



***The Wit To Win***

**How to Integrate Older Persons  
With Developmental Disabilities  
Into Community Aging Programs**

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**How To Integrate  
Older Persons  
With Developmental Disabilities  
Into Community Aging Programs**

by  
Philip LePore  
Matthew P. Janicki

1990

**New York State Office for the Aging**

Mario M. Cuomo, Governor

Jane G. Gould, Director

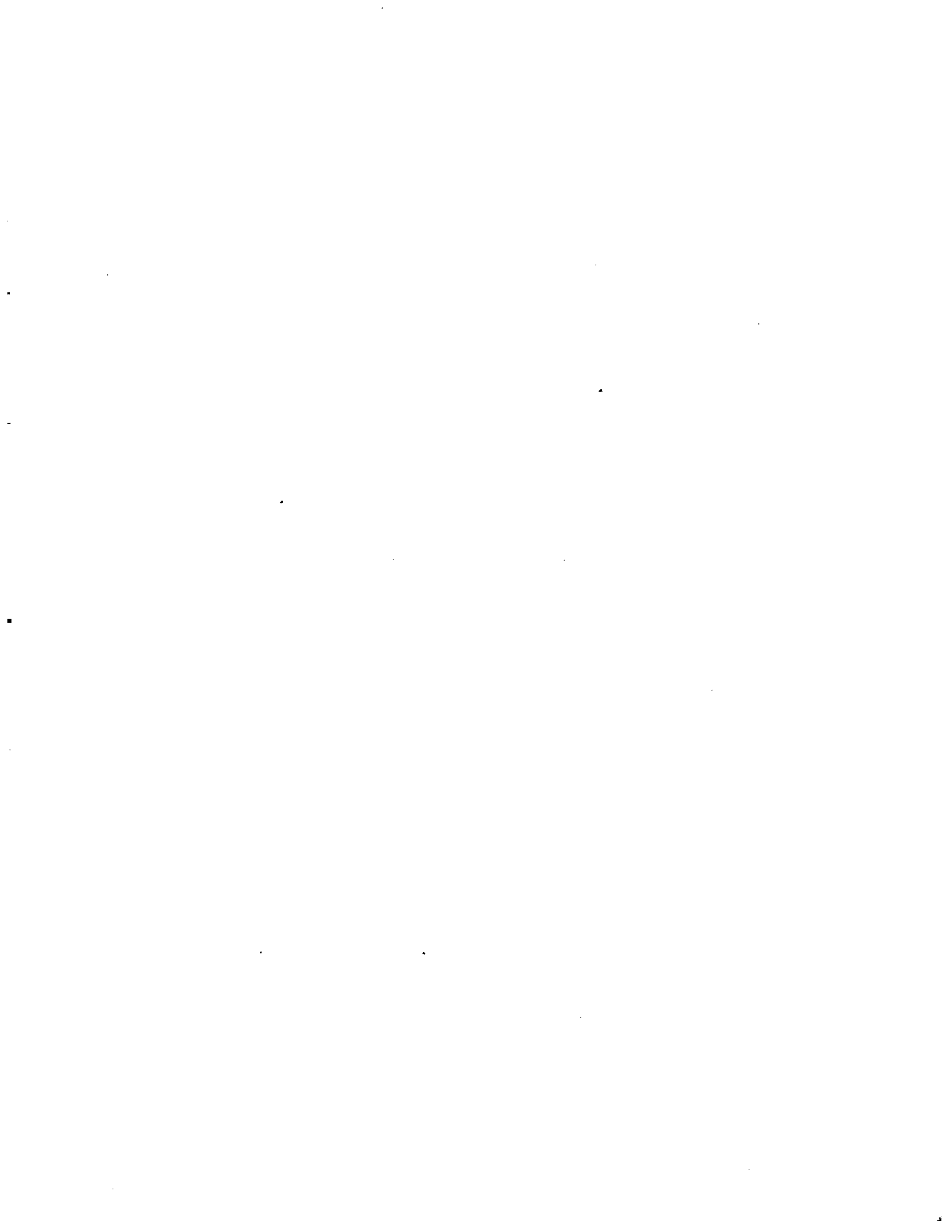
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**He drew a circle that shut me out -  
Heretic, rebel, a thing to flout.  
But Love and I had the wit to win:  
We drew a circle that took him in!**

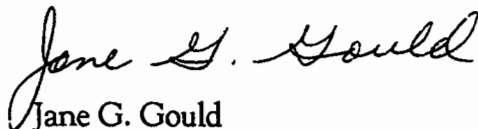
*Outwitted - Edwin Markham*

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**T**his manual is the product of an intensive state and local community effort to integrate older persons with developmental disabilities into such aging network services as senior centers, adult day care, and nutrition programs.

We share our successful experience with you so that you can also help older people with developmental disabilities benefit. In turn, we hope that you will share your experiences with us by sending your observations and comments to Philip LePore, Project Director, NYS Office for the Aging, 2 Empire State Plaza, Albany, NY 12223-0001.



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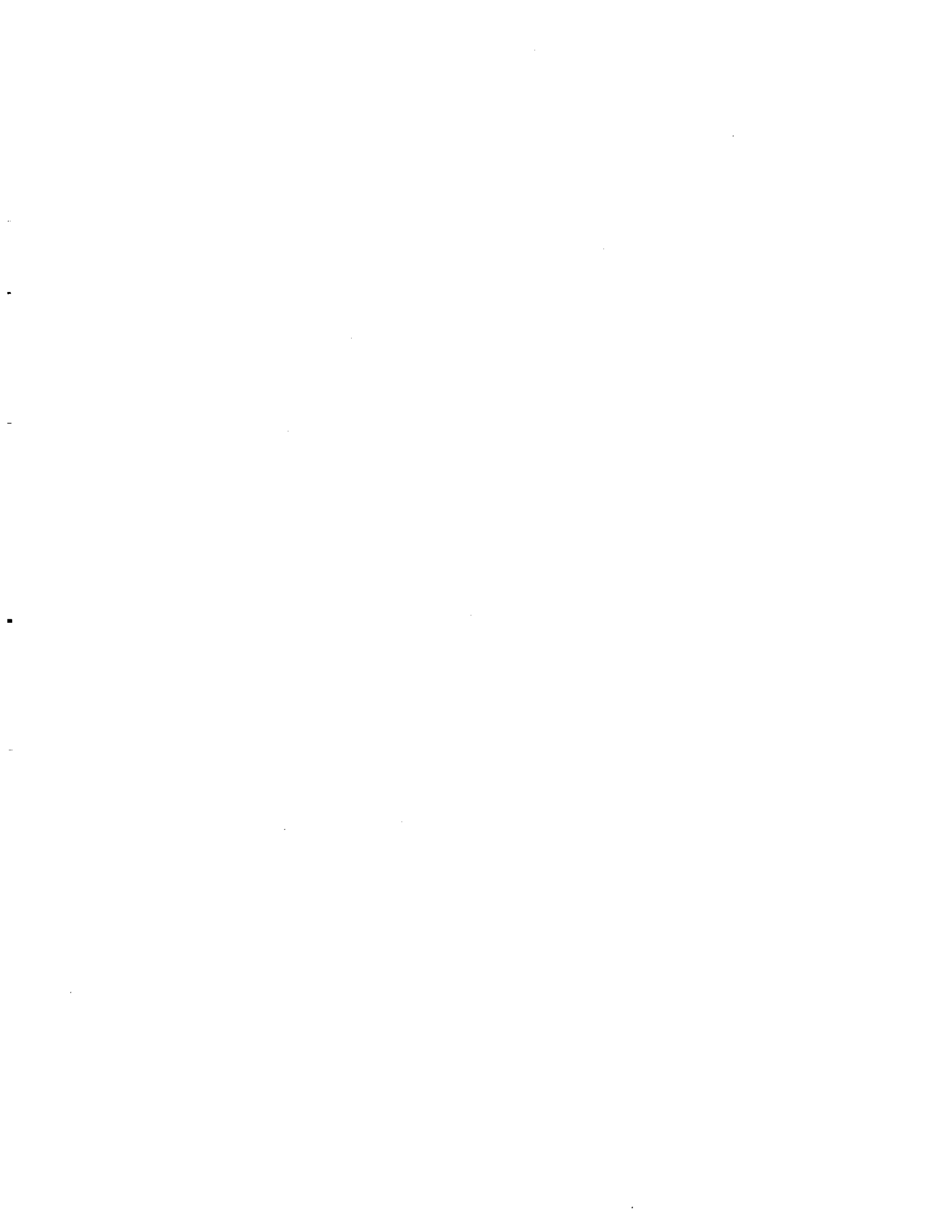
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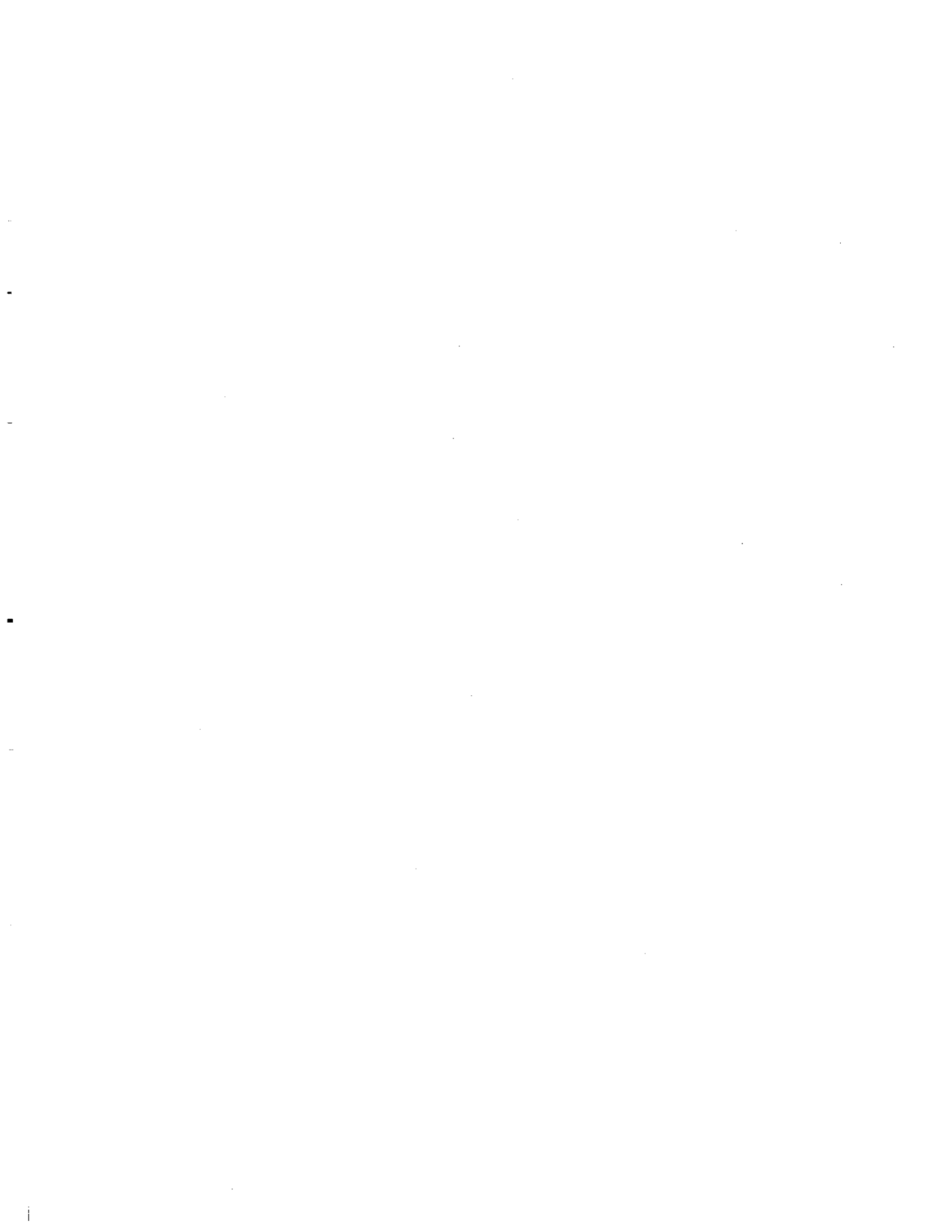
## Introduction

This manual is a guide for service providers in both the aging and developmental disabilities networks. The guide 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 readers as they begin to try to improve accessibility and use resources in their own community.

*How to Integrate Older Adults* is the result of a multi-year initiative among the New York State Office for the Aging, Office of Mental Retardation and Developmental Disabilities, and the Developmental Disability Planning Council to first identify barriers and then develop and test strategies for integrating older persons with developmental disabilities within aging network programs.

The information was distilled from the actual experiences of four county-based demonstration projects which tested the feasibility of helping older New Yorkers with developmental disabilities access and use a variety of local aging service programs. These included nutrition programs, senior centers and social adult day care programs. The demonstration projects were located in both rural and urban areas of New York State and were under the auspice of both aging and developmental disabilities agencies. During the first year of the Project, they successfully integrated more than 70 older New Yorkers with developmental disabilities into community aging programs.

Most important, we learned that to successfully integrate older persons with developmental disabilities we must expand the way we think about people and their limitations. Seniors with developmental disabilities can be successfully placed in a variety of generic community aging programs; enjoy participating with their age peers; and if given the opportunity to participate, be accepted.



## How It Began

In the early 1980s, the collective efforts of the State Office for the Aging (SOA), the Office of Mental Retardation and Developmental Disabilities (OMRDD), and the New York State Developmental Disabilities Planning Council (DDPC), produced a series of initiatives focusing on the aging of the state's older disabled population. The OMRDD produced a major public policy report in 1983 and the agencies jointly held a statewide conference on this issue in 1985. Both embarked on major internal analyses on the direction to take with further program development.

This led to recommending a series of demonstration initiatives, to be underwritten by the Developmental Disabilities Planning Council, that would test out the feasibility of integrating older persons with lifelong disabilities into aging network programs. Following a call for proposals, the DDPC awarded several development grants across the state that would promote integration.

### The SOA Aging & Developmental Disabilities Integration Feasibility Demonstration Project

Thus the Aging & Developmental Disabilities Integration Feasibility Demonstration Project was born. Its task was to test the feasibility of serving elderly persons with developmental disabilities within aging network programs. The project was based on the hypothesis that local generic aging service programs such as senior centers, nutrition sites and social adult day care programs could readily serve persons with developmental disabilities. An integral question was, "Could it help older persons with developmental disabilities mainstream or enhance their skills, while having an equally neutral or positive effect on the regular participants at these sites?"

The Project was undertaken in two phases. The first phase analyzed the barriers to integration and formulated strategies to address those barriers. This effort resulted in the publication of a report on the barriers and strategies (or recommendations) for overcoming them. Readers are referred to the publication *Barriers to and Strategies for the Integration of Older Persons with Developmental Disabilities within Aging Network Services* (NYS Office for the Aging, 1987) for a full description.

The second phase involved setting up and evaluating four county-based demonstration projects. These were set up to test the project integration feasibility premise by actually attempting to integrate seniors with developmental disabilities into a variety of community aging programs. Each project was allowed to develop its own integration methodology. The progress of the local demonstrations was carefully monitored and assessed by SOFA.

The four demonstration projects set as their goal to aid some 55 developmentally disabled seniors access and use community aging programs. At the end of the first year of the Project the goal had been well exceeded. Some 70 older persons with developmental disabilities had been successfully integrated into 15 discrete aging service sites.

