 **ICF/IID Program Background & History**

**Intermediate Care Facilities for the Developmentally Disabled:**Meeting the Long Term Care Needs and Maximizing the Potential of Individuals with Intellectual and/or Developmental Disabilities by American Health Care Association

**Introduction**

Prior to 1971, facilities for the people with intellectual disabilities (formerly, "mental retardation") developmental disabilities were financed solely by state, local and private funding. Many facilities were plagued by overcrowding and poor conditions. Dramatic changes were the order of the day, compelling Congress and the Nixon administration to act.

An amendment to the Social Security Act was passed and enacted into law that year, establishing special facilities financed with federal dollars. These facilities were called "Intermediate Care Facilities for the Intellectual Disabled" or ICFs/IID. Today, ICFs/IID form a long-term care and training delivery system for individuals with intellectual and developmental disabilities (ID/IID). These individuals are commonly referred to as "clients," "residents," or simply as individuals. Changes and improvements in ICF/IID support and training services have created one of the most progressive and technically advanced programs anywhere in the world. For residents, quality of life has improved dramatically, as access and choice have become hallmarks of the ICF/IID program. Support and training programs now provide them with increased opportunities to live in more home-like, less restrictive settings and, to the extent possible, to become a more integral part of their communities.

**Rosa's Law** is a [United States](https://en.wikipedia.org/wiki/United_States) law, which replaces several instances of "mental retardation" in law with "[intellectual disability](https://en.wikipedia.org/wiki/Intellectual_disability)" was signed into law by President [Barack Obama](https://en.wikipedia.org/wiki/Barack_Obama) on October 5, 2010. The law is named for Rosa Marcellino, a girl with [Down syndrome](https://en.wikipedia.org/wiki/Down_Syndrome) who was nine years old when it became law, and who, according to President [Barack Obama](https://en.wikipedia.org/wiki/Barack_Obama), "worked with her parents and her siblings to have the words 'mentally retarded' officially removed from the health and education code in her home state of Maryland."  Rosa's Law is part of a long line of changes that has been ongoing since the early 1900s. Words such as *idiot* and *moron* were common in court documents and diagnosis throughout the early 1900s. In the 1960s, changes in the law led to the use of such terms as *mental retardation*. With the loss of *idiot* (IQ 0-25), *imbecile* (IQ 26-50) and *moron* (IQ 51-75), specific descriptors of IQ-based intelligence were abandoned because of public sentiment. Under Rosa's law, these would be described respectively as profound, severe and moderate levels of intellectual disability.

**ICF/IID Services and Goals**

ICFs/IID provide a wide variety of services based on client needs, which vary according to age and level of intellectual and developmental disabilities. In addition to providing a home-like environment with personal and support services, ICFs/DD serve as teaching/training facilities that make use of sophisticated client assessment tools to determine clients' medical, dietary, psychological and social needs. Broad ranges of services are offered in ICFs/IID to meet the complex needs of clients while enhancing their quality of life.

Many individuals reside in ICFs/IID from youth until old age, which means that these facilities become a *true home* and staff become a second -- and sometimes the only -- family for some residents.

ICFs/IID vary from facility to facility and state to state, although they all are bound by federal regulations. Despite facility variations, a common goal among facilities is to assess what individuals are capable of doing, to help them maximize their potential, and to do so with professionalism and compassion. This comprehensive approach to helping individuals acquire the skills necessary for maximum independence--and to helping them maintain optimal functioning - is referred to as "active treatment." Active treatment, the foundation of the ICF/IID program.

**Levels of Intellectual Disabilities**

Levels of intellectual disabilities ("mental retardation") have been described according to four main categories -- mild, moderate, severe and profound -- which are based on IQ scores and some assessment of adaptive skills. These four levels are rated according to the following IQ measurements:

Mild: IQ of 50-70  
Moderate: IQ of 35-49  
Severe: IQ of 20-34  
Profound: IQ below 20

**Client Characteristics**

Federal Medicaid guidelines define intellectual disabilities as significant sub-average general intellectual functioning resulting in or associated with concurrent impairments in adaptive behavior and manifested during the developmental period. *(Definition previously used by the American Association on Mental Retardation).*

*Significant sub average intellectual functioning* is defined as measured intelligence, commonly expressed as I.Q. of 70 or less. *Impairments in adaptive behavior* refers to inabilities to perform personal and interpersonal functions at age-appropriate levels.

*The developmental period* is the period from conception to age 18.

