Aging and Developmental Disabilities

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Module IV: Transitions and Social Adjustment
  Unit IX: Informal Support Systems .................................................................96
  Unit X: Aging and Retirement ................................................................. 105
  Unit XI: Death and Dying ................................................................. 113
  Unit XII: Planning for the Future ................................................................. 128

Module V: Issues in Service Coordination
  Unit XIII: Case Management ................................................................. 134
  Unit XIV: Development Disabilities Services in North Dakota ................................................................. 145
  Unit XV: Aging Services in North Dakota ................................................................. 150
  Unit XVI: Integrating Older Persons with Developmental Disabilities into Community-Based Activities ................................................................. 160

Feedback Answer Key ..................................................................................175
MODULE IV: TRANSITIONS AND
SOCIAL ADJUSTMENT

UNIT IX: INFORMAL SUPPORT SYSTEMS

OBJECTIVES: After completing this unit, staff members should be able to:

Describe what constitutes informal support systems for elderly as well as elderly individuals with developmental disabilities.

Identify strategies to increase social support and friendship networks for elderly individuals with developmental disabilities.

Describe the negative effects of relocation and identify strategies to minimize these effects where relocation is necessary.

INTRODUCTION

In our society, it is the informal support network, primarily the family, that provides most services for elderly persons. An individual's social support system is all of the people relied upon to meet one's social, psychological, and physical needs. Although some support is provided through formal agencies or institutions, most of what we generally refer to as social support arises from and through interpersonal relationships.

Relationships are reciprocal connections between people that are based in social roles such as spouse, mate, parent, child, sibling, relative, friend, or neighbor. Relationships are probably the most important aspect of our lives. Life, without close, supportive family and friends, can be very lonely. That loneliness can be as serious a threat to emotional and physical health as any diagnosed disease. In fact, it was found that individuals with few or weak social ties were twice as likely to die at any age than those with strong ties (House, Umberson, & Landis, 1988).

Family. The key supportive relationship of later life often is the spousal or intimate partner relationship. In fact, more than one-half of all elderly in the United States are married and are living together in independent households. Sexual intimacy remains an integral part of couple relationships in later life. For many elderly, especially the widowed, relationships with adult children are extremely significant. Many studies present a generally positive picture of parent/child relationships in the later years. Many adult children continue to live in close proximity to their parents.

Statistics indicate that 75% of all older people are grandparents. Generally, ties between grandparents and grandchildren tend to be strongest when the grandchildren are young and interaction is greatest during this period. Teenagers tend, generally, to shy away from relationships with their grandparents.
Most people become grandparents in their mid or late forties, and by the time individuals reach the age 65, it is fairly uncommon to have very young grandchildren. About 40% of older people are great-grandparents. This involves older individuals in relationships with very young children.

About 80% of older people have living brothers and sisters. Some studies indicate that sibling bonds may have the greatest significance for the elderly person who has never married.

**Friendships.** Friends are persons with whom older individuals have an intense and continuous relationship. Most older adults social network includes friends and acquaintances from their former workplace, their neighborhood, and various church groups, civic organizations, and other clubs or community activities (i.e. bowling team, senior center, Lions, etc.) They are the source of emotional support and companionship.

### INFORMAL SUPPORTS FOR THE ELDERLY INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

The fact that individuals with mental retardation seldom marry significantly reduces sources of social support in old age. The informal support networks of adults with mental retardation who live at home are composed primarily of other family members, particularly parents and siblings (Krauss, Seltzer, & Goodman, 1992). Although some studies portray siblings of persons with mental retardation as affected negatively by their experiences, Krauss, Seltzer, Gordon, and Friedman (1996), found that adults with mental retardation who lived with their parents had continuing relationships with their brothers and sisters. Fully 30% of the adult siblings said that they spoke to their brother or sister with mental retardation on the phone at least weekly, and 41% said they visited at least weekly.

The informal support networks of adults with mental retardation who live away from their families differ markedly from those of persons who live in family settings. Krauss and Erickson (1988), noted a comparatively small presence of family members within the networks of adults who live away from their families. Seltzer (1985) reported that no more than one-third of the persons with mental retardation living in public and private residential settings have contact with siblings in later life.

Individuals who are separated from or have outlived their families, often become dependent on the service system for social support. Researchers (Krauss & Erickson, 1988; Kennedy, Horner, & Newton 1990) have found that paid staff constitute the largest proportion of network members of adults who live in nonfamily settings. Amado, Conklin, & Wells (1990) describe the social network of this population by saying,

"Although individuals with disabilities are living in their communities and participating in community activities, they often do not have the opportunities to build the kinds of relationships that the rest of us take for granted. Too often persons with disabilities have no real best friend, or the relationships are limited to their immediate family, human service staff, and other people with disabilities."

97
RELOCATION OF ELDERLY PERSONS WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES

During the past several decades, large numbers of individuals with mental retardation/developmental disabilities have returned to a variety of community based facilities after living for many years in state institutions. After moving to a new community-based settings, many have been relocated once or twice again. Although moving can be difficult for older individuals with developmental disabilities, the long term advantages for individuals who move to superior environments should not be ignored. When older individuals with developmental disabilities move, several issues should be kept in mind:

(a) Habilitative Services: Older individuals with mental retardation/developmental disabilities usually receive fewer habilitative services and less staff attention than do younger individuals. When relocation occurs, every effort should be made to improve services and staff attention.

(b) Preparation for the Move: The negative consequences of relocation can also be lessened by allowing the individual to participate in the decision making process, to visit the new site prior to the move, and to participate in pre-move preparatory counseling. Research findings indicate that involving individuals in making decisions about the move makes for better adjustment to the change. Voluntary moves are more likely to result in improved individual well-being.

(c) Intact Support Networks: To most of us, stressful events are cushioned by the presence and support of close friends and family. Earlier we discussed the importance of support networks for older persons. According to Heller (1985), there is evidence to suggest that peer relationships are particularly meaningful for older persons with mental retardation/developmental disabilities. These relationships may have begun years ago in institutional settings. Adaptations to new environments may be facilitated when individuals move to a new location along with friends.

According to Lawton (1980), the best environment for any older person is one that challenges that person to achieve a performance level. Without this challenge, the older individual could fall into a comfortable pattern of maintenance with the risk of so little stimulation that boredom, apathy, and finally, the anxiety of stimulation deprivation could occur.

MAINTAINING AND INCREASING SOCIAL AND FRIENDSHIP NETWORKS

Retaining established friendships is important to elderly individuals. However, as individuals grow older, small and constricted friendship networks are likely to decline even further. Research findings indicate that there are fewer social networks among older individuals than among their younger counterparts. In addition, new friendships are more difficult to make. This is a stage of life, where life long friends are tracked and often
rediscovered among the elderly in general. It would seem important, then, that old work
associates stay in touch and friendships made in state habilitation centers and/or
community placement earlier in life be nurtured and maintained.

This is also the time when new associations and friendships may be sought out among the
most "sociable" of elders. Following our theme of looking to the gerontological literature for
hints regarding possible "best practices" among the elderly with developmental disabilities,
the use of generic services to widen social networks may be a route for the socially
engaged and socially skilled individual. The local senior center and nutrition site, other
community activities such as trips, concerts, and additional senior programs such as adult
day care centers may all provide social support.

**Normalized Settings as a Source of Status and Social Support**

Most communities offer many opportunities for interesting, enjoyable, and productive activities for older persons. Some activities will be better choices than others for a specific individual who seems ready for new experiences in the community. Successful inclusion hinges upon matching the individual's abilities, interests, and needs to compatible programs. Good matches are based on assessments of both the individual and the community settings.

Even though the local senior center may offer similar games, crafts, and exercises often pursued in segregated programs for individuals with developmental disabilities, the fact that the individual chooses to be in a normalized setting with age peers is a triumph in itself. This is especially the case when the individual with disabilities is accepted and integrated into the social networks of nondisabled peers. Although this optimistic scenario is not always fulfilled, when it is accomplished research evidence suggests tremendous benefits for individuals with developmental disabilities (Kultgen, Rinck, Calkins & Intaglia, 1986).

**Steps for Supporting Friendships**

Relationships range in closeness from casual acquaintances to intimate friendships. Looking at our own friendships, we know that we have many acquaintances, but few become close friends. We also know that many of our friendships have taken a long time to develop.

Staff cannot make people be friends with each other. Instead, the agency's efforts should be directed at maximizing the opportunities for people with disabilities to get to know others, and maximizing the opportunities for others to get to know the individual with disabilities. We must make these opportunities happen on as individualized a basis as possible. John must be known as John, not as "one of those people who live in that group home." When maximizing the numbers and depth of potential acquaintances and friends, maximizing the opportunities and continuing to support those opportunities over time, the "click" of real friendship will have the best chance to happen.
Amado (1990) identified the following steps for human service agencies who wish to support a person with disabilities to widen his or her circle of relationships and develop deeper friendships:

- **Discover the person’s interests, gifts, and capacities.** This is not an assessment but requires looking at the individual in a different light, look for strengths rather than weaknesses.

- **Create a Vision.** What kinds of relationships does the person want? Is there anything about existing relationships that the person would like to see change?

- **Use Connecting Strategies.**

  2) **Focus on Opportunities for Relationships rather than on activities.** Going to a movie, bowling, to the mall might be activities but offer little chance to meet and get to know people. However, one individual accompanied by a staff person, if necessary, could go to a neighborhood cafe on a frequent basis. If he or she repeatedly went at the same time that the “regulars” were there for their coffee break, there is a greater likelihood of results. The results may not be immediate friendships to last a lifetime, but instead a familiarity that may lead to relationship.

  2) **Look for Opportunities.** Friendship opportunities will present themselves - a neighbor who shares the individual’s interest in vegetable gardening, a church bulletin announcement recruiting volunteers for a fund-raising bazaar, a friend of a friend who shares the individual’s interest in photography, animals, or crafts.

  3) **Strengthen and Rekindle Existing Relationships.** Even if the individual’s family has not been very close, there may be a member who would welcome the chance to become more involved. Help the individual to maintain or reestablish contact with family members. Look for ways that the individual can be an active and contributing member of his or her family - sending cards (and gifts) for birthdays and holidays, keeping in touch by letter or phone, sending photos and keeping an album with family pictures, or inviting family members to visit.

  4) **Model How to Meet New People.** How do others go about meeting new people? Look in the yellow pages under clubs and organizations for people who share the person’s interests; watch the newspaper for announcements of events and activities of interest.

- **Present a very important person.** Strategies for making introductions are like setting up a blind date. When introducing the people to each other, try to make them as comfortable as possible. Do everything you can to make sure that the two people hit it off from the start.
Anyone can be introduced in a way that is both realistic and that emphasizes his or her best qualities. First describe the things about the person that others would like. ("He has a great sense of humor; he grew up on a farm; he wants to learn to cook; and he's a big sports fan.").

When introducing an individual with a disability to a community member, there is a delicate balance to be struck. It is essential to respect confidentiality and share only information that agency policy allows. Staff should provide enough information about the individual so that the new person knows what to expect or can respond to the individual's needs. However, they should avoid giving information that's not really useful and might damage the individual's image and future relationships.

It helps to have new people get to know each other around familiar faces before they spend time alone. It is important to set up the conditions as much as possible to ensure success. After the new friends have a chance to get to know each other and share activities while staff are present, the companion may need to know more about the specific needs of the individual and what to do if problems occur.

· Supporting and Nurturing Relationships and Real Friendship. Having opportunities to meet people is an important first step to developing meaningful, supportive relationships. However, it is just the first step. People need time together to get to know each other better and to share experiences. From there, friendships develop. Staff may need to assist the individual to call their new friend to extend invitations for activities and provide supports such as transportation.

· Teach the Individual Reciprocity. Few relationships can grow strong without reciprocity. Reciprocity means giving, receiving, sharing, cooperating and communicating. Too often, service providers and families unconsciously overlook the possibility that a person with disabilities has something to contribute. Helping the individual learn how to be a friend, may be the most important support we can provide. Service providers can help the individual learn about being a friend by modeling and talking about how to be a friend, and by encouraging the individual to reciprocate in his or her relationships with them and with others.

· Demonstrating How It's Done. One of the most effective ways to support people with disabilities in friendships is to demonstrate how it's done to others. People will learn how to relate to individuals with disabilities by watching staff. If staff speak in a patronizing tone, others will learn to do the same. If staff do everything for the person with disabilities, others will believe the person is dependent. If staff constantly treat the person with a disability as a "client," others will treat them as someone who is "different" rather than a member of the community. Service providers can demonstrate very powerfully to others how to successfully engage the person in conversation and involve them in activities.

· Help the Person Broaden Their Range of Interests. For some individuals with disabilities, limited experiences in the community have left them with very few areas
of interest. Sometimes because the person’s range of activities has been so narrow, or his or her life experiences so limited, one interest may have become almost and obsession or a “fetish.” The more interests a person has, the more activities he or she is likely to enjoy, and the more he or she is likely to have in common with other people.

Most of acquaintances don’t become close friends. When they do, when two people really do “click” as friends, there almost seems to be an element of “magic” involved. In supporting friendships for persons with disabilities, staff can’t ensure that element of magic. They can, however, create opportunities for individuals with disabilities to meet as many people as possible. Service providers and families can support the connections growing and can promote as many occasions for magic as possible.
References


FEEDBACK EXERCISE IX

1. Describe what constitutes an informal support system for elderly individuals as well as elderly individuals with developmental disabilities.

2. Relocation of older individuals with developmental disabilities, although sometimes necessary, could be detrimental to their lives. What should staff do to make the transfer as painless as possible?

3. List five steps agencies can adopt to support an individual with disabilities to widen his or her circle of relationships and develop deeper friendships.
UNIT X: AGING AND RETIREMENT

OBJECTIVES: After completing this unit, staff members should be able to:

List the five functions of work which could predict a successful retirement.

Understand the variation of opinions among professionals of what constitutes active programming and explain how an individual can retire under the mandate of active programming.

Explain the importance and describe the positive effects leisure activities may have on older individuals with developmental disabilities.

INTRODUCTION

It was not until the mid-thirties with the passage of the Social Security Act that anyone could without large savings even consider retirement. Since the establishment of Social Security, coverage has expanded from those in commerce and industry only to almost all but a small minority of the workforce.

The average length of retirement in 1900 was 1.2 years. In 1980 an average of 13.8 years was spent in retirement. In addition to social security, many retirees now receive private pension benefits along with other benefits such as Medicare, which cover a good share of medical expenses. In spite of all these benefits, retirees experience, on the average, a 50% reduction in income when they retire.

ADJUSTMENT TO RETIREMENT

In contrast to the negative attitudes toward retirement held earlier in the century (Foner & Schwab, 1981), most of today's adults view retirement as an earned right. For many it is anticipated as a new and exciting stage of development. Individuals are finally able to structure time and tasks to their own liking, to pursue interests long deferred and make choices constrained only by personal resources. This optimistic picture cannot, however, be true for everyone.

In general, the transition from work to retirement is not successful unless the following work functions are replaced. These functions include:

a. Work as a source of income.
b. Work as a way to structure time.
c. Work as a source of status.
d. Work as a source of social interaction and social support.
e. Work as a meaningful life activity.
For members of the general society, adjustment is related to income after retirement. In fact, retirees with the highest incomes and who feel financially secure are the ones most likely to be satisfied with retirement (Atchley, 1983). On the other hand, those individuals who are not financially secure may find their activities and aspirations severely limited in their retirement years. Additional sources of dissatisfaction may arise when the individual has depended on the job to structure his/her existence in terms of time and in terms of his/her most meaningful life activity. If the work role was the only role from which a person derived his/her status, as well as the only setting in which social support and social interactions had meaning, retirement most probably represents a dismal alternative.

RETIREMENT AND INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Unfortunately, these factors predicting dissatisfaction with retirement often apply to persons with developmental disabilities who have been in supported employment for much of their adult lives. The social and personal changes associated with retirement can be traumatic unless transitioning has occurred. The loss of income and change in friendships after leaving a workplace and becoming involved in a new settings can be difficult. Monies earned may be the only discretionary income for this group of older adults and may pose a major barrier to wanting to retire.

As a result, we need to respect the individual's wishes regarding retirement when an option to work or retire exists.

Such an option, may not be possible. The time may come when energy levels begin to decline and the decision is made for the individual by the employer. Currently, few individuals in their seventies, let alone late sixties, are still in supportive employment.

Many, are still in active programming that takes place outside the residential setting. However, daily attendance at recreational and/or developmental program sites may also be too much for failing energies. If staff are not available to provide adult day care in a residential setting, then slow paced leisure pursuits within the home are not available to the older person. If the individual does not have enough energy for daily out of the residence activities, they may be prematurely transferred to a nursing home.

RETIREMENT AND ACTIVE TREATMENT

Because of the mandate for active programming and the comparative unavailability of community residential programs that allow the individual to pursue retirement activities within the home setting, program options for older individuals need to be somewhat "creative" if retirement is to be an alternative. Although, some states are beginning to recognize the individual's right to retire from work skills training programs and employment programs, how much formal structured activity should be mandated (active treatment) may still be debated.

