li>• Counseling</li> </ul>
School-related needs	<ul style="list-style-type: none"> <li>• Cognitive testing and educational assistance</li> <li>• Individualized education programs (IEPs)</li> <li>• Teachers and school counselors who are informed about epilepsy</li> </ul>
Employment-related needs	<ul style="list-style-type: none"> <li>• Vocational programs, vocational rehabilitation programs</li> <li>• Disability-related organizations and government agencies</li> </ul>
Transportation-related needs	<ul style="list-style-type: none"> <li>• Social service organizations</li> <li>• Local transportation agencies</li> <li>• Government agencies</li> </ul>
Housing-related needs	<ul style="list-style-type: none"> <li>• Social service organizations</li> <li>• Nonprofit organizations, including faith-based organizations</li> <li>• Government agencies</li> </ul>
Recreation and leisure	<ul style="list-style-type: none"> <li>• Camps</li> <li>• Sports and recreational programs</li> </ul>
Assistance for family members and caregivers	<ul style="list-style-type: none"> <li>• Respite care programs</li> <li>• Support groups for family members</li> </ul>

NOTE: As indicated throughout the report, family members, friends, caregivers, and others are key providers of social and psychosocial support.

<sup>a</sup>The Epilepsy Foundation is a nonprofit organization with a national office and more than 50 affiliates nationwide that offer varying services.

SOURCE: Adapted from IOM, 2008.

## Community Services and Quality of Life

Epilepsy is much more than seizures. For people with epilepsy, the disorder is often defined in more everyday terms, such as challenges in school, uncertainties about social and employment situations, limitations on driving a car, and questions about independent living. Family members also may struggle with how to best help their loved one and maintain their family life. Because of the range of seizure types and severities and the high rate of comorbid health conditions, the types of issues that have an impact on quality of life for people with epilepsy and their families and the degree to which they are affected vary widely. As a result, the range of community services potentially needed may be quite extensive (Table 6-1).

The availability of community services can play a significant role in improving quality of life for individuals with epilepsy and their families. Quality of life is a person's subjective sense of well-being that stems from satisfaction with one's roles, activities, goals, and opportunities, relative to the individual's values and expectations within the context of culture, community, and society. According to the World Health Organization, "Quality of Life is defined as individuals' perceptions of their

position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."

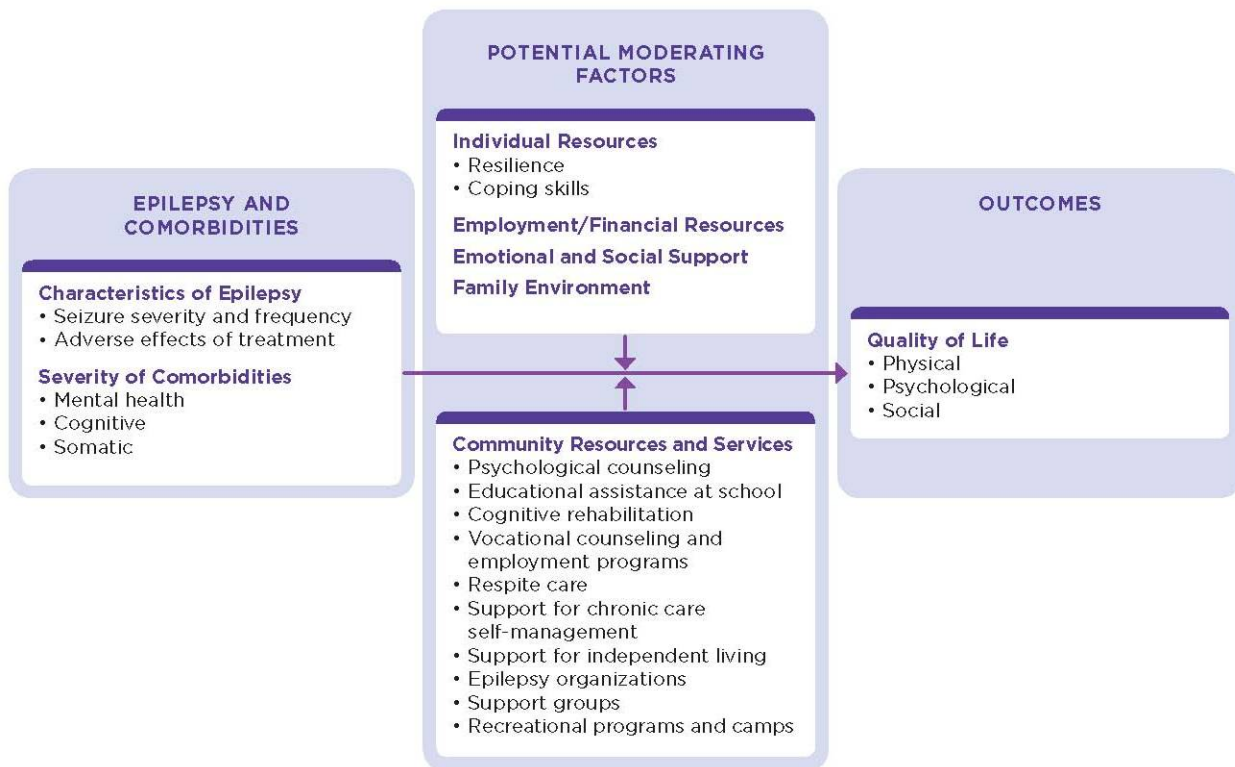
Many epilepsy-specific and non-epilepsy organizations are involved in community services, from transportation to employment to education to recreation. Collaborations are needed that tap into the energy and dedicated efforts of individual organizations and that work to coordinate and evaluate ongoing programs and identify best practices for community services for people with epilepsy. A strength of the epilepsy community is the depth and number of epilepsy organizations and involved individuals; building on and coordinating their work is critical to further improvements in the quality of life for people with epilepsy.