*Individuals with related conditions* are those who have a severe, chronic disability that meets all of the following conditions:

1. Cerebral palsy, epilepsy, or any other condition, other than mental illness, found to be closely related to mental retardation because this condition may result in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment of services similar to those required for those persons.
2. Manifested before the individual reaches age 22 (Age 18 in California) and likely to continue indefinitely.
3. Results in substantial functional limitation in three or more of the following areas of life activity: self-care, understanding and use of language, hearing, mobility, self-direction, capacity for independent living (42CFR, Section 435.1009)

Most individuals living in ICFs/IID have severe to profound intellectual disabilities and are likely to have multiple disabilities and impairments, such as cerebral palsy, epilepsy, speech/language impairments, and hearing and visual impairments.

**Trends in Size and Institutional Status of Facilities Serving Mentally Retarded and/or Developmentally Disabled Population**

The trend in caring for individuals with an intellectual and/or developmental disability over the last 20 years or more has been marked by a dramatic shift from large state-run institutions to smaller, privately run facilities. By federal definition, a large facility is defined as one that houses more than 15 beds, and a facility with fewer than 15 beds is considered small.Most large facilities are state run, averaging 119 beds nationally.

Today, a strong deinstitutionalization trend is moving beyond the shift from public to private facilities. Home- and community-based (HCBS) waiver services are taking on a growing role, and some states have converted ICFs/IID to HCB services or have considered eliminating ICF/IID programs. These waiver programs do not require federal oversight or the rigorous attention to individual training and support programs currently required in ICFs/IID.

In 1981, HCBS programs were established under Section 1915(c) of the Social Security Act, offering states the option of requesting waivers for individuals who otherwise would receive services in a Medicaid-approved institution, such as an ICF/DD. "The intent of the law was clearly to help States provide options to persons who prefer non-institutional care. It was not to mandate that ICF/DD clients who are eligible for institutional care be placed in alternative home and community-based settings against their will. The law allows for such placements when States make it available and when clients choose it." Nevertheless, some states do not offer the option between ICFs/IID and waiver program services, and individuals automatically are placed in waiver programs.

**ICF/DD Emphasis on Resident Outcomes**

The former Health Care Financing Administration (HCFA) now CMS, issued a revised ICF/IID survey protocol October 1, 1996, with surveyor training occurring in spring 1996. The new survey protocol calls for an outcomes-based, customer-focused approach to facility surveys. This new approach emphasizes customer responses and staff performance rather than review of facility records. While there are eight conditions of participation with which facilities must comply, the survey process stresses four of those categories of participation: active treatment services, client protection, client behavior and health care services. A general understanding of these four general categories of participation is crucial to understanding the basic ICF/IID program. They are summarized below:

**Category 1: Active Treatment**

To be certified to receive Medicaid funding, an ICF/IID must meet federal standards for 24-hour health care and continuous individualized active treatment for residents. Active treatment is the cornerstone of the ICFIID program and involves a comprehensive team approach to teaching residents critical skills and behaviors. In general, the goal of the active treatment requirement is to assure that individuals acquire behaviors that help them to function as independently as possible, given their disability. 7

*Admission*: Individuals admitted to ICFs/IID must need and be receiving active treatment services. Before admitting a client, facilities conduct an evaluation, which includes background information and assessments of the individual's functional, developmental, behavioral, social, health and nutritional status. The purpose of the evaluation is to assure that the facility can meet the client's needs and that the client will benefit from placement in the facility.

*Assessment:* Within 30 days following admission, facility interdisciplinary teams are required to perform accurate assessments or reassessments as a supplement to the pre-admission evaluation. This assessment must take into consideration the client's age and the implications for active treatment.

The assessment must also:

* Identify the problems, disabilities, and their causes;
* Identify the client's developmental strengths;
* Identify the client's developmental and behavioral management needs;
* Identify the client's need for services without regard to the actual availability of services needed; and
* Include physical development and health, nutritional status, sensorimotor development, affective development, speech and language development, auditory functioning, cognitive development, social development, adaptive behaviors or independent living skills necessary for the client to be able to function in the community, and, as applicable, vocational skills.

*Individual Program Plan (IPP) and the Interdisciplinary Team (IDT):*  All clients must receive an individual program plan developed by an interdisciplinary team that represents a range of professions, disciplines, or service areas. The team members must be able to identify the client's needs and design appropriate programs to fulfill them. The IPP must be developed within 30 days after admission. For some clients, their goals may be as basic as maintaining or avoiding loss of a particular skill. For others, their goals may be more advanced, such as managing their own bank account.