The local demonstration projects used a variety of staffing patterns to assist in the integration process; these included:

- volunteer companions
- paid companions
- paid staff, and
- shared staff

The older persons who participated in the demonstrations were integrated into:

- senior nutrition sites
- senior centers, and
- social adult day care programs

The local demonstration programs conducted the integration process both by making individual placements and by making group placements at one time.

What did we learn from the Aging and Developmental Disabilities Integration Feasibility Project?

- Elderly persons with developmental disabilities can be successfully integrated into existing aging programs.
- Elderly persons with developmental disabilities can and do benefit from being integrated into local aging services programs. *[For example, many formed new friendships or experienced activities previously unavailable to them.]*
- Integration can be successfully achieved using different methodologies.
- The means of successfully integrating older persons with developmental disabilities involves networking with interested agencies, service providers, and people.

Assessment of the demonstrations showed us that our original hypothesis had merit and that our suppositions were workable. Our conclusion was based on the analysis of data and documentation collected during site monitoring visits and from pre- and post-assessments of the individuals served, other elderly site users, and site staff attitudes. The assessment data of the individuals served indicated improvements in the following areas:

- interpersonal skills
- self concept, and
- self esteem

Further, assessments of site staff and participants showed positive responses to the joint use of aging network community programs by elderly persons who have developmental disabilities.

## Madeline

**M**adeline moved into a family care home and is attending Day Care on a daily basis. At first, her behavior was generally uncooperative and withdrawn. She is beginning to be more involved. While a staff member was showing the Center to someone that Madeline knew, Madeline took hold of his arm and spontaneously began to give him a guided tour.

**S**he is now affectionately known as the Center tour guide - a role of which she is extremely proud.

## **Audrey**

**Audrey has had no involvement in community activities and has lived with her elderly mother.**

**On her first visit to day care it was like watching a blossom open. Her enthusiasm and joy for being with others influenced everyone. Audrey attempted every activity offered - asked for help as needed and expressed her delight with the "new world" by her happiness and joy. Everyone around her feels wonderful just to be with her.**

The diversity of the local county demonstration projects enabled the State Office for the Aging to gather valuable information about a range of programmatic features, including:

- appropriateness of sites
- planning processes
- integration methodology
- barriers to integration
- staffing
- user suitability
- networking, and
- interagency coordination

## General Concepts to Know About

The term *developmental disabilities* encompasses a variety of conditions. These can include *autism, cerebral palsy, epilepsy, mental retardation, learning disabilities*, and other *neurological impairments*. These disabilities are not mental illnesses, nor are they diseases. Instead, they constitute a lifelong mental or physical impairment which became apparent during childhood and has hampered an individual's ability to participate in mainstream society, either socially or vocationally. In addition, some people with one disability, such as mental retardation, can also have another disability, such as epilepsy.

The developmental disabilities definition contains the following elements; the disability must --

- (1) have originated before the person attains age twenty-two,
- (2) have continued or can be expected to continue indefinitely,
- (3) constitute a substantial handicap to that person's ability to function normally in society.
- (4) result in substantial functional limitations in three or more of the following life activity areas: self-care, receptive or expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency.

In recent years, much attention has been given to the rights of people with disabilities. The efforts of many interest groups have resulted in legislation that is designed to improve accessibility in buildings, increase education and employment opportunities, increase access to social services, and offer realistic portrayals of persons with disabilities in the media.

These developments -- resulting from the recognition that people with disabilities are people first and consequently are valuable and equal members of society -- help people who have disabilities lead more satisfying, productive lives.

However, many people still view individuals with disabilities as lesser people -- to be pitied, feared or ignored. These attitudes may arise from a fear of someone who is different in any way or simply from a lack of information about disabilities. As much as the disability itself may affect a person's life, being treated as a lesser person prevents a person with a disability from leading a productive life and enjoying the same opportunities as others.

This manual gives suggestions on how to relate to people with disabilities, how to look beyond the disability and appreciate the individual's abilities and personality -- the things that make each of us unique and worthwhile.

## Understanding "developmental disabilities"

The best way to understand what a developmental disability is, is to think of it as a condition that an individual may have had since birth or childhood, has prevented him or her from being fully independent, socially or vocationally, as an adult, and continues on into old age.

Developmental disabilities may cause a person to be slower in their thinking or less agile in their movements. They may be associated with impaired speech or social judgement. When severe, they may also be associated with other impediments such as seizures or impaired movement, and deficits in sensory, language, and social abilities.

Such disabilities are important to identify and understand during childhood and adolescence, since much can be done to help people achieve maximum independence within the bounds of their disability. With old age, such considerations are less important since the pressures of work and competition are minimal.

These lifelong disabilities mirror, in many ways, the impairments that are associated with late life. The importance of accurate diagnosis is lessened with old age. The critical factors for assessment are the functional skills or limitations of the individual.

Some of these conditions, in their more severe forms, that fall under the rubric "developmental disabilities," are briefly described below:

**Autism** is a condition characterized by severe disorders in learning and behavior that begin in early childhood and have a marked effect on informational learning, developmental rate and sequences, responses to environmental events, communication, and interpersonal relations. It is not a mental illness, but is possibly caused by a physical disorder of the brain. Persons mildly affected by autism might simply appear naive or eccentric. Those more severely affected are withdrawn and may display repetitive or unusual behavior, such as rocking, and may also be mentally retarded.

It is rare to see a person diagnosed with autism in old age since there is a mellowing effect of the symptoms during mid-life. Most older persons who were autistic as children are considered to be mentally retarded in old age. Otherwise little else is known about the interaction of age and autism.

**Cerebral palsy** is a group of dysfunctions characterized by difficulty in muscular control and sensory functions, affecting mobility, speech and arm and hand movements. Cerebral palsy is usually attributed to brain injury before birth and is often associated with low birth weight. However, brain damage or injury at any time can cause much the same symptoms.

The effects of cerebral palsy can be mild to severe. The severe forms are associated with developmental delay and motor impairment, and thus an individual is considered to be developmentally disabled.

Individuals with certain forms of cerebral palsy often have severe speech problems, thus causing the observer to think they are mentally retarded, which is not always true.

There is no cure for cerebral palsy, but many of the problems that people with cerebral palsy experience can be effectively aided by various therapies and prosthetic and computer assisted technologies.

Little is known about the interaction of aging and cerebral palsy with the exception that with advancing age women with cerebral palsy appear to have a greater mortality rate than men. Physically, because of a lifetime of muscular dysfunction, age appears to have a much more deleterious effect. Many older persons with cerebral palsy lose muscular abilities sooner. The co-prevalence of arthritis among older persons with cerebral palsy is also high.

When with an older person with severe forms of cerebral palsy:

- Speak directly to the individual, not to a friend or companion.
- Try to give your whole, unhurried attention if the person has difficulty speaking.
- Do not complete the speaker's sentences; let the person finish.
- Do not be afraid to ask the person to repeat something.

**Epilepsy** involves a number of disorders of the nervous system that result in abnormal electrical charges of brain cells. These cause sudden seizures, muscle convulsions, and partial or total loss of consciousness. Persons who have minimal or mild seizures are not developmentally disabled. Most persons with epilepsy are not mentally retarded. Only the severe forms of epilepsy fall into the category of a developmental disability and in these instances, the individual may also have mental retardation.

Seizures are a primary characteristic of epilepsy, but they can be controlled or prevented by the use of medication. Most seizures last only a few minutes and many individuals receive enough of a warning to avoid falling or becoming injured.

Little is known about the interaction of aging and having seizures over a lifetime. Epidemiological studies appear to indicate a shorter life expectancy, particularly among those individuals with multiple disabilities (such as epilepsy and mental retardation).

If an older individual has a seizure:

- Keep calm -- you cannot stop a seizure once it has started.
- Do not restrain the person.

Clear the area of hard, sharp, or hot objects which could injure the individual. If the person is lying down, place a pillow or rolled-up coat under the person's head.

*Mental retardation* is defined as subaverage intellectual functioning that originates during the developmental period and is associated with impairment in adaptive behavior. Mentally retarded persons characteristically have limited ability to learn and difficulty in using what they have learned. Mental retardation has a variety of causes, including premature birth, genetic abnormalities, malnutrition, exposure to toxic agents, or social deprivation.

The level of mental retardation varies greatly from person to person. Although one individual may eventually be integrated within the mainstream of society, another individual who is more disabled may always require some degree of supervision. Most people with mental retardation are capable of learning to care for themselves and to function in society.

Some persons with mental retardation may have difficulty fitting in socially because of limited social judgement -- however, with guidance and practice most problems can be overcome.

With advanced age, older persons with mental retardation generally experience the same rate of physical and medical problems as other seniors. Contrary to some beliefs, persons with mental retardation do not normally age

**M**orning coffee is a very special time. The seniors will discuss what they have done during the week and what they plan to do over the weekend. One time, they were talking about a dance they planned to attend. They started happily teasing one another about who would dance with whom!

**O**ne senior was very upset because her case manager had scheduled a dental appointment for her on the same day that she was to attend day care. She was so troubled about missing day care, she cursed all the way to, during, and back from the dentist.

earlier than other age peers of the same cultural or socioeconomic background.

One major difference is among persons with *Down syndrome*, a prevalent cause of mental retardation. Persons with Down syndrome do age earlier and appear to suffer a greater co-incidence of Alzheimer's disease. Early aging occurs in the fourth decade and about one of three older persons with Down syndrome shows the behaviors associated with Alzheimer's disease (usually by the mid-50s).

When communicating with an older person with mental retardation:

- Use easily understandable sentences.
- Give instructions that are clear and concise.
- Talk to the person as a person -- talk to adults as adults, not as children.
- Take more time to listen and understand what the person is saying.

*Neurological impairments* is a term that encompasses a diverse group of conditions, all of which relate to some form of central nervous system dysfunction. Included in the definition are conditions such as *severe learning disabilities*, *spina bifida*, *Tourette's syndrome*, *neurofibromatosis*, *Prader-Willi syndrome*, and *sensory impairments*. Many of these conditions are rare and are usually found in children and adolescents, somewhat among adults, but rarely among seniors.

Among seniors, the lifetime effects of a learning disability may be seen in an individual's inability to read, write, or readily recognize symbols.

Little is known about the effects of aging upon other conditions considered to be neurological impairments, with the exception that, in many instances, these conditions are

associated with a shortened lifespan. Many persons with severe neurological dysfunctions do not live to old age.

## Problems Using Local Services

The definitions of the various disabilities provide many clues to the kinds of difficulties older adults with developmental disabilities may face. Many of them continue to have trouble expressing themselves. Many have difficulty getting about and the conjunction of impairments associated with aging may make getting about ever more difficult. Many have physical difficulties that lead to other problems. Many have not had the richness of experiences available to other older adults over the lifespan. These are some of the problems that older persons with developmental disabilities may experience.

However, within the context of these problems there are other systemic problems found within both the aging and disabilities networks that arise when older adults try to use mainstream senior services. The New York State Office for Mental Retardation and Developmental Disabilities and the State Office for the Aging found that the following barriers or obstacles to integration often occur:

- attitudinal
- information and communication
- financial
- programmatic
- education and training

The State Office for the Aging's report, *Barriers to and Strategies for the Integration of Older Persons with Developmental Disabilities within Aging Network Services*, offers a fuller explanation of each of these barriers or obstacles. An abstract of the key points follows:

### Attitudinal barriers

Aging network personnel often overestimate the difficulties of dealing with persons with developmental disabilities. These personnel express concerns that they would not know what to do in case of a seizure or if the disabled

person should act "strange." They also fear that including persons with developmental disabilities might upset their regular clientele at congregate sites.

Developmental disabilities system personnel are sometimes overprotective. Some might lack sensitivity to the special needs of older developmentally disabled persons. Some believe that "we can do it better than anyone else," thus ignoring the potential benefits of integration for the older developmentally disabled person.

Some families of persons with developmental disabilities are overprotective, and some are reluctant to use a formal caregiving system of any kind.

Some older persons with developmental disabilities fear change, the loss of friends, or the act of going out alone. That makes them reluctant to participate in aging network programs. Because they generally have learned to be passive in the presence of authority figures, the free environment at senior sites can be problematic and, in itself, a barrier.

Perhaps the greatest attitudinal barrier to integration is the problem of negative stereotypes about developmental disabilities and older persons with developmental disabilities among non-disabled persons. Disabled persons are subject to prejudices resulting from assumptions that they are childlike, have problem behaviors, and look different.

Non-disabled persons of all ages, including elderly persons are often reluctant to share common services with peers who have disabilities.

### Information and communication barriers

The lack of substantive information about older persons with developmental disabilities is an impediment to integration.

The lack of communication among agencies can pose special problems. Neither system knows much about the other.

Confidentiality of records and problems in sharing information can be a barrier.

The lack of a comprehensive intake and referral system can impede coordination and the use of generic aging services by older persons with developmental disabilities.

### **Financial barriers**

The current program overload and shortage of funds, coupled with a lack of fiscal incentives to support special initiatives, clearly contribute to the absence of linkages that could expand integration.

Fragmented funding sources is an obstacle as is competition for limited financial resources and the tendency to preserve traditional spans of responsibility.

Another barrier is the regulatory and compliance standards required by the developmental disabilities system for reimbursement.

### **Programmatic barriers**

Social services programs have different staffing and program standards than health-related and habilitation programs, so coordinating the two can be difficult.

Developmental disability system requirements for active treatment and goal-based programming of persons with developmental disabilities can be seen as insensitive to the needs of some older individuals who may necessarily be more "retired" than active.

The aging network lacks staff members trained and experienced in providing supervised care to persons with developmental disabilities.

The absence of adequate transportation is a major problem.

The architectural design of some aging service sites make them inaccessible to seniors with disabilities.

### **Education and training barriers**

There is a lack of adequately trained professionals who know about both aging and developmental disabilities and who understand the means needed to meet the programmatic and life support needs of older persons with developmental disabilities.

Agencies lack funding for cross-network training activities.

Some professionals resist cross-network integration.

## The Aging Network

The term *Aging Network* refers to the system responsible for furnishing services to persons aged 60 and over. That system is part of a national network on aging established by the Older Americans Act and headed by the U.S. Administration on Aging. It is comprised of 57 State Units on Aging, some 664 Area Agencies on Aging, 721 state and local advisory councils and thousands of nutrition and supportive service providers operating at the community level.

In New York State the aging network is comprised of state and local government agencies as well as a large variety of community level service provider agencies.

### Role of the State Office for the Aging

The lead agency at the State level is the NYS Office for the Aging. Under the federal Older Americans Act and New York State statute, the State Office 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. In general terms, the Office is responsible for the following:

- Management and administration
- Designation of planning and service areas
- Development of intrastate funding formulas
- State plan development
- Service system development
- Needs assessment
- Establishment of priorities
- Systems development
- Program development
- Services development
- Program operations
- Training
- Advocacy

- Policy and program design
- Pooling and coordination
- Community involvement
- Capacity-building and technical assistance

In New York, the State Office for the Aging supports and monitors a network of county-wide aging offices throughout the State. The local county aging offices (also called area agencies on aging), are, with few exceptions, part of county government. The non-governmental aging offices provide the same services as their county government counterparts, but have private not-for-profit sponsorship. In New York City, the aging office is a city government agency and serves all five boroughs.

