

Improving Health Care for People with Developmental Disabilities: Cultural Competencies for Providers and Systems

This document highlights competencies for health care providers and systems in order to meet the needs of transition age youth and adults with developmental disabilities. It includes types of knowledge, skills and attitudes necessary to provide high quality care and services to this population.

Knowledge

- **Definition of Developmental Disability.** California law defines a developmental disability as a condition that originates before an individual turns 18; continues or can be expected to continue indefinitely; and constitutes a substantial impairment in three or more areas of major life activity including: (1) self care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living, and (7) economic self sufficiency. Common forms of developmental disabilities include autism, cerebral palsy, intellectual disability and epilepsy.
- **Clinical knowledge specific to developmental disabilities.** Clinical knowledge includes causes, symptomology, characteristics, and the natural history of developmental disorders, as well as the specific medical conditions that are known to co-occur with developmental disabilities. Additional topics include diagnostic testing, psychotropic medications, behavioral interventions, use of adaptive equipment, and management of chronic disease.
- **Conducting developmental and behavioral screenings.** This knowledge area encompasses how to perform a developmental and behavioral screening for transition age youth and adults, as well as how to make an appropriate referral for assessment for medical care.
- **Understanding of the health care system and community resources.** This includes an understanding and awareness of the complex system of agencies and community resources that support people with developmental disabilities. This topic also includes the eligibility criteria for services and how to refer patients to these community resources. Key players in the health care system for people with developmental disabilities include the following:
 - **Regional Centers.** In California, Regional Centers provide diagnosis and assessment of eligibility for services, as well as help plan, access, and monitor needed services and supports. There is no charge for the diagnosis and eligibility assessments.
 - **California State Council on Developmental Disabilities.** The State Council of Developmental Disabilities is established by state and federal law as an independent state agency to ensure that people with developmental disabilities and their families receive the

services and supports needed. The Council includes 13 regional Area Boards throughout California that provide advocacy, public information, and program planning and monitoring.

- **California Children’s Services.** California Children’s Services provides diagnostic and treatment services, medical case management, and physical and occupational therapy services to children under 21 years of age with medically eligible conditions, which include some developmental disabilities.
- **Community Resources.** Community resources are significant players in the system of care and include community-based organizations serving people with developmental disabilities and their families.
- **Legal rights of people with developmental disabilities.** This knowledge area includes relevant legislation for people with developmental disabilities, as well as the rights of individuals and their families. Examples of rights for people with developmental disabilities include the right to prompt medical care and treatment; freedom from harm, unnecessary physical restraint or isolation; freedom from excessive medication, abuse and neglect; and freedom from hazardous procedures. This topic also includes information about advocacy services and eligibility criteria for these services. Key examples of relevant legislation and rights include the following:
 - **The Lanterman Act.** This Act set forth legislative intent to extend the Regional Center network of services throughout the state of California. The Lanterman Act is unique in that it grants an entitlement to services for Californians with developmental disabilities. This legislation declares that persons with developmental disabilities have the same legal rights and responsibilities guaranteed to all other persons by the federal and state constitutions and laws, and charges the Regional Center with advocacy for and protection of these rights. The Act lists the specific rights guaranteed to persons with developmental disabilities.
 - **Clients’ Rights Advocate.** The Office of Clients Rights Advocacy states that a clients’ rights advocate (CRA) can consult with and help people who have a developmental disability and their families get services; can directly represent people with developmental disabilities in administrative hearings; and can provide training about rights to consumers, their families, and interested community groups. CRAs can also investigate complaints about the denial of any right to which a consumer is entitled, if the complaint involves a facility.
 - **Protection and Advocacy System.** The Developmental Disabilities Assistance and Bill of Rights Act of 2000 provides for a program to support a Protection and Advocacy system in each state, territory, and Native American Consortium to protect and advocate for persons with developmental disabilities. California’s Protection and Advocacy System aims to advance the rights of Californians with disabilities by filing lawsuits on behalf of individuals or groups and by investigating charges of abuse and neglect. They also build peer/self advocacy groups; forge community partnerships; advocate for change in laws, regulations, and public policy; and provide information to those who may not know their rights.

Skills

- **Communication and interviewing skills.** This skill includes strategies to gain a history, screen and evaluate an individual with developmental disabilities, particularly when the patient may be nonverbal.

Communication skills also include the ability to effectively obtain and share information with families or caregivers.