*Implementation of the Individual Program Plan:* Once the interdisciplinary team has developed the IPP, clients must receive a continuous active treatment program consisting of needed interventions and services. These interventions and services must accomplish the objectives of the IPP. All staff who work with the client must implement the clients’ IPP.

*Reviews:* The active treatment process also calls for review and revision of the IPP by a qualified mental retardation professional. Revisions are called for in situations such as completion of objectives identified in the IPP or the loss of skills gained.

*Reassessment and/or Discharge:* At least annually, the comprehensive functional assessment of the client must be reviewed by the IDT for relevancy and updates, and the IPP must be revised as appropriate. If a client is to be discharged, the facility must develop a summary of the client's developmental, behavioral, social, health and nutritional status, as well as a post-discharge plan of care that will assist the client in adjusting to the new living environment.

**Category 2: Client Protections**

The federal client protection standards identify the rights of all clients, such as freedom from unnecessary drugs and physical restraints and the provision of active treatment to prevent their use, freedom from abuse, and the provision of opportunities to participate in social, religious, and community activities, to name a few. Client protection standards also call for systems that protect a client's personal funds and the client's access to personal funds. In addition, the standards lay the groundwork for appropriate communications with clients, parents and guardians. Staff treatment of clients and necessary measures to prevent mistreatment, neglect or abuse also are discussed in the regulations.

**Category 3: Client Behavior**

Client behavior standards underscore the importance of facility practices that maximize client choice and autonomy. Facility policies address the degree to which client choice will be incorporated in daily decision-making. To the extent possible, clients participate in the formulation of these policies.

In managing inappropriate client behaviors, facilities emphasize client safety, welfare, and the protection of human rights. In directing client behavior, ICFs/IID primarily focus on positive behavioral management programs that reward appropriate behavior, thereby eliminating undesirable behaviors. Use of more intrusive techniques is regulated under federal law and must be part of the client's IPP in order to be applied. Such methods are never used for disciplinary purposes or for the convenience of staff.

**Category 4: Health Care Services**

The approach to health care services in ICFs/IID relies on the interdisciplinary team approach to meeting client's needs and underscores preventive care.

Physician services must be accessible round-the-clock. Together with licensed nursing staff, physicians are required to develop a medical care plan of treatment for only those clients who require 24-hour nursing care. This medical plan becomes a component of the individual program plan. Annual physical examinations to evaluate vision and hearing and to ensure proper immunization and screening for tuberculosis are provided for each client. Staff as well as clients are trained in appropriate health and hygiene methods, in order to control communicable diseases. Comprehensive dental services, pharmacy services and systems for monitoring drug administration also must be arranged by the facility.

**Summary**

These four primary (core) conditions of participation -- active treatment, client protection, client behavior and health care services -- reflect the survey processes' new resident focus and emphasis on outcomes. Overall, the goal is to encourage interaction with and assessment of individuals who reside in ICFs/IID, rather than a heavy reliance on reviewing written records.

**Staffing**

*Staff Qualifications*: Federal standards require that active treatment programs be established and monitored by qualified intellectual disabilities professional (QIDP). The QIDP is a professionally trained individual who is responsible for overseeing implementation of the IPP. The QIDP must meet the qualifications outlined in the ICF/IID conditions of participation. Other staffing requirements state that direct care staff must be on duty and awake round-the-clock to take appropriate action in case of emergency. Support staff also must be provided to assure that direct care staff are not distracted from their duties.

*Staffing Ratios*: Direct care staffing requirements are based on client age and level of disability. Direct care staffing is defined as present on-duty staff calculated over all shifts in a 24-hour period.

*Staff Training:* ICFs/IID provide employee training to ensure that staff can perform their duties effectively. For employees who work with clients, this training focuses on skills to help them meet clients' developmental, behavior, and health needs. Staff also are required to demonstrate the essential skills to implement individual program plans for the clients for whom they are responsible.

**ICFs/IID Medicaid Expenditures**

ICF/IID services represent a significant segment of the long-term care spectrum. Because adults with developmental disabilities require lifelong support, these adults are highly dependent on public programs to finance their long-term care needs. Medicaid is the primary pay or of ICF/IDD services, although some clients are considered disabled children and may access their parents' Medicare and Social Security.

**Conclusion**

Since the ICF/IID program began, many individuals have been able to live in *home-like, less restrictive settings*. Individuals receive long-term care in an environment where individual potential is maximized and personal needs are thoroughly assessed and fulfilled. Professional staff and government oversight work together to assure that the needs of individuals living in ICFs/IID are the driving force behind services provided.