There are 59 local aging offices representing all of the counties in New York State as well as the St. Regis Mohawk Indian Reservation, and the Seneca Nation of Indians (which includes the Cattaraugus and Allegany Reservations) - these are the only Indian Reservations so designated east of the Mississippi.

### Role of Local Aging Offices

The local aging offices have the responsibility to plan, coordinate, advocate and facilitate the development of comprehensive service delivery systems at the local level to meet the long and short term needs of older persons in their designated service area.

Each local aging office prepares a multi-year plan and annual updates which identify the needs of older persons, existing services, and gaps between needs and services. The plan also identifies objectives, priorities and specifies which services will be provided to meet those needs.

Local aging offices are responsible for seeing that the following categories of services are provided via a provider agency or if unavailable, then, directly by their office:

- Services associated with access to

## **Lucille**

**F**or the first time in Lucille's life she is functioning at a higher level than some of her peers.

**She constantly watches out for others, especially Alzheimer's patients who wander. During luncheon trips she helps staff members by holding purses and coats or pushing wheelchairs.**

**She loves the involvement here, and enjoys participating as a contributing member of the center.**

services (transportation, outreach, and information and referral).

- In-home services (homemaker and home health aide, visiting and telephone reassurance, chore maintenance, and supportive services for families of elderly victims of Alzheimer's disease and the neurological and organic brain disorders of the Alzheimer's type).
- Legal assistance

The following are examples of the kind of services provided by a local aging office either directly or through a service delivery contract with a provider agency in the community.

### **Information and Referral**

Frequently, older people need services but do not know where to turn to receive them. By calling the aging office, senior citizens are linked with appropriate services and provided necessary information.

### **Outreach**

This service provides outreach workers to staff community gathering points (such as nutrition sites) and to make home visits where necessary. Outreach workers help those who are in poor health, who live in isolated areas or who have low income get the services and or information they need. They provide entitlement counseling for a wide range of services and benefits available to older people. Senior citizens who need assistance from an outreach worker can schedule a visit by calling the aging office to secure a visit by an outreach worker.

### **In-Home Services**

A case manager does a needs assessment and recommends services; prepares a service plan; and monitors the continuing provision of services needed to maintain a person in their home. In-Home services are provided by the New York State EISEP program (*Expanded In-Home Services for the Elderly Program*). EISEP

provides non-medical in-home services to disabled elderly persons who need supportive services.

## **Transportation**

Transportation for senior citizens to medical and other necessary appointments may be provided by volunteer drivers who are reimbursed for mileage or by an aging office van with a full time driver. Shopping assistance may also be available.

## **Escort**

Escort may be provided by the county aging office's outreach staff who accompany senior citizens if they need extra help in arranging for needed services.

## **Public Information**

To keep senior citizens up to date on programs, services, and other information of interest to older people, most aging offices publish a newsletter which is mailed monthly or bi-monthly. Other publications may also include: a directory of county services; a financial organizer; a long term care directory and a senior discount merchants directory. In addition, newspaper articles, speaking engagements and radio announcements are prepared and used to make important information available to older residents.

## **Alzheimer's Disease and Related Disorders Support Groups**

Some aging offices offer support groups, individual counseling, resource materials and a monthly newsletter to help family and caregivers of people with Alzheimer's disease and related disorders.

## **Congregate Meals**

A congregate meal program offering hot, nutritious meals is provided in a variety of locations and sites by the aging office's Senior Nutrition Program. Monthly menus are published and posted at all nutrition program sites.

## **Home Delivered Meals**

Meals can be delivered if a senior is frail, disabled and or homebound. Frozen meals ready to reheat are available for weekends and for areas which do not have daily delivery in some counties. These home delivered meals are provided under the New York Supplemental Nutrition Assistance Program.

## **Nutrition Education and Counseling**

The aging office's Registered Dietitian provides informative programs on nutrition during regular visits to nutrition program sites. The Registered Dietitian may also write articles for the monthly newsletter as well as prepare nutrition tips to include with home delivered meals and provide individual nutrition counseling as needed.

## **Recreation**

Recreation programs, activities and services may be directly furnished by the aging offices at a variety of sites including nutrition program locations. In addition, aging offices provide information about the state Senior Games Program and may sponsor local Senior Game Programs.

## **Visiting and Telephone Reassurance**

An aging office, sometimes in cooperation with the Retired Senior Volunteer Program, may provide trained volunteers to call or visit older people who are homebound and/or physically or socially isolated.

## **Home Helper/Handyman**

This referral service provides senior citizens who need assistance in maintaining a home, performing routine or seasonal chores, personal care, or minor home repairs with a list of people in their area who are eager to do the requested work. The program also provides employment to senior citizen workers as well as making information about competent workers available to senior citizens.

## **Enriched Housing**

This service may be provided by a county aging office under the regulation of the New York State Department of Social Services. Eligible residents of senior housing complexes may arrange for assistance with personal care, shopping, cooking and housework through the Enriched Housing program.

## **Energy Assistance**

The aging office assists senior citizens in meeting their energy needs by providing energy information, outreach and assistance with applications for HEAP (*Home Energy Assistance Program*). By screening applications, the county aging office certifies those over 60 who are eligible to receive federally funded energy assistance and related programs such as *Weatherization*, *Project SHARE*, *Care and Share*, and *Energy Conservation Bank*.

An aging office also assists people who are ineligible for these programs in solving fuel related problems. The Energy Program Coordinator and Office for the Aging outreach workers provide entitlements counseling for a wide range of programs and benefits available to older people.

## **Discount Cards**

Senior citizens over 60 may be able to obtain a discount card from the local aging office. Discount cards and a merchants' directory make it possible for senior citizens to purchase goods at lower cost.

## **Adult Day Care**

Adult day care may be provided for older people who are disabled, live in isolated areas, or who need some assistance in order to remain independent and active in their communities. Adult day care offers supportive services in a group setting. Programming includes a hot meal, socialization, recreation, individual and family counseling, and training in skills needed to remain independent despite one or more handicapping conditions.

## **Insurance Counseling**

Insurance counseling may be provided by the local aging offices. The service helps older people with health insurance problems through counseling, policy review sessions, explanation of forms, and through informative workshops.

## **Legal Services**

Legal services are provided by the aging office via a subcontract with a community legal aide agency. The service is designed to improve the availability of legal services to the elderly, including representation on matters affecting their rights, entitlements, benefits, and other matters directly affecting their general welfare and independence. Referrals to private lawyers are made when appropriate.

## **Respite**

The aging office may provide a respite program which will allow caregivers of older family members to prearrange for care when a vacation or necessary absence from home is planned or for regular weekly respite for the caregiver.

## **How Aging Programs are Funded**

The State Office for the Aging receives funding, in part, from the following:

- the Federal Older Americans Act, and
- State funding authorized for programs such as the Supplemental Nutrition Program (SNAP); Community Services for the Elderly Program (CSE); the Expanded In-Home Services Program (EISEP).

Through these statutes the State Office funds the local aging offices to provide a range of aging service programs.

## **Funding for Local Aging Offices**

The local aging offices draw upon the State Office funding to provide mandated services. In addition, they are also free to attract other funding to support services they want to provide. Depending upon the funding source the local aging office may or may not have broad discretion in deciding what types of services to support.

Local aging office programs and services are supported by the following funding sources.

### **Older Americans Act Title III-B - Federal Funds**

Under Title III-B funding, 90% of the funds provided to the local aging office must be used for social services. Up to 10% may be used for office administration. Title III-B funds can be used to provide the following services:

- Transportation/Outreach
- Information and Referral/Legal Services
- Public Information Advocacy/Ombudsman
- Home Helper/Handyman/ID/Discount Cards
- Insurance Counseling/Escort
- Friendly Visiting & Recreation
- Telephone Reassurance

### **Older Americans Act Title III-C - Federal Funds**

Under Title III-C funding, 90% of the funds provided to the local aging office must be used for nutrition program services. Up to 10% may be used for program administration. Title III-C funds are used to provide the following services:

- Home Delivered Meals
- Congregate Meals
- Nutrition Education
- Outreach

### **SNAP-Supplemental Nutrition Assistance Program - State Funds**

New York State SNAP funding provides additional funding for home delivered meals to frail, isolated, or homebound senior citizens. SNAP funds are also used to provide the following services:

- SNAP Home Delivered Meals
- Nutrition Education
- Nutrition Counseling
- Outreach

### **Older American Act Title V Senior Employment Program - Federal Funds**

Title V funding supports the Senior Employment Program. Under Title V, part-time employment opportunities are developed for low income persons 55 and older. The funding supports worker's wages and benefits. These workers assist with the following services:

- Transportation
- Outreach
- Adult Day Care

### **Community Services for the Elderly - State Funds**

Community Services for the Elderly (CSE) State funding is used to provide planning, coordination, and services for the frail elderly. The following services may be supported under CSE:

- Adult Day Services
- Outreach Service
- Alzheimer's Support Groups
- In-Home Services
- Transportation
- Case Management
- Respite Services
- Telephone Reassurance
- Home Delivered Meals

## **Sue**

**Sue was not involved in community activities and was very dependent on her mother for care.**

**Since attending the senior center, she has blossomed. She enjoys the camaraderie of others, and is very vocal. She participates in activities, and is beginning to function more independently.**

## **Andy**

**Andy is a very quiet gentleman who rarely interacted in community activities. Since attending the Senior Center he has become very verbal. He enjoys attending luncheon trips and shows increasing involvement.**

## **Other Funds**

As mentioned earlier, local aging offices are free to secure funding from other sources to expand existing services or provide new services not covered by the previously mentioned funding. The following are examples of some additional services and their funding sources:

- **Senior Recreation** funded by the State Recreation for the Elderly Program.
- **Enriched Housing**-self supporting (regulated by the New York State Department of Social Services) as an adult home with a combination of Federal SSI, and state subsidies. HEAP (Home Energy Assistance Program) provides low income seniors with a grant to cover winter heating costs. HEAP is funded by a Federal Energy Assistance Grant.
- **Adult Day Care** programming funded by a member item legislative grant-in-aid.
- **Senior Companion Program** funded by an Action (Federal Volunteer Agency) grant.

## **Special Note About Funding**

The State and Federal funding sources used by local aging offices to provide services generally require a "local match". The local match varies from 10% to 25% and depending upon the program, may be cash or in-kind.

## **The Older Americans Act Disability Amendments**

When the Older Americans Act Amendments of 1987 (PL 100-175) were signed into law in November, 1987, this legislation contained a number of new provisions specifically addressing older Americans with lifelong disabilities.

A number of the provisions called upon the federal Commissioner of the Administration on Aging to develop new initiatives addressing the needs of older Americans with a disability, develop linkages with the Administration on Developmental Disabilities, and promote greater access for older Americans with a disability to Older Americans Act services.

Other provisions called upon the state units on aging and the area agencies on aging to develop stronger linkages with state and local disability agencies, promote more effective community long term care services, and conduct needs assessments, program development and case finding efforts. The provisions also definitively spelled out the inclusion of older Americans with disabilities into Older Americans Act services.

Specifically, the following disability related provisions were incorporated into the Older Americans Act:

Two new terms were added to the Act: disability and severe disability.

- **Disability** refers to a mental or physical impairment, or a combination of mental and physical impairments, that results in substantial functional limitations in one or more of the following areas of major life activity: (a) self-care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, (g) economic self-sufficiency, (h) cognitive functioning, and (i) emotional adjustment.
- **Severe disability** refers to a severe, chronic, condition that is attributable to mental or physical impairment, or a combination of mental and physical impairments, that (a) is likely to continue indefinitely; and (b) results in substantial functional limitation in three or more of the major life activities noted above.

The Commissioner of the Administration on Aging (AoA) is required to undertake a number of activities, including:

- develop planning linkages with the Administration on Developmental Disabilities.
- advise, consult and cooperate with the Administration on Developmental Disabilities, the federal agency that administers the Developmental Disabilities and Bill of Rights Act (the Commissioner of the Administration on Developmental Disabilities is in turn required to reciprocate in areas related to the purposes of the Older Americans Act).

The state aging agency is to coordinate planning, identification, assessment of needs, and services for older individuals with disabilities with the state agency with primary responsibility for individuals with disabilities, and develop collaborative programs, where appropriate, to meet the needs of such older individuals with disabilities.

Area agencies on aging are required to undertake outreach efforts to identify individuals eligible for assistance under the Act, including older individuals with severe disabilities.

Area agencies on aging can offer meals at a nutrition site to younger persons who are disabled who reside at home with and accompany older individuals who are eligible under the Act.

For an excellent description of the history and general provisions of the Older Americans Act of 1965, as amended, see *An Orientation to the Older Americans Act*, a manual published by the National Association of State Units on Aging (Washington, DC, July, 1985).

# The Developmental Disabilities System

The term *developmental disabilities system* refers to the many agencies, both private and public, which plan, coordinate, administer, offer, or finance services for persons of all ages who are developmentally disabled. 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.

## Overview

Early advocacy for equal educational opportunities led to the passage of PL 94-142, the Education for All Handicapped Children Act. With the implementation of this Act (and its amendments), individuals with handicapping conditions were expected to be fully integrated within the mainstream of society's opportunities and activities.

Recent revisions to that Act have done the same for preschoolers, and amendments to the Vocational Rehabilitation Act, for work age adults. With the inclusion of disability-related provisions in recent amendments (PL 100-175) to the Older Americans Act, the same expectations have been set for older individuals with lifelong disabilities.

For persons with developmental disabilities, reaching old age always was a reality; however, it was a reality that was subordinated to other developmental concerns. In the past, most persons with severe developmental disabilities had a relatively short lifespan and many adults with developmental disabilities spent much of their lives in public institutions. Consequently, their aging was not of immediate concern.

However, increased longevity, resulting from more readily available services and im-

proved health status, and the added visibility of many elderly persons with developmental disabilities now living in the community, have contributed to a greater awareness of their lifespan development and aging.

In New York the developmental disabilities services system is divided by agency and age.

Infants with disabilities are the responsibility of the health system with support from the Office of Mental Retardation and Developmental Disabilities.

Children with disabilities are the responsibility of the education system; those children who are substantially handicapped, as well as their families, can also receive services from the Office of Mental Retardation and Developmental Disabilities.

Adults, minimally handicapped, may be the recipients of services from the vocational rehabilitation agency; those persons more disabled and needing special services receive them through the Office of Mental Retardation and Developmental Disabilities.

## Role of the Office of Mental Retardation and Developmental Disabilities

The Office of Mental Retardation and Developmental Disabilities (OMRDD) is the state agency with authority and responsibility, under the state's mental hygiene law, to provide services to persons with developmental disabilities. The OMRDD is organized into 20 regional or district offices. (See Appendix for listing of the district offices).

The OMRDD serves as a regulator of services, as well as a major provider. Combined, the OMRDD and its vast network of provider agencies provide for some 4,000 foster family care home spaces, 10,000 community residence spaces, and 40,000 adult day program spaces. The agency also operates a family support

program that aids families with a disabled member through respite, and other support services.

The driving philosophy of the OMRDD and its provider network is to maximize the community integration and mainstreaming of persons with developmental disabilities.

In the area of senior services, the agency and its network operate numerous group homes or community residences which predominantly serve seniors. The agency has also expanded its Family Support Program, by having local adult day care programs underwritten by this program. In 1989, the OMRDD also expanded its adult day training capacity to include senior day programs.

