

**A Guide to
Residential Services for Persons with
Mental Retardation or Developmental Disabilities
(MR/DD)**

Society changes. Today, for example, there is greater understanding, acceptance and a more open environment for people with mental retardation or developmental disabilities (MR/DD); they have the opportunity to learn and develop throughout their lifetimes. There have been many agents of this change: the advent of community Intermediate Care Facilities for the Mentally Retarded (ICFs/MR); progressive laws such as the Developmental Disabilities Act (1970); the Individuals with Disabilities Education Act (1975); additions to the Social Security Act (1981); the Americans with Disabilities Act (1990); and, educational services such as Special Education that emphasizes mainstreaming in public schools. Another change agent has been locating small facilities and group home residences in communities.

Over time, long term care has been redefined to include, with the inception by the federal government of ICFs/MR in 1971, services and supports for persons with MR or DD (referred to as “residents” or “clients”). Today, community ICFs/MR and the Home- and Community-Based (HCB) waiver program provide a progressive and technically advanced care and quality of life environment, with access and choice the hallmarks of these services. Support and training programs provide more opportunities for clients to live in settings they choose with greater access to the full benefits of the community-at-large, jobs, socialization, etc.

The result is that clients in all settings have the opportunity to live their lives characterized by health, happiness, dignity and productivity to the maximum extent possible for the individual.

An important aspect in understanding the environment of this special community is that, according to the federal Centers for Medicare & Medicaid Services (CMS), which regulates facilities, the median number of clients served in an ICF/MRDD facility is 6 clients. Even a seemingly larger ICF/MR, in terms of the total number of beds, may not have every client in one building. Rather the ICF/MR may operate several freestanding community homes with only a few beds each or it may be organized as a series of small

residences arrayed in a campus-style setting. Larger facilities may not offer the intimacy of smaller ones yet these facilities tend to serve the most difficult clients and offer a wide array of in-house or contract client support services to meet their needs. However, for ICFs/MR, there is one constant--the licensure and inspection regimes remain the same irrespective of how they are organized. This contrasts with group homes under the HCB waiver program that may only have a few clients in a staffed (or unstaffed) residence with minimal government involvement, supervision or oversight.

Individuals with MR

Mental retardation--sometimes referred to as an intellectual or cognitive disability--is a functioning level characterized by significant limitations in both intelligence--IQ below 75--and conceptual, social and practical adaptive skills. Most people living in ICFs/MR have severe to profound mental retardation, and are likely to have multiple disabilities and impairments, such as cerebral palsy; seizure disorders, such as epilepsy; visual and hearing impairments; and behavioral or psychiatric disorders.

The following points are essential to understanding mental retardation, which can be caused by many conditions that impair development of the brain before birth, during birth or during early childhood:

- Mental retardation is characterized by related limitations in two or more of the following adaptive skill areas: communication; home living; community use; health and safety; leisure; self-care; social skills; self-direction; academics; and, work. The condition manifests before age 18.
- Limitations usually coexist with strengths.
- In order to profile needed supports, limitations are identified.
- With appropriate supports, over a sustained period, persons with mental retardation often can improve and show increased autonomy and independence.

Individuals with DD

People with developmental disabilities are at least five years of age and have a severe, chronic developmental disability with an impairment(s), mental or physical, that occurred before they were 22 years of age with the expectation that the disability(ies) will continue indefinitely. The developmental disability limits the person in three or more of the following life activities: language (receptive and expressive); learning; self-care; self-direction; economic self-sufficiency; independent living; or mobility.

Persons with developmental disabilities also need a combination of and sequence of special, interdisciplinary treatment or other services that are individually planned and coordinated and are for an extended duration. This may include people with mental retardation. However, not every person with mental retardation meets the criteria for developmental disabilities or vice versa.

ICFs/MR Program

ICFs/MR, which are health care facilities for long term residents, generally serve people with more severe disabilities than non-ICF/MR residential services. These facilities generally offer a wide array of therapies, and an on-site medical staff to meet the complex and changing needs of clients, while also providing support to families. Personal and support services add to the quality of life and help motivate clients to learn practical life skills in socialization, employment, recreation, etc. ICFs/MR, whose clients

range from youngsters to the elderly, often serve as a true home, with staff becoming a second and sometimes sole family for some residents.

Emphasis on Client/Resident Outcomes

A notable distinction between the ICF/MR programs and the HCB waiver program that supports group homes is the level of oversight from federal and state agencies, which enforce regulations through a process known as “surveying.” Conducted annually, or as needed, a team of surveyors examines staff performance in achieving individual client goals and focus on the four core pillars of ICF/MR service:

1. Active Treatment

Active treatment is the cornerstone of the ICF/MR program. This treatment involves a team approach to teaching residents instrumental skills and socially responsible behaviors so that individuals can live a meaningful, happy and productive life. This approach helps individuals acquire the skills necessary to gain maximum independence, to maintain optimal functioning, or to prevent regression. Major components of an active treatment program include:

A) Admission and Assessment: Facilities conduct a pre-admission evaluation, which includes background information and assessments of the individual’s functional, developmental, behavioral, social, health and nutritional status. Within 30 days of admission, the facility’s interdisciplinary team performs a thorough assessment to supplement the pre-admission evaluation. The assessment primarily identifies a client’s:

- Strengths and developmental and behavioral management needs;
- Condition, disabilities, and their causes;
- Need for services and, as applicable, vocational skills.

B) Individualized Plan and Review: Clients and their families or representatives, along with the interdisciplinary team, develop an individualized plan that identifies goals. For example, goals can seek to improve or avoid loss of a particular skill or teach a person a new skill, such as, to manage their own bank account or bathe themselves. To be successful, and to enhance the client’s self-esteem, active treatment programs must be continuous and consistent. The individualized plan is reviewed at least annually and at benchmarks for the client such as completion of objectives or new interests arise. When appropriate, staff will develop a comprehensive discharge plan that assists clients in adjusting to a new living arrangement.

2. Client Rights

ICFs/MR promote the exercise of individual rights and rigorously uphold the rights of all clients, such as freedom from unnecessary drugs and physical restraints, freedom from abuse, and the provision of opportunities to participate in social, religious, and community activities. In essence, for many clients, ICF/MR staff act as frontline advocates ensuring and protecting client rights inside or outside the facility.

3. Client Behaviors and Facility Practice

Individual programs emphasize positive techniques to teach socially responsible behavior. However, facility practices are designed to protect the client and ensure that interventions to manage inappropriate behavior respect the safety, welfare, civil and human rights of every client.

4. Health Care Services

ICF/MR staff develops a medical care plan for clients who require one and physician services are accessible for those who need it. Other points include:

- Annual physical exams are provided.
- Staff and clients are trained in health and hygiene methods.
- Dental and pharmacy services plus systems for monitoring drug administration are arranged by the facility.

There is more to the survey process but these are its most client-centered components. Surveyors also inspect for compliance with life/safety codes, building cleanliness, etc.

Client Profiles

The following are typical examples of how the ICF/MR setting serves the individual.

Rick, 34 years of age. Diagnosis: *Seizure disorder requiring continuous medical supervision. Severe visual impairment.*

Interdisciplinary Team Recommendations:

- Training in mobility skills;
- Training in employment skills;
- Application of special techniques to compensate for impaired vision; and,
- Supervision, support, and guidance by team including house manager, direct care professionals, RNs, and qualified mental retardation professionals.

Result: Part-time employment in landscaping and house maintenance.

Sharon, 28 years of age. Diagnosis: *Severe tongue and chewing disorder, emaciation.*

Interdisciplinary Team Recommendations:

- Develop specific feeding techniques;
- Personalize meal plans and eating schedules; and,
- Address food allergies;

Result: Dramatic improvement in intake of healthy foods. Weight increased from 67 to 84 pounds. food allergies neutralized.

Geraldine, 58 years of age. Diagnosis: *Severe mental retardation, schizophrenia, depression, eating disorder (tube fed), non-verbal, withdrawn.*

Interdisciplinary Team Recommendations:

- Psychiatric evaluation and medication prescribed;
- Reality orientation, small group activities;
- Close monitoring and adjustments of food intake; and,
- Discovered Geraldine's love for music, purchased tape player and Elvis tapes.

Result: Weighed 83 pounds upon admission, now weighs 128 pounds. No longer requires tube feedings and eats soft foods rather than liquid. Speaks, attends a day placement seniors program five days per week.

Facility Profile

The following is a true story though names were changed or removed.

New home, new hope. A new community provides independence and care for the developmentally disabled.

For 49-year-old Hugh—who loves fishing and baseball but sometimes throws a temper tantrum when asked to eat his vegetables—being able to live at the new Residence by the lake is a triumph.

It almost was not so. Twelve years ago, the County Board voted to phase out the institution that had been home to those with profound developmental disabilities, including mental retardation, since about 1955.

The action followed the national trend to de-institutionalize disabled people to smaller group homes throughout the community.

However, a group of parents and others spoke up, and the County Board listened. Today, advocates celebrate a new \$5 million town-home community for people with profound developmental disabilities, mental retardation and complicated medical and behavioral problems.

The three institutional buildings were replaced by eight stand-alone town homes on the bank of the lake.

Staffing

ICFs/MR, operated by both private and public entities, provide employee training to ensure that staff performs their duties effectively. Staff training continues throughout the year, and includes topics such as: infection control; detection of abuse and neglect; client rights; and disaster preparedness.

Direct care staffing is based on client age and level of disability. The composition of the MR/DD resident population impacts staffing levels since, overall, MR/DD residents require fewer clinical (medical/nursing) interventions and more counselor-type supervision, than, say, nursing facilities. The demand for and availability of direct care staff is different for ICFs/MR than in other settings that require more intense clinical resources. The lower average acuity and greater independence of their resident populations may make them more attractive to prospective employees.

Compared to ICFs/MR community residences, HCB “group homes” do not receive extensive federal and state monitoring and are not required to provide the rigorous attention to individual training and support programs available in the ICFs/MR setting.

HCB and Group Homes

In 1981, the federal government established the home and community-based (HCB) program, which serves persons--children or adults--with physical or developmental disabilities, mental retardation, mental illness or the elderly. States can make HCB programs available to persons who are eligible for nursing facilities, ICFs/MR or hospitals under Medicaid; this provides a mechanism for qualified individuals to be cared for in their homes or at group homes in the community, while still receiving Medicaid payments. This “waiver” of Medicaid rules allow clients greater choice in living arrangements.

Like ICFs/MR, HCB programs are optional benefits of a state’s Medicaid program. States must apply to the federal government for a “waiver” of certain statutory requirements of the Medicaid program to offer HCB programs. When a waiver is granted a state may cover, at its discretion, a wide variety of non-medical and social services and supports that allow people to remain at home or in the community, including personal care, homemaker assistance, care in alternative residential settings like group homes, adult day care, adult foster care and other services. Again, states have discretion in what services to offer. To determine eligibility, case managers screen for Medicaid eligibility and identify the appropriate level of services and supports. They customize care plans based on the person’s needs, preferences and availability of services.

An HCB program may provide these seven services:

1. Case management
2. Homemaker
3. Home health aide services
4. Personal care services
5. Adult day care
6. Habilitation
7. Respite care

State governments may offer other, non- medical services, such as transportation, in-home support services, special communication services, minor home modifications and adult day care subject to approval. Medicaid does not pay for room and board.

ADA and the Olmstead Decision

People with mental retardation or developmental disabilities are covered by the Americans with Disabilities Act of 1990 (ADA) though there are no specific provisions aimed at these individuals. The ADA bans discrimination based on disability and gives people civil rights protections based on race, sex, national origin and religion. The ADA guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation and government services.

An outgrowth of the ADA was the U.S. Supreme Court decision in June 1999, called *Olmstead v. L.C.* This lawsuit, along with the ADA, has implications for ICFs/MR and HCB group homes. The Court’s decision in *Olmstead* interpreted the ADA to mean that states could not require persons with disabilities to remain inappropriately institutionalized in order to receive health care services. However, there is no standardized, national program for Olmstead implementation as each state defines how it will address the requirements of the Olmstead decision.

The Supreme Court also stated that a state’s responsibility to provide health care in the community was “not boundless,” that the placement in the community had to be appropriate and desired by the individual

being placed. This decision has accelerated efforts to place disabled individuals in HCB programs and has created more interest in community settings for people needing MR/DD services.

(NOTE: *This is not a comprehensive review of the ADA or the Olmstead decision.*)

The Key is Choice

ICFs/MR, group homes and home care each have advantages, and it is up to the client, family or legal representative to decide which setting matches the best interest and capabilities of the client in the most integrated, least restrictive, and safe setting. All three choices are meant to provide a person with independence and dignity, while retaining ties to family and friends and being a part of the community and productive to the greatest extent possible.

How You Speak Matters

Another important aspect in understanding the MR/DD community is that language matters. Some people may think suggestions about appropriate terminology is an overdose of political correctness. Others see it as adjusting how we speak and write as a way to overcome stereotypes and to put the person out front of their disability. Following are some suggestions you may find helpful:

- ✓ **Put people first.** Use phrases like “a woman with arthritis,” “persons with disabilities,” etc. Avoid featuring the disability and making that the object of the phrase, such as, “the mentally retarded,” “crippled people,” and so on. Do not lead off with the disability.
- ✓ **Avoid sensationalizing a disability.** Use phrases like “person who has AIDS” or “man who has downs syndrome.” Avoid words like “crippled with,” “afflicted with,” “victim of,” etc.
- ✓ **Avoid Generic Labels.** This is implicit in the previous paragraphs. Use phrases like “people who are blind,” or “a person with mental retardation.” “The retarded,” “the deaf” are phrases that lump people into one stereotype and de-personalizes the individuality of the person.
- ✓ Two other points to remember: *emphasize abilities*; and, *show/think interaction*.

Excerpted from The Arc of the United States, “Guidelines For Reporting and Writing About People with Disabilities,” The Arc of the United States, online at www.thearc.org/misc/writingguides.htm

**For more information contact the
American Health Care Association (AHCA) at 202-842-4444 or
write to AHCA, 1201 L St. NW, Washington D.C., 20005**

Produced under the guidance of the MR/DD Residential Services Subcommittee.

Guide to MR/DD Residential Services

FAST FACTS

A facility is considered an “institution” by the federal government if it has 4 or more beds.

About 12% of children, ages 5-17 (6.1 million)¹, have difficulty performing one or more everyday activities related to learning, communication, mobility and self-care. About 0.9% of these children (459,000)¹ have difficulty with self-care and are likely to need long term care assistance. Boys are almost twice as likely to have difficulty performing everyday activities than girls are¹.

2001 Facts:

<u>Number of individuals residing in nursing homes:</u>	1.45 million ²
<u>Patients with MR in Nursing Homes:</u>	41,338 (2.84%) ²
<u>Number of Residents in MRDD facilities:</u>	105,380 ²
<u>ICFs/MRDD Facilities:</u>	6,486 ²
<u>ICFs/MRDD Total Beds:</u>	124,748 ²

Age Distribution for Persons with MR and/or DD Population³

- Under age 17 59%
- Age 17-64 38%
- Age 65+ 03%

2001 Selected Client Characteristics for ICFs/MRDD²

Client characteristics are not mutually exclusive.

<i>Characteristics</i>	<i>Number</i>	<i>Percent</i>
Age:		
Under 22	9,013	8.6%
22-45	54,461	51.7%
46-65	35,018	33.2%
66+	6,888	6.5%
Mild MR	13,858	13.2%
Moderate MR	16,883	16.0%
Severe MR	23,251	22.1%
Profound MR	49,439	46.9%
Autism	7,603	7.2%
Cerebral Palsy	21,606	31.6%
Epilepsy Controlled	33,258	31.6%
Epilepsy Uncontrolled	8,344	7.9%
Speech/Language Impairment	59,339	56.3%
Hearing Impaired	13,406	12.7%
Visual Impaired	32,612	30.9%
Drugs to control Behavior	41,269	39.2%
Physical Restraints	8,852	8.4%
Off-campus Day Program	51,749	49.1%

Distribution of Persons with MR and/or DD in Residence Size⁴

There has been a dramatic decline in the number of children with MR/DD who receive care in large institutions (16 or more beds) and a shift toward care in smaller residences.