Active programming has been defined as objectively measurable interventions, based on individual need assessment, that have as their goal the promotion of growth and
improvements in health, skills, and habits required for independent living (Catapano, Levy, & Levy, 1985). If the reader is serving individuals residing in ICF/MR facilities, in programs funded by Medicaid, or in programs that have adopted Medicaid standards for active treatment, then retirement programming may be problematic. In a national study of programs serving elderly individuals with disabilities, the researchers found:

A need to "creatively circumvent" regulations that require six hours a day of active treatment unless the participant received a medically based waiver. The perceived need to circumvent the regulations was based on the declining motivation or capacity of an elder to continue his or her participation in a day program that was either viewed no longer appropriate (especially if the program was oriented toward vocational skill training) or as requiring more stamina and regularity of participation than the elder could sustain. For these persons, the need to allow for either flexibly scheduled participation in preexisting day programs primarily oriented toward recreational and leisure time pursuits was particularly acute. (Seltzer & Krauss, 1987)

What can be done under the circumstances described above? It is argued that age-appropriate recreation and leisure activities incorporated into day services for the elderly can fall within the category of active treatment programming. For other persons with developmental disabilities, programming that is directed at minimizing debilitation due to injury or illness may be more critical to their well being and quality of life than objectives that specify measurable growth and improvement (Catapano et al., 1985).

WHEN TO RETIRE?

It is recommended that individuals with developmental disabilities should have the same retirement options as the general population. If the individual is in a work setting, a prevocational program, an adult development program, and expresses a strong desire to remain in the setting, his/her wishes should be respected. It could well be that the present program is a source of social support ("this is where my friends are"), a source of status ("I make money here"), a meaningful life experience ("I have an important job"), and so forth.

However, at some point the focus of developmental training for adults with developmental disabilities should transition from active involvement in work to a meaningful retirement period (Cotton, 1994).

Several aspects of the person's life should be examined to identify how retirement would affect his/her quality of life.

- **Work assessment**: How well is the individual functioning in his/her current work position? Both the demands of the environment and the skills of the person should be assessed. The match between these two can provide information about the types of supports or interventions needed to assist the individual to remain employed or retire. Both teaching skills and changing the environment (e.g., assistive devices, task sequence) can help the person keep his/her job.
• **Choice.** What does the person want to do? Making a choice between working or retirement is frequently hard, even for people without disabilities. The older worker may not understand what retirement means. He or she may never have been exposed to the opportunities beyond their day program or employment setting. They may have a misconception about what retirement is. The following strategies may help the person decide whether to retire or not.

- The person may need to be shown choices. Consider visiting various places.
- Describe retirement so the person understands. Give examples of individuals who have retired, especially friends of the person who is considering retirement options.
- Have someone who has retired talk to the individual about their experiences.
- Allow the person to participate in a retirement program part-time while still working.

• **Finances.** How will retirement affect the individual’s financial situation? For some persons with developmental disabilities, finances are not a significant barrier to retirement. If the wages they earned prior to retirement were very low, they will not experience a drop in income at retirement. They also may reside in state-funded residential settings and receive Social Security Disability funding.

However, if the individual has been competitively employed, the reduction in their take-home pay may affect the ability of the older person to live independently. A detailed analysis of how the change in income would affect the individual’s lifestyle and options should be reviewed.

• **Social supports:** Will retirement affect the individual’s social support network? The social support networks of persons with developmental disabilities have been generally found to be narrow and limited, almost exclusively restricted to where they live and where they work. If retirement might bring about a decrease of social support, special attention should focus on developing relationships to fill the gap.

• **Recreation/leisure:** What additional activities could the person do in their “free time” if they retire? Those who retire will have more free time. They will be able to pursue activities that might not have been possible before.

• **Community inclusion:** How well is the person included in community activities; a physical presence or an active participant? The purpose of this assessment is threefold: (1) to identify the person’s level of community participation; (2) to identify where in the community the person is currently conducting activities, and (3) to identify where the person could be participating more in integrated activities.

108
Once all the assessments are complete, the time comes to assist the individual in choosing to retire or to continue working. If the older individual expresses the desire to leave the work setting, and/or is released by the employer against their wishes, or the job or alternative program is clearly detrimental to health and well-being, a retirement option should be pursued. Even if the person does not want to retire now, planning for that time should begin.

**TRANSITION TO RETIREMENT**

The individual should be presented with an orientation to available options. Helping them assess what was meaningful to them about the way in which they previously spent their day will help ensure that their needs will be met in the plans made for their retirement.

Cotton (1994) presents the following definition of retirement for aging persons with mental retardation: “Retirement is graduation to another stage in the development of the individual. It is not and cannot be synonymous with the term quitting. Retirement is a time, after the necessities are accomplished, to do what one wants to do; to explore new interests and friendships; and to have leisure time to engage in activities of the person’s own informed choosing.” He explains this definition as follows:

1) **After the necessities are accomplished.** It is imperative that the person maintain the activity of daily living skills that they have acquired as much as possible.

2) **To explore new interests and friendships.** The individual is encouraged to participate in activities and settings with which they are familiar, as well as new activities. The emphasis is on life-span development and those experiences available to other persons not diagnosed as mentally retarded. This will increase the likelihood of acquiring friends based upon common interests.

3) **Engage in activities of the person’s own informed choosing.** When the individual has had the opportunity to be involved in a wide array of options, they will be in a position to select how and where they will spend their leisure time. Our task is to ensure the options are broad and varied so that regardless of the skill level of the individual, they may truly be provided with choices enabling them to retire “to” something and not just quit.

**RETIREMENT AND LEISURE EDUCATION**

Leisure, as defined by early Greek philosophers (Fain, 1986), refers to pursuits that carry a moral imperative - an "ought," so to speak. Leisure, in the classical sense, is something one does to fulfill human potential. It becomes "an end in itself" and requires no further justification. Although it is hard to define just what it is, what it is not can be easily specified. Leisure is not an activity designed as a reward for work or, in the case of the nonemployed individual with developmental disabilities, for active programming well done. For the older adult with disabilities, leisure could mean any self-directed activity that helps
to make that adult "all that he can be."

When leisure is defined this way, pursuing a leisure activity becomes a developmental task and may entail the learning of new skills as well as maintaining previously learned skills. Can the older individual learn new skills? It should be noted, that although age 55 may mark the beginning of old age in some persons with developmental disabilities, cognitive deficits are not usually apparent until after the age of seventy. As a consequence, there is no reason to assume that older persons with mental retardation cannot continue to learn new skills. Declines in motor skills and impairments in vision and hearing may occur much earlier than seventy, however, and so proposed skill development should be sensitive to the limitations these possible losses can impose.

Cotton (1994) recommends that habilitative services for older individuals with mental retardation include an emphasis on leisure education.

"Leisure education is basically a program which has a primary focus on providing training for the individual in ways to effectively utilize their leisure time. It differs from recreation in that recreation is the way we choose to spend our time after we have considered all the options available to us. One of the gaps in the training endeavors for person with mental retardation is the lack of emphasis which has been placed upon leisure education. Traditionally, the emphasis has been on self-help skills, functional academics, activities of daily living, and vocational development. Time left after training in those areas was relegated to recreation. The majority of recreation has been staff or parent directed and too often based upon what was easily available or those things with which the provider was familiar and enjoyed doing."

Leisure education programs should be structured utilizing resources available in the community. The role of the staff in such a program is that of an instructor/facilitator. The broad areas of training could include the following:

- Graphic arts including photography as well as other visual arts
- Musical experiences-Vocal, instrumental, and creative movement
- Crafts
- Nature studies which would include cookouts and camping
- Community resource orientation and utilization (Library, Senior Center, YW/ YMCA, churches, restaurants, etc.)
- Athletic activities - both as an observer as well as a participant including involvement in such activities as Senior Games, etc.
- Culinary activities including hosting parties for friends
- Table games including such activities as card and board games, & puzzles
- Gardening including vegetable gardening as well as flower beds, and flower arranging.
- Exercise programs based upon the abilities and desires of the individual
- Introduction to computer technology and ways in which it can be both fun as well as educational
- Water activities including swimming, fishing, and boating.
- Hobbies including collections, crafts, etc.
Many of the above areas lend themselves to the individual being either a participant or an observer. All of these areas are flexible enough to meet the unique physical and cognitive abilities of the individual. The list of specific experiences within each of the areas is limited only by the creativity of the staff.

VOLUNTEER ENDEAVORS

In some cases leisure pursuits may mean the opportunity to fulfill the expressed desire to help someone else through volunteer activities. For others it may mean an opportunity to finally integrate into settings where the social stimulation from individuals without disabilities is offered. The later years should afford opportunities for self-fulfillment which may have been delayed by obligations to the role expectations of the middle years.

Cotton (1994) says that volunteer activities

"...enable the person who may have been viewed previously as less functional, than the majority of persons, to be more highly valued. Among the settings in which a person may volunteer are the Retired Senior Volunteer Program (RSVP), the Foster Grandparent Program (FGP), Senior Service through the local Area Agency on Aging, the American Association of Retired Persons (AARP), as well as service organizations such as the Red Cross or the Salvation Army. In most settings there are also many opportunities for involvement in informal voluntary endeavors. Other such opportunities would be with Head Start Programs, as well as programs of early intervention for persons with handicapping conditions. The latter settings would also provide opportunities for intergenerational activities which are conducive to growth and development in a mutually advantageous or interdependent fashion."

MAINTENANCE OF ACTIVITY OF DAILY LIVING SKILLS
AND ADJUSTMENT TO DECLINE

For many older individuals with failing eyesight and hearing and declines in motor skills and coordination, skill maintenance and adjustment to decline may be the important goals. It is critical to continue to provide the training and reinforcement which will allow those skills previously developed to be maintained. The kind of developmental skills advocated here are those that enhance quality of life and help meet developmental tasks of the life cycle, that is, the realization that one has become all that s/he can be.


FEEDBACK EXERCISE X

1. List the five functions of work which could predict successful retirement.

2. What is active treatment and how should it be applied to older individuals with developmental disabilities?

3. When should an individual with developmental disabilities retire?

4. Define leisure:

5. List five areas of training in leisure education that could be structured both within your agency setting and in your community.

6. What benefits can be obtained by the older adult with developmental disabilities through volunteer endeavors?
UNIT XI: DEATH AND DYING

OBJECTIVES: After completing this unit, staff members should be able to:

List and explain the four phases of mourning individuals experience as a result of death.

Describe Ross's stage theory on death and dying.

Explain misconceptions and provide facts about the ability of persons with mental retardation to understand death.

WHEN, WHY, AND WHERE DO PEOPLE DIE?

Life expectancy has increased by approximately 30 years since the turn of the century. The increase in life expectancy is called the "Mortality Revolution." The most important reason is advancements in public health including improvements in sanitation and the control of infectious diseases. Clean drinking water, preventing the spread of typhus, and immunization against contagious diseases has drastically reduced infant mortality. Tuberculosis, a leading cause of death, was eliminated from the list of the ten leading causes of death by 1977. However, even with improvements in public health, members of the lower socioeconomic status have a higher mortality rate than those further up the socioeconomic scale (Goldschneider, 1971). Presently the leading causes of death are heart disease, cancer, and cerebrovascular disease (stroke). Heart disease and stroke have been linked to increased levels of stress. According to research, in the early decades of this century most people died at home. Now most deaths occur in institutions. For the elderly person this means nursing homes or hospitals.

BEHAVIORAL AND ATTITUDINAL DIMENSIONS OF DEATH AND DYING

DEATH

Reactions to one's own death vary widely. Elizabeth Kubler-Ross's book On Death and Dying (1969) is by far the most well known work on the subject and will be briefly reviewed. Ross's stage theory of dying has obvious similarities to the grief process described earlier and represents the grief a person feels when faced with the prospect of the loss of his or her own life. Obviously, a stage theory is most applicable when one is faced with an extended terminal illness, yet most persons have at least a brief warning that death is imminent and can use that period to experience some of the growth implied in the age theory of death.

The following account borrows heavily from Russell Ward's (1984) succinct review of Kubler-Ross's work. It is Kubler-Ross's contention that the dying go through five reaction stages. These stages are as follows:

(1) Denial. According to Kubler-Ross, nearly all patients react to the news that
they are dying with initial denial. This is a healthy buffer allowing the patient to absorb the initial shock. But this denial may continue if others go along and are not open to dealing with the person’s fears and concerns. Most persons are eventually willing to talk about their dying, but have little opportunity to do so.

(2) **Anger.** This stage involves a "why me?" reaction and the anger may be displaced on staff or on family. When this happens, family and staff need to respect and understand these feelings.

(3) **Bargaining.** Here the patient may bargain (often with God) to live long enough to reach some deadline or to postpone death as a prize for good behavior. This may reflect a partially successfully "will to live." There is some evidence of an "anniversary reaction" where mortality rates are lower before special dates such as birthdays, holidays, and awaited reunions (Kalish, 1981). As examples, John Adams and Thomas Jefferson both died on the Fourth of July, a date of obvious significance to them both.

(4) **Depression.** This stage is an expression of grief over leaving life, as well as loved ones, behind. Here, as with anger, others must open the door for the expression of such feelings.

(5) **Acceptance.** Kubler-Ross maintains that acceptance of death is achieved only when the dying person is able or allowed to express earlier feelings such as anger and depression. This final stage is not a happy stage, but rather is almost void of any feelings. It is in the words of one of Kubler-Ross's patients, "the final rest before the long journey."

In addition, Kubler-Ross suggests that hope is an element that persists throughout the entire process. Hope allows the person to cope with the most difficult times. Always respect this hope (Barbera, T. V., Pitch, R. J., & Howell, M.C., & 1989).

The stages should not be interpreted as an inflexible sequence. The dying person may shift back and forth between stages (for example, denial and acceptance) or skip some of the stages entirely. There is no one way to die. The real importance of the work of Kubler-Ross is the emphasis she puts on allowing the dying to express their feelings, however difficult and uncomfortable this may be for us.

As indicated above, dying adults usually, but not always, welcome open awareness. Glasner and Strauss (1966) delineate four types of awareness:

- **Closed,** when the patient is not aware that his/her illness is terminal;
- **Suspected awareness,** where the patient becomes suspicious but doesn’t know for sure that death is imminent;
- **Mutual pretense,** where both the patient and attending hospital staff both know the patient’s condition but deny this to one another; and
Open awareness, where all concerned parties can address the reality of the patient's condition.

Whether or not to move to open awareness depends on several factors. Mutual pretense allows privacy to the patient, and for some dying persons this is of overwhelming importance. To others, an overwhelming need to express feelings and emotions makes an open context preferable. The caregiver needs to be sure s/he is responding to the patient's wishes rather than his or her own inclinations when choosing the awareness context to be used.

PREPARING FOR THE INEVITABILITY OF EVENTUAL DEATH

Thus far, we have been discussing responses to impending death. We will now consider the older person's reaction to the inevitability of eventual death. Let us assume that most people develop expectations in young adulthood of the identity they wish ultimately to achieve. That is, the developing individual has some notion of the roles and status s/he wishes to develop. When the expectations are fulfilled, i.e., "I did what I set out to do and I did it well," a positive self-concept results.

Victor Marshall (1975) studying the residents of a retirement community in Canada found that older persons who had fulfilled their perceived role obligations throughout their lives found the idea of death legitimate and appropriate. They expressed no particular desire to live to be 100, in fact, that idea held little appeal. An eighty year old woman, when asked how long she would like to live replied, "I feel I've lived my life, and I don't want to be a care to anybody. That's why I'm glad to be here [in Glen Brae, the retirement village]. No, I don't want to mourn when I go. I've had a good life. It's time" (Marshall, 1975).

In general, the residents of this community see death as an appropriate end to a life well lived. Fears they do have center around the dependency and pain that a long protracted death most certainly would involve. It should be noted that the positive attitudes of this group can be traced to a mutual socialization process where death is discussed, where norms develop about how to handle the deaths of fellow residents, and where an emphasis on caring about the living is paramount.

LIFE REVIEW

Marshall refers to the process wherein the individual evaluates his past history and comes to the conclusion that s/he fulfilled his or her obligations to the best of given abilities as the legitimation of biography. In the setting he researched, most people were able to do this. But this life review process does not always produce such positive results.
Robert Butler (1963) postulates the universal occurrence in older people of an inner experience or mental process of reviewing one’s life. The tendency toward reminiscence among older people attests to this process. Erik Erikson's notion of ego integrity -- the task of "getting it all together," of seeing one’s life as having been worthwhile -- echoes this theme. Butler calls our attention to the negative interpretation sometimes given to the tendency to review life: "often the older person is experienced as garrulous and living in the past, and the content and significance of his reminiscence are lost or devaluated." The emphasis, however, should be on the positive function of life review.

Life review successfully completed should lead to serenity and wisdom. According to Butler (1963), reflecting on the past does not, however, always lead to positive conclusions about past actions. The end result, he claims, may be terror and depression. Old conflicts may have never been successfully resolved, resulting in anxiety and deepened depression. In such cases, Butler suggests some form of psychotherapy. Through psychotherapy, the depressed and/or anxious older person may be helped toward the reorganization of personality. (Just how life review might be used in the therapeutic setting -- a number of techniques are currently in use -- is a subject beyond the scope of the present discussion).