### **Programs and Services for Older Persons with Developmental Disabilities**

The program options available to older New Yorkers with a developmental disability include:

- supportive apartments
- community residences
- foster family care homes
- day treatment programs
- senior day programs
- sheltered workshop programs
- supportive work programs
- respite and other family supports

#### **Supportive apartments**

These are a form of community residence where from one to three adults live by themselves, but receive drop-in supervision. This residential model is for those adults who

#### **John**

**John attended a state school for much of his adult life. He was deinstitutionalized and lives in an adult home. Initially he was in a day treatment program. Staff felt that John was too high functioning for that program and referred him to a seniors' program. He began in a special transition-assistance program. After a short time, John was able to participate in the program independently.**

**Eventually, John became a Retired Senior Volunteer. He assists others in wheelchairs and assists senior center staff in decorating for parties, clean-up, and moving furniture. John also attends a peer support group for others with disabilities to discuss positives and negatives of their community program. John is well-liked by all and has become an integral member of the senior center.**

are the most capable. They usually serve as a bridge to independent living. These are operated by the state OMRDD and its network of voluntary agencies. Referrals for admission can be made to the agency which operates the program.

### **Community residences**

Community residences or group homes may take many forms. One is the supported community residence which is funded by State funds. These residences provide housing for up to 14 adults. Generally, these residences provide housing for adults who are more independent and vocationally and socially capable. There are over 30 such residences across the state which provide housing for older and elderly adults.

A variation of this residence is the ICF-MR/community residence, which is funded through Title XIX Medicaid funds. These residences provide housing and active treatment to individuals who have greater dependency and care needs.

Community residences have shift staff who provide supervision, companionship, training and other support services. They are operated by both the state OMRDD and its network of voluntary agencies. Some 17% of the residents are elderly. Referrals for admission can be made to the agency which operates the residence.

### **Foster family care homes**

Foster family care homes are the oldest residential model in New York. These homes, supported by State funds, provide for board and care, as well as some training for adults who need some level of supervision. Foster family care homes are private homes, certified to be used as housing for up to 4 adults with developmental disabilities. Some 34% of the foster family care residents are elderly.

A variation of this residential model is personal care homes. These are foster family care homes where one or both of the home's owners are certified to provide Medicaid reim-

bursable personal care services. Residents of personal care homes are generally more dependent and disabled. The foster family care program is operated by the OMRDD. Referrals for admission can be made to the OMRDD's district office.

### **Day treatment programs**

Day treatment programs are day programs funded by Title XIX Medicaid funds. These programs provide a range of habilitation activities and therapies that comprise a program of active treatment. Currently, some 40 day treatment programs across the state provide specialized services to seniors.

These programs are similar in structure to medical model adult day care programs. Senior day treatment programs are operated by both the state OMRDD and the voluntary agencies. Referrals for admission can be made to the agency operating such a program.

### **Senior day programs**

Senior day programs are built upon the social adult day care model. They are funded by state and local funds on a 50%/50% basis. These programs, originally "day training" programs, are designed to provide a range of habilitation and social activities for seniors. Currently some 25 senior day programs are operating across the state.

OMRDD is experimenting with 100% state funded senior day programs; in 1989, six such programs were funded as demonstrations. Senior day programs are operated by both the state OMRDD and the network of voluntary agencies. (For information about these demonstrations, refer to *New Directions for Seniors: Senior Day Program Demonstrations*, available from OMRDD - see appendix.) Referrals for admission can be made to the agency operating such a program.

### **Sheltered workshop programs**

The state's network of sheltered workshops provides vocational training and work services to adults of all ages. Many seniors are

still enrolled in workshops or are admitted for work training. Sheltered workshops are operated by disability agencies, both those that specialize in mental retardation and those whose clientele include persons with various physical or social disabilities.

Such programs are funded by various sources, including contract income, grants, and state funds from the OMRDD, other disability agencies, and the Office of Vocational Rehabilitation. Referrals for admission can be made directly to the workshop or through the Office of Vocational Rehabilitation.

### **Supportive work programs**

Supportive work programs involve placing the worker in a competitive production or service work setting. Such programs are usually operated in conjunction with sheltered workshops and provide job coaches and on-site supervision to aid the worker to adapt to the job and job tasks. Referrals for admission can be made to the agency operating such a program.

### **Respite and other family supports**

The OMRDD's family support program is designed to assist a person with a developmental disability who resides with his or her family receive special supports to help him or her remain at home. Referrals can be made to the agency operating such a program or to the OMRDD district office.

**B**everly and her sister live in an adult home. A relative, who claimed to be their legal guardian, was neglecting her responsibilities for their finances and medical care. The adult home administrator had been "fighting" with the guardian for the past three years on the same issues. It developed that the relative was not actually the legal guardian and therefore had no legal right to make decisions for the sisters.

Help was sought from several legal agencies, including a protection and advocacy agency (P&A), but all refused to take the case, stating that it was not in their jurisdiction. The adult home was requesting legal guardianship and had agreed to become representative payee for the sisters. After many phone calls, a meeting of all agencies which had been contacted about the case was convened. The P&A finally agreed to take the case. In the meantime, the sisters were enrolled at a senior center with a Senior Companion. They now attend part-time and the attorney at the P&A is following up with surrogate court to appoint legal guardianship for the women.

## How the Aging and Developmental Disabilities Systems Differ

The disability system has its roots in two significant movements in the United States:

- the vocational rehabilitation legislation and program initiatives that addressed the needs of returning disabled World War I veterans and led to the development of a system of vocational rehabilitation services -- which eventually included other persons whose disabilities may have been congenital or originated in childhood - such as mental retardation and the other developmental disabilities.
- the parent advocacy movement that followed World War II and parent organizations such as the Associations for Retarded Children (now Associations for Retarded Citizens) which led the fight for legislation and funding of special services within specialized or generic settings dedicated to persons with mental retardation.

The derivation of the professionals that comprise the disability system's workforce also is different. Much of the technology upon which the mental retardation derived disability system is based is drawn from special education and rehabilitation - and is directed toward imparting new learning. Because its roots are in education, its focus is on individual training and development.

The language and orientation of developmental disabilities services reflects this background. For example, needs are assessed on individuals, services are planned around an "individual program plan," the terminology used is "habilitation" and "training," and most interventions/services are directed toward the

individual within the context of a setting that is individual-oriented.

The aging network'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 network'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 network 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 network is a group oriented modality and the rehabilitation technology that is drawn into it is based upon mitigating the problems associated with aging and maintaining independence as long as possible.

With regard to aging network programs, such as multipurpose senior centers, adult day care programs, congregate meals sites, and the community-based activity centers that make up a great part of the aging network's services, this difference is exemplified by:

- the lack of case orientation (as opposed to the disability system where case managers are an important ingredient),
- consumer freedom to come and go (as opposed to the disability system where intake and discharge form a "gatekeeper" function),
- assessment based upon functional need identifiers (as opposed to the disability system where diagnostics

and clinical descriptors are prevalent),

- sustenance of functional abilities and socialization (as opposed to the disability system where there is a continual emphasis on new learning and training), and
- a temporal orientation, providing services to a age-specific clientele (opposed to lifespan, "cradle to grave" care and case management in the disability system).

A fuller explanation of these differences can be found in *Aging and Disabilities: The Intersection of Needs and Resources*, a training manual for workers in aging and developmental disabilities agencies produced by the Center on Aging at the University of Maryland. (See Appendix).

## **Jesse**

**Jesse lives at the developmental center. He was assigned a Senior Companion and now participates three days a week at the senior center. Jesse has never before had the opportunity to participate in a community program. For the first time in his 78 years he is now socializing and involving himself in activities offered at the senior center. The response from other participants has been very positive. Staff at the developmental center state that on the days he attends the senior center he appears at the breakfast table with a large grin on his face.**

## **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. We'll go over each of these in more detail and explain how they can be useful.

### **Social Adult Day Care Programs**

Social Adult Day Care Programs are congregate programs which provide a structured environment for seniors who are frail and/or require supervision. The programs offer participants the opportunity for socialization and usually have daily programming built around recreation and other structured activities. Assistance with personal care is usually provided. Transportation may also be furnished. The programs have a nutrition component, typically a hot lunchtime meal. Social Adult Day Care Programs do not have to be certified, but usually function within general standards for such programs. Sites tend to be open 5-9 hours a day, 3-5 days a week. Social Adult Day Care Programs generally have a daily fee; most charge from between \$17 to \$30.

### **Participation By Persons With Developmental Disabilities:**

Social model adult day care programs are similar in many respects to the day training or day habilitation programs operated for adults by agencies serving persons with developmental disabilities. Because of their similarities, many older adults with developmental disabilities can readily adapt to the settings and programs. Admission is usually facilitated when operators meet the individual being referred and determine the extent of similarity with existing users. Under the SOA Integration Feasibility Demonstration Project many older persons with developmental disabilities were successfully placed in day care programs.

Indeed, we observed no problems at any of the sites. The comments of one of the demonstration site directors echoed those of the other program administrators when the director noted that the day care setting created an environment in which hidden talents blossomed. He reported that many of the older persons with developmental disabilities tended to function at or above the level of the "regular" seniors in his day care program. "Integration" he said, "is not an issue in day care because most attending have the same level of disability."

### **Senior Center Programs**

Senior centers are usually community facilities used for the organization and provision of a spectrum of services for persons aged 60 and over. Most senior centers are open daily from 9 am to 5 pm. Participation is usually free though a membership card and monthly newsletter may be offered for a small fee.

Senior center programs typically offer participants opportunities for creative expression (arts and crafts) and for social interaction (dancing events, cards, billiards, bingo, etc.). Recreational activities such as cards, conversation and watching the latest turn of the weekday soaps on the center TV, are the most popular.

Some centers have extensive program arrays which may include physical conditioning activities, college level courses, programs on computers, as well as opportunities for participating in organized volunteer activities. Generally, all senior centers offer a midday hot meal to participants.

### **Participation By Persons With Developmental Disabilities:**

Senior centers can offer those persons with developmental disabilities who are able to participate, an opportunity to grow and function in a relatively unstructured and unsupervised environment. Older persons with developmental disabilities who were successfully placed in senior centers under the SOFA Integration Feasibility Demonstration Project showed, as a group, marked improvements in social interactions, social behavior and in developing friends and friendships.

Senior centers are social institutions and as such are bound by the social groupings that form in them. Care must be given that persons you integrate into senior centers are not isolated. Those persons with the greatest chance of benefiting are individuals with a strong sense of social self, willingness to get involved in novel activities, and ability to function within fairly unstructured circumstances.

### **Senior Nutrition Programs**

Community nutrition programs are the most numerous type of congregate programs for senior citizens. Under the nutrition program, hot midday meals are provided for seniors aged 60 and over, 3 to 5 days a week. Spouses and companions under age 60 or persons with developmental disabilities under the care of nutrition program participants are also eligible to participate.

Seniors are requested to contribute a specific amount toward the meal, which is planned by a nutritionist. The suggested donation is usually between one and three dollars. Most programs use an unmarked envelope

system to allow a person to contribute what ever he or she can afford.

Nutrition program services are provided in a wide variety of facilities, such as senior centers, churches, town halls, schools and in buildings owned by community groups, such as the VFW.

Local nutrition program sites tend to take on many of the characteristics of a senior center. The sites sometimes serve as the only focal point and meeting place for seniors in the community. Often following the meal, announcements of community events will be made and a recreational activity will be offered for those who can stay. Unlike a senior center, activities, if offered, are usually concluded before mid-afternoon. Most nutrition-only sites open by mid-morning and close right after lunch if a planned activity is not held.

### **Participation By Persons With Developmental Disabilities:**

Nutrition program sites offer the opportunity for seniors with developmental disabilities to be a part of a daily community group and to socialize with others while enjoying a midday meal. Under the SOA Integration Feasibility Demonstration Project a number of older persons with developmental disabilities successfully participated in the hot meal program and in the activities which followed.

Nutrition sites typically have minimal staffing, consequently the persons you select to use a nutrition site should be able to take care of themselves or even help others. Site managers are especially appreciative of volunteers who can help set up the meal and pick up after. At some sites, older persons with developmental disabilities helped with the staging of the meal program.

### **The Benefits of Participation in Local Aging Programs**

Participation provides a link to the community which should be part of the depend-

ent adult's lifestyle, when that is possible and appropriate.

Participation offers a break from routine.

Participation provides an entry into a "normal" community group which can have a stimulating and positive effect on the day-to-day behavior and feelings of the dependent adult.

Participation provides exposure to a variety of experiences which tend to challenge intellectual capacity and make life more interesting and pleasant. For seniors with developmental disabilities as well as for the well-elderly seniors, local senior citizen programs can and do forestall mental and physical deterioration that might otherwise occur.

Persons working in local community aging programs of the type described above have offered specific reasons why they find the placement of older persons with developmental disabilities valuable. They say participation in their program offers older persons with developmental disabilities the following opportunities:

- an environment in which they can spend time with others their own age,
- alternate programs for daily activities,
- opportunities for socialization rather than isolation at home,
- programs appropriate and interesting for them,
- opportunities for retirement and for social and recreational activities,
- activities close to their homes,
- a gain in self-confidence,
- an increase in the degree of comfort the individuals feel as 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.

## Site Staff Report

When asked about the contributions the seniors with developmental disabilities made to their programs, site staff from the local demonstration projects offered the following comments:

*It has helped our regular program participants to know how lucky they are just to grow old and not have a handicap.*

*Offered a new enlightenment for the well elderly about developmental disabilities and what it means to be developmentally disabled.*

*It makes our participants more aware and more sensitive to the problems of other people.*

*My seniors appreciate their own good health from having seniors with developmental disabilities in their everyday life.*

*Makes our seniors reach out more and appreciate what they have both physically and mentally.*

*They (the seniors with developmental disabilities) are usually cheerful and enthusiastic about program activities which contributes in a beneficial way to the collective good spirits of the whole group.*

*They (the seniors with developmental disabilities) are often willing to volunteer their time and abilities (to*

help the program run better)."

*They help to monitor (in a day care setting) lower functioning frail elderly seniors who wander or may choke. They observe behavior and alert staff of potential problems.*

*They show love and concern even with their disabilities.*

*They show they are human beings needing love and care too.*

*They contribute friendship, help fellow seniors and challenge established values and ideas about individuals with developmental disabilities.*

Now that we have identified the programs most appropriate for integration efforts, we are ready to explain how to carry out integration.

**In one area of the state a network was formed through the partnership of a college-based institute of gerontology, a local ARC and a staff development unit at the regional developmental disabilities agency.**

**The network group did a local needs assessment, surveying agencies about the people they served, the services they provided, and what was needed in their community, that ended up as a broadly distributed report. Other activities have included a monthly training series and conferences on aging and developmental disabilities.**

**Annually they hold an awards dinner and recognize the contribution of someone amongst them who has done something special for older persons with a developmental disability**

## How to Get Started: Networking

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. One of the demonstration project administrators from an agency serving elderly persons with disabilities in Buffalo, N.Y., stressed the relationship of networking to integration this way: she said, "The process of integrating older persons with developmental disabilities into local aging programs is a process of networking."

Successful networking involves ongoing communication and "base building" by having the people you know help put you in contact with the people you need to know. Networking serves various functions:

- Networking helps to identify a base of interest and build a constituency able to lend support, influence and help when necessary.
- Networking opens the doors to opportunity. Doors which might not open any other way.
- Networking is an essential process for bringing the two systems (aging and developmental disabilities) together.