## Improving Quality of Life for People with Epilepsy and Their Families

Moving forward with improving and sustaining community services is vital to the well-being of people with epilepsy, particularly those with cognitive and physical disabilities. People with epilepsy and their families typically face an array of challenges to daily living that vary with the severity and nature of the epilepsy disorder and may change as the individual grows older. The negative effects on quality of life can be severe and involve family and social relationships, academic achievement, and opportunities for employment, housing, and the ability to function independently. Family and community support is critical across a range of services. As a result, the committee urges improvements in community services and programs to ensure that they are

- individually centered to meet the needs of the person with epilepsy;
- locally focused, taking into account the full range of resources in the area;
- easily accessible;
- thoroughly evaluated;
- closely linked to health care providers, particularly epileptologists and epilepsy centers; and
- innovative and collaborative in working with organizations and agencies focused on other neurologic and chronic conditions or on similar service needs.

As discussed throughout this report, individual, family, and community resources can help reduce the negative effects of epilepsy and associated comorbidities on the quality of life of individuals with epilepsy and their families (Figure 6-2).

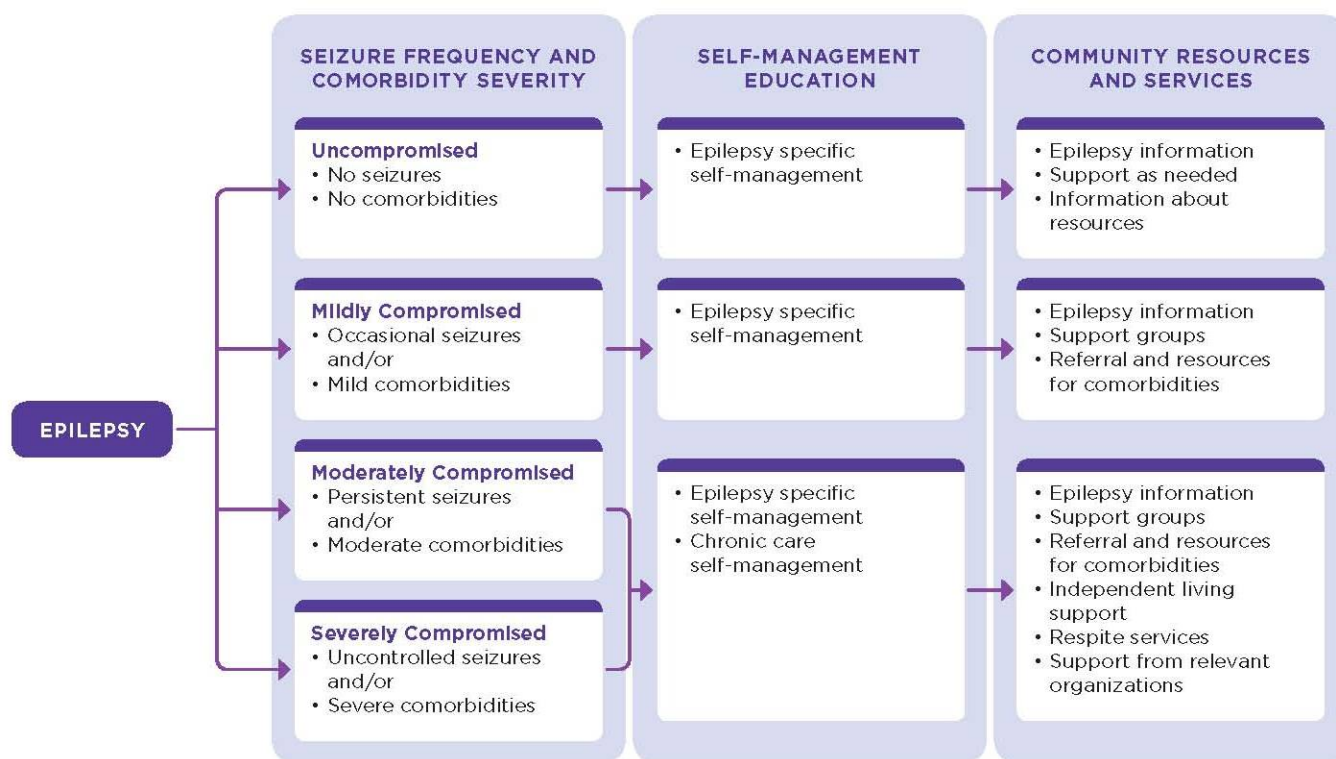


**FIGURE 6-2**  
Factors integral to quality of life for people with epilepsy.