- **Observation skills.** Observation skills are critical when working with patients with developmental disabilities, especially to identify behaviors that may be affecting or may be resulting from the patient's health condition. This skill includes the ability to observe subtle changes in a patient's behavior as these changes may in some cases require medical attention. Observing subtle changes, as well as gathering the information about such changes and being alert to caregiver reports about such changes, requires additional time and openness on the part of the provider.
- **Physical examination skills.** Physical examination skills specific to working with patients with developmental disabilities include providing assistance with the positioning of the physical exam as well as patience in working with patients who may need extra time to be coaxed and talked through the exam procedure. This also includes the ability to engage in preplanning and diagnostics in order to assist the patient immediately and effectively.
- **Ability to recognize specific service needs.** This skill requires that providers are able to recognize and acknowledge that patients with developmental disabilities may have specific services needs that are above and beyond the needs a typical patient.
- **Ability to recognize that a person with developmental disabilities may not be able to be served in a typical medical setting.** This skill recognizes that patients with developmental disabilities have individualized needs and may need to be served in alternate settings, such as through home visits or at board and care facilities.
- **Ability to identify, coordinate, and communicate with members of the patient's interdisciplinary team.** This skill encompasses the recognition that a multi-disciplinary team is required in order to adequately care for a patient with developmental disabilities. Members of the patient's interdisciplinary team include those who will help implement the assessment or plan for a patient who has a developmental disability. These members may include case coordinators, service providers, specialists, and caregivers. In addition to identifying the team members, this skill also includes the ability to effectively coordinate the services for the patient. The ability to communicate with other agencies and community resources will ensure that patients are receiving complete and appropriate services.

Attitudes

- **Compassion and sensitivity.** Sensitivity to the needs and experiences of people with developmental disabilities includes having compassion, good listening skills, and flexibility, as well as an understanding of the context in which individuals live and how that may influence treatment compliance. This also encompasses recognition of the challenges that people with developmental disabilities face on a daily basis and any types of accommodations they may need.
- **A patient- and family-centered attitude.** Health care providers should strive to tailor their care according to what the patient wants. This encompasses extending respect to the patient by using

appropriate terminology, interacting directly with the patient, and including the patient in the conversation. In addition, this attitude includes being respectful towards families and providing support when needed. Strong relationships with patients who have a developmental disability and their families are necessary in order for patients to trust and have confidence in their providers.

- **Cultural sensitivity.** Cultural appropriateness reflects the ability to for providers to be sensitive to differences. In this context, culture encompasses not only race/ethnicity and language, but also the disability culture. Cultural sensitivity includes using respectful terminology (e.g., people-first language), providing language assistance when necessary in order to communicate with patients, and providing medical care in a manner that takes into consideration the patient's culture.
- **Acceptance of information from multiple sources.** Given that patients with developmental disabilities may not be able to report for themselves, providers must be trained to recognize and accept that health information may be provided from not only the patient, but also through multiple vehicles, including caregivers and health advocates.
- **Recognition of the additional time necessary to serve patients with developmental disabilities.** In order to adequately serve and meet the needs of patients with developmental disabilities, providers must be prepared to spend additional time with these patients, as they often experience more complex medical problems compared to the general population. They often need more time for examinations and procedures both physically and while trust and cooperation can be developed and maintained.

Training Settings

Health care provider training may take place in a number of settings, including the following:

- **Health Care Professional Schools.** Health professional schools, including medical schools, nursing schools, and schools of dentistry, may be effective training sites for practitioners to build a foundation of the knowledge, skills, and attitudes necessary to provide quality care for people with developmental disabilities.
- **Academic Clinic Settings.** Clinic practices that are part of academic training centers may be effective training sites for both intern and resident physicians in specialty training programs, as well as community providers interested in learning how to better serve people with developmental disabilities.
- **Community based social service agencies.** Community organizations, including social service agencies and regional centers, may also serve as training sites. Since these agencies are already providing other services for people with disabilities, they would be a prime site where providers would have the ability to work first-hand with youth and adults with developmental disabilities.
- **Community clinics.** Local community clinics, especially those that are part of or affiliated with county medical centers, federally qualified health centers, safety net clinics and other publicly funded resources, can also provide opportunities for training health care providers in how to support and provide care for people with developmental disabilities. These sites may be ones that already serve a significant number of people with developmental disabilities, since many of these patients are covered by public health insurance. Thus, establishing training sites at clinics where the people are already

receiving care offers an excellent opportunity to improve care as well as train additional providers in how to render appropriate care to people with developmental disabilities.

- **Group practices.** Physician group practice settings may also serve as potential training venues for working with patients with developmental disabilities. This is particularly feasible if one member of the group identifies him/herself as the practice “champion” for serving people with developmental disabilities. This provider would then become the practice “expert” on health care issues for these patients, and serve as the mentor for others in the practice interested in improving their skills in caring for people with developmental disabilities.