### Networking for Integration

To successfully network, it is helpful to identify the steps and sequence of steps needed to bring about the results you want to occur. As with all processes, the actual sequences will vary with location, the groups you are working with, and your own style. However, consider the following steps:

- Identify a core group of people from your system who are interested in integration. Ask the people you know to refer you to those they feel should also be involved in initial discussions.
- Meet informally as a small group to identify needs and barriers, consider directions and delineate resources available to help with integration activities.
- Identify others in your system who should be involved in a general meeting on integration.
- Meet as a larger group to review the subjects discussed in the small group and determine consensus.
- Identify the single person in either system to be the liaison with providers in the aging network and its local aging office and the developmental disabilities agencies.
- If you have contacts in either network who are supportive of the integration concept, invite them to participate in your large group meeting.
- Ask the contacts to help you (if necessary) set up an introductory meeting with the local aging office director. The introductory meeting has several purposes:
  - to explain that you represent a network of provider agencies and organizations serving seniors in the developmental disabilities community.
  - to share your need for placement opportunities in local aging programs for seniors who may be eligible.
  - to invite the aging office director

or the representative you met with to attend a larger group meeting with your network to discuss aging and developmental disabilities.

- Ask the aging representative to also invite others from their network to attend your meeting.
- Similarly, ask the local developmental disabilities program administrator to such a meeting to help draw in the key officials.
- Use the large group aging/developmental disabilities meeting to dialogue between networks and to begin to chart future directions for integration activities. Try to come out of this initial meeting with the following:
  - preliminary steps which should be taken, and
  - a commitment to continue the two network dialogue and a date for the next meeting.
- If possible, meet with a core group of key people from both networks who are willing to look at special concerns.
- Remember, at the group meeting (if it isn't too large) to have all involved introduce themselves and their agency, and if time allows, tell what they do.

Networking and the networking meetings set the stage for building the relationships needed to make integration a reality.

## Setting Up Local Task Forces

In several of the localities in which the demonstration programs were conducted, local agency staff and administrators developed task

forces or committees on aging and developmental disabilities. A listing of such task forces or committees is given in the appendix.

The setting up of such a task force may need to be a precursor to other activities when your focus of activities is in a highly urbanized metropolitan area. Rural areas, composed of few agencies and interested or affected staffers, can come to cooperative decision making over a meal at a local restaurant. However, highly urbanized areas, with a complexity of staff interactions, agency territories, and disparate funding and oversight sources, need a more structured brokering approach.

If your needs are to organize such a group in a major metropolitan center, we would suggest that you follow the suggestions outlined above in the section on *Networking for Integration*, but direct your activities in a more formalized manner. For example, to get such an effort off the ground, you may need a formal auspice -- that is, the sanction and support of a formative group whose reputation and role is such that it will draw participants to the task force. Such an entity might include:

- the local government mental health or mental retardation/developmental disabilities department
- the local county aging office or department
- a university center on developmental disabilities or gerontology/geriatrics
- a foundation
- a community planning body or interagency council
- a health systems agency or similar group

Secondly, there may need to be much

## **The Hudson Network**

**I**t first began with a few phone calls among colleagues; then more. It seemed as if the staff at a number of Hudson Valley agencies needed to talk. The common topic was the seniors they were serving. One administrator, viewed by the others as a leader in their area, decided to call a meeting. The informal meeting led to another where state and regional officials were invited.

The group decided to become more formal, adopt a name and have regular meetings. Now they meet bi-monthly and invite speakers. At the meetings they exchange information, discuss how they handle regulations and program requirements, and help each other with program practices and advocacy. What started with a few like-minded persons exchanging telephone calls, has blossomed into a formal network that has authority and influence.

more formal approach to setting up the group. You may need to do the following:

- You may need to send formal letters inviting participation to the participating agencies and their representatives.
- You may have to think about who specifically to invite who will “spark” discussions and keep them within the objectives of the group.
- You may need a “charge” from a governmental entity to enable you to coalesce the agency participants around a tangible objective.
- You may need to have a formal chair or convener appointed (from either the group or by the sponsor) to help lead the meetings and keep the agenda on task.
- You may need to break up your overall group into committees that are charged with specific tasks.
- You may need to be more formal in your recording of attendance and minutes of meetings; these will need to be distributed in a timely manner prior ensuing meetings.
- You may need other “carrots” to keep participants involved; these might include helping design a short and long range plan; recommendations for budget requests or allocations; publicity or public education campaigns; legislation review and lobbying; needs assessments; and policy review.

## How to Select Programs

Affording people with developmental disabilities the opportunity to participate in community senior citizen programs is what the integration effort is all about. For many seniors with disabilities, integration into local aging programs provides the first opportunity to join with peers and be part of a true community program.

Integration hinges upon matching up programs with the needs of disabled seniors and disabled seniors with programs. However, it is not as simple as it seems. Integration, if it is to be successfully achieved, involves networking, planning, and the implementation of a series of coordinated activities.

This begins the section describing the activities that should be undertaken to promote integration. The information was distilled from the experiences of county-based demonstration projects which successfully integrated seniors with developmental disabilities into a variety of generic aging programs.

The sections that follow address a variety of topics related to helping you get started with an integration effort. In this chapter, we have included the topics of selecting adult day care, senior centers, and nutrition programs; and considerations of site factors. In the next chapter we will discuss the selection of participants, the concept of retirement for persons with developmental disabilities, and integration approaches.

In the presentation of the topics which follow, the following assumptions have been made:

- that interest in integration is coming from the disability network, and
- that program selection (as opposed to selecting participants) is the first consideration.

## Program selection

Within the aging network there are three basic types of congregate community programs. In most cases, one or more of the following types of programs can be found operating in your community.

### Social Adult Day Care Programs

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.

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 on an out-patient basis who have emotional problems or mental illness.

#### Admission:

Admission requirements for social adult day care may vary from program to program. Usually a person must be 60 years of age or older to participate and have an impairment which requires some assistance or guidance with activities of daily living. Some programs also take people who have become socially isolated or are in need of companionship and stimulation. Others admit younger persons who are chronically impaired. In contrast to senior centers or nutrition programs, persons using adult day care programs are admitted only after a preliminary screening process.

#### Contributions and Fees:

Most day care programs charge a fee based upon a daily or weekly rate. At some day care programs a contribution is requested, with the amount determined according to the dis-

abled individual's or his/her family's ability to pay.

### **Program Evaluation:**

In evaluating what goes on at day care sites look for the following:

- Personal care activities
- Nutrition programming
- Physical and recreational activities
- Social work services
- Transportation

### **Day Care Program Advantages:**

- Programming is oriented on the basis of individual need.
- Staff have experience with persons who have various disabilities and impairments.
- Non-disabled participants share similarities in functional abilities with older persons with developmental disabilities.

### **Day Care Program Disadvantages:**

- Staff ratios at day care sites tend to be lower than those found in the developmental disabilities network day training and day treatment programs.
- Social adult day care programs do not operate under a fixed set of standards so programming may vary in offerings and quality from site to site. The State Office for the Aging is currently developing standards for social model day care.
- Categorical funding for social adult day care programming does not

exist. Most programs receive only limited funding from a sponsoring agency (if there is one) and are chiefly supported through participant fees. The limited funding often precludes being able to provide formalized counseling and case work services.

### **Tips for integrating a social adult day care program**

- Ensure that the functional abilities of the person selected for integration are generally the same as other participants.
- Go over the program with the individual so they know what to expect from the program.
- Be sure the day care program manager is briefed on the person who is being placed; give particular emphasis to any particularities in behavior.
- Be sure that emergency contact telephone numbers for the case manager or other person responsible for the individual are available at the program site.

### **Senior Center Programs**

These programs typically offer a slate of weekly activities often including a daily, hot lunch time meal. Some program sites have TV, game, craft, and other activity rooms where multiple activities occur simultaneously. Depending on the center site, some 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.

### **Admission:**

Senior center programs are typically

open to all persons aged 60 and over and often are open to persons in their fifties as well. Some center programs may require the user to be a resident of the locality in which the site is situated, if the program is exclusively supported with funds from the locality.

### **Contributions and Fees:**

In general, senior centers do not charge for use. Most offer a "membership card" to participants for a small fee (usually a dollar or so). The card provides the participant with a sense of belonging and may also entitle the holder to discounts from area merchants. At some centers, the purchase of a "card" helps support a monthly newsletter or a special center activity. Most center participants purchase cards even though it is voluntary.

Senior centers are typically supported by a variety of funding sources. The funding, as a rule, does not cover the level of programming generally found at most senior center sites, so participants are usually asked to pay a small fee to help cover the cost of certain activities or events.

### **Program Evaluation:**

In evaluating senior center programs look for:

- Attitude, personality and enthusiasm of the center director or program leader.
- Meeters and greeters; these are the folks who help new people feel comfortable when they show up at the center for the first time.
- Outreach activities especially with regard to serving individuals with special needs (low income, minority, frail, isolated, disabled, impaired and institutionalized elderly). New participants are the future life blood of any center. Interest and efforts in outreach can indicate if the center has an interest in reaching out to commu-

nity residents.

- Extent of participant involvement in the center programs.
- Perception and status of the center within the aging community.
- Linkages the center has with other services, activities and opportunities in the community.

### **Senior Center Program Advantages:**

- Provides a "right at home, right in the community" experience.
- Offers the opportunity to socialize and be part of a daily community group.
- Offers a diversity of activities.
- Environment can be stimulating.

### **Senior Center Program Disadvantages:**

- Staff are not likely to have had experience with the needs of older persons with developmental disabilities.
- Supervision is minimal.
- Environment is relatively unstructured.
- There is a potential climate for bias and discrimination against participants with developmental disabilities.

### **Tips for Integrating Senior Centers:**

- Select participants based on their ability to function in a program for the *well aged* population.
- Set up a staff-sharing relationship, if possible.
- Inform senior center staff that

participants are developmentally disabled, and inform them of any special needs they might have.

- Focus on the abilities of the participants while being honest about their limitations.
- Be prepared to be very flexible and accommodating.
- Minimize as much as possible the extras that are requested of center staff.
- Take the time to acquaint yourself with both the aging and the developmental disabilities systems. 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 helping persons who are developmentally disabled, and who is most approachable?
- Expect that there will be individuals who will not like or accept older persons with developmental disabilities, just as there are those who do not like or accept other people for other reasons.
- Provide individualized training to the people who have been selected in the skills needed to make the transition to a senior center. Good hygiene practices and social skills are particularly important to acceptance at a senior center.

## **Nutrition Programs**

Nutrition (or 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 day care site,

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.

A complementary program to the senior nutrition program is the home delivered meals program, where a home-bound senior can receive a hot noontime meal.

### **Admission:**

Participation is open to all persons aged 60 and over. Spouses and companions under age 60 and persons with a disability under the care of nutrition program participants are also eligible to receive a meal.

### **Contributions and Fees:**

Nutrition programs do not charge a fee. Participants are requested to make a contribution toward the meal. The amount of the suggested contribution is posted at every nutrition site. Sites use an envelope system to allow a person to contribute what he or she can afford. In New York, sites generally ask for a donation of between \$1.00 to \$3.00, although the actual cost of the meal may be greater.

### **Site Evaluation:**

In evaluating nutrition program sites, look at the following:

- Attitude, personality and enthusiasm of the nutrition site manager.
- Involvement of the site council. Site councils are participant groups who meet to discuss how the meals, programs and other aspects regarding the site are working.

- Programming available at the site.
- Policy for table selection. Find out if participants are allowed to exclude others by saving seats or if a "first to the table best seated" policy is in use.

***Nutrition Program Advantages:***

- Sites are found in most communities.
- Provides a community location for a hot meal in the company of peers.
- Social atmosphere provides opportunity to make friends.
- Site offers the opportunity to volunteer setting up the tables for the meal or helping prepare meals for the home delivered meals program if food preparation is done on site.

***Nutrition Program Disadvantages:***

- Most nutrition-only sites are open for only a few hours a day.
- Activity programming at sites is often limited or non-existent.
- Openness to new participants may be a problem.

**Tips for integrating nutrition programs:**

- Find a buddy or companion who will accompany the person on his or her first few visits.
- Consider taking several people together to the site so they will feel more comfortable.
- Work out the donation arrangements beforehand; make sure the person has the expected donation to give at the door.

**Mary came from Poland when very young. She married and had four children. Her husband physically abused her to the point that she began having seizures. She was placed in a state school, never to see her family again. At the time, she spoke very little English. When given an IQ test, her language barrier was not taken into account, and she was rated mentally retarded. Recently deinstitutionalized, she now lives in a community residence.**

**Mary exhibited many behavior problems but, nevertheless, was placed for a trial period at the senior center. Her behavior problems ceased and she has become an accepted member of the center. She plays cards with a select group of females and participates in any activity offered. She has been assigned a Senior Companion. She attends part-time at the senior center and part-time at an adult day care program so that her medical needs can be monitored. Since her placement she rarely has behavior problems at the residence. All Mary wanted was an opportunity to sit back and enjoy life and at the age of 76 she deserves that.**

- Ensure that the person has reasonably good eating skills so that he/she will not stand out as different.
- Brief the person on how the meals are presented and ensure that he or she is experienced with the style meal service used at the site.
- Go over the week's menu beforehand so the person can express any concerns over food preferences before going; pick a day when the meal served is something that the person likes.
- Use a site near where the person lives, so if they wish, they could walk to the site.

### Site Considerations:

Based upon these descriptions, the types of sites selected for integration depends upon the following factors:

- What types of sites are available?
- Is the programming appropriate?
- Is the site in the appropriate community or area?
- 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 your seniors?

### Further thoughts

Congregate aging service programs supported with Older Americans Act funds are required to be open to participation by all seniors, but, in reality, are constrained by funding limitations. Nutrition programs, for example, often limit the number of meals they are able to serve at any one site and typically have a maximum number they can serve during any funding year.

Successful integration comes from cooperation developed through understanding, compassion, and sensitivity to needs of persons with disabilities rather than the force of law.

As a general rule, local aging program sites can refuse to accept seniors who are unqualified for some valid reason other than that they are developmentally disabled.

The best sites and programs for seniors with developmental disabilities are those which provide the best opportunity for integration to succeed.

The site manager, center director or program leader sets the climate for the site.

### Do the following

- Inventory the aging program sites in area.
- Visit the sites, look at the facilities and stay long enough to get a feel for what is happening there.
- Talk to the site director.
- Talk to the participants.
- Look for an environment that encourages friendship.
- Trust your gut level feelings about the appropriateness of the site.
- Try not to get "hung up" with a site director who may be reluctant to let persons with disabilities participate. Move on. For every reluctant program site director, several others stand ready and willing to work with you.

## How to Involve Participants

In this chapter we cover the topics of selecting participants, whether to integrate people individually or in groups, and how to actually conduct integration activities. Also covered are retirement considerations and preparatory steps for transitioning to retirement. Each of the areas covered in this chapter are related to how to engage the older person in the decision making process about integration.

### Selection of participants

The participant selection process goes hand in hand with the site selection process. Both are interwoven and interdependent to the extent that a person who may fit in at one type of site may not work out at another type of site even though the programming there is similar. Therefore, a thorough knowledge of site operation and climate for acceptance is essential and in most cases a prerequisite, to selecting the people for integration. One of the demonstration project directors summed it up this way when she said, "Seniors who have developmental disabilities have struggled for acceptance their whole life long. This may be their final program. It should be one with an atmosphere of acceptance."