## Educational Needs Across the Spectrum

Building a trusting and collaborative relationship that enables quality care requires clear communication between health care providers and the individual with epilepsy, family members, and caregivers. Health professionals need to convey information in ways that take into account health literacy and cultural sensitivities. Because of the diverse nature of the epilepsies, some people with epilepsy will need more educational assistance than others. Figure 7-2 depicts how different severity levels of seizures and comorbidities could be linked to different levels of education and resources. Epilepsy-specific education may meet the needs of people with mild forms of epilepsy or those who are mildly compromised—people who may be seizure-free and have no associated comorbidities or those with occasional seizures or mild comorbidities. However, individuals who are seriously compromised—those with uncontrolled seizures and severe comorbidities—will have much greater resource and educational needs. These individuals and their families will need comprehensive education that would include both epilepsy-specific and chronic care self-management program elements.

Some moderately compromised adults also might benefit from both epilepsy-specific education and chronic care programs, such as the Chronic Disease Self-Management Program (CDSMP). A possible benefit of this combined approach, which could be usefully tested through research, is that some somatic comorbidities associated with epilepsy, such as cardiovascular disease, diabetes, and osteoporosis, could be improved through participation in a generic chronic care program. The finding that online delivery of the CDSMP effectively improved health status suggests that online programs, both epilepsy-specific and generic for chronic conditions, could provide benefits for people with epilepsy who otherwise would not have access to them.