**HOSPICE**

Assuming that the older person facing death has successfully reviewed his life, resolved conflicts, and integrated his experiences in such a way that serenity and a sense of wisdom are the result, then the person can conclude that his or her life has been an appropriate one. How can an appropriate death be assured? Reviewing Weisman's (1972) treatment of this theme, his underlying assumption seems to be that one should die the way one lived. For those who have realized their emotional and spiritual needs, who have been "in control" during their lifetime, then the way to die is with the same needs attended to and with the same sense of autonomy intact. The hospice movement is dedicated to these ideals. Therefore, hospice as a place and hospice as a concept to be practiced in the “home” setting, if one so chooses, provides an alternative to death in an institution designed to give care rather than as a place to die.

**MOURNING**

Mourning is a fact of life. Individuals mourn the loss of a child, a parent, a spouse, a friend, etc. The process of mourning can be divided into four phases. It must be noted that all persons do not experience all stages nor do they necessarily experience them in the order given.

*Phase one* involves the initial response to death, which is usually one of shock followed by denial. When death is anticipated, this shock response may occur when a person first receives the news of a hopeless diagnosis for a loved one.

It is during the *second phase* that the individual experiences grief in the sense of deep psychic pain. There may be a strong desire to recover the lost person. A "normal" reaction would include the realization that nothing can be done. A possibly
unhealthy reaction at this stage is indicated when the bereaved continues to fantasize about the dead person.

The third phase of mourning is marked by a more realistic recognition of loss and is characterized by what has been called the separation reaction. "The separation reaction involves disorganization and despair as the mourner realizes that the dead one is no longer externally present". (Huyck & Hoyer, 1982, p. 494). When the mourner comes face to face with loss, a variety of feelings can be experienced. Anxiety over the loss may reflect the very real dependency the survivor had on the deceased person. In the case of the frail elderly, the loss of a spouse may mean institutionalization for the survivor when the dependency was physical as well as emotional. Anger and guilt may also become manifest at this stage. Guilt may be based on the awareness that one could have done more for the deceased, but is more likely to be irrational in nature.

During the fourth phase of mourning, recovery begins. The survivor is able to integrate within his/her own identity the identity of the deceased. When the lost person is internalized, he or she cannot be lost. It is at this point that normalization of the survivor's life begins. She or he can look for other sources of love with the realization that, although the uniqueness of the deceased can never be replaced, other sources of support can be found.

Staff members need to remember that the grief process may be arrested and, as a result, the reality of the loss is never fully faced. Although this may be a protective mechanism utilized to avoid the severe psychic pain of separation, the results of repression may have serious consequences at a later point in life. Case histories exist where "grief work" has been put off for five to forty years after the death event. Extensive therapy may be needed to resolve the problems this denial has either caused or exacerbated. Among the problems associated with the repression of grief are severe depression, long-term apathy, illogical fears, and a continuing sense of unreality. Sometimes, there is the problem of aggravated physical illness and even death following bereavement.

**LOSSES EXPERIENCED BY INDIVIDUALS WITH DISABILITIES**

People with mental retardation develop attachments and experience loss, throughout their lives. Like other individuals they may experience the death of loved ones. Unlike others however, in addition to the emotional trauma connected to the loss of a beloved parent or relative, the individual may be losing his/her primary advocate and the person most able to help the person adapt to grief.

Unique experiences to people with mental retardation include long-term separations from their families as a result of institutionalization. Attachments with their care providers, who they later are separated from by a change in residence, or a change in staff employment may cause feelings of loss which the individual may need to grieve.

While the focus of this unit is on grieving and loss experiences related to death and dying, any life change can produce physical and psychological expression of grief. Even changes
that the observer may view as positive such as a move to a new apartment or a promotion at a job may be perceived as a loss, if the change involves leaving a situation that the person found familiar and comfortable. In addition to the inevitable stress associated with change, a sense of loss may predominate and promote actual grieving. Overbeck (1996) suggests that we define grief “as the emotional and behavioral reactions to a stressful event which is accompanied by a sense of significant loss.”

EMOTIONAL AND BEHAVIORAL CONSEQUENCES OF DEATH AND DYING FOR ADULT INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

There is no reason to suppose that persons with mental retardation will not suffer typical reactions to bereavement. In fact, they may have additional special difficulties. They are infrequently involved in counseling or preparation for impending death of a loved. Because of the nature of their disability, they may be denied many of the social, verbal, and sensory opportunities of realizing the death, which are available to other people. Usually they receive little or no assistance through the mourning process because professionals, caregivers, and others fail to recognize their need. These are individuals whose poor adaptive skills may make it difficult to cope with everyday stress, yet they are somehow expected to cope with the loss of a significant interpersonal relationship with little or no help. The inappropriate way in which services are organized and delivered for persons who require emergency placement after the loss of aging parents sometimes compounds losses faced by the person with a disability. (Oswin, 1985)

ERRONEOUS REASONS FOR NOT PROVIDING GRIEF COUNSELING

Grief counseling is frequently not part of the habilitation plans of individuals who are mentally retarded. Deutsch (1985) proposed that reasons for this lack of emphasis may include any combination of the following:

1) Care providers frequently feel inadequate or uncomfortable in dealing with the topic of death.

2) Many people believe that individuals with mental retardation do not understand the concept of death.

3) Some care providers believe that individuals with mental retardation are unable to develop attachments and therefore won’t experience grief. Others feel that people with mental retardation can and do form attachments. But, due to poor memory and time concepts, once the attachment figure is absent, the individual will “forget” the person.

4) Others recommend that, since many individuals with mental retardation may have limited coping skills, they should be spared any “unnecessary” stress.

5) There are those who believe that it would be easier for people who are mentally retarded to accept the loss of a loved one if that information were shared with them over a period of time.
All of these rationalizations make life easier for the care provider, but much more difficult for the individual with mental retardation.

**RATIONAL FOR DEATH AND DYING EDUCATION AND GRIEF COUNSELING FOR INDIVIDUALS WITH MENTAL RETARDATION**

Previous research tied comprehension of concepts of death and dying to developmental level. Individuals with mental retardation were thought to be unable to understand the concept of death because of their limited cognitive functioning. However, more recent research suggests that chronological age may serve as an index of experience in persons with mental retardation (Lipe-Goodson & Goebel, 1983). These more recent studies suggest, in part, that adults who have had experience with death, loss, funerals, spiritual/religious opportunities may accumulate knowledge beyond what older cognitive theories would suggest. Harper & Wadsworth (1993), in personal interviews with adults with moderate to severe mental retardation, noted that verbalized responses reflected a literal and reasonably accurate understanding of the finality of death.

Everyone has an idea on death at some conceptual level, even though some rarely make their perceptions known to others. Everyone understands death as a loss. Other responses reflect developmental progression: i.e. the belief that death is reversible is gradually replaced by the understanding that death is permanent and final. The challenge is to try to understand what the person who is mentally retarded does understand, how to “listen” to them as they express their understanding and feelings, and to communicate our empathy.

Research indicates that problems associated with denied and repressed grief in individuals with mental retardation are very similar to the problems experienced in the general population. Inadequate or incomplete mourning may have several consequences, including the denial of the reality of the loved one’s death, the idealization of the loved one, a decrease in self-esteem, and feelings of guilt. The individual may develop fantasies of an ongoing relationship or a reunion with the dead person. It is important to bear in mind that having a intellectual disability will not preclude anybody from the wide range of normal bereavement reactions, but will put them at risk of suffering additional problems.

Although limited, there are examples of programs to provide death and dying education and grief counseling for individuals with mental retardation in the literature. McDaniel (1989) reported a group counseling experience developed for adults with mental retardation who had friends and family members who had died in the recent past. Interviews were held prior to the group work to conduct social, medical and family history assessments. During group sessions, members discussed fears, feelings, and methods of coping with grief. Other topics included wills and preferences for funeral arrangements. As a whole, the group counseling was considered very successful.

Emerson (1977) investigated precipitating stress for individuals, who previously had shown few problems, who had suddenly, for no apparent reason, started presenting either verbal or physical aggression or extreme withdrawal. In 50% of the cases, there had been either the death or the loss of an individual close to the person preceding the onset of
symptoms. Therapy involved assisting the person to recognize that a loss has occurred, facilitating emotional release, and anticipating a period of grieving with accompanying changes in behavior.

Yanok & Beifus (1993) designed and used an experimental curriculum, with a sample of verbally expressive adults with mental retardation. Guided group discussions of experiences with death were used as a format for the experimental group. Following the field testing of the curriculum, a brief oral examination was administered. Total percentage of correct exam responses by experimental subjects (81.2%) was statistically greater than that of control group members (55.6%). Findings from this pilot study suggest that individuals with mental retardation have a need for and indeed can benefit from a formal program of death education and grief counseling.

DEATH EDUCATION

Duetsch (1985) discussed the need for death education/counseling for persons with mental retardation and suggested that education prior to death of loved one should be integrated into habilitation plans. Researchers who used the CALM (Yanok & Beifus, 1993) curriculum made the following recommendations for prospective curriculum developers in death education for individuals with mental retardation.

1. Community-based instructional approach should be implemented emphasizing experiential learning within the natural environment. Field trips to area funeral homes, cemeteries, and churches should be supplemented by guest presentations from morticians, physicians, and the clergy.

2. Community standards of conduct at funeral homes and cemeteries should also be taught.

3. The knowledge that death is a universal, irreversible, and inevitable outcome of the natural aging process should be conveyed to participants during each session. At the same time, they should be assisted in understanding that fatal injuries and incurable illnesses can suddenly shorten the life span.

4. The social permissibility of public displays of bereavement for a loved one should be conveyed to participants. They should be assured that indifference or relief also may be reasonable reactions to the death of a stranger or someone who has endured great pain while for many months or years.

5. Pertinent new vocabulary should be presented with particular emphasis on defining and discussing euphemisms for death (i.e. passing on, kicking the bucket).
6. A curriculum pertaining to death education may be more meaningful if taught on a weekly basis spanning several months, than if presented on successive days over a brief period of time. Throughout these weekly sessions, participants should be encouraged to speak freely about their own mortality as well as that of others.

Teaching strategies suggested include modeling by the instructor, viewing demonstration videos, and verbal instruction to facilitate the learning of socially acceptable responses to loss and mourning. Behavior rehearsal or role playing allow participants to practice public and private displays of grief, such as prayer or meditation, conduct at funeral services, and the conveying of condolences to the family. Following the rehearsal of these personal-social skills of bereavement, immediate feedback and reinforcement of appropriate behaviors should be provided.

The researchers also maintained that the goal of such a program may be conceptualized as controlled, incremental doses of distress that are intended to immunize students to the concept of death and hasten their recuperation from more severe cases of personal loss in the future. Professionals who see this as an important part of their role believe in the necessity of not only building individual’s independence through teaching practical survival skills, but in developing essential emotional strengths. (Moise, 1978).

**GRIEF COUNSELING**

Individuals should be encouraged to discuss the feelings which have arisen and to speak freely about the concept of death. Responses which encourage individuals to stifle their grief or to “be brave” should be avoided. Support, guidance and counseling may be necessary for some time following the death.

The Kennedy Aging Project of the Shriver Center suggests the following guidelines/procedures of assistance for staff when working with an individual with mental retardation who is experiencing a loss:

1) The individual does need to be told right away about a family member’s death. The only question should be who informs the person and how.

2) Encourage participation in family rituals for death.

3) Allow the grieving person to express as much grief as he/she is feeling and willing to share. Grieving takes time-months, weeks, often years.

4) Communicate with the grieving person on a consistent basis (a few times a week). Do not avoid people who are grieving because their pain and loss makes you uncomfortable. Do not change the subject when dying or loss is mentioned.

5) Be patient with the sometimes erratic progress an individual may make in dealing with death. The person may experience confusion, forgetfulness, or denial.
6) Tailor all interactions to the person’s level of understanding and communicative ability.

7) Be aware that one person’s grieving or death may remind others of their own previous losses and unresolved grieving processes.

8) Be careful of the following phrases because of what they imply: “went to the hospital and died”, “died in his sleep”, “got sick and died.” This will help prevent the person from believing there is a causal relationship between hospitals and death, sleep and death, etc.

Hollins (1995) provided additional recommendations to assist persons with disabilities with dealing with death and loss.

1) Actively seek out nonverbal rituals with which most cultures surround death. They are particularly helpful to people with developmental disabilities who may not find solace in the written or spoken word. Counseling picture books may be helpful in explaining what happens when someone dies.

2) Respect photos and other mementos - In the early stages of a bereavement it is quite common to avoid pictures and possessions and places which are associated with the person who died. As time passes, such mementos may come to be treasured and can become a useful measure toward resolution of grief. People with a developmental disability should be helped to choose some keepsakes, and this choice should be offered again at a later date when some of their emotional pain has subsided. Sometimes people make unexpected choices, but these should be respected.

3) Minimize change - It is advisable to minimize changes in routine and changes in residence or of caregivers at a time of grief. As a rule of thumb, major changes should be avoided for at least one year.

4) Avoid assessment of skills - If a caregiver has died, it may seem sensible to assess an individual in order to provide the best service or supports. However, this can be the worst time to assess someone whose behavior and skills may have regressed because of the emotional energy being expended on grieving.

5) Assist searching behavior - By revisiting old haunts and going to the cemetery, caregivers can assist appropriate searching behavior to support emotional recovery. Hoarding behavior may suggest that more help of this kind is required. The person who disappears or is found wandering may be trying to find their lost home and family.

6) Support the observance of anniversaries - Many religions have formal services a year after someone has died. This is especially true at the time of the anniversary of an important loss.
Many of the previous suggestions had to do with allowing the person to communicate what they are feeling. This is an added challenge when helping a person with mental retardation who also has limited communication skills. Suggestions to encourage communication include:

1) Assume that the person experiences loss, sadness, and some anger when someone close to him/her has died. Expect a range of responses from nothing to profound depression.

2) Let him/her express their feelings in any way that is comfortable.

3) Let the person know that these feelings are okay.

4) Take time, do not rush away.

5) Ask questions that allow the person to reveal what s/he is thinking and feeling (Haarstad, 1995).
   a. Are you feeling sad? Do you miss John?
   b. Susan is dying. Would you like to say good-bye?
   c. I didn’t get to come to the funeral. Will you tell me about it?
   d. Do you think about Sheryl sometimes? What do you remember? What did you do together?
   e. Could we talk about your mother? Did she like the summer time?

6) Answer questions factually, in concrete terms, in words the person can understand. Haarstad (1995) gave the following examples of answers to questions about death as a guide to staff assisting a person with a disability who is experiencing a loss.

   Q: What happened to John? How come he died?
   A: John couldn’t breath anymore. His heart stopped beating. It was too hard for John to go on living, so he died. He’s dead now.

   Q: How did John die?
   A: John had cancer. Some people who get cancer get very weak. They don’t feel like eating. It gets hard to move. They hurt all over. Sometimes they stop living. Then they are dead.

   Q: What will happen to Elaine at the funeral?
   A: Elaine is dead. Her body is resting in a special box called a coffin. The box is closed. We can’t see her body. Elaine can’t feel anything. She is dead. We will pray, sing songs, and remember what Elaine was like when she was alive. We can say good-bye even though she can’t hear us. It might help us feel better.
Remember that speech is only one channel, a small part of communication. Meaning in conversation comes not just from words but from voice quality, eye contact, body language, signs and gestures, and touch. When communicating with a person with mental retardation, staff should recognize and utilize the communication method that the person uses. Touch is a particularly important channel of communication during grief counselling. Human service workers often avoid touching or hugging. However, sometimes touching is the most effective, nonthreatening way to show concern and understanding. The touch of a hand or hug is all that is needed to reassure the person that you are there for them (Barbera, T., Pitch, R., & Howell, M. C. 1989).

**THERAPEUTIC INTERVENTIONS FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES WHO ARE GRIEVING**

If the individual’s grieving seems extended, debilitating, or unresolved, the team may seek a specialist for consultation. Unfortunately, referrals for consultation with specialists are typically made very late. It is important to make referrals, especially mental health referrals, as soon as any serious grief reactions are noted such as aggressive behavior, persistent irritability, mutism, loss of skills, inappropriate speech (i.e., asking “Where is dad?” all the time), self-injury, tearfulness, and disappearing (Hollins, 1995).

Lead by a professional therapist, guided imagery and role playing are powerful techniques that may help individuals who have spent years actively working to avoid accepting the reality of their loss (Duetsch, 1985). Cognitive therapy may be helpful for individuals who are experiencing depression as a part of the mourning process. Depression after death of a loved one, is typically not only a result of experiencing a great loss, but also of the interpretation which one places on that loss. Cognitive therapy assists the individual to examine his or her interpretation of events, and provides new self messages as alternatives to irrational beliefs.

People who are in the midst of mourning are frequently hesitant to risk experiencing another loss. They may not accept the support of other care providers, and may actively reject those who attempt to provide assistance for them. Alternative beliefs and behaviors can be developed through cognitive therapy. Also, social skills training can be used to assist the individual in learning more appropriate social behaviors and in feeling more confident in situations where he or she no longer has the support of the deceased.
CONCLUSION

The experience of grief and working through the various phases of the loss process becomes, for many an all too frequent experience. However, most older persons are eventually able to work through their grief with the help of others.

Understanding losses and dealing with grief among older individuals with developmental disabilities may present additional challenges. The permanence of death may not be as well understood among some individuals with mental retardation/developmental disabilities. However, every person, has some notion of death. Some responses to death such as anger and sadness are universal, no matter what the person's age or developmental level.

