

# HOSPICE IN THE ICF/ID

# An Aging America

The U.S. Census Bureau<sup>1</sup> calculated the 2010 population at 308,745,538. Of that, people age 50 and over comprise 24% with 17 million Americans being between the ages of 75 and 85. By 2050 that number is estimated to reach 30 million, according to the National Institute on Aging.<sup>2</sup>

# An Aging America

The "graying" of the American population also includes adults with developmental disabilities. While the average life expectancy for individuals with developmental disabilities was 19 in the 1930's, the age rose to 66 by 1993 (*Janicki, Dalton, Henderson & Davidson, 1999*).<sup>3</sup>

# An Aging America

This creates new issues for individuals residing in ICFs/ID, related to death and dying. The need for Hospice services in the ICF/ID setting is occurring more frequently than it has in the past.

# WHAT IS HOSPICE?

The goal of Hospice is to promote comfort for individuals who are approaching the end of their lives.

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Individuals qualify for hospice if their physician determines they have a condition that, with normal progression, will lead to death within 6 months.

Hospice care may continue for an indefinite length of time.

# WHAT IS HOSPICE?

Hospice care treats pain and disease symptoms so the individual can focus on what is important to them during their remaining time.

# WHAT IS HOSPICE?

Hospice provides grief counseling to individuals, caregivers, and family members during, as well as after, the dying process.

# Can Hospice work in an ICF/ID setting?

There is no requirement to transfer an individual to another health facility with a higher level of nursing care.

Individuals who live in an ICF/ID have the option to continue to reside in the ICF/ID and receive hospice services as long as their care needs are met and are consistent with their wishes or best interest.

# When Hospice and ICF/ID Work Together

A signed agreement between the facility and a hospice of the individual's choosing, must be in place and education of all persons, including the individual and family members, should occur well before services are needed or initiated.

# When Hospice and ICF/ID Work Together

The ICF/ID and the Hospice should share common philosophical values in end-of-life care and the active treatment concept of maintaining function to the maximum extent possible in the face of a deteriorating condition.

# When Hospice and ICF/ID Work Together

All staff should understand and respect that there are two sets of Federal regulations with which both care teams must comply.<sup>4,5</sup>

# When Hospice and ICF/ID Work Together

Each of the providers should orient the other to its requirements and should provide education to staff members.

# When Hospice and ICF/ID Work Together

Both Hospice and ICF/ID have an Interdisciplinary Team (IDT), Plan of Care (POC), and Patient Rights with many similarities and some differences.

# When Hospice and ICF/ID Work Together

Coordination of care and mutual expectations are paramount.

The ICF/ID as well as the Hospice provider must open lines of communication, centering on the individual's needs.

# When Hospice and ICF/ID Work Together

A coordinated plan of care must identify all services necessary to meet the physical, medical, psychosocial, and spiritual needs of the individual.

This plan must identify who will be responsible for providing each of these services.

# When Hospice and ICF/ID Work Together

The coordinated plan of care describes the responsibilities of each entity for the assessment and management of pain and comfort.

The plan must include procedures to assure the individual receives timely medications and treatments for optimum pain relief.

# When Hospice and ICF/ID Work Together

The ICF/ID facility staff continue to function as caregivers, family, and members of the treatment team.

# ICF/ID Regulations<sup>4</sup> to consider:

W192 – For staff who work with clients, training must focus on skills and competencies directed towards clients' health needs.

# What does this mean to me?

Hospice and the ICF/ID must provide ongoing training to staff about hospice philosophy, and the implementation of the individual's Plans of Care.

# ICF/ID Regulations to consider:

W194 – Staff must be able to demonstrate the skills and techniques necessary to implement the frequently changing IPP.

# ICF/ID Regulations to consider:

W196 – Each client must receive a continuous active treatment program which includes...the prevention or deceleration of regression or loss of current optimal functional skills.

# What does this mean to me?

Active treatment must go on, but will change based on needs identified in the IPP.

If behaviors are present, they will continue but interventions will change based on needs identified in the IPP.

# ICF/ID Regulations to consider:

W253 - W254:

Significant events that affect the individual's IPP and that contribute to an understanding of their level of functioning must be documented.

# What does this mean to me?

The Comprehensive Functional Assessment (CFA) and the Individual Program Plan (IPP) must be revised and updated when an individual starts hospice, and as their needs change.

# ICF/ID Regulations to consider:

W332 – Nursing must be involved in the development, review, and update of the IPP.

What does this mean to me?

Nursing from both Hospice and the ICF/ID should be members of the IDT in the IPP process as well as in the development of any medical care plan.

# ICF/ID Regulations to consider:

W340 – Nursing responsibilities include the ongoing training of ICF/ID staff regarding individual's health care needs.

# What does this mean to me?

Both Hospice and ICF/ID nursing should be involved in staff training having to do with the physical care of an individual receiving hospice services.

# ICF/ID Regulations to consider:

W367 – W386 may be affected by the presence of controlled medications that are not usually found in the facility, such as morphine.

# What does this mean to me?

The presence of controlled substances increases with hospice care. ICF/ID processes concerning medication storage, inventory, handling, and persons qualified to access and administer such medications should be closely monitored.

# ICF/ID Regulations to consider:

W422 – The ICF/ID must provide enough space in the individual's bedroom to permit the use of wheelchairs, walkers, and other adaptive equipment the individual might require.

# What does this mean to me?

Hospice services will likely include the placement of a hospital bed, wheelchair, commode, and other medical equipment. Living and sleeping areas may need to be altered to accommodate this equipment.

# IN SUMMARY

The ICF/ID is home, both emotionally and physically, to many people.

With understanding and coordination, it is possible to successfully provide for their right to complete their life at home.

# References

<sup>1</sup> United States Census Bureau. (2010). Retrieved from <http://www.census.gov/prod/cen2010/briefs/c2010br-09.pdf>

<sup>2</sup> Retrieved from <http://www.nia.nih.gov/newsroom/2012/08/federal-report-details-health-economic-status-older-americans>

<sup>3</sup> Janicki, M.P., Dalton, A.J., Henderson, C.M., & Davidson, P.W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation*, 21, 284-294.

<sup>4</sup> *State Operations Manual Appendix J - Guidance to Surveyors: Intermediate Care Facilities for Persons With Mental Retardation*. Retrieved from [http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap\\_j\\_intermcare.pdf](http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap_j_intermcare.pdf)

<sup>5</sup> *State Operations Manual Appendix M - Guidance to Surveyors: Hospice*. (Rev.69, 12-15-10). Retrieved from [http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap\\_m\\_hospice.pdf](http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap_m_hospice.pdf)