**FIGURE 7-2**

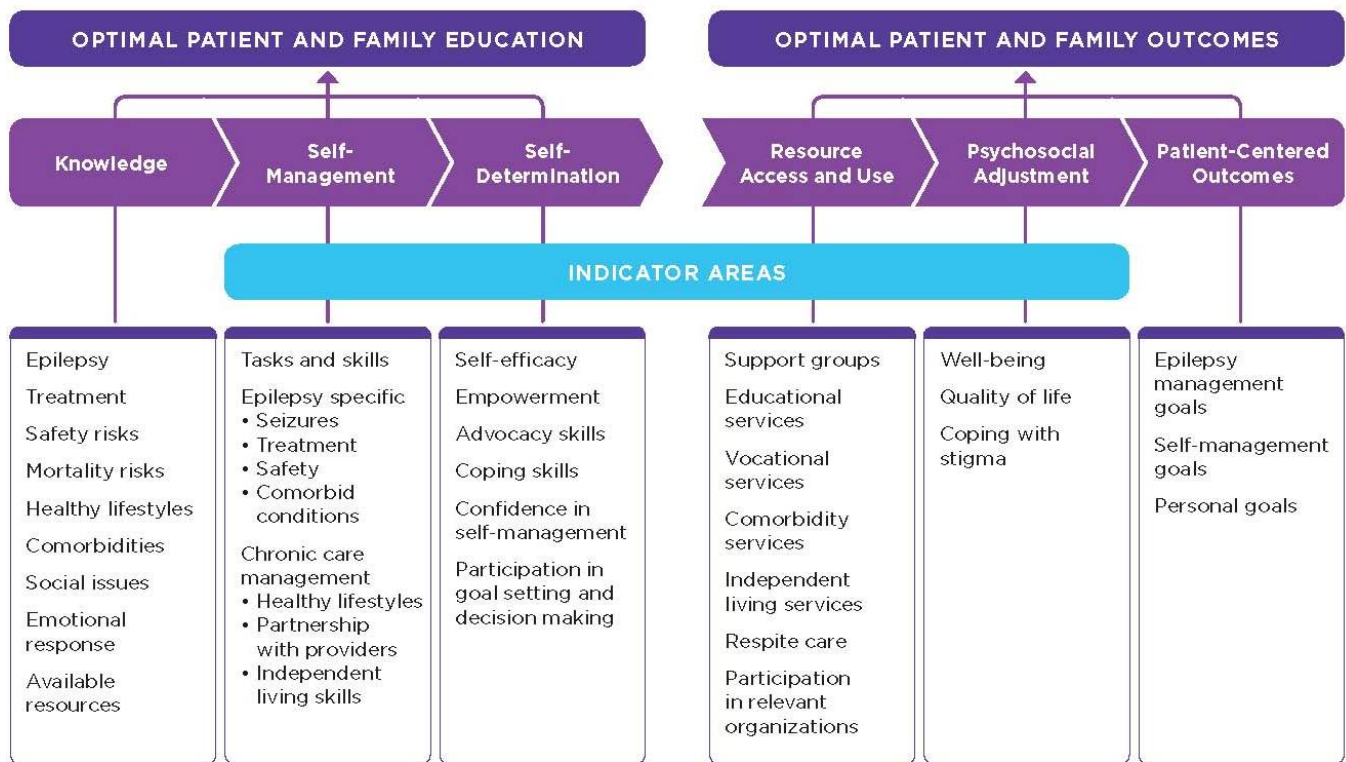
Linking seizure frequency and comorbidity severity to self-management education and community resources and services.

## Optimal Educational Outcomes for People with Epilepsy and Their Families

The committee's vision for optimal patient and family education and outcomes is depicted in Figure 7-3. The education side of the model includes three major domains—knowledge, self-management, and self-determination—and the corresponding indicator areas necessary for optimal patient and family education. The indicator areas define a combination of knowledge, perceptions, tasks, and skills that can be used to measure the efficacy of education programs.

Because there is not a direct cause and effect between the quality of patient education and health outcomes and because health outcomes can be affected by a complex array of factors, the committee concentrated on outcomes more directly related to education. Therefore, the outcomes side of the model focuses on those that can result from optimal education: access to and use of community resources, psychosocial adjustment, and patient-centered outcomes. Corresponding indicator areas define a range of desirable services and patient outcomes. For example, educational programs focusing on self-management and self-determination would prepare people to take advantage of community resources, such as support groups and educational services; similarly, educational programs focusing on increasing knowledge about treatment would help individuals set and monitor epilepsy management goals. Thus, the outcome indicators are important measures of the success of educational efforts.

Designing educational programs to achieve optimal outcomes requires consideration of the characteristics of program participants such as health literacy, cultural diversity, age and developmental stage, cognitive ability, severity of disease, and gender.



**FIGURE 7-3**

Education for people with epilepsy and their families to promote optimal outcomes.

SOURCE: Adapted from Colagiuri and Eigenmann, 2009. Reprinted with permission from John Wiley and Sons.