Persons with mental retardation have a right to and can benefit from both death education and grief counseling. In fact, they can suffer from being denied both. If losses experienced by individuals are denied and grief work is not encouraged, feelings of loneliness or depression, or aggression and extreme withdrawal may occur. The most serious obstacle, however, often lies in the lack of information and knowledge among staff members/service providers on how to handle grief and losses among individuals with developmental disabilities. Suggestions include:

1) **RECOGNIZE** that a loss has occurred and verbalize that.

2) **EXPLAIN** death realistically and with concepts appropriate to the individual's level of understanding.

3) **ALLOW** the individual to express feelings.

4) **EXPECT** a period of grieving and realize that tolerance and time are needed.

5) **INTEGRATE** education about death and dying into the training curriculum for individuals with developmental disabilities.
REFERENCES


FEEDBACK EXERCISE XI

1. List and explain the four phases of mourning individuals experience as a result of death.

2. List the five stages patients go through as they react to impending death according to Kubler-Ross.

3. List and describe the four types of death awareness delineated by Glasner and Strauss.

4. Briefly discuss the "life review" process with its positive as well as negative aspects.

5. What are some of the consequences experienced by individuals with developmental disabilities when losses are denied and grief work is not encouraged.

6. List five suggestions you may follow when you support individuals with developmental disabilities who have experienced losses.
UNIT XII: PLANNING FOR THE FUTURE

OBJECTIVES: After completing this unit, staff members will be able to:

Describe why families may postpone making plans for the future.

Describe why families should consider developing a plan for the future with their family member with a disability.

List some important considerations in developing a future plan.

Introduction

Families of people with disabilities face a future filled with many questions. Parents of an adult with disabilities, must be concerned about their own aging and retirement as well as the well being of their child. They may wonder how their son or daughter’s social, emotional, and physical care needs will be met when, due to declining health or death, they are no longer able to do so.

Barriers to Future Planning

Failure to plan ahead may result in the person with the developmental disability being subjected to both the emotional trauma of sudden separation from his or her parent and to inappropriate placement when a crisis occurs (Heller & Factor, 1988). Still, many parents put off planning for years and neglect to make arrangements for their offspring. (Tyler, Mann, & Fruge, 1984). Even those parents with the best intentions are often sidetracked.

Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, (1989) suggest several reasons why families fail to develop formalized plans for the future for their family members with a disability. Even though their worries about the future linger at the back of their mind, parents may be so consumed with the problems of today, that the future gets pushed aside. Planning for the future is an emotionally charged issue. It may mean confronting one’s feelings about mortality, painful memories, and concerns about the unknown. For some it is an inability to face the thought that a time will come when they will no longer be able to assist

in making decisions and provision of the care and security that their child requires.

Barriers to future planning identified by parents of children with developmental disabilities (Campbell & Essex, 1994) include a lack of information in the service community, differing opinions among professionals involved, high costs and lack of understanding of the issues by lawyers and/or financial planners, and difficulty in accessing the system.
Role of the Service Provider

As service providers to individuals with developmental disabilities, we may become involved with families who want or need to make plans for the future. Tyler, et al. (1984) recommend that families need counseling, not only in the medical/genetic/ developmental areas, but in making lifelong decisions. While families' receptivity to comprehensive planning is influenced by a host of personal, emotional, and economic factors, future planning can ultimately ease parents anxieties and make transitions for their child less traumatic. Campbell & Essex, 1994, suggest that increasing family awareness of planning issues will impact the likelihood that planning would occur.

Because of the complex issues involved, staff will need to refer questions relating to future planning to the appropriate agency staff member. In addition, families will often need the assistance of a third party such as an attorney or financial planner. These issues can become so complicated and the search for professionals with experience so tedious that many families procrastinate initiating this task. Referrals to family support groups such as the local Association for Retarded Citizens (Arc) may be a good first step to finding local experts on legal, financial, and government issues that affect or could affect aging individuals with disabilities.

Overview of Planning

A future plan is different for every individual. However, Berkobien, (1991) provides some general rules to remember in developing a plan:

- Future planning involves more than just financial and legal planning. It focuses on all major areas of the person's life such as: living arrangements, educational programs, employment or other meaningful daily activities, leisure time activities, and personal needs.

- Family members, professionals and others, including the individual with mental retardation, should share in developing the plan. The plan should also reflect what the person with mental retardation would like for his or her life.

- Future planning is an ongoing, dynamic process. It should be reviewed regularly to determine if it is still serving its intended purpose, and revised appropriately as situations change.

- The plan must take into consideration state rules and statues regarding services, legal issues and financial matters which vary from state to state, and sometimes from county to county. Laws which affect planning also can change over time. (p. 2)
A good plan is comprehensive and reflects shared decision making. The individual with a disability should be the primary decision maker in the development of the plan. Although, family members, professionals, and others assist/share in developing the plan, the plan should reflect what the individual wants.

Families differ in the method they prefer to arrive at a plan for the future. Some are very systematic, others prefer to take a more intuitive approach, choosing options that “feel right.” As professionals we cannot presume to know more about what is best for the family. However, we can provide information about issues to consider, resources available, and support them in their efforts to develop a plan around the wishes of their family member with a disability.

Turnbull, et al. (1989) recommend a series of preference checklists to introduce families to some tools they can use to identify their son or daughter’s preferences in employment, living arrangements, relationships, and life in the community. The results of the checklists are used to evaluate current or potential environments that will match the individual’s desires. Berkobien (1994) suggests that parents write a “letter of intent” to be kept with their will. The purpose of the letter of intent is to communicate and document parental preferences to others. It provides a guideline to others who may become responsible for decisions. It is not legally binding, but does serve to give others an introduction to the person and suggestions for decisions.

Parents may carry frustrations of dealing with service providers, school personnel, and professionals, from other battles in their son or daughter’s life. As issues of retirement begin to emerge, families may again struggle to understand how services will change for their family member. They may need counseling to understand how the aging process is impacting their family member. At this period of life, the individual may have out lived his/her parents, and other family members may play a significant role in the person’s life.
References


FEEDBACK UNIT XII

1. List three reasons why families may postpone making plans for the future.

2. State two reasons why families should consider developing a plan for the future with their family member with a disability.

3. List four important considerations in developing a future plan.
MODULE V: ISSUES IN SERVICE COORDINATION

INTRODUCTION

Service coordination between agencies and service providers is an important part of providing the necessary services to elderly adults with developmental disabilities. In a time of funding limitations and program reductions, cooperation and networking between agencies will be necessary to avoid duplication of services and gaps in the service delivery system. As we encourage individuals to become participants of the "generic" aging services, we must become aware of the issues and concerns that integration may bring forth. The Developmental Disabilities system has developed specialized services and programming for a specific population. The Aging Services Division system has services established for a broad target population of people 60 years of age or older. The elderly adult who has developmental disabilities, may have the option of receiving services from both service delivery systems. Aging Services and Developmental Disabilities Divisions share the goal of meeting the needs of elderly adults with developmental disabilities with quality services.

Unit XIII of this manual will address the provision of case management. It will look at what case management is and what services you can expect from generic case management. This section will address who the participants are and the controversies that exist in the provision of case management.

Unit XIV will look at the service delivery system that exists in North Dakota for individuals with developmental disabilities. It will address the relevant issues in service coordination for the elderly individuals who have developmental disabilities.

Unit XV will discuss the service delivery system of Aging Services of North Dakota. This section will look at the Title III funded programs such as Senior Centers, Home-Delivered Meals, Congregate Meals, Health and Wellness, Transportation and Outreach services. It will discuss the Home and Community-Based Services and issues in service coordination.

Unit XVI which follows has been prepared by using excerpts of the "Wit to Win" manual, a guide for service providers in both the Aging and Developmental Disabilities Networks, developed by the New York State Office for the Aging. It describes ways to help elderly persons with developmental disabilities find and use generic community programs for senior citizens. It discusses successful methodologies, addresses programmatic features and offers ideas and suggestions for service providers on how to improve accessibility and use community resources.

Throughout this module, it will be evident that communication and interaction between agencies and/or systems will have to occur to assure the coordination of services for elderly adults who have developmental disabilities. Once the coordination of services starts to happen, older adults with developmental disabilities will have the opportunity to be involved in all services that can help them to lead independent, richer lives to their fullest potential.
UNIT XIII: CASE MANAGEMENT

OBJECTIVES: After completing this unit, staff members will be able:

To outline the range of services provided by case management.

To list the participants involved with the case management process.

To discuss the controversies in the field of case management.

CASE MANAGEMENT: A DEFINITION, IN HISTORICAL PERSPECTIVE

Case management is a complex, problem-solving process whose purpose is to obtain, integrate and coordinate social, psychological, and health services for individuals and their families. This process involves a series of interrelated procedures, which are fully described later in this section.

It is important to state at the outset of this discussion that case management is performed both by formal professionals and by informal networks of family and friends. Indeed, these informal networks provide a great deal of supportive case management service and ideally work in tandem with the professional case manager.

As a specialized area of professional competence, case management evolved during the 1960s along with many other social and health service programs then emerging throughout the United States. The need for such specialization arose when it became clear that the rapid proliferation of these programs resulted in a fragmented and inefficient delivery system. Concerned governmental public agencies (such as those involved with Medicaid) therefore created specific positions, called case managers, to place the responsibility for securing needed social and health services within one location. During the 1970s, these integrative initiatives developed into full governmental case management programs and services for numerous populations.

Today, the task of case management is no longer confined to governmental agencies. It is also carried on by voluntary, nonprofit agencies, as well as by private practitioners. Because of the variety of its roles and functions, and the many different kinds of agencies which are committed to case management, it has taken on somewhat different meanings and connotations within various types of agencies. Case management is now practiced by many professionals (e.g., social workers, registered nurses, psychologists, gerontologists) as well as nonprofessionals. As a consequence of this diversification, controversies (outlined below in this section) have arisen as to which persons are best suited to perform case management, and what services should be included under the concept.

Geriatric Case Management

Geriatric case management is the same comprehensive, coordinated service described above, provided by a variety of professionals and non-professionals, but it is specifically
intended to help only frail or sick elderly and their families. Its goals can include:

1. Helping the elderly to remain safe, independent and happy, within their own homes and communities for as long as possible.

2. Helping the elderly and their families cope with transitions to more dependent status when needed (e.g., living with a family member or aide on a part-time or full-time basis; accepting nutritional and health care interventions; assistance with finances and transportation, etc.).

3. Helping those elderly and their families who need to consider a move to a more protected living environment, such as senior housing, enriched housing, a continuing care facility, or nursing home.

4. Helping the elderly and their families cope with the individual’s physical and mental deterioration, dying, and death.

Range Of Services Provided By Professional Geriatric Case Managers

1. **Assessment**

   The first step of assessment is the systematic gathering of information that identifies the strengths and weaknesses of an elderly individual/patient's present medical and psychiatric condition and functional capacities. Such information is obtained through interviews conducted with individuals/patients, their families, friends, and involved professionals. These interviews generally take place in hospitals, homes, or on the telephone. The purpose of the interviews is to determine many diverse aspects of the individual's life situation. Among the crucial areas of concern are:

   - Level of disability
   - Current and past illnesses
   - Present emotional state
   - Event(s) precipitating case manager involvement
   - Past history of coping abilities
   - Formal system support (hospital, doctor, senior center, bank, postman, clergy)
   - Informal system support (family, friends, neighbors, grocer)
   - Economic status
   - Living arrangements
   - Interests
   - Personal appearance

After concluding the interviewing process, the case manager proceeds with the crucial task of interpreting the data. This is the most important aspect of case management, for without this interpretation there can be no effective plan. Assessment requires professional training and is most often done by Social
Workers and Registered Nurses. Social workers see this interpretation phase as an analytical process that incorporates physical, psychological, social, and cultural aspects of the individual's life. The interpretation is usually elaborated in a narrative account, weaving the identifying data into coherent explanations and evaluations. Nurses often think of assessment as part of skillfully developed and numbered problem list, in which each identified problem is followed by a list, which gives brief Subjective and Objective observations, followed by a concise Assessment and Treatment Plan (SOAP).

**Treatment Planning.** Treatment planning involves making creative use of the assessment to produce an appropriate array of activities and services for individuals and their families. Treatment plans state specific short- and long-term goals. Consultation with individual, family, and other significant supports assist in the planning process and help the case manager to set up the most realistic, attainable goals.

2. **Counseling**

Case managers counsel the individual, family, friends, and other involved professionals to help them with issues related to chronic illness, disability, loss of status and finances, environmental problems, family stresses, etc. They help individuals and their families deal with a range of intense emotions such as anger, resentment, anxiety, guilt, loneliness, sadness, depression, love, and hate. These emotions may have a long history or, on the other hand, may result from the stresses of problems identified during the assessment.

3. **Referrals**

Referrals are used to obtain needed services for elderly individuals. There are three main service categories to which these elderly are referred:

   a. **General Health Services**
      Examples: Hospitals, doctors, specialty nurses, physio-therapists, occupational therapists, speech therapists, home health aides.

   b. **Community Services**
      Examples: Housing organizations, senior centers, adult day care centers, respite centers, cleaning services, self-help groups, Meals on Wheels, religious organizations, transportation services, entitlement programs, nursing homes.

   c. **Specialists**
      Examples: Dietitians, specialty social workers, lawyers, psychotherapists.

The utilization of the above services by many individuals and their families is often achieved only after much counseling, which in turn depends upon a number of preliminary steps. These include investigating various referral sources' admission
criteria, processing many complicated forms, and attending preliminary interviewing
visits with and without individuals and their families.

4. **Maintaining An Effective Care Plan**

Through regular home visits and telephone calls, the case manager strives to
maintain an effective treatment plan, but this plan is never written in stone. The
plan is periodically reviewed, and, if necessary, altered as the condition of the
individual changes. The multiphased processes of effective care plan maintenance
therefore include: obtaining, monitoring, supervising, coordinating, and reassessing
of services. Such constant activity keeps a treatment care plan strong, and insures
that the most appropriate and economical services are given.

5. **Dealing with Special Needs**

Alzheimer's disease and other forms of dementia, hospice work, and extreme
physical disability are among the most taxing situations for elderly individuals, their
family, friends, and aides. Case managers need to maintain especially close
contact with individuals and their informal and formal supports throughout the
radical changes in needs that often characterizes these difficult cases. Aides need
to be particularly well screened, selected, and trained. They may be given daily
supervisory case management support, especially while the care plan is being
refined and stabilized. The wandering, incontinence, and agitation typical of
individuals with Alzheimer's disease, for example, will usually lead to premature
nursing home placement if the family doesn't have a strong geriatric case
management team to help them care for their loved one.

6. **Financial Planning**

There may have to be many counseling sessions before elderly individuals and/or
their families can accept such ideas as:

a. the "spending down" to Medicaid level;

b. cost sharing with nonprofit community agencies to receive aide services;

c. accepting referrals: (a) for governmental entitlements (Medicare, Medicaid,
Meals-on-Wheels), (b) to lawyers, and (c) to other financial planners; and

d. spending money for needed medical specialists.

Out of a trusting case management relationship, it becomes possible to overcome
typically destructive patterns of behavior, such as denial, undue pride, pretended
poverty, the fear of abandonment, and undue suspiciousness. Only then can the
financial aspects of long-term care planning progress.
PARTICIPANTS IN CASE MANAGEMENT

Individual

A sometimes unrecognized resource in case management, and the most important resource when the person is competent, is the individual, who can assume (and has the right to demand) responsibility for obtaining, monitoring, and supervising many of the services provided to him/her. Abrupt changes in health status may make formal, professional case management necessary at some time, but a sensitive partnership and sharing of the case management tasks increases the independence and self-esteem of the individual, as well as greatly assisting the professional case manager.

Social workers are trained in a variety of communicative skills that enable them to interact empathically with individuals and their families. They must make assessments which take into account the physical, psychological, social, and cultural factors in the lives of individuals. They must know how to match resources with the needs of the person. Through their training, they need to become aware of the importance of encouraging empowerment and of establishing productive links between individuals and the communities in which they live. Home Care Social Workers, associated with hospital and free standing, nurse directed programs in the community, obtain particular skills in the case management of homebound, at risk elderly through their home-visiting.

The Registered Nurse (RN)

Registered nurses understand the symptomatology of many physical diseases and are licensed by the state to perform numerous therapeutic services. They are knowledgeable about activities of daily living, exercise, and nutrition. Many nurses have specialized education in the psychological aspects of illness. They can be authorized to administer medications, and have a close working relationship with doctors. Because nurses often do not carry the stigma often associated with mental health workers such as social workers, they may, be more easily accepted by the elderly person. Once accepted and trusted for the medical assistance they provide, they can perform some traditional social work tasks.

Other Graduate and Postgraduate Professionals

As previously indicated, individuals working in a variety of disciplines provide case management services. These include doctors, and specialists in public health, gerontology, psychology, and special education. Many are in private practice.

Some are available 24 hours a day for both telephone calls and home visits, and can see the individual immediately. They are able to give the individual a great deal of attention and provide the maximum in services since they can control their caseloads and are working with individuals with adequate financial resources.


**Developmental Disabilities Case Managers**

Case managers, as state employees, have varied educational backgrounds and opportunity for inservice training on their jobs. Faced with high case loads, limited resources, and constantly changing regulations and procedures, their work remains a constant challenge in assuring in-depth individual consumer involvement.

**Family Members and Friends**

As previously indicated, this informal support system provides much of the care for elderly individuals. They are often more accessible and able to offer more individualized and idiosyncratic assistances than formal case managers. Family members and friends provide many material and affective supports, drawing on lifelong patterns of involvement with the individual. When not overwhelmed themselves by other family or work responsibilities, and when in good health themselves, they can be: facilitators, protectors, advocates, buffers and intermediaries with bureaucracies, and sources of information about concrete entitlements (housing, pensions, medical care, insurances, etc.). Involved family and friends need the help of professional case managers for the development of assessment and treatment care plans, and for support and advice when crises occur.

**The Paraprofessional**

Home aides with various titles (home attendants, personal care workers, home health aides, homemakers, home managers, etc.), have more daily contact with individuals with disabilities than any other formal system representative. They are a critical force in maintaining people safely at home. When given appropriate support, paraprofessions are uniquely suited to handling some case management duties.

Another helpful group is the home care agency’s administrative staff. They first receive calls and frequently provide consumers with reassurances, respond to service complaints, provide financial and scheduling information on community resources, and are a telephone socializing outlet for home-bound elderly.

**CASE STUDY**

**Identifying Information**

Mrs. Collins, an alert, intelligent, very frail, 85-year-old, was widowed two years ago. She lives alone in a third-floor walkup studio apartment, located on a tenement block within a mainly affluent urban neighborhood. Mrs. Collins has lived her entire life on this block. She and her devoted husband had been the superintendent of a small apartment house across the street from where she now lives. They both attended services at the Catholic church up the block and shopped in the next door grocery store. Mrs. C. has always been very strong willed, hardworking and independent and today proudly calls herself a “loner.” Mr. and Mrs. Collins never had children; her only sister is dead, but she receives calls and visits from her two married nieces, who live 75 miles away.
Three months ago, Mrs. Collins began rejecting her nieces' calls and visits. Neighbors had observed that her tendency to withdraw began with her husband's death. She stopped going to church, refused church visits and calls, went out shopping only once a week, and stayed inside to rest most of the time. One concerned neighbor alerted a community social service agency that assigned a social worker who made a home visit. Mrs. Collins refused to open the door stating that she was well and had a right to her privacy. The agency maintained weekly telephone contact, much to Mrs. Collins' displeasure.

**Precipitating Event**

Mrs. Collins fell in her home. Her neighbor heard cries of pain and called the superintendent, who opened the dirty apartment, found Mrs. Collins on the floor and called "911." During hospitalization, Mrs. Collins was diagnosed as having congestive heart failure (CHF) and a fractured shoulder as a result of her fall. It was the foot and leg edema, associated with CHF, that limited and finally hindered her walking, leading to the fall. Mrs. Collins was well cared for in the hospital. Her community social worker maintained regular phone contact, which was now gratefully accepted. Her edema was reduced by medications. The hospital social worker, at the time of discharge, contacted the hospital's home care department which would provide a visiting nurse and physiotherapist paid for by Medicare. Medications were prescribed and transportation services arranged. The social worker from the community agency, learning of the hospitalization and discharge with no home aides, informed the hospital social worker of Mrs. Collins' past social history and the need for some hours of aide services. Both workers learned from the nieces that Mrs. Collins had adequate savings and with a mighty effort from all concerned professionals and the nieces, Mrs. Collins accepted an aide 20 hours a week from a local, private, nonprofit home care agency specializing in strong case management involvement by registered nurses and social workers.

**Initial Assessment**

Mrs. Collins is reactively depressed following the death of her husband two years ago. Childless, with minimal family involvement and facing multiple losses (the death of her devoted husband, retirement from work, heart disease, and aging), she continues to struggle to maintain as much independence as possible. It appears unlikely that Mrs. Collins, given her past "loner" lifestyle, will greatly change her behavior; however, fear of the possibility of another fall has allowed her to accept the placement of an aide, and she sees that the quality of her life has already somewhat improved. If the aide remains sensitive to Mrs. Collins' need to do as much as possible for herself, Mrs. Collins may accept her permanently. Ongoing supportive case management around concrete issues important to Mrs. Collins, as enumerated in the following plan, will probably be accepted:

**Plan:**

1. Maintain weekly case management involvement.
2. Consider future psychiatric assessment.
3. Consider involvement in a senior group.
4. Consider more involvement from family and friends.
5. Place and support aide 4 hours, 5 days per week to:
   a. Be a companion
   b. Encourage Mrs. Collins to go out
   c. Shop
   d. Help with cooking
   e. Do laundry
   f. Do light housekeeping
   g. Monitor medications
   h. Monitor nutritional status
   i. Observe legs for edema

One Year Later

Mrs. Collins likes and has totally accepted the Jamaican aide she continues to hire privately. The aide cooks “Island” food with her, and brings her granddaughter to visit occasionally. These two very positive additions to Mrs. Collins’ support network have exposed Mrs. Collins to a new culture, increased her interest in eating and in new foods, and given her controllable companions, unlike her family. While recuperating, she accepted RN and SW case management monthly visits for 4 months, then strongly rejected both, since their treatment planning goals conflicted with her own. She continues to tolerate weekly telephone calls from the community social worker. Depression has been replaced by anger and mild suspiciousness toward any new professional. She sees her physician and makes needed medical plan changes when encouraged to do so by her case manager aide, who reports any physical changes to the agency. An agency nurse assesses the aide’s oral report over the phone and instructs the aide. The agency nurse calls Mrs. Collins’ doctor if the aide reports unusual changes.

Mrs. Collins has developed a positive, strong telephone relationship with the home care agency’s administrative assistant, whom she calls weekly to discuss her bill. This seems to be a kind of telephone reassurance on her part, on her terms, enabling her to maintain a sense of control over her life through these business calls.

Mrs. Collins’ depression had ended. She is accepting the aide, is seeing her physician regularly, takes her medications regularly, and eats regularly with good weight gain. Her appearance has improved and her living environment has been upgraded with the addition of a new sink and reclining chair. Several reassessments by the social worker and nurse over the year have indicated that items 2, 3, and 4 of the original care plan are presently unneeded or unacceptable by the individual. The present plan consists of only items 1 and 5. The individual is doing very well at home.

Although the case example given above is different in several significant ways—particularly because of a past history of strong independence— from the situation individuals with developmental disabilities will find themselves in, it does illustrate some aspects of aging that can confront all persons. After making minor adjustments, it would not be difficult to make this a case example of an elderly person with mild or moderate mental retardation or epilepsy living in an urban setting. In this and in most other cases, it would seem advisable
to take as a starting point the assumption that elderly persons with developmental disabilities are more like than unlike their nondisabled age peers.

**CONTROVERSIES IN THE CASE MANAGEMENT**

Current projections indicate that by the year 2050 a quarter of our population will be over the age of 65. Obviously, such a development will require even more comprehensive and varied services to meet the needs of this rapidly growing population. At the same time, however, there is no agreement about how to provide services. Because case management is done by people coming from many different disciplines there are many viewpoints about the appropriate function of case management. Several of the controversies that have arisen in recent years concerning case management and the changing demographic structure of the United States are briefly summarized below:

1. Many people fear that governmental funding agencies are trying to save money by employing workers with limited case management training. It is felt that these less costly workers, who perform limited concrete services, don't really meet the person’s psychological needs. It is also felt that these workers are overworked and under supervised. Some critics feel there is a prevalent "administrative perspective" that permeates large public agencies, and that overlooks the human needs of elderly persons who are dependent.

2. In those agencies that employ case managers, the same "administrative perspective" is thought to sacrifice the full use of valuable professional skills such as counseling, because of the need to process heavy caseloads, and because of other constraints.

3. The title case manager offends many of professionals who bear the title. They resent referring to individuals who are elderly as "cases," and resent the bureaucratic assumption that just because an elderly person lacks money and is placed on Medicaid, for example, he/she needs to have his/her whole life supervised.

4. Social work worries that its members, who become part of the new specialty, profit making Geriatric Care Management (GCM), may be shifting away from traditional social work values. Some traditional social workers fear the development of a separated, two tiered case management service system--one for the rich, and one for the poor--as GCM continues its development. Some public service social workers also worry that GCM staff, by helping only wealthier individuals, are leaving those with more problems and fewer resources to the already overburdened public sector. GCM staff maintain that their fees are not high when their separate overhead expenses are considered. Also, their middle class consumers are ineligible to receive services from many nonprofit agencies.
NEW DIRECTIONS

Large business corporations, wanting to cut down the enormous cost of employee absenteeism, are setting up contracts with a variety of governmental, voluntary, and private case managers. These companies want to help valued employees who are frequently away from work providing care to chronically ill, often elderly family members, while at the same time reducing health costs for the company.

It is unclear whether these and some other positive new directions will develop into a significant trend, and thus begin to reverse the radical cutbacks of the 1980s. Public agencies, pessimistic about future government financial support, are beginning to speak of becoming "partners in care" with private case managers, and of accepting middle class consumers for pay. Hard economic times pave the way for creative planning, and new political partnerships.
FEEDBACK EXERCISE XIII

1. What is the purpose of case management?

2. What are some of the goals of geriatric case management? List at least three.

3. List at least eight crucial areas covered by the interviewing process conducted by professional geriatric case managers.

4. What are the three main service categories to which elderly individuals are referred?

5. Who are the participants in case management?

6. What are some of the controversies in the case management field?
UNIT XIV: DEVELOPMENTAL DISABILITIES SERVICES
IN NORTH DAKOTA

OBJECTIVES: After completing this unit, staff members will be able to:

Review the North Dakota Developmental Disabilities Case Management System

Identify the issues relevant to service coordination with the Developmental Disability System

INTRODUCTION

The developmental disabilities system refers to the many agencies, both public and private which plan, coordinate, administer, offer, or finance services for persons with developmental disabilities of all ages. Early efforts to develop services for persons with such disabilities were primarily focused on children with mental retardation. However, the field of developmental disabilities has matured with the realization that its efforts must include all facets of the lifespan and all types of disabilities that impede typical growth and development.

THE NORTH DAKOTA CASE MANAGEMENT SYSTEM

The case management system is a function of the Department of Human Services. There are regional offices in each of the eight human service centers located throughout the state.

Case management services assist eligible individuals:
1) to obtain services they need
2) to access entitlements
3) to pay for the services
4) to assure the quality and effectiveness of the services.

To obtain case management services, an individual and/or family may apply at one of the human service centers. The regional case management system also receives referrals from schools and other agencies. Once an application is received, the regional Developmental Disabilities staff will review all of the data to determine if the applicant meets the eligibility criteria as established by the Department of Human Services. If the individual is deemed eligible for services, a regional case manager is assigned to the individual. The regional case manager will be responsible to gather all necessary information to open a case file and to make referrals to the appropriate agencies for specific services. The North Dakota Case Management System has an "Individual Service Plan (ISP)" team to determine what services will be needed by the individual and to decide who will provide these services. The ISP team may include the following individuals:

1. The person requesting the services
2. Case managers
3. Family members
4. Guardian
5. Advocate
6. Any other professionals and/or service providers deemed necessary

The ISP team meeting is facilitated by the Regional Case Manager. A document called the Individual Service Plan (ISP) is a direct result of the team meeting. This document is a reflection of the decisions made by team members and authorizes entrance into the Developmental Disabilities funded services. Once the individual is involved in the services, the regional case manager assists in initiating any other necessary services and monitors the quality and appropriateness of services being received by the individual. The ISP team meeting is held annually or as often as the regional case manager feels that it is necessary to complete reviews and changes to services.

ISSUES OF SERVICE COORDINATION FOR THE OLDER ADULT WITH DEVELOPMENTAL DISABILITIES

As the older adult with developmental disabilities is living longer, we have a unique challenge of providing appropriate and necessary services to meet their needs. The aging process and developmental disabilities have some similar characteristics. They are:

1. Both tend to affect all areas of life activity
2. Both can be severely debilitating
3. Both are lifelong in duration
4. Both tend to be devalued by society

With these in mind, it is easy to understand why the older person with developmental disabilities is so vulnerable to inappropriate services, i.e. not enough services, duplication of services, or the wrong services or treatment altogether. It is very important that case managers working with older individuals with developmental disabilities be aware of the following issues that may hinder the service coordination between agencies:

1. Symptoms of the aging process may be masked by the characteristics of the developmental disability. As the adult with developmental disabilities grows older, he/she experiences changes that occur with the aging process. These changes may be very limiting for the individual but may not be recognized by the staff as a symptom of aging. The staff may attribute the limitation to the disability versus the "normal" part of the aging process.

2. Services need to reflect the changing needs of the individual. As an individual ages, new needs will arise. It is likely that a combination of services will be needed to meet the new needs. This may include specialized services offered through the Developmental Disability system or the "generic" services provided by the Aging Services system.

3. Health care services need to be maintained. This population may be vulnerable to a variety of health problems. The reasons include:
   a. Past medication usage
   b. Poor health habits
c. Sporadic and incomplete medical care

d. Sedentary lifestyles and impairments to mobility

e. Symptoms of aging process

f. Complications associated with the developmental disability.

Health care services are essential to maintain the physical, medical, emotional, and mental health of the older adult with developmental disabilities.

4. The older individual with developmental disabilities should be treated as an adult. There is a tendency to treat individuals who have developmental disabilities or are elderly as children. We tend to make decisions for them, talk for them, and encourage activities for them; without considering their wishes and desires. We need to treat them as competent adults.

5. Individual needs should be considered when retirement options are considered. For some individuals, to continue vocational training into the retirement years is considered wasteful, inappropriate or even programmatic harassment. There are other individuals for whom the option of retirement is quite inappropriate as the person continues to have needs that can be met through vocational training. There is no right or wrong answer, except what the individual desires and needs.

6. Individuals experience the social stigma of having a developmental disability as well as being older. It is hard enough to deal with the social stigma that is associated with having a developmental disability but now the individual also faces the stigma associated with being older. They will need to overcome the social barriers, rejection by others, possible exploitation and abuse/neglect by the system as well as by other individuals.

7. Changes in support systems for the older individual with developmental disabilities. As we all become older our support systems change. We may marry, have children, establish several circles of friends, etc. For the older individual with developmental disabilities, the support systems may be difficult to replace as they grow older. As their parents and siblings die, there may be limited number of people to replace these support systems as these individuals may not have married or had children. The support systems will change each time the individual moves to a different type of service. (Example: An individual moving from a group home to a long term care facility. The individual will have new staff and new peers to become his support system).

8. Funding conflicts exist in the service delivery system. It is essential for each system and/or service provider to be aware of all services that are provided within the community and to become familiar with the eligibility criteria. Once the service providers have this information, it is possible to discuss funding for needed services. This will involve open communication and compromise between service delivery systems as well as between service providers.
9. **The complexity of the service delivery system.** Staff of the service delivery system should recognize how confusing the system appears to individuals with disabilities and/or families. Within the service delivery system there are several models of service delivery such as medical, developmental, rehabilitative, habilitative, etc... and each model stresses unique goals and approaches. To avoid duplication of services, it is essential to see the regional case manager as a link to the service delivery system and coordinator of services.

10. **New approaches and ideas for programming should be encouraged.** North Dakota has taken many great steps in providing appropriate, quality programming for the older individuals with developmental disabilities since the early 1980s. It will be just as important to be as creative and resourceful in the 1990s as we are faced with budget limitations, limited staff and fewer local resources. New ideas and approaches need to be shared by service providers throughout our state.

**SERVICES THAT ARE AVAILABLE TO THE OLDER ADULT WITH DEVELOPMENTAL DISABILITIES**

The services that will be appropriate will depend on the needs of the person. The case management system assures that the individual's needs are the most important factor in determining appropriate services. An example of some of the services that could be appropriate may include:

**Residential**
- congregate care group home
- supported living arrangements
- individualized supported living arrangement
- adult family foster care

**Day Services**
- developmental day/work activity
- adult day care
- supported employment

In some situations, the services provided by a long-term care facility may be appropriate. This would include the nursing and basic care facilities.

**SUMMARY**

In the State of North Dakota, we have a case management system that can determine eligibility and access services within the developmental disabilities service delivery system. (It will be vital in the 1990s to coordinate and network services with the limited funding and available resources). Regional case managers can provide an important link to other service delivery systems. Above all, we need to continue our focus on the individual needs of the aged individuals with developmental disabilities and to assure that services are appropriate to those needs.
FEEDBACK EXERCISE XIV

1. What is the Individual Service Plan and who participates in the team?

2. The aging process and developmental disabilities have some similar characteristics. List those.

3. It is important that case managers as well as staff or service providers working with individuals with developmental disabilities be aware of the issues that may hinder the service coordination between agencies. List at least seven of those issues.
UNIT XV: AGING SERVICES IN NORTH DAKOTA

OBJECTIVES: After completing this unit, staff members will be able to:

Understand the purpose of the Older Americans Act
List the services provided by Title III Funded Programs
Discuss the delivery of Home and Community-Based Services
Discuss the issues of service coordination within the Aging Service System
Identify approaches that may lead to better service coordination

THE AGING NETWORK

The Aging Service System refers to the system responsible for furnishing services to persons 60 and over. That system is a part of a national network on aging established by the Older Americans Act and headed by the U.S. Administration on Aging. The North Dakota Aging service delivery system is comprised of state and local government agencies as well as a variety of community level service provider agencies. Under the federal Older Americans Act and North Dakota Statute, the state office of Aging Services has responsibility for a wide range of planning, coordinating, and funding activities. In addition, it serves as the state level focal point for aging concerns and advocacy.

OLDER AMERICANS ACT

Older Americans Act of 1965 is the foundation for the service delivery system established for the Aging Services Division of the Department of Human Services. The Older Americans Act assures that needed services are available and accessible to those who are 60 years of age and older. The Older Americans Act targets its services to elderly individuals with the following characteristics: rural, minority, socially needy, severe disabilities, greatest economic need, and limited English speaking ability. It also targets persons with Alzheimer’s disease and related disorders and their caregivers. A copy of the Older Americans Act can be reviewed with the Regional Aging Services Coordinator at each of the human service centers.

COMPONENTS OF TITLE III PROGRAMS

The Older Americans Act of 1965 directs each state to evaluate and provide for supportive services including nutrition and multipurpose senior centers. In North Dakota, we have developed a variety of programs which are funded by Title III monies. These programs include congregate meals, home-delivered meals, chore services, senior centers, outreach services, health and wellness services, transportation, telephone reassurance, escort and
shopping assistance, information and assistance, legal assistance, and education. Title III provides some funds to Senior Companion Services. A description of these services include:

1. **Senior Centers**
   A senior center is a community gathering place where older people come together for activities and services. The goal of a senior center is to promote the physical and mental well-being of senior citizens by providing a variety of health, nutritional, social and educational services. There are over 200 senior centers located throughout North Dakota. Most centers are independently owned and operated by senior groups. Many different types of people attend senior centers including those with low, middle, and upper incomes, retired and employed, rural and urban, healthy and frail, men and women, disabled and non-disabled. The use of the center is open to all seniors.

   Donations are encouraged, since centers are maintained by local community support. Building and renovation costs are funded through senior citizens mill levy funds, federal grants and much local support. Operating expenses are funded by local mill levy funds and local fund-raising events sponsored by the senior groups.

2. **Congregate/Home-Delivered Meals**
   Congregate meals are nutritious meals served in a group setting for older people. Home-delivered meals is a service which provides nutritious meals to persons who are home bound and unable to prepare their own meals.

   The requirement for each program is that the recipients be 60 years of age or older. Spouses and family members with disabilities residing with the recipient are also eligible for meals. At congregate meals, a special effort is made to encourage older people who may be lacking skills to prepare meals, lacking finances to provide adequate meals, lacking socialization opportunities, and lacking access to other needed services. Home delivered meals are for those who are homebound due to illness or frailty, have difficulty in preparing meals, and do not have daily assistance from family, friends, and neighbors. The meal programs are supported by federal, state, and local funding. Participants are asked to contribute to the cost of the meal according to their ability to pay. At each meal site, a suggested contribution may be posted but no one is denied a meal because they are unable to pay. Meal tickets are used in some locations.

3. **Health and Wellness**
   Senior service providers offer a variety of health and wellness programs. Not all senior service providers offer all levels of health services. Health services include:

   A. Health screening programs - areas covered by health screening may
include: blood pressure, pulse rate, urine analysis, hemoglobin, vision, hearing, glaucoma tests, breast exams, foot care, vaccinations, etc.... Health screenings are usually done on a monthly basis and conducted by trained medical staff. Referrals are made to appropriate agencies as necessary.

B. Education and Health Maintenance - Senior center staff offer a variety of self-help programs such as: nutrition, disease prevention, stress management, drug usage, knowing your rights, accident prevention, etc... Most senior centers offer regular exercise programs.

C. Emotional Wellness Programs - Senior centers may offer peer counseling and various support groups. Examples of support groups include: alcoholism, coping with cancer, alzheimer, etc.

4. Transportation

Across North Dakota there are transportation services for persons 60 and older. These services provide rides for older people to: medical appointments, senior centers, grocery and drug stores, nursing homes and hospitals, etc.. Funds to operate the transportation program come from state, federal, and local sources. Older persons may contribute for their ride according to the local program suggested fee but no one is denied transportation if they can not contribute. The local senior service provider handles arrangements for transportation including schedules and ride reservation policies.

5. Outreach/Telephone Reassurance/Information & Assistance/Escort and Shopping Assistance

Anyone needing information regarding services for seniors, may call the information and referral service which is provided by a statewide contract with a qualified agency. The primary purpose of the service is to link the person to the appropriate individual and/or agency. This agency offers a statewide toll free Information and Referral (I & R) telephone number called Senior Info Line (1-800-451-8693).

Outreach services are provided to those who are 60 and older. Outreach programs seek out and inform older persons face to face of services in the community. The outreach worker can assist the older person in obtaining needed services.

Telephone Reassurance is a program where volunteers provide a daily phone call to an older person to assure their safety and well-being.

Escort and Shopping Assistance consists of service to assist older persons in
securing services outside their home environments.

Legal Assistance is provided for older individuals who need legal help and do not have anywhere else to go for that help.

HOME AND COMMUNITY-BASED SERVICES

The purpose of Home and Community-Based Case Management (HCBS) is to assist functionally impaired individuals to achieve and maintain independent functioning to the extent each individual is capable by assuring that appropriate services are provided. HCBS case management service is provided by county social service boards. Case management provides a link between community resources, qualified service providers and the client/applicant accessing the needed services.

1. Services

The North Dakota Department of Human Services includes in its array of home and community-based services for the aged and disabled: Case Management, Adult Day Care, Adult Family (Foster) Care, Chore Services, Family Home Care, Personal Attendant Care, Homemaker Services, Home Health Aide, Respite Care, Environmental Modification, Specialized Equipment, Training for Family Caregivers, and Adaptive Assessment.

A. Case Management, Home and Community-Based Services
   The provision of specialized assistance based on the results of a comprehensive assessment for the individual desiring or needing help in selecting or obtaining resources and services and in coordinating the delivery of the services.

B. Adult Day Care Services
   A program of social and related support services for individuals over age 18 years provided on a regularly scheduled basis, which includes services needed to insure the highest level of functioning of the individual.

C. Adult Family (Foster) Care
   Includes the provision of 24-hour room, board, and supervision, and personal cares to adults who are determined to be unable to function independently or who may benefit from a family home environment. The care is provided by a licensed private home.

D. Chore Service
   The provision of one time or intermittent home maintenance such as seasonal cleaning, minor home repair, snow removal from sidewalk. The service may be provided to individuals who reside in their own home or rental housing, where the rental agreement does not include the provision of these tasks.
E. Family Home Care
   The provision of room, board, supervisory and personal care on a 24-hour basis by the spouse or one of the following relatives, or the current or former spouse of one of the following relatives: parent, adult child, sibling, grandparent, adult grandchild, adult niece, or adult nephew of the individual in their home or the caregiver’s home.

F. Homemaker Service
   The provision of non-personal care tasks such as housekeeping, laundry, and shopping, which enables the individual to maintain independence needed to remain in their home.

G. Home Health Aide Services
   The provision of intermittent assistance with personal health care, such as: tub and bed baths; skin or foot care; that enable the individual to remain in their home.

H. Nonmedical Transportation
   The provision of transportation that enables individuals to access essential community services such as a grocery or pharmacy in order to maintain themselves in their home.

I. Personal/Attendant Care
   The purpose of this care is to help the individual with activities of daily living so he or she can live at home.

J. Respite Care
   The provision of temporary relief to the individual's primary caregiver for a specified period of time. The caregiver is relieved of the stress and demands associated with continuous daily care.

K. Environmental Modification Service
   Structural modification to the home that enables the recipient to function with greater personal independence and safety. This includes areas of the home needed to complete daily activities essential to maintain hygiene, safety, and health.

L. Specialized Equipment: Specialized equipment and supplies includes devices, controls, or appliances, specified in the plan of care, which enable recipients to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live.

M. Training for Family Caregivers: To improve the skills of a non-paid primary caregiver family member.
2. Funding Sources

There are 4 primary funding sources that are used for Home and Community-Based Services. They are:

A. Private Pay

B. Service Payments for the Elderly and Disabled Program (SPED)
   This is a program authorized by state law under which a Qualified Service Provider may be reimbursed by the Department of Human Services for the provision of in-home and community-based services provided to eligible elderly and disabled persons.

C. Expanded SPED - is a state funded program which is a companion to the Basic Care Assistance Programs that pays for care in Basic Care facilities. The eligibility criteria is the same. If services can be provided in the home or community, institutionalization (basic care facility) is avoided.

D. Medicaid Waiver for Aged and Disabled
   A program authorized by federal law enabling states to provide, under Waiver of several Medicaid requirements, specific nonmedical services to aged and disabled persons at risk of institutionalization. In-home and community-based services are provided to avoid the individual’s institutionalization and, by use of those services, to reduce costs.

E. Traumatic Brain Injured (TBI) Medicaid Waiver
   A program authorized by federal law enabling states to provide services to persons with a diagnosis which is not degenerative or congenital, of traumatic brain injury resulting in significant emotional, behavioral, or cognitive impairments.

F. County Title XX Block Grant

3. Qualified Service Providers

Effective July 6, 1989, state law requires that each person eligible for services under NDCC 50-06.2 (comprehensive Human Service Programs) must be free to choose among available qualified service providers that offer competitively priced services. The law states that county social service boards must inform each eligible client of the qualified service providers available in their county to provide the services needed by the eligible elderly or physically disabled client. A Qualified Service Provider can be county social service board and/or independent contractor which agrees to meet standards for service and operations established by the North Dakota Department of Human Services.
NORTH DAKOTA LONG-TERM CARE OMBUDSMAN

In 1983, the North Dakota Legislative Assembly passed and the Governor signed into law Senate Bill 2070, establishing a statewide Long Term Care Ombudsman Program in skilled, intermediate, basic and swing bed long-term care facilities. The Ombudsman program, is administered through the Department of Human Services, Aging Services Division. The Ombudsman is an impartial mediator resolving problems or complaints received from residents, their families and friends, facility staff and the general public. The Ombudsman will investigate and attempt to resolve complaints of residents of long-term care. The Ombudsman also provides community education, recommends changes needed in law, and promotes resident, family and community involvement in long-term care.

COMPARING THE AGING SERVICE DELIVERY SYSTEM AND THE DEVELOPMENTAL DISABILITIES SYSTEM

The Developmental Disability System differs from the Aging service delivery system. Much of the technology on which its based is drawn from special education and rehabilitation and its focus is on individual training and development. Individualized services are planned around individual’s goals and needs. The terminology used is "habilitation" and "training" and most intervention/services are provided within the context of a setting that is individual-oriented.

The aging system's roots offer a different history. Special services to elders have been part of our social fabric for years, but the basis was in social services and various generic and informal community supports necessary to maintain normal functioning as long as possible.

As an extension of generic community social services, the aging system’s services were not universally focused until the passage of the Older Americans Act in 1965. When specialized services evolved, a major focus was on sites and settings that could draw together diverse services that could be used by elderly persons in the community.

The technological emphasis in many aging programs is not on the individual, but on service provision and the availability of social environments for socialization and companionship -- the focus is on the group. In general, the aging system tends to be group oriented and the rehabilitation technology used is based upon modifying the problems associated with aging and maintaining independence as long as possible.

AGING PROGRAM OPPORTUNITIES

Many local offices for the aging support a number of congregate programs for older persons which may also be suitable for some older persons with developmental disabilities. The programs may be directly operated by the office for the aging or provided via subcontract by a community agency. As a general rule, the programs are open to any person aged 60 and over.

The types of congregate programs which offer participation opportunities for seniors with developmental disabilities include social model adult day care programs, senior centers,
and senior nutrition programs. In most cases, one or more of the programs can be found in your community.

**Adult Day Care Programs**

**Social Model.** These programs typically provide daytime care and activities for seniors who are frail and/or require supervision. Activities and programs tend to be individualized to meet the specific needs and abilities of participants. They serve as a respite for families who must provide for their elderly relatives.

**Medical/Psychiatric.** Other program models of day care also exist. Medical day care programs, operated by agencies certified by the Department of Health, admit seniors with medical care needs who do not need to be in a 24-hour nursing care setting. Psychiatric day care programs, operated by mental health agencies, serve persons who have emotional problems or mental illness on an outpatient basis.

**Senior Center Programs**

These programs typically offer a slate of weekly activities often including a daily, hot meal. Some program sites have TV, game, craft, and other activity rooms where multiple activities occur. Depending on the center site, activities may be directed by paid or volunteer leaders. Participation in activities is voluntary and on a first-come, first-served basis. Senior center site users generally tend to be healthy, active, and self-selecting in what they do at the center.

**Nutrition Programs**

There are two types of nutrition programs: congregate meals and home delivered meals. Congregate meal programs are those sites where a hot midday meal is provided in a congregate setting to persons aged 60 and over. Persons under age 60 may be served if they are a spouse or are disabled and live with a person age 60 or older. The setting for a nutrition program may be at a senior center, or community site such as a church, school, town hall, or community center, etc.

The primary purpose of the nutrition program is to serve the noon time meal to those who wish to participate. Nutrition sites serve as a focal point and meeting place for seniors. Often they are the only available places in the community where seniors can meet. Many sites have activities and programs around the meal.

The home delivered meal program is where a home-bound senior can receive a hot noontime meal. Meals may be provided through liquid supplements or frozen meals, depending on the needs of the individual.
SUMMARY

The Aging Services Division has developed an array of services to assist the older adult to remain as independent as possible and to lead a quality of life that promotes health and safety. The older adult with developmental disabilities may have the option of the participation in some of these programs. It is important to know how these programs operate and how to access them.
FEEDBACK EXERCISE XV

1. What kind of services are provided by Title III Funded Programs in North Dakota?

2. List and describe at least seven home and community-based services provided by the North Dakota Department of Human Services.

3. Briefly describe the North Dakota Long-Term Care Ombudsman Program and its responsibilities.

4. How do the Aging and the Developmental Disabilities Systems differ?
UNIT XVI: INTEGRATING OLDER PERSONS WITH DEVELOPMENTAL DISABILITIES INTO COMMUNITY-BASED ACTIVITIES

OBJECTIVES: After completing this unit, staff members will be able to:

- Appreciate the benefits of participation in community-based activities for seniors.
- Describe strategies for successful integration of people with developmental disabilities in community senior citizens programs
- Describe staffing arrangements to make integration successful
- Explain the use of companions or volunteers to facilitate integration

INTRODUCTION

Many people have come to believe that we are better as individuals, families, communities, and as a nation when individuals with diverse backgrounds and abilities are included in community life. As a result, new approaches to support people with disabilities have been developed. These programs are based on the concept of inclusion or helping each person with a disability live, work, and recreate in regular community settings of their choice. Key components of inclusive services include:

- People with disabilities are the primary decision makers about their own lives.
- Persons with disabilities are offered the training and/or supports necessary to achieve their unique potential.
- Training and supports are provided in community settings in ways that are natural to the setting.
- Wherever possible, natural supports are fostered. Natural support means assistance is provided by a neighbor, co-worker, or other community member.
- Persons with disabilities are provided the opportunity to give back, as well as to receive.
- Individuals with disabilities are assisted to develop relationships with family, friends, neighbors, and co-workers.

Service providers play a critical role in supporting individuals to live and work in the community. However, the goals of expanded social networks and increased community access for older adults with developmental disabilities can only be fully realized by relying on supports that exist naturally in the community.
Research shows that most older people with developmental disabilities are capable of participating with minimal assistance in community-based activities available to people without disabilities. Model projects across the country have demonstrated how staff, peer companions, and program participants of community aging programs can be utilized to assist older persons with developmental disabilities to access the community. The purpose of this unit is to provide information for individuals who will be coordinating community inclusion efforts as well as those who will be supporting older individuals with developmental disabilities at community activities.

**BENEFITS OF PARTICIPATION IN COMMUNITY-BASED ACTIVITIES**

Participation provides a link to the community that should be a part of the older adult's lifestyle. Community-based activities offer a break from routine. This exposure to a variety of experiences challenges intellectual capacity and make life more interesting and pleasant. For older people, including those with developmental disabilities, such programs can avert mental and physical deterioration that might otherwise occur.

For older persons with developmental disabilities, participation provides entry into a "normal" community group which can have a stimulating and positive effect on the individual's day-to-day behavior and self esteem. Community-based activities can offer older persons with developmental disabilities, an opportunity to participate in a relatively unstructured and unsupervised environment. In model projects across the country, older persons with developmental disabilities have demonstrated, as a group, marked improvements in social interaction, social behavior, and in developing friends and friendships.

People working in community-based aging programs have offered specific reasons why they find inclusion of older persons with developmental disabilities valuable. They say participation in their programs offers older persons with developmental disabilities the following opportunities:

- an environment in which they can spend time with others their own age,
- opportunities for socialization rather than isolation at home,
- a gain in self-confidence,
- opportunities for recreational activities and interesting programs,
- a chance for membership and feeling part of a group,
- the chance to learn new skills, and
the chance to learn that sometimes they can function at near, or even above the level of non-disabled people.

Older persons with developmental disabilities are not the only people who gain from integration efforts. When asked about the contributions the individuals with developmental disabilities made to their programs, staff from community aging projects reported the following benefits:

- Offered a new enlightenment about developmental disabilities and what it means to be developmentally disabled.

- Makes regular program participants more sensitive to the problems of other people.

- Helps regular program participants reach out more and appreciate what they have both physically and mentally.

- The individuals with developmental disabilities are often willing to volunteer their time and abilities to help the program run better.

- The individuals with disabilities contribute friendship, help other participants, and challenge established values and ideas about individuals with developmental disabilities.

**NETWORKING FOR SUCCESSFUL COMMUNITY INCLUSION**

Care must be given that persons with disabilities participating in community-based activities for older persons are not isolated in the new setting. The goals of inclusion are more than merely accessing a new activity or program; they are increasing social interaction and participation. If a person attends a community event, but sits alone and is never spoken to by others, their quality of life has not been enhanced and s/he will not experience the benefits mentioned in the previous section.

For a person with a developmental disability to be truly accepted and to become a part of the community activity, club, or organization, a carefully planned approach is necessary. Getting started involves networking. Networking describes the sometimes informal, but decidedly crucial, process of reaching out, making contacts, sharing information, and building trust to help make things happen.

Networking often begins with phone calls or conversations among colleagues providing services to older persons. In some communities, these informal contacts have led to the organization of task forces or committees designed to make integration a reality. Networking involves “base building” by having the people you know help put you in contact with people you need to know.
While there is no one right way to accomplish the goals of inclusion for people with disabilities, successful demonstration projects have offered the following guidelines for building relationships among the diverse community-based programs for older persons.

- Identify a core group of people who are interested in inclusion.

- Meet informally as a small group to establish a vision, identify needs and barriers, and delineate resources available to help with integration activities.

- Learn what is available to older persons in your community.

- Identify others who should be involved in efforts to expand community access for older people with disabilities. (Volunteer organizations, churches, clubs, community recreation programs, libraries, Senior Center, etc.).

- While careful planning is important, don’t get stuck there. As soon as possible, take some action to implement your plan. Match an older person with a disability to a program that meets his/her needs and provide the supports necessary to make it a successful experience for everyone.

- Maintain contact after the integration efforts have begun. Partners in the process should take time to identify positive outcomes and problem solve any challenges to be overcome. Successful networking requires ongoing communication.

Increased opportunities for integration for older persons with developmental disabilities in community-based activities depends on the level of commitment of the staff involved, their alertness to opportunities for inclusion, and their willingness to act after careful planning. Success is determined more by the creativity, cooperation, and follow-through of those involved than on the financial resources available or the skills and needs of the participants seeking “to be included”.

**PREPARING TO PARTICIPATE**

While integration has been successfully achieved by placing people one at a time as well as by integrating small groups, this manual encourages approaching participation in community-based activities on an individual basis. Stroud and Sutton (1988) explain:

“The privileges and pleasures that are possible in community activity participation are sometimes lost when a large group of persons with development disabilities attends together. The visibility of the large group, the obvious presence of staff in attendance, the yellow bus or van, and other evidence of regimentation do not always contribute positively to the way they are received. An ‘institutional effect’ is immediately apparent to others. The group with developmental disabilities remains separated and usually misses the experience of merging into the social situation.”
PLANNING FOR COMMUNITY INCLUSION

Activity/Site Selection

Most communities offer many opportunities for interesting, enjoyable, and productive activities for older persons. Some activities will be better choices than others for a specific individual. Successful inclusion hinges upon matching the individual's abilities, interests, and needs to compatible programs. Good matches are based on assessments of both the individual and the community settings.

Interests, strengths, and weakness are identified after evaluating the person's physical health, self-care, social skills, leisure skills, preferences, conversation ability, and personality characteristics (i.e. shy, outgoing, etc). Using this information, staff should look for community settings where the individual will be accepted based on his/her strengths and interests. Coaching and skill building in weak areas may contribute to success, but avoid spending so much time getting ready, that the individual never gets to participate. Rather than striving for perfection, do enough preparation to minimize embarrassment and frustration, then assist the person to learn through supported experiences at his/her chosen activity.

Example: Harold loves to be around people, enjoys playing games, and has good conversation skills, but he eats with his mouth open and takes food from the plates of others. Rather than insisting that he learn better meal time manners before he begins attending the Senior Center, investigate the programs at the center and see if there are other activities that Harold could begin accessing now. Help him choose activities that will focus on his strengths and not require the skills that are weak. Perhaps Harold would want to go for bingo on Friday afternoon, or play pool with his neighbor on Tuesday morning. Continue to help him learn appropriate meal time skills so that soon he would be accepted at mealtime also.

Other factors to consider in site selection may include:

- Is the programming appropriate?
- Is the facility accessible to persons with developmental disabilities?
- Is transportation to the site available or not too expensive or difficult to find?
- Are the hours of operation compatible with your staffing schedule?
- Is the site manager or program director interested in working with you to provide opportunities for seniors with disabilities?
PLANNING FOR COMMUNITY INCLUSION

Stroud and Sutton (1988) offer many of the following guidelines for promoting community access:

- **Know the community setting to be accessed.** Community members assisting the person who will be attending the activity can assist by finding out what is expected of those who participate: times to arrive and depart, suitable clothing, fee requirements, rules for participation.

- **Be realistic about the older adults with developmental disabilities.** How will the regular participants at the selected program view the person with a disability? Help individuals with disabilities avoid embarrassment, rejection, or disappointment. Prior to attending, they should be assisted to develop skills needed to meet the expectations of people they will encounter.

- **Don't wait for perfection.** Avoid requiring older adults to “measure up” to arbitrary standards of a “typical” senior citizen before they begin to participate. Advance preparation should focus on ensuring that the individual will enjoy the experience and that the person is accepted by others.

- **Offer choices and encourage decision making.** The older person should be the primary decision maker regarding activity selection. Due to limited exposure and experience to community activities, the individual may need encouragement to try new activities to expand his/her range of choices. Ultimately, however, the older person should be given the opportunity to suggest, decide, accept, or refuse activities.

- **Friends or companions can accompany older adults to new places.** Peer companions, either volunteer or paid, can provide encouragement, information, and minimal assistance for the person with developmental disabilities. The companion also serves as a role model for regular program participants and can be the key to fostering new friendships for the person with a disability.

**USING PEER COMPANIONS TO ENHANCE PARTICIPATION**

**Benefits**

Peer companions are an alternative to staff taking groups to community activities and provide some of the following benefits for integration efforts:

- expands the efforts of regular staff

- draws less attention to the new participant; makes the integration effort seem more natural than when the person is accompanied by staff

- Provides one-on-one assistance/support so the new participant isn’t left in an
awkward situation or isolated from other participants

• helps ease the fears a new participant may have

• helps ease the fears of staff and regular program participants at the community-based activity

• gives the community valuable and meaningful volunteer opportunities which provide both the companion and the person with a disability with an opportunity for companionship and friendship

**Recruiting**

Finding companions can be a challenge, but many programs have been successful in finding friends to help with integration activities. Coordinators of a project in Minnesota (Amada, Conklin, & Wells, 1990) gave the following advice,

“The only way to discover if someone would be willing to meet someone, or do something with someone, is to ask. Sometimes we’re reluctant to ask others to do things. We typically expect that people will say ‘no.’ However, over and over again in the Friends project, staff were amazed at what happened when they simply asked. They thought others would be reluctant, or need more information. Over and over again, people simply said ‘yes.’ And not only ‘yes,’ but ‘yes, no problem’ or ‘sure, have her come over today.’”

Here are some guidelines for finding companions:

• Start with people you know. See if friends, relatives, and acquaintances of your agency staff are interested in becoming companions.

• Check with the following agencies for leads on potential companions: Green Thumb Program, Retired Senior Volunteer Program, Senior Companion Program, other agencies using volunteers.

• Look for companions among the following organizations: retired teachers, church groups, retired nurses, residential centers for senior citizens, community civic groups, etc.

• Ask others who they know that might be interested. Older persons themselves often know someone who may be interested in becoming a companion.

**Companion Selection**

Look for people who have the following qualities or potential for developing the following qualities: sensitivity, understanding, commitment, reliability, and patience. The companion should be matched appropriately with the person who will be attending the community-based activity. Look for shared interests and arrange for individuals with disabilities and companions to become acquainted before attending activities.
Getting Started

Programs that use peer companions or community friends to support individuals with disabilities in the community suggest that certain steps be taken to ensure that both partners in the relationship will have a positive experience.

1) The program needs to be coordinated by an individual who will be responsible for recruiting, screening, and providing orientation for the companions.

2) A formal application process may be implemented that includes reference checks and interviews. This process can be used to learn more about the new person so they can be paired with someone who has similar interests and hobbies.

3) The applicant should receive a description of what is expected and be informed of the supports available.

4) Because many companions or community friends may have had little exposure to people with disabilities, many programs offer a brief orientation training for new people. Training gives the companion a chance to ask questions and relieve any apprehensions they might have about their ability to assist a person with a disability in community activities.

5) A contact person who can be called for advice and who will touch base with companions on a regular basis is critical to success.

Training for Companions, Participants, and Site Staff

Most developmental disabilities agencies offer a training program which can be appropriately tailored to prepare companions, participants, and aging program site personnel for integration. Companions, like any other volunteers, benefit from well designed training activities.

The training program for companions, participants, and aging program site personnel should have the following purposes:

- To explain the purpose of integration

- To explain the similarities and the differences between the person with disabilities and the other older persons

- To acquaint companions and staff with the special needs of the person with disabilities and the ways to handle those needs

- To acquaint companions and staff with action to be taken in case special problems arise
· To explain the reason why participation is so important for persons with disabilities

· To explain developmental disabilities and mental illness (the difference between mental retardation and mental illness is not often understood)

· To explain their role and what is expected

Staff who developed the Friends project in Minnesota found that companions did not need training to “be like staff”, to “handle” certain behaviors the right way. Project staff discovered that the community members are often quite capable of figuring things out for themselves. Whatever they do naturally in their activities and communications is often just fine, and just what is wanted and needed.

Introducing People

Reputations of people with disabilities are often built on single incidents or on descriptions of what the individual can’t do, what needs “fixing,” or what’s “different.” Once an individual gains a reputation for being strange or offensive (demanding, aggressive, etc.), a vicious cycle begins. People expect the “deviant” behavior, respond to the person with aversion or rejection, and the individual never has the opportunity to overcome the reputation.

We need to provide adequate information to someone who is going to spend time with an individual to insure everyone’s comfort and safety. If someone is going to be responsible for an individual who needs medication, has seizures, or a physical condition that could require assistance, the person needs to know exactly what to do to manage a potential situation. This would also be true regarding individuals who might do something to injure themselves or someone else. However, we need to guard against being overprotective or exaggerating the potential problems, especially when we’re introducing a person for the first time.

While it is important to think through each strategy for potential problems, research has shown that sometimes “institutional” behaviors are not good predictors of behavior in community settings. When an individual has the opportunity to participate in interesting activities, the “institutional” behaviors often disappear. When we give individuals the chance to be at their best, more often than not, their abilities surpass our expectations.

Site Visits

It is helpful if the companion is a regular participant in the program the older person with a disability is hoping to attend. In such cases, the companion would know the routine, expectations, and “rules” at the site. However, if the companion is not familiar with the program, introducing the companion to the staff at the community based activity is an important part of a new companion’s orientation. Site staff introductions serve to build confidence and establish the foundation for communication among parties involved. If the plan is for the companion and the older person with a disability to blend in unobtrusively
with the regular site participants, the initial companion/site staff meeting will help to establish how that will be accomplished. This introductory meeting will also help to assure the site staff that the companion is there to help and that the new participant will not mean extra work for them.

The person with a disability may need to be introduced to the new program gradually. There may be uncertainty and/or resistance. Remember upon retirement, the individual is leaving a familiar setting and friends. Upon entering a new program they are expected to form new friendships and participate in new activities.

Rather than have everything hinge on one visit, arrange for a series of trial visits and then evaluate the experience with both the senior and site manager. The question of whether the regular program participants should know who is coming to join them is complicated. Experiences in other projects suggest that program type, site staff and level of disability of the person who will attend, hold the keys as to how this should be handled.

Here are some general guidelines:

- Most social adult day care participants are in the program because they have functional impairments and need to be supervised. In this environment it is not likely that it would be necessary to make an announcement that a person with a developmental disability will be participating.

- Senior centers and nutrition sites tend to be highly social environments. In most cases, a person with any kind of visible deficit or differentness is going to be noticed. The site manager may need to explain to the regular participants what is happening and enlist the support of the group so the new person is properly welcomed. Conversely, saying nothing and letting the individual be their own advocate is also a possibility.

**Role Clarification**

While a companion's presence can serve as a security blanket of sorts for the person who may have no other friends at the site, the companion's role should be to encourage and help the person to develop other friendships. Ideally, it is hoped that the individual will ultimately be able to get along without the assistance of the companion.

The companion also serves as a role model or informal teacher to the regular participants at the community activity. One of the most effective ways to support people in relationships is to demonstrate how it's done. Others will relate to persons with disabilities based on the example set by the companion and staff at the site.
For example:

- If the companion speaks to the person as an adult, others will do the same.
- If we encourage the person to participate in activities, others will learn the person is capable.
- If we redirect questions asked of us, to the individual with a disability, others will begin socializing with the person we are assisting.
- If we treat the person as our friend, others will see them as a member of the organization or as their friend.

By observing the interactions between the older person with a disability and companions, it is possible for regular program participants to learn:

- the value of friendships with individuals with disabilities
- that people with disabilities have many things to contribute
- how to assist a person with a disability while still encouraging independence
- how to approach the person with a disability as another adult, not as a child
- how to provide opportunities for socialization and communication to older persons with disabilities

**Integration Tips**

- Select potential sites based on the quality of leadership found at the site.
- Set up a staff sharing relationship, if possible.
- Inform aging program staff of the nature of the developmental disability, and of any special needs the seniors being integrated might have.
- Focus on the abilities of the people to be placed while being honest about their limitations. Don’t define them by their disabilities.
- Be prepared to be very flexible and accommodating.
- Minimize as much as possible the extras that are requested of site staff.
- Build in incentives which will make local senior programs want to take persons with disabilities.
Take the time to acquaint yourself with both the aging and the developmental disabilities systems. Get to know the people you will be working with, what conditions they are working under, and, therefore, who would be most likely to be enthusiastic about integration. Find out who is most approachable.

Follow through on all assurances of support that you make.

Answer the questions honestly and within the bounds of confidentiality, about those you wish to place. Always try to focus on the person rather than the disability.

Respond quickly to concerns of all involved: seniors integrated, families, center staff, program staff, regular program users, and others. Making sure everyone is as comfortable as possible can be the key to success, especially early on.

Expect that there will be individuals who will not like or accept seniors with developmental disabilities, just as there are those who do not like or accept other people for other reasons.

Provide those selected for integration with individualized training in the skills needed to make the transition into a senior center. Good hygiene skills are particularly important to acceptance.

Do not define the program to the person who has the disabilities as one in which he or she is "being integrated." Define the program on its own terms without relating it to this person's special circumstances. It is an opportunity to make new friends and do different things.

**Staffing for Different Purposes**

Consider staffing for these various reasons:

First, depending on the size and scope of the integration effort, full or part time staff may be needed to coordinate integration activities between aging and developmental disabilities agencies.

Second, at the program site, thought has to be given to the number and types of staff needed to aid in the integration effort.

Third, staff sharing arrangements need to be considered when additional staffing is necessary.

As you see, staffing can be done in various ways. To conserve resources, build communications, and enhance the chances for success of your integration effort, look for opportunities to share resources and staffing with other agencies. Some examples drawn from pilot projects include:
• an adult day care project director who also coordinated a county wide integration effort.
• staff from a developmental disability agency being shared with a senior center to help with a small group of seniors with developmental disabilities who were integrated into the center. The shared staff also helped the nondisabled people with the center's programs and activities.

• area agencies for the aging that provided office space and staff time for conducting integration efforts.

The variety of staffing arrangements that will facilitate integration are virtually limitless. The key is to bear in mind that it can be done, and to look for opportunities to do it. Depending on the size and scope of the integration effort, full or part time staff may be needed to coordinate integration activities between agencies.

**Staffing for Interagency Coordination**

It makes sense to develop a focal point or clearinghouse for coordinating integration activities. A focal point also reduces duplication efforts and offers an economy of scale by concentrating the manpower needed to effect integration in one place.

Finding staff to coordinate is usually done by identifying an agency and a staff member within the agency who is interested and capable of serving as the focal point for helping with integration activities. Once designated, networking activities can begin.

**Site Staffing**

Companions may assist with the entry process and in some cases, continue on at the sites with the seniors who are integrated. The necessity for adding new or additional staff to help the seniors who are integrated, varies according to the following factors:

• site type (senior center, nutrition program, adult day care program),

• level of disability and/or activity level of the seniors being placed, and

• number of persons being placed at the site.

Senior centers and nutrition programs planning to serve people with more pronounced impairments are likely to need additional staff. Day care programs tend to be familiar with seniors who are impaired and may be able to cover new participants with existing staff, if operating capacity is not exceeded. If only a few people are placed at a site, and they integrate well with the existing users, it is not likely that the number of permanent site staff will need to be increased.
Shared Staff

One consideration an agency can give to enhancing the potential for integration is to increase the available staff at a senior program site through a staff sharing approach. When this has been tried within demonstration projects, it proved to be very fruitful.

In one example, the developmental disabilities agency out-stationed full time staff at a number of senior centers. This shared staff approach proved to be an innovative and successful solution to the problem of increasing site staff and finding people with the appropriate skills and knowledge to help with the seniors who would become part of the center's clientele.

For the center, it was an opportunity to pick up a new staff member. This was an opportunity warmly received because many senior centers are minimally staffed. The center director was particularly enthusiastic about the staff placement. The out-stationed staff person ran the center ceramics program, and tended to the needs of five seniors with develop mental disabilities who had begun using the site. The reaction from the out-stationed staff person was similarly enthusiastic; she enjoyed the opportunity to become involved in the center's program.

Staff sharing is an option which tends to fit in nicely with the concept of service integration. Site staff too, can be integrated to the advantage of all concerned - the host agency, the referring agency, the traditional users of the program, and the seniors who may already be familiar with the staff person assigned to the host agency. Also, when budget or hiring limitations exist, staff sharing should be considered as a way to address those concerns. Do the following:

- establish an area focal point or clearinghouse for coordinating integration efforts.
- designate a person to have responsibility for coordinating integration activities.
- consider sharing and out-stationing staff with community providers as means of maximizing effectiveness and minimizing costs.
FEEDBACK EXERCISE XVI

1. What are some of the benefits of participation by seniors with developmental disabilities in local aging programs?

2. What is networking and what steps need to be taken for integration?

3. In considering sites for integration certain factors must be considered. List at least five of these factors.

4. Why does this manual encourage approaching participation in community-based activities on an individual basis?

5. List five guidelines for promoting community access identified by Stroud and Sutton:

6. What are some benefits of peer companions accompanying older adults to community activities?

7. What purposes should the training for peer companions serve?

8. List at least 10 integration tips.

9. What staffing arrangements may be needed to make integration happen?
Aging and Developmental Disabilities II
(Module 895.35)

FEEDBACK EXERCISE IX Answers

1. Describe what constitutes an informal support system for elderly individuals as well as elderly individuals with developmental disabilities.
   Informal support systems for the elderly constitute children/grandchildren, siblings and children of siblings, old friendships from work, community activities, and neighbors. These informal networks generally are much more limited for individuals with developmental disabilities.

2. Relocation of older individuals with developmental disabilities, although sometimes necessary, could be detrimental to their lives. What should staff do to make the transfer as painless as possible?
   1. Habilitative services - make every effort to improve service and staff attention.
   2. Preparation for the move - visit new site, allow individual to participate in pre-move decision making process.
   3. Intact support networks - Adaptations to new environments much easier with groups of peers than singularly relocating each one.

3. List five steps agencies can adopt to support an individual with disabilities to widen his or her circle of relationships and develop deeper friendships.
   a. Discover the person’s interests, gifts, and capacities. Look for strengths rather than weaknesses.
   b. Create a vision of relationships the person wants.
   c. Use connecting strategies for new and existing relationships.
   d. Present a very important person.
   e. Supporting and nurture relationships and real friendships. Assist the individual to call to extend invitations for activities and provide supports such as transportation.
      - Teach the individual reciprocity.
      - Demonstrating how to relate to individuals with disabilities for others
      - Help the person broaden their range of interests.

FEEDBACK EXERCISE X Answers

1. List the five functions of work which could predict successful retirement.
   a. Work as a source of income;
   b. Work as a way to structure time;
   c. Work as a source of status;
   d. Work as a source of social interaction and social support;
   e. Work as a meaningful life activity

2. What is active treatment and how should it be applied to older individuals with developmental disabilities?
   Active treatment is defined as objectively measurable interventions, based on individual need assessment, that have as their goal the promotion of growth and improvements in health, skills, and habits required for independent living. Age-appropriate recreation and leisure activities or volunteer activities incorporated into day services for the elderly can fall within the category of active treatment programming. For other persons with developmental disabilities, programming that is directed at minimizing debilitation due to injury or illness may be more critical to their well being and quality of life than objectives that specify measurable growth and improvement. Programming directed at assisting the person to succeed in integrated retirement options may also be considered (ie. social skills, communication, grooming, community orientation, making choices, etc.)

3. When should an individual with developmental disabilities retire?
   Respect the wishes of the individual of retirement age. Retirement option should be pursued only when individual wishes to retire or has to because of health reasons. Planning should begin early. Consider each of the following factors:
   a. Work assessment of the individual and the environment
   b. What does the person want?
   c. Financial impact of retirement
   d. Impact on social support
   e. Recreation/leisure skills
   f. Level of community involvement

4. Define leisure:
   Any self-directed activity that helps to make that adult “all that he can be.” It is not an activity designed as a reward for work.
5. List five areas of training in leisure education that could be structured both within your agency setting and in your community.
   (Answers will vary—see chapter for some examples)

6. What benefits can be obtained by the older adult with developmental disabilities through volunteer endeavors?
   - social stimulation from individuals without disabilities
   - opportunities for self-fulfillment
   - social role enhancement
   - opportunities for intergenerational activities

FEEDBACK EXERCISE XI Answers

1. List and explain the four phases of mourning individuals experience as a result of death.
   a. Initial response to death, which is usually one of shock followed by denial.
   b. Individual experiences grief in the sense of deep psychic pain.
   c. A realistic recognition of loss and is characterized by what has been called the separation reaction.
   d. The survivor is able to integrate within his/her identity the identity of the deceased.

2. List the five stages patients go through as they react to impending death according to Kubler-Ross. Denial, Anger, Bargaining, Depression, Acceptance.

3. List and describe the four types of death awareness delineated by Glasner and Strauss.
   Closed - when the patient is not aware that his/her illness is terminal.
   Suspected awareness - the patient becomes suspicious, but does not know for sure that death is imminent.
   Mutual pretense - where both the patient and attending hospital staff both know the patient's condition, but deny this to each other.
   Open awareness - where all concerned parties can address the reality of the patient's condition.

4. Briefly discuss the "life review" process with its positive as well as negative aspects.
   Life review process - reflection on one's life and the events that occurred during one's lifetime.

   Positive: should leave to serenity and wisdom. View life as an appropriate one.
   Negative: results in anxiety and depression. Review life as negative experience. Need some form of psychotherapy.

5. What are some of the consequences experienced by individuals with developmental disabilities when losses are denied and grief work is not encouraged.
   - feelings of loneliness or depression
   - aggression and extreme withdrawal

6. List five suggestions you may follow when you support individuals with developmental disabilities who experienced losses.
   a. Recognize that a loss has occurred and verbalize it.
   b. Explain death realistically, and with concepts appropriate to the individuals level of understanding.
   c. Allow the individual to express feelings.
   d. Expect a period of grieving and realize that tolerance and time are needed.
   e. Integrate education about death and dying into the training curriculum for individuals with developmental disabilities.

FEEDBACK UNIT XII Answers

1. List three reasons why families may postpone making plans for the future.
   - Parents may be so consumed with the problems of today, that the future gets pushed aside.
   - Planning for the future is an emotionally charged issue.
   - For some it is an inability to face the thought that a time will come when they will no longer be able to assist in making decisions and provision of the care and security that their child requires.
   - A lack of information in the service community, differing opinions among professionals involved, high costs and lack of understanding of the issues by lawyers and/or financial planners, and difficulty in accessing the system.

2. State two reasons why families should consider developing a plan future.
   Planning can ultimately ease parents anxieties and make transitions for their child less traumatic.

3. List four important considerations in developing a future plan.
Future planning involves more than just financial and legal planning. It focuses on all major areas of the person's life such as: living arrangements, educational programs, employment or other meaningful daily activities, leisure time activities, and personal needs.

Family members, professionals and others, including the individual with mental retardation, should share in developing the plan. The plan should also reflect what the person with mental retardation would like for his or her life.

Future planning is an ongoing, dynamic process. It should be reviewed regularly to determine if it is still serving its intended purpose, and revised appropriately as situations change.

The plan must take into consideration the state in which the individual resides. Rules and statutes regarding services, legal issues and financial matters vary from state to state, and sometimes from county to county. Laws which affect planning also can change over time.

FEEDBACK EXERCISE XIII Answers

1. What is the purpose of case management?
   Case Management is a complex, problem solving process whose purpose is to obtain, integrate, and coordinate social, psychological, and health services for needy families and individuals.

2. What are some of the goals of the geriatric case management? List at least three.
   a. Helping elderly to remain safe, independent and happy within their own homes and communities for as long as possible.
   b. Counseling the elderly and their families to consider a move to a more protected environment, such as senior housing, nursing home.
   c. Helping the elderly and their families cope with individual/patient physical and mental deterioration, dying, and death.

3. List at least eight crucial areas covered by the interviewing process conducted by professional geriatric case managers.
   a. Level of disability.
   b. Current and past illnesses.
   c. Present emotional state.
   d. Events precipitating case manager involvement.
   e. Past history of coping abilities.
   f. Formal system of support (clergy, hospital, doctor, bank, senior center).
   g. Informal system of support (family, friends, neighbors, doorman, grocer).
   h. Economic status.
      - living arrangements    - personal appearance    - interests

4. What are the three main service categories to which elderly individuals are referred?
   a. General health services
   b. Community services
   c. Specialists

5. Who are the participants in case management?
   The individual, RN, professionals from a variety of disciplines, case managers, family members and friends, paraprofessionals.

6. What are some of the controversies in the case management field?
   a. Agencies saving money by hiring workers with limited case management training.
   b. Administrative perspective which overlooks the human needs of dependent elderly.
   c. Case managers do less counseling because of heavy caseloads and various agency constraints, such as hospital diagnostic-related group.
   d. The title case manager offends many.
   e. Resent having elderly individuals/patients called "cases."
   f. Resent bureaucratic assumption that because an elderly person lacks money and is placed on medicaid, he/she needs to have his/her whole life supervised.

FEEDBACK EXERCISE XIV Answers

1. What is the Individual Service Plan and who participates in the team?
   A plan written for the individual that determines what services will be needed by the individual and who will provide these services.
2. The Aging process and developmental disabilities have some similar characteristics. List those.
   a. Both tend to affect all areas of life activity
   b. Both can be severely debilitating
   c. Both are lifelong in duration
   d. Both tend to be devalued by society

3. It is important that case managers as well as staff or service providers working with individuals with developmental disabilities be aware of the issues that may hinder the service coordination between agencies. List at least seven of those issues.
   a. Symptoms of the aging process may be masked by the medications of the developmental disability.
   b. The services need to reflect the changing needs of the individual.
   c. Health care services need to be maintained.
   d. To treat the older individual with developmental disabilities as an adult.
   e. To look at individual needs when the option of retirement is considered.
   f. The social stigma of having a developmental disability as well as being older.
   g. The change in support systems for older individuals with developmental disabilities.
      - To resolve funding conflicts in the service delivery system
      - The complexity of service delivery system is confusing to clients and/or families
      - To encourage new approaches and ideas for programming.

FEEDBACK EXERCISE XV Answers

1. What kind of services are provided by Title III Funded Programs in North Dakota?
   - Congregate meals
   - Home - delivered meals
   - Senior centers
   - Outreach services
   - Health and wellness services
   - Transportation
   - Telephone reassurance
   - Escort and shopping assistance
   - Information and assistance
   - Legal assistance
   - Education

2. List and describe at least seven home and community-based services provided by the North Dakota Department of Human Services.
   A. Case Management, Home and Community-Based Services: Provision of specialized assistance based on the results of a comprehensive assessment.
   B. Adult Day Care Services: A program of social and related support services provided on a regularly scheduled basis one or more days per week.
   C. Adult Family (Foster) Care: Includes the provision of 24-hour room, board, and supervision, and personal cares in a licensed private home.
   D. Chore Service: The provision of one time or intermittent home maintenance such as seasonal cleaning, minor home repair, snow removal from sidewalk.
   E. Family Home Care: The provision of room, board, supervisory and personal care on a 24-hour basis by the spouse or one of the following relatives, or the current or former spouse of one of the following relatives: parent, adult child, sibling, grandparent, or adult grandchild of the individual in their home or the caregiver’s home.
   F. Homemaker Service: The provision of non-personal care tasks such as housekeeping, laundry, and shopping, which enables the individual to maintain or develop the independence needed to remain in their home.
   G. Home Health Aide Services: The provision of assistance with personal health care that enable the individual to remain in their home.
   H. Nonmedical Transportation: The provision of transportation that enables individuals to access essential community services such as a grocery or pharmacy.
   I. Personal/Attendant Care: Care is to help the individual with activities of daily living.
   J. Respite Care: The provision of temporary relief to the individual’s primary caregiver for a specified period of time.
   K. Environmental Modification: Structural modification to the home that enables the recipient to function with greater personal independence and safety. This includes areas of the home needed to complete
daily activities essential to maintain hygiene, safety, and health.

L. Specialized Equipment: Specialized equipment and supplies include devices, controls, or appliances, specified in the plan of care, which enable recipients to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live.

M. Training for Family Caregivers: To improve the skills of a non-paid primary caregiver family member.

N. Adaptive Assessment

3. Briefly describe the North Dakota Long-Term Care Ombudsman Program and its responsibilities. The Ombudsman is an impartial mediator resolving problems or complaints received from residents, their families and friends, facility staff and general public. The Ombudsman will investigate and attempt to resolve complaints of long-term care. Also provided is community education, recommends changes needed in law, and promotes resident, family, and community involvement in long-term care.

4. How do the Aging and the Developmental Disabilities Systems differ? Developmental disabilities system - much of its technology is drawn from special education and rehab and its focus is on individual training and development. Aging service system - basis was in social services and various generic and informal community supports necessary to maintain normal functions as long as possible.

FEEDBACK EXERCISE XVI Answers

1. What are some of the benefits of participation by seniors with developmental disabilities in local aging programs?
   a. Provides a link to the community.
   b. Offers a break from routine.
   c. Provides an entry into "normal" community group.
   d. Provides exposure to a variety of experiences.
   e. Environment in which they can spend time with others their own age.
   f. Opportunities for retirement and for social/recreational activities.
   g. A chance to learn new skills as well as possibly forestall mental and physical deterioration that might otherwise occur.
   h. The chance to learn that sometimes they can function at near, or even above the level of non-disabled people.

3. What is networking and what steps need to be taken for integration? Networking is the sometimes informal, but decidedly crucial, process of reaching out, making contacts, sharing information, and building trust to reach out and make things happen.
   a. Identify a core group from your system who are interested in integration.
   b. Establish a vision, identify needs and barriers, and delineate resources.
   c. Learn what is available in your community and identify others who should be involved.
   d. Take action.
   e. Maintain contact, evaluate efforts, and problem solve.

3. In considering sites for integration certain factors must be considered. List at least five of these factors.
   a. What types of sites are available that match the individual's interests.
   b. Is the programming appropriate?
   c. Is the facility accessible to persons with developmental disabilities?
   d. Are the hours of operation compatible with your staffing schedule?
   e. Is the site director interested in working with you to provide services to your seniors?

4. Why does this manual encourage approaching participation in community-based activities on an individual basis? When a group attends an institutional effect is immediately apparent to others. The group with developmental disabilities remains separated and usually misses the experience of merging into the social situation.

5. List five guidelines for promoting community access identified by Stroud and Sutton:
   - Know the community setting to be accessed. Times to arrive and depart, suitable clothing, fee requirements, rules for participation.
   - Be realistic about the older adults with developmental disabilities. Assist them to develop skills needed to meet the expectations of people they will encounter.
   - Don’t wait for perfection. Avoid requiring older adults to “measure up” to arbitrary standards of a “typical” senior citizen before they begin to participate.
   - Offer choices and encourage decision making. The older person should be the primary decision maker regarding activity selection, however the individual may need encouragement to try new activities to expand his/her range of choices.
   - Friends or companions can accompany older adults to new places.
6. What are some benefits of peer companions accompanying older adults to community activities?
   - Expands the efforts of regular staff
   - Draws less attention to the new participant; makes the integration effort seem more natural than when the person is accompanied by staff
   - Provides one-on-one assistance/support so the new participant isn't left in an awkward situation or isolated from other participants
   - Helps ease the fears a new participant may have
   - Helps ease the fears of staff and regular program participants at the community-based activity
   - Gives the community valuable and meaningful volunteer opportunities which provide both the companion and the person with a disability with an opportunity for companionship and friendship

7. What purposes should the training for peer companions serve?
   - To explain the purpose of integration
   - To explain the similarities and the differences between the person with disabilities and the other older persons
   - To acquaint companions and staff with the special needs of the person with disabilities and the ways to accommodate those needs
   - To acquaint companions and staff with action to be taken in case special problems arise
   - To explain the reason why participation is so important for persons with disabilities
   - To explain their role and what is expected

8. List at least 10 integration tips.
   a. Select potential sites based on the quality of leadership found at the site
   b. Set up a staff sharing relationship, if possible
   c. Be prepared to be very flexible and accommodating
   d. Focus on the abilities of the people to be placed while being honest about their limitations
   e. Minimize as much as possible the extras that are requested of site staff
   f. Follow through on all assurances of support that you make
   g. Expect that there will be individuals who will not like or accept seniors with developmental disabilities
   h. Provide those selected for integration with individualized training in skills needed to make the transition into a senior center
   i. Respond quickly to concerns of all involved
   j. Answer questions honestly and within the bounds of confidentiality about those you wish to place
      - Take the time to acquaint yourself with both the aging and DD systems

9. What staffing arrangements may be needed to make integration happen?
   - experienced persons to help guide and evaluate the integration effort
   - one or more persons to work directly with the people being integrated
   - shared staff