One of the keys to integrating older persons with developmental disabilities into certain types of community aging programs is in finding people who have the potential to be accepted at the site. Acceptance at certain sites is essential to integration. Without acceptance by the peer group, integration in its fullest sense, can not really occur. Nowhere is acceptance more important than at senior centers and nutrition sites.

### Participant Selection for Senior Centers and Nutrition Sites

Senior centers and nutrition sites are environments in which the emphasis is on social

skill and behavior than outright intelligence. This means persons who have appropriate social behaviors but lower cognitive abilities could be and should be considered for integration into some senior centers and nutrition sites.

Senior centers and nutrition sites do not have the ability or capacity to handle participants with behavior problems. For these sites, consider seniors who do not have problem behaviors and those with only occasional occurrences of a problem behavior.

In general, persons considered for integration into senior centers and nutrition sites should:

- be 60 years of age or older
- be continent
- be self-medicating
- be no danger to themselves or others
- have appropriate skills in grooming, hygiene, eating
- have a minimum of problem behaviors
- have appropriate social behavior
- have the capacity for appropriate social interactions

The demonstration sites of the Integration Feasibility Demonstration Project were able to integrate several persons with problem behaviors into senior centers and nutrition sites. In these situations we carefully watched to see if the new settings had an affect on behavior. We were pleased to find:

- occurrences of problem behavior declined to virtually none or only occasional.
- there were no increases in problem behavior for any of the persons in this group who were integrated into

- senior centers and nutrition sites.
- social interactions improved dramatically.
- social behavior improved.

The greatest improvement occurred in the development of friends and friendships.

This positive outcome means that selection of participants based upon hard and fast rules may, in fact, disqualify those with the potential to grow and benefit from the opportunity to be with peers in a community environment. With that in mind and if a site (through its site manager or director) is willing to take a chance, we strongly suggest trying also to integrate persons with minor behavioral problems but assessed as having the potential to grow and improve.

### **Participant Selection for Social Adult Day Care Programs**

Unlike participants at nutrition sites and senior centers, who tend to be "well" elderly, those attending social adult day care programs are typically persons who have impairments which limit their activities of daily living. In this regard, persons with developmental disabilities share many similarities with the clientele served at day care sites.

Initial screening for day care site integration should be on the basis of how well their functional ability and behavior, rather than their disability, coincides with that of the participants already enrolled in the program.

Since day care programming takes place in a social environment, individuals considered for integration should have the potential to adapt to a social setting and not have problem behaviors or be a danger to themselves or others. Programming at day care sites is usually paced to an older, more dependent population so persons selected should be matched to the same activity level occurring at the site.

In general, persons selected for integration into social model adult day care programs should:

- be 60 years of age or older
- be of no danger to themselves or others
- be able to function on a level comparable to the clientele being served in the program, and
- not have problem behaviors

Social model day care programs may vary in their ability to serve persons who are:

- not self medicating
- incontinent
- have dietary restrictions, or (at the other end)
- function at a high degree of independence

Contact the programs directly to find out if they are able to accept persons with these limitations or capabilities.

### **Importance of Confidentiality**

Since many older persons with developmental disabilities may have been served when they were younger by the mental retardation system, some cautions apply with regard to confidentiality of records and personal information. Written permission is needed in order to release personal or confidential information.

Exercising common sense when giving out information will help protect these individual's civil rights and avoid violations of the mental hygiene law. As with any of the clientele of a program, you should be sensitive to needs for confidentiality. Following these basic guidelines will help you to make informed decisions.

The key point to keep in mind, is that everyone has a right to privacy and not to have

the details of one's private life shared with others.

Before revealing information about an individual served by your agency to someone else (whether it be another person using the program, someone from another agency, the press, or relatives), stop and ask yourself whether it is the kind of information you would want released about yourself. Even if you decide it is ok, go a step beyond and ask if it is the kind of information that might cause anyone to avoid or demean that individual, to dislike them, or to regard them as less than equal.

Another guideline you should always follow is "the need to know." Before revealing information about someone in your program, ask yourself whether the person needs to know that information. If not, don't reveal it. Also, don't ask state or other private agencies to reveal information about a person in your program which has no relevance to the service you are providing.

The mental hygiene law prohibits the release of personal or clinical information about individuals with mental disabilities who are, or who were, served by a state program. Don't ask staff of other programs to violate the law.

## Participant choice

Integration, if it is to be successful, also involves giving the participants a voice and choice in the matter. Once a person has been identified as a candidate for integration, they should be given a choice as to whether or not they would like to participate in the program. If they are reluctant, it may help to arrange a visit for them to see the site or to even participate on a trial basis. Often reluctance has to do with being reticent, not wanting to change one's routine, or losing familiar social contacts.

Those who agree to participate at the program site should be assessed on a regular basis by the developmental disabilities agency to determine how the setting is working out for them. Sometimes a participant may find that he or she no longer wants to attend the program for

a variety of reasons. These reasons may include finding the other participants more disabled than oneself, not "connecting" with the activities and routines, or some other personal factor.

For example, we found one participant, who was attending a day care program on a regular basis, deciding that he no longer wanted to be around other "older persons" and wanted to go elsewhere. In this instance - self-image, derived from being seen with other older persons - was a factor (even though the participant was generally of the same chronological age). This phenomenon, by the way, is not uncommon among many older adults. In another instance, a participant wanted to return to the workshop he was previously in because he felt the loss of his workshop's weekly check.

When selecting participants for integration, remember the following key points:

- Participants need to be given a voice and choice in helping to determine what is appropriate and what is working for them.
- Participants' ongoing reaction to a site into which they have been introduced should be assessed on a regular basis.

## Retirement

Among persons who are not vocationally impaired, there are often a number of considerations that impact decision-making related to retirement. One is related to the primary gain associated with work, a salary; this is usually substituted by Social Security benefits or a pension upon retirement. Another, is related to the secondary gains associated with the work place, such as friendships, a place to go, and the personal identity that is defined by one's job. Further, most persons, when considering what to do upon leaving the workforce, think in terms of what will replace work. This notion of replacement leads to "retiring to." It is easy to achieve "retirement from," but it is not that easy to achieve "retirement to."

For anyone, the social and personal changes associated with retirement can often be traumatic when bridging does not occur as part of the transition process. For a person who is disabled, and has been dependent upon his or her workplace for social sustenance, the loss or change of friends when moving to a new program can pose a significant barrier. This is why selecting among retirement options available to seniors in the community can help to plan the "retirement to."

Some strategies that could mitigate problems associated with retirement for persons with developmental disabilities include:

- the use of pre-retirement counseling
- partial retirement (where the individual slowly transitions from work to retirement), and
- increasing socialization through the use of non-disabled "senior friends" and involvement in socialization programs.

A "senior friend" can help a person with a disability acclimate to new settings that offer retirement activities as well as serve as a bridge to the friends he or she may have left in the work setting. One source of such "senior friends" is the OMRDD's Senior Companion Program.

One area that poses problems for agencies working with retirement age individuals is the lack of a "pension policy." Most disabled individuals do not receive earned social security benefits or pensions to use as income in retirement. For those individuals who are earning money in sheltered workshops or in some type of day programming, the lack of money upon retirement can become a major problem. Even if the actual amount received was small, the earned money has strong symbolic value.

Many older workers who are developmentally disabled are reluctant to retire when

they are faced with the loss of their cherished income. This results in a dilemma: when faced with a desire to stop working and relax but lose income, or continue to work and lose the freedom that may come from retirement, most elderly workers chose to continue to work. Consideration needs to be given to the impact of loss of income upon the individual's retirement and acceptance of involvement in a new program site.

There is another side to this problem. Involvement in senior group activities that are offered at senior centers, such as an outing or a trip, may include a nominal fee. Further, even participating in the congregate meals program involves some expense since sites ask for a donation. An older person should have the dignity associated with "paying your own way" since many senior activities are peer oriented. This consideration of maintaining the older individual's dignity and self-respect when he or she moves from the work setting to a local senior program, is very important.

Consequently, it is advisable to carefully review what concerns the older person may have about retirement and then employ a strategy that will bring about "retiring to." This may mean:

- reviewing with the persons what retirement means to him or her and what they want to do
- discussing the retirement options
- implementing phases to pre-retirement that employ visits, partial involvement in a new site, and pairing with a "buddy" to aid in the social adaptation to a new site.

### **Pre-Retirement Preparation Activities**

The transition to senior age activities and programs needs to be handled with sensitivity and care. Like other people, a person with a lifelong disability needs to experience life's milestones. The transition from worklife to

retirement is one of those transitions. Remember that retirement parties and retirement gifts are important, concrete, transitional features. However, pre-retirement counseling and other types of preparation are also important. Transition formalities need to be preceded by discussions of retirement and planning for it.

It is important that a person who is able to continue working be given the option of continuing to work. That does not necessarily preclude integration into the aging system programs, because the integration can be done on a part-time basis, leaving time for employment. But the individual should always be offered options, and the wishes of the individual should be respected.

One problem can arise out of a situation in which the elderly person is no longer able to conduct his or her work to the satisfaction of the job supervisor, and the job supervisor feels that the person should leave work. Such a situation will require special attention by the case worker and the caregiver. It could affect the success of your integration effort, so you should be aware of what's happening.

In all situations, counselors need to support and encourage persons, especially in the early stages of a new program. Let them know retirement is normal and okay.

### **Pre-program visits for participants**

The person needs to be introduced to the new program gently. There will be uncertainty and there might be resistance. Remember upon retirement, the individual is leaving a familiar setting and friends. Upon entering a new program you are expecting the individual to form new social attachments and participate in new activities on their own.

As with other people, this is often difficult for persons with limited intelligence or who are physically disabled. Positive reinforcement is critical at this stage.

If the person has been working, whether in sheltered or supported employment or in the general work force, the work ethic is likely to be

firmly entrenched in that person's mind. There has been little preparation for retirement and little anticipation of it.

The person's informal social network is often tied to the job. Wages, an important ingredient of our society, are an important issue to such individuals. Often when older persons leave a work setting they forfeit their weekly check. This can be an obstacle to integration and needs to be considered carefully.

### **Further thoughts on pre-retirement:**

- Before changing the individual's program engage him or her in a discussion about the process, what they can expect from the change and the benefit and losses, and most importantly, what they would like to do.
- Once, the transition has been agreed upon, engage in a formal transition ritual -- a party or ceremony for retirement.
- Try retirement planning within a group, so a sense of solidarity is built up and provides a cushion for the change.
- Find a means to replace the valued workshop check (if there is one) with a retirement pension check.
- Try visits to places that the person might like to go upon retirement, such as the local senior center or nutrition site.
- Try a phased retirement process, through which the individual gradually disengages him or herself from their current program.

## Integrating Individuals vs. Groups

Integration can be successfully achieved by placing people one at a time as well as by integrating small groups into selected sites. While this manual is based on the premise that people will be integrated as individuals - even when several persons are placed at one time - it is also possible for a group of people who have been together over a period of time to be successfully integrated into a local aging program. As you will see, both approaches have advantages and disadvantages.

Integration can be achieved in two ways:

- Group integration
- Individual integration

### Group Integration

One of the Office for the Aging demonstration projects used group placement as an integration methodology. The demonstration project was under the auspices of a developmental disabilities agency in a large city. The plan was to integrate people who had been together for years, as complete groups, into a number of neighborhood senior centers.

Part of the rationale for the approach was that it might help to make for an easier transition. It is not unusual for the participants at some senior centers to form cliques making it difficult for new people, irrespective of any disability they may have, to comfortably participate. At some older and well established neighborhood senior center sites it can be a barrier which can be difficult to circumvent.

By having the disabled seniors enter the site as a group they, in effect, became their own clique and the immediate pressure to be a part of the existing group was gone. Each member of the group was free to move out into the larger group, find other friends, join other cliques. But if things did not work out -- say, if a person was

rejected -- they could always return to the original group.

By coincidence, in this example, the seniors were brought as a group of five to the center on a day when special festivities were taking place and the mayor was visiting. In the commotion of all that was going on, the coming of the new participants went largely unnoticed.

To make group integration work and to stimulate the group within a group to interact, an essential ingredient was provided. The developmental disabilities agency assigned a full time staff person to serve as a program aide at the senior center. In addition to helping with the new participants, the aide found enjoyment in taking over and running the center's ceramics program for all who were interested.

In this example of group integration, the aide was the necessary catalyst and was needed to assist with the additional work load and help structure activities which would bring people together. Without the staff aide, it is unlikely that the center would have taken on the additional responsibility so easily or that meaningful integration would have occurred at the site.

The group (4-5 persons) integration approach offers some of the following advantages:

- It is more efficient (timewise) to integrate a group into a site than one individual at a time.
- It tends to be a more cost effective way to achieve integration.
- It provides a certain level of comfort to the seniors being integrated because they are attending the site with their friends.
- It becomes attractive to the local aging program site when staffing assistance is offered.

The group integration approach also has some potential disadvantages:

- It is a more difficult concept to “sell” in the aging community unless “perks” such as shared staff are provided.
- Aging service sites are typically fearful of the impact a group of seniors with developmental disabilities might have on the regular level of site participation.
- It requires an ongoing effort at the site to structure developmentally disabled seniors group participation into the existing program.
- Initially, the participation of a group of developmentally disabled seniors is likely to be met with resistance from the regular participants.

#### Further thoughts concerning group integration:

Group integration at a number of senior center sites was successfully achieved due to some of the following factors:

- The developmental disabilities agency that selected the people to be placed was well known and respected in the community in which it operates.
- The senior center directors did not have to be convinced to try group integration at their sites. They “wanted” to see if it would work successfully.
- The developmental disabilities agency coordinator for the integration project was skilled in working with the aging community and sensitive to the needs and concerns of those staffing the aging service programs in their area.
- There was a willingness on the part of the developmental disabilities

agency to provide necessary staffing assistance to the aging sites.

### Integration of Individuals

In many ways, even if group integration is being conducted, it still concerns the integration of individuals.

The methodology for integrating people individually varied only slightly among the various demonstration sites. Most importantly, all of the demonstration project directors stressed the following: because integration involves moving a person to a new setting, and away from where he or she have been, sensitivity is needed to ensure that the person being integrated will not be shuffled from one site to another. They felt strongly it was important to consider each such move as possibly the “last” move for that person.

The following are key points to remember when integrating individuals:

- The site manager or program director should fully understand the nature of the persons’ disability and the behaviors common to that disability. Keep in mind, most people don’t know what constitutes “being developmentally disabled” or what might be expected in the way of attending behavior.
- Always explain to the site manager or program director why this particular individual needs to be placed and how they will benefit from placement at the site.
- Always introduce the site manager or program director to the senior and their companion, if one is assigned. It may be necessary to spend the first day at the site with the senior, companion and site manager to make everyone feel comfortable.

- Consider offering both the senior and the site manager a trial visit at the site. Both may feel better if they know they have the option to change their mind.

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.

## To Tell or Not to Tell

The question of whether the regular program participants should know who is coming to join them is one that vexed some of our demonstration program coordinators. From their experiences there wasn't a clear verdict. It appears that site type, site staff and level of disability of the person being placed, 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 may be as attractive.

## 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 developmentally disabled seniors, 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 is disabled 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.
- Look at the site first and ask "who are the people who will be able to adapt and eventually fit in?"