	<u>1-6 Residents</u>	<u>7-15 Residents</u>	<u>16+ Residents</u>
<u>1987</u>	27.4%	19.0%	53.6%
<u>1998</u>	58.8%	15.7%	25.6%

Total Residents: 1987--255,637; 1998--344,162.

The Medicaid program is the most important program for people with mental retardation and/or developmental disabilities.

Medicaid Funding for Home and Community-Based (HCB) Services⁵

Historically, Medicaid long term care expenditures have financed services delivered in nursing homes, ICFs/MR and other institutions, but the proportion of spending directed to home and community-based care has increased steadily over the past decade. Medicaid spending on home and community-based services was about \$18 billion (27%) of the \$68 billion spent on long term care in fiscal year 2000. The primary means by which states provide home and community-based services is through an optional approach called home and community based services waivers. States must apply to the federal government for these waivers.

HCB Waivers/Medicaid Spending by Group⁶

- MR and/or DD 76.7%
- Aged and Disabled 21.3%
- Other 2.0%

Trends in Medicaid LTC Spending for Institutional and HCB Care, 1990-2001⁷

	Total Spending <u>FY 1990</u>	Total Spending <u>FY 2001</u>
HCB Care	\$ 3.9 Billion	\$22.7 Billion
Institutional Care (NFs & ICFs/MR)	<u>\$25.6 Billion</u>	<u>\$54.0 Billion</u>
Totals:	\$29.5B	\$76.7B

2001 Medicaid Spending for HCB Services⁷

- Home Health \$ 2.6B
- Personal Care \$ 5.3B
- HCB Waivers \$14.9B

2001 Medicaid Spending for Institutional Care⁷

- Nursing Facilities \$43.4B
- ICFs/MRDD *private* \$ 6.5B
- ICFs/MRDD *public* \$ 4.1B

The proportion of Medicaid long term care spending devoted to HCB services varies widely among states. For example, in 2001, 11 states devoted 40% or more of Medicaid long term care expenditures to community-based care; 30 states devoted 20% to 39% and 9 states and the District of Columbia devoted less than 20%.⁸

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1. America's Children: Key National Indicator of Well-Being, Federal Interagency Forum on Child and Family Statistics, 1999 as reported in "Long-Term Care Chart Book: Persons Served, Payors and Spending," The Urban Institute, May 5, 2000.
 2. OSCAR-MRDD 10/2002 (HSRE/KJD)
 3. S.A. Larson and L. Anderson, Excerpts from an Analysis of the 1994 and 1995 NHIS-DS, Research and Training Center on Community Living, University of Minnesota, 2000 as reported in "Long-Term Care Chart Book: Persons Served, Payors and Spending," P. 30, The Urban Institute, May 5, 2000.
 4. R.Prouty et al., Residential Services for Persons with Developmental Disabilities: Status and Trends through 1998, Institute on Community Integration, University of Minnesota, May 1999 as reported in "Long-Term Care Chart Book: Persons Served, Payors and Spending," The Urban Institute, May 5, 2000.
 5. HHS, HCFA, Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, 2001, as reported in "Long Term Care: Implications of Supreme Court's Olmstead Decision Are Still Unfolding," Testimony Submitted to the Senate Special Committee on Aging, September 24, 2001.
 6. Harrington et al. 1915 © Medicaid Home and Community Based Waiver Participants, Services and Expenditures, 1992-1997 as reported in "Long-Term Care Chart Book: Persons Served, Payors and Spending, The Urban Institute, May 5, 2000.
 7. MEDSTAT Group, from HCFA Form 64 Data.
 8. CMS Form 64 (HSRE/KJD)