## How to Use Staff and Companions

To successfully carry out integration, someone has to do the work. The effort needs staff -- someone in-charge, one or more persons to work directly with the people being integrated, and some experienced persons to help guide, and evaluate the integration effort. The effort can also use "buddies" or companions -- persons drawn from age peers who wish to help and aid the person with a disability.

While staff is needed, you do not need an empire. The leader of the effort can be someone with other duties who works part-time to bring integration about. Those who work with the people who are being integrated can be part-time or even temporary employees. The professionals who may be involved, need not be officially on staff. They can be people from other agencies who are willing to help, either voluntarily or on a paid basis.

## 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 aide in the integration effort.

Third, staff sharing arrangements need to be considered when additional staffing is necessary to the success of the effort.

As you see, setting up the staff can be geared toward various directions. The goal

## Participant Selection Tips

- Select people who can "make it."
- Select people who would enjoy being with other people and have a positive attitude toward socialization.
- Select people who would want to participate in this kind of program.
- Select people who would be able to derive positive benefit from the experience.
- Select people who would be physically and emotionally ready for the give-and-take of social integration.

should be to create, with the resources available, a staff that can handle the effort you contemplate.

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 the 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 developmentally disabled seniors who were integrated into the center. The shared staff also helped the non-disabled people with the center's programs and activities.
- area agencies for the aging that provided office space and staff time for conducting integration efforts.

Staffing arrangements to make integration happen are virtually limitless. The key is to bear in mind that it can be done, and to look for opportunities to do it. Let's explore the different aspects of staffing and some means to do it.

Depending on the size and scope of the integration effort, full or part time staff may be needed at an overall level to coordinate integration activities between aging and developmental disability agencies. In the State Office for Aging local demonstration projects, the coordination effort was managed at a county level by permanent staff from either an aging or developmental disability agency supported with special funding made available by the State.

### **Staffing For Interagency Coordination**

During the course of the demonstration projects, we found that it makes sense to de-

velop a focal point or clearinghouse for coordinating integration activities. With a focal point, coordination is enhanced. The sharing of information and resources is also made most useful. 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 (see *How to Get Started - page 27*).

### **Site Staffing**

The majority of the local demonstration sites did not require permanent staff to be added at the locations where people were integrated. The demonstration sites did, however, use companions to assist with the entry process and in some cases, had the companions continue on at the sites with the seniors who were integrated. (More about the use of companions later in this chapter.)

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.

One of the SOFA demonstration projects integrated groups of five people at one time into senior centers. The scale of the integration effort, as well as the impact on the site required that consideration be given to increasing the staff at each center. The developmental disabilities agency found an imaginative solution by using a staff sharing approach.

### **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. We found that when this was tried within the 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 developmental 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 aging service providers as means of maximizing effectiveness and minimizing costs.

### **Use of Companions or Volunteers**

The use of a "buddy system" or assigned companions varied significantly among the SOFA demonstration projects. Some of the project coordinators felt that the companions were essential to the success of the integration effort they mounted. Some found the companions to be an impediment.

One demonstration project coordinator, expressed the importance of companions this way: "the use of companions can determine the success of a placement. Without them, integration may be jeopardized."

Another project coordinator was against the use of companions and didn't use any. The reason stemmed from personal experiences where companions, because of their own needs, fostered dependency when independent behavior was the goal.

Our experience with the integration demonstration projects confirms that where it is appropriate and necessary, companions can be an integral part of the integration process.

**A**t one of the demonstration sites, the 'buddy system' worked very well. Two new seniors, coming from the same home were introduced to the adult day service gradually. For a couple of weeks they attended only the nutrition part of the day care. Once comfortable in the setting, they asked if they could participate in the whole day care program. Thus, they were welcomed into day care.

**One woman brings in pictures she has drawn for the staff along with wild flowers she has picked. She said she thanks God for letting her come to the Friday Adult Day Care Program.**

Having program companions provides some of the following advantages; it:

- helps to ease the fears a new participant may have
- helps to ease the fears an aging program site manager may have
- gives the community valuable and meaningful volunteer opportunities provides both companion and senior with an opportunity for companionship and friendship

### **Finding companions**

Finding companions to serve on a full or even part time basis, can be a challenge. Many programs, however, have been successful in finding reliable volunteer companions to help with integration activities. Here are some guidelines for finding companions:

- Start within your own agency. See if the friends, relatives and acquaintances of your regular agency work force are interested in becoming companions.
- Check with the following agencies for leads on potential companions:
  - county aging office,
  - voluntary action center,
  - Green Thumb Program, and
  - other area volunteer organizations such as:
    - Retired Senior Volunteer Program
    - Senior Companion Program,
    - other agencies using volunteers.

Also look for companions from among the following:

- retired special education teachers
- retired nurses
- churches and synagogues
- residential centers for senior citizens

- college volunteer programs preferring to work with seniors
- community civic groups

Advertise for companions in the local media. Get the assistance of a local advertising agency to develop a catchy lead line advertisement. Like the Uncle Sam recruiting poster for new Marines, aren't you too just looking for a "few good people"? See also, if the advertising agency will donate their services.

Peers can also be companions. Within the broad range of possibilities is also the notion of having peers serve as companions. Several of the demonstrations used seniors with developmental disabilities as companions to persons in a day care program who were more profoundly disabled.

Be sure to explain your needs and willingness to exchange volunteer duties with those who have scheduling or transportation problems

In New York, a good source of senior companions to aid adults with developmental disabilities is the NYS OMRDD Senior Companion Project. Modelled upon the federal program set up under the National Domestic Volunteers Services Act, the NYS OMRDD Senior Companion Project is totally state-funded.

There are senior companion program stations throughout the state and located within each of the OMRDD's district offices. Under the program, low income senior volunteers are recruited to work for 20 hours per week. In return, they receive a tax-exempt stipend, meals and transportation assistance.

Many senior companions in the OMRDD program are assigned to older persons with developmental disabilities. A good number are assigned to senior program sites throughout the state. For information on the NYS OMRDD Senior Companion Project call the Director for the Senior Companion Program at (518) 474-7005 or write the program c/o NYS OMRDD, 44 Holland Ave-

nue, Albany, NY 12229-0001. Your program could qualify as a volunteer placement site.

## Companion selection

Agencies and organizations using volunteers often have personality profiles to guide them in the selection process. Use a profile which meets your needs. Look for people who also have the following qualities or potential for developing the following qualities:

- sensitivity,
- understanding,
- commitment,
- reliability, and
- patience

Companions can also assist with site activities and provide care to those who need it. Finding a volunteer with leadership and activity skills is a special plus.

## Introductions

Introducing the companion to the site staff is an important part of a new companion's orientation. Site staff introductions serve to build confidence and establish the foundation for communication between the parties involved.

If the plan is for the companion (and also the senior being placed) to blend in unobtrusively with the regular site participants, the initial companion/site staff meeting will help to establish the ground rules for how that will be handled and how emergencies will be managed.

The introductory meeting will also help to assure the site staff that the companion is there to help and that the new participant will not be a burden or mean extra work for them.

Once trained, the companion should be matched appropriately with the person who will

be attending the senior program site. The seniors and companions generally need to become acquainted before going to a site. The method of introduction should follow the developmental disabilities agency's established protocol for such meetings. The meeting should also be assessed to find out if compatibility problems exist.

If the companion/senior match is successful, a site visit can be arranged. This should be viewed as an opportunity for the senior to determine if he would like to continue on at the site.

Introducing a person to a site can also be done with the assistance of a family member, caregiver, or case worker with whom the person is well acquainted, if a companion is unavailable to assist.

If the trial visits prove successful, there should be a follow up meeting between the site manager, companion, case worker responsible for the person and the integration coordinator. At the meeting, the aging program site manager or program director should be given the following:

- information related to the person's needs,
- pertinent behavioral information,
- information concerning possible emergency needs, telephone numbers, etc.
- information about the companion and where to call if the companion has an emergency, and
- any other information which will assist and prepare key site personnel to help with the needs surrounding the integration of a developmentally disabled person at their site.

Regular participation can follow. If the plan is for the companion and person to blend in unobtrusively into the site program, the

companion should keep an eye on the person without hovering or being perceived by other people as the guardian for a particular person.

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, where appropriate, should be to encourage and help the person to develop friends and friendships. Ideally, it would be to get along without the constant assistance of the companion, if possible. Once genuine integration has been accomplished, the companion may no longer be needed at that site or for that particular person.

Companions can be a valuable addition and asset to an integration effort. But consider also that an integration effort built upon the use of companions is also an effort dependent upon the availability of companions.

## **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. Most agencies using volunteers have a suitable training program which can be utilized in whole or part, if appropriate.

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 disabled person and the mainstream person
- To acquaint companions and staff with the special needs of the

disabled person 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

The NYS OMRDD has a training packet specifically for the training of new senior companion volunteers. This orientation packet can be used to train companions drawn from other sources. To obtain a copy of this training/ orientation packet contact: Director for Senior Companion Project at (518) 474-7005 or write the program c/o NYS OMRDD, 44 Holland Avenue, Albany, NY 12229-0001.

### **Additional Training Resources**

There are a number of resources you can tap to aid in training staff, participants and volunteers in better understanding aging and developmental disabilities. These include:

- the training curriculum on developmental disabilities available through the OMRDD's district office staff development units.
- the training curriculum on aging and developmental disabilities available through the OMRDD's bureau of aging services.
- the training program available through the University of Roches-

ter's Aging and Developmental Disabilities Training Program.

- the training available through the network of area agencies on aging.

For information on the training program offerings at the University of Rochester's Aging & Developmental Disabilities Training Program, contact the Program's Director, University of Rochester, Box 671, Medical Center, 601 Elmwood Avenue, Rochester, NY 14642; 716 275-2986.

## How to Support Integration

The integration process also involves a number of aspects which support an integration effort and make it successful. These support aspects include:

- funding
- outreach
- public relations
- record keeping
- monitoring and evaluation

In this last section you will find advice and information on these various supporting aspects.

### Funding

Financial supports for older persons with developmental disabilities using aging network programs can come from a number of sources. OMRDD funds both residential and day services in a variety of ways. With regard to day services, currently no dedicated funding exists that specifically is set aside for seniors. However, existing program funding can be adapted to finance a seniors program. For example, for seniors living at home, \$1000 a year is available under the family support program. Family support monies are available from the DDSO. Such monies can be used to pay for respite in adult day care and other special assistive services.

In other instances, when the seniors are "620 eligible," that is, they had been institutionalized for a specified period and otherwise meet eligibility requirements under section 620 of the social services law, they can be supported by 100% funding from the state to the program via the county community services board. Again, such funding can pay for adult day care services.

In other circumstances, when the county will agree to pay the local share, day

training monies can be made available under the local assistance program. In these instances, such monies can be used to pay for adult day care services. Another potential funding source is the day training innovations initiative currently being tried out in several counties. Under this funding, the state pays 100% of the costs of day training services.

Programs interested in OMRDD funding should contact their DDSO and discuss the alternatives available to them.

### Outreach

Our experience with the demonstration projects indicated that less than half of persons aged 60 and over, who are developmentally disabled, were known to the formal developmental disabilities provider system. Given this, it is our expectation that you may wish to reach out to older persons currently unknown to your agency.

The following is a list of a variety of outreach activities that can help to locate seniors who may benefit from being placed in community aging programs. In order to locate such people:

- Use publicity releases or advertising to let people in the community know what you're trying to do. Be sensitive as to how you present your outreach effort to the public.
- Contact churches and church sponsored social service agencies whose leaders might have reason to be aware of disabled persons in the community.
- Contact support groups, fundraising agencies, and volunteer groups that work with or for disabled people.
- Contact caregivers of persons known to be disabled to find out if

they know of other disabled individuals.

- Contact adult homes, nursing homes, hospitals, senior citizen high rises and other congregate units, and shelters where disabled persons might live.
- Contact the Department of Social Services, home health care agencies, the Association for the Blind, adult day care centers, Family Support Services, and the local housing authority, as well as other agencies that might deal with disabled individuals.
- Consider enlisting student interns from local university departments of social work and gerontology to gather information about persons with developmental disabilities in the community.

One problem an outreach effort can encounter is the matter of not being certain whether someone qualifies as being developmentally disabled, especially in the case of mental retardation. An elderly person who is retarded but who has lived a long time in the community might be able to pass as non-handicapped. An elderly person who is functionally impaired and seems to have difficulty might seem to be retarded.

While the functional distinctions may not really matter and since the important aspect is service need, identification of a person with a developmental disability is linked to being able to trace evidence of disability back to childhood. This identification may only prove useful if additional services are being requested of the locality's developmental disabilities providers -- such as housing, family support services, or case management. Such documentation may be necessary to release funds to support the services.

One outreach tool is a check of functional life indicators. They help show lifelong

deficits. Many local agencies use such tools. Check around to locate one useful to your purposes

Networking helps in the outreach process. It is recommended that contacts be initiated with a broad number of local agencies. Talks before human service organizations can also help in alerting the agencies of the outreach effort.

## Public Relations

One of the first decisions to be made is whether an integration effort should be publicized to the general public at all. In some localities it may be valuable to do so and in others it may cause problems for the integration effort. For this reason, it is important to know your locality in order to decide whether publicity will be helpful or harmful.

In a rural county, "grapevine" publicity may precede published information. See if the "grapevine" can be used to help set the climate for acceptance. Newspaper articles can also be helpful in educating and informing the community of new developments. (*See example of such newspaper stories in the appendix.*) In a small community such newspaper articles are likely to include people who attend the senior program sites. If local program participants are cliquish and do not readily accept strangers, then such publicity might lead to failure. Always consider carefully the possible impact of publicity.

In urban areas, human interest stories usually tend to engender support. But, small neighborhood programs where integration has been tried and is successful, may find difficulty getting media exposure.

Public relations efforts can include articles in general circulation and professional publications. It can include presentations to the general public and to professional groups. It can even include attending public hearings conducted by the aging system or the developmental disabilities system to discuss the issue.

**Rose will get all dressed up for day care. A staff person asked her why she gets all dressed up? She replied, "I have to look special to go to Day Care."**

**Lee calls himself the "Puzzle Champion!" He doesn't want to leave at the end of the day unless his puzzle is completed. Before he discovered the jigsaw puzzles, he would just sit and do nothing.**

**Morning coffee is a very special time. The clients will discuss what they have done during the week and what they plan to do over the weekend. One time, they were talking about a dance they planned to attend. They started happily teasing one another about who would dance with whom!**

It can include articles in newsletters for RSVP, home health care, and other agencies. The effort might include form letters to contact the developmental disabilities network, volunteers, agencies, and others for information and referrals. One useful way of handling such information is to first send a letter, enclosing a flyer about the program, and then following up with telephone call.

Another way is to make presentations to developmental disability system organizations and to volunteer organizations, visiting aging network agencies and speaking with coordinators. Such networking is very important. It is sometimes difficult to contact the right people.

When considering a public relations effort do the following:

- keep in mind your geographic area and ask yourself if the story will lead to greater or lesser receptivity by program users?
- use a personal touch to your stories, highlighting a "buddy" arrangement or praising a volunteer. give a human interest angle to a disabled senior. Often the outside world has no idea how hard life has been for this person or what the opportunity to participate with peers now means to them.
- spend some time with the reporter from your local paper who covers human interest stories -- this can help in giving your story a proper framework.

## **Record Keeping**

Extensive record keeping has been a hallmark of the developmental disabilities system. Naturally, when seniors from the disabilities system become enrolled in local aging programs, reporting and monitoring requirements follow them. While there is an ongoing attempt made to keep paper work to a

minimum, there are instances where reporting requirements become quite onerous. For aging program providers serving persons from the disabilities system, the rule of thumb to follow is: if the paperwork is going to be too much, ask the disability agency to assume the responsibility for it.

It is reasonable for the aging program provider to keep a minimum of records, usually attendance logs, information on acclimation, and other data that may be used to trigger payments. Goal planning and service plans should be left to the referring agency. Participant records should be kept in a locked cabinet to maintain the confidentiality of all persons, disabled or non-disabled, who are using the program.

Of special value to both the aging and disabilities regional networks will be your experiences with the problems you encountered and the strategies you used to resolve the problems. Share your experiences.

## Monitoring and evaluation

Monitoring and evaluation should be an ongoing part of the integration process. Under the SOA demonstration project, the local demonstration programs monitored the progress of the integration activity at aging program sites by using the following types of evaluations:

- Site evaluation
- Participant evaluation

A site evaluation is used periodically to identify the responses of site staff and non-developmentally disabled site participants to the integration of persons with developmental disabilities. By conducting site monitoring on a regular basis it is possible to identify and address problem areas as they come up.

A site survey should look at the following:

- attitudes of the regular participants and site staff toward participants with developmental disabilities

- space sharing, interaction and participation by the regular participants
- development of friendships and interpersonal relationships by the regular participants with those who have disabilities

## Potential problem areas

A participant evaluation or assessment should be used to periodically monitor the progress of participants who have been integrated into local aging programs. Unlike typical user evaluations, we found the most useful information on a persons progress at a site to come from assessments made of the following areas:

- extent of social interactions with staff, other disabled peers, regular participants, strangers, etc.
- friendships with staff, disabled peers, non-disabled peers and others.
- increase or decrease in problem behaviors such as verbal and physical aggression, socially inappropriate behaviors, refusal to participate, withdrawal, stealing, etc.

Agencies using companions should monitor the volunteer's progress and satisfaction. An appropriate monitoring format can usually be obtained from a director of volunteer services.

## Future Trends

Up to this point the manual has focused on the integration of persons with developmental disabilities into aging network programs. The developmental disabilities system however, offers a unique and exciting potential to serve non-developmentally disabled seniors who qualify for a social model adult day care environment.

Throughout the state, agencies which have primarily served persons with mental retardation or other developmental disabilities are now establishing and operating specialty programs open to all seniors who might benefit. Many of these programs were originally built off the mental hygiene system's "day training program" model. Now they are also serving non-handicapped seniors in senior day programs. These programs can be found in areas where:

- social model adult day care does not exist
- integration efforts have not yet begun or been successful
- local resources are limited in terms of operating social model adult day care
- developmental disabilities agencies are well established and have decided to offer senior services as part of their services' array
- the disability agencies and county aging office have worked out an arrangement for the site to be designed as an adult day care program

These programs offer an opportunity for older persons who have functional limitations that are age-associated such as dementia, severe mental degeneration resulting from Alzheimer's disease, or where severe physical limitations

require special care to benefit from an existing resource in the community.

Such programs serve as an example of programmatic integration. This means that the program, itself, has become integrated into the greater aging network through a number of means, such as:

- being designated an adult daycare program site by the county aging office
- having the site be designated a congregate meal site under Title III of the Older Americans Act
- having the seniors who are enrolled in the program co-participate with other impaired seniors in activities developed by the county aging office or one of its local agents, or
- developing the site's program such that a portion of the enrollee's time is spent at other locales, such as another adult daycare program, senior center or activity program, or congregate meal site

One benefit of developmental disabilities senior day programs is that the programs can offer a transitional experience and learning opportunities. Disability programs tend to be highly structured and focussed on goal-directed activities. In contrast, aging network programs are relatively unstructured, leaving participation and involvement in activities largely to the individual.

To experience satisfaction and success in transitioning to using community aging network programs, many disability agencies are recognizing that individuals retiring to senior activities need a period of acclimation. This time helps relieve the constant structure and prepares them for retirement where volition and self-definition are key to participation. These senior day programs serve as a bridge to community aging network programs.

## How to Open OMRDD Senior Day Programs to the Aging Community

As localities examine the costs of providing special services to the seniors with impairments in their community, the notion of cooperative programming and site sharing will become more attractive. If you, as a service provider, are interested in serving non-developmentally disabled seniors, do the following:

- contact the county aging office and discuss becoming designated as an adult daycare site
- contact the operator of the county nutrition program and discuss having your senior day program become a congregate meal site
- discuss with your board the notion of opening up enrollment to other seniors with similar functional deficits and needs
- contact the senior companion project coordinator at your local B/DDSO and discuss becoming a senior companion program site
- discuss with your county aging office how you might enter into an agreement to share transportation responsibilities for seniors in your local area
- get listed in the county aging office's local resource directory as an adult daycare site, disabled seniors assistance service, or other service -- depending upon what you wish to offer
- participate in local senior day activities and fairs where aging network agencies display their wares and promote their services participate with the county aging office in casefinding efforts of homebound seniors with disabilities who are currently unknown to the local care systems

**R**ecently an ARC opened a senior day program in a county without any adult day care program. Many of the adults in the ARC program, which in appearance and manner is like many other senior centers, have retired from workshops or employment. They are free to come whenever they wish and participate in a range of activities. Now the board has opened up the program to other seniors in the community, who because of latelife impalrments, need a similar program. A recent visitor commented that she couldn't tell who was who.

## APPENDICES

*Overview: The New York State  
Office for the Aging*  
**Aging - Developmental Disabilities  
Demonstration Project**

Project Name: The Aging/Developmental  
Disabilities Integration Feasibility  
Demonstration Project.

Project Type: Three-year demonstration  
April 1, 1986 - March 31, 1989.

**Purpose:** The purpose of the demonstration project was to test the feasibility of serving developmentally disabled elderly persons in congregate settings such as senior centers, nutrition sites and social adult day care programs.

**State Agencies Involved:** The New York State Office of Mental Retardation and Developmental Disabilities; the New York State Developmental Disabilities Planning Council; the State Office for the Aging.

**Funding:** The Project was funded with Federal monies from the New York State Developmental Disabilities Planning Council. The Project has an annual budget of \$102,000. The State Office for the Aging provides a 30% matching share. The Developmental Disabilities Planning Council provides the remaining 70%.

**Project Operation:** During Phase I the Project identified barriers and developed strategies for placing developmentally disabled elderly persons into existing aging network programs.

Phase II involved setting up and monitoring four local county demonstration projects. Two urban (Erie and Monroe) and two rural (Madison and Cattaraugus) counties were selected. Each local demonstration project developed its own methodology for integrating developmentally disabled elderly into local aging network programs.

The local demonstration projects were under the auspices of the following sponsors:

*Erie - People Inc., (A not-for-profit agency with a long history of serving persons with developmental disabilities) Buffalo, New York.*

*Monroe - Regional Council on Aging, Inc., (Operator of the Garson Meyer Senior Center) Rochester, New York.*

*Madison* - Madison County Office for the Aging (the area agency on aging), Morrisville, NY.

*Cattaraugus* - Cattaraugus County Office for the Aging (the area agency on aging), Olean, NY.

Phase III included the tabulation of data from site and client evaluations as well as the development and publication of a project "How To" manual. The manual was designed to be a guide for helping both aging and developmental disabilities service providers to integrate developmentally disabled seniors into appropriate local aging service programs.

The State Office for the Aging/Developmental Disabilities Project was conducted with the support of the New York State Office of Mental Retardation and Developmental Disabilities.

The Project findings include the following:

- Elderly persons with developmental disabilities can be successfully integrated into existing aging programs.
- It is necessary to lay a foundation for interagency cooperation at the local level which includes communication among providers, sharing of information, and interagency referrals.
- Integration can be achieved using different methodologies including placing people individually or in small groups.
- Programmatic and policy barriers need to be addressed first for coordination and integration to be successful.
- Elderly persons with developmental disabilities can and do benefit from being integrated into local aging services programs. For example, persons integrated into senior centers experienced an increase in new friendships and a decline in problem behaviors.
- Personnel and financial resources are needed to support integration activities.

- It was necessary for the State to provide ad hoc technical assistance in order to facilitate local cooperation.
- Local integration demonstrations exceeded the goal of placing 55 persons by actually integrating 70 persons into various aging network programs.

**Office of Mental Retardation and Developmental Disabilities** *Contact Person:* Dr. Matthew Janicki, (518) 473-7855

**State Office for the Aging** *Contact Person:* Philip LePore, (518) 486-2727

**New York State Developmental Disabilities Planning Council** *Contact Person:* Arthur Maginnis, (518) 432-8233

**New York State Office of Mental  
Retardation and Developmental  
Disabilities**

**District Developmental  
Services Offices**

*counties*

*served*

*Address*

**Queens**

Queens BDSO  
Gertz Plaza, 92-31 Union Hall St., Rm.  
5206, Jamaica, NY 11433  
(718) 262-4772

**Bronx**

Bronx BDSO  
1200 Waters Place, Bronx, NY 10461  
(212) 430-0700

**Kings**

Brooklyn BDSO  
111 Livingston St., Brooklyn, NY 11201  
(718) 834-6641

**Broome, Chenango, Delaware, Otsego, Tioga,  
Tompkins**

Broome DDSO  
Glenwood Rd., Binghamton, NY 13905  
(607) 770-0211

**Chemung, Livingston, Schuyler, Steuben,  
Wyoming**

Craig DDSO  
Sonyea, NY 14556  
(716) 658-2221

**Allegany, Cattaraugus, Chautauqua**

J. N. Adams DDSO  
110 West Third St., Suite 1, Jamestown,  
NY 14701  
(716) 664-3141

**Orange, Rockland, Sullivan**

Letchworth DDSO  
2 Secor Rd., Thiells, NY 10984  
(914) 947-1115

**Nassau, Suffolk**

Long Island DDSO  
415-A Oser Rd., Hauppauge, NY 11788  
(516) 434-6013

**New York**

Manhattan BDSO  
111 Eighth Ave., New York, NY 10014  
(212) 741-3866

**Monroe**

Monroe DDSO  
Basin Park, 1160-A Pittsford-Victor Rd.,  
Pittsford, NY 14534  
(716) 248-4605

**Ontario, Seneca, Wayne, Yates**

Newark DDSO  
703 East Maple Ave., Newark, NY 14513  
(315) 331-1700

**Albany, Columbia, Greene, Schenectady,  
Schoharie, Rensselaer**

Eleanor Roosevelt DDSO  
Balltown & Consaul Rds., Schenectady,  
NY 12304  
(518) 370-7370

**Herkimer, Lewis, Oneida**

Rome DDSO  
Box 550, Rome, NY 13440  
(315) 336-2300

**Richmond**

Staten Island BDSO  
1150 Forest Hill Rd., Staten Island, NY  
10314  
(718) 983-5321 or -5322

**Clinton, Essex, Franklin, St. Lawrence, Jefferson**

Sunmount DDSO  
Tupper Lake, NY 12986  
(518) 359-3311

**Cayuga, Cortland, Madison, Onondaga, Oswego**

Syracuse DDSO  
416 West Onondaga St., Syracuse, NY  
13202  
(315) 4250-5311

**Dutchess, Ulster, Putnam**

Wassaic DDSO  
149 Union St., Poughkeepsie, NY 12601  
(912) 473-5050 or -5051

**Westchester**

Westchester DDSO  
580 White Plains Rd., Tarrytown NY 10591  
(914) 631-8188

**Erie, Genesee, Niagara, Orleans**

West Seneca DDSO  
2001 Niagara Falls Blvd., Tonawanda, NY  
14150  
(716) 691-3341

**Fulton, Hamilton, Montgomery, Saratoga, Warren,  
Washington**

Wilton DDSO  
10 Railroad Place, Saratoga Springs, NY  
12866  
(518) 583-2810

## **New York Aging & DD Network Groups**

### **Hudson Valley - Catskill Network on Aging**

Alvah Canfield, Ph.D.  
Sullivan County ARC, BOx 812, South  
Fallsburg, NY 12779  
(914) 434-3415

Ronald Lucchino, Ph.D.  
Institute of Gerontology, Utica College,  
Burrstone Rd., Utica, NY 13502  
(315) 792-3129

### **Westchester Interagency Geriatrics Task Force**

Sharon Gelfand  
Westchester DDSO, 580 White Plains  
Ave., Tarrytown, NY 10591  
(914) 631-8188

### **Erie County Developmental Disabilities Subcom- mittee on the Elderly**

Tena Garas  
Heritage Center, 101 Oak St., Buffalo, NY  
14203  
(716) 856-4201

### **Western New York Consortium on Aging and Developmental Disabilities**

Mary Petrakos Terranova  
People, Inc., 1550 Hertel Ave., Buffalo, NY  
14216  
(716) 832-4444

### **NYC Task Force on Aging and Mental Retarda- tion and Developmental Disabilities**

Marilyn Howard  
Hunter-Brookdale Center on Aging, 425 E.  
25 St., New York, NY 10010  
(212)481-4350

### **Monroe County Council on Aging and Develop- mental Disabilities**

Jenny Overeynder  
UAPDD - Box 671, University of Roches-  
ter, 601 Elmwood Ave., Rochester, NY  
14642  
(716) 275-2986

### **North Country Aging and Developmental Disabili- ties Network**

Marion Balch  
Lexington Center, 465 North Perry St.,  
Johnstown, NY 12095  
(518) 762-0024

### **Southern Tier Aging and Developmental Disabili- ties Network**

Diane McDaniels  
Otsego Regional Center, Edmunston  
Program, RD 4, Box 51D, Oneonta, NY  
13820  
(607) 965-8114

### **Cortland Area Task Force on Aging and Develop- mental Disabilities**

Judith Hayes  
Sequin Community Services, Syracuse  
DSO, 55 Tompkins St., Cortland, NY  
13045  
(607) 756-5637

### **Rome DDSO Elderly Advisory Committee**

Kathy Bishop  
Staff Development, Rome DDSO, Box 550,  
Rome, NY 13440  
(315) 339-6750 ext. 327

### **NYS OMRDD**

#### **Bureau of Aging Services**

Matthew P. Janicki, Ph.D.  
NYS OMRDD, 44 Holland Ave., Albany,  
NY 12229  
(518) 473-7855  
(518) 474-7086/FAX

### **Central New York Network on Aging & Develop- mental Disabilities**

Angela Z. VanDerhoof  
Oneida County ARC, 14 Arnold Ave., PO  
Box 4759, Utica, NY 13504  
(315) 735-6477  
or

### **NYS Office for the Aging - Aging and Develop- mental Disabilities Project**

Phil LePore  
State Office for the Aging, 2 Empire State  
Plaza, Albany, NY 12223-0001  
(518) 486-2727  
(518) 474-0608/FAX

## Local Offices for the Aging

*Listed by County*

### Albany

Co. Dept. for the Aging, 112 State St., Rm. 710, Albany, NY 12207 518 447-7180

### Allegany

Co. Office for the Aging, 17 Court St., Belmont, NY 14813 716 268-9390

### Broome

Co. Office for the Aging, Co. Office Bldg., Government Plaza, Binghamton, NY 13902 607 772-2411

### Cattaraugus

Co. Dept. for the Aging, 255 N. Union St. Olean, NY 14760 716 375-4114

### Cayuga

Co. Office for the Aging, 160 Genesee St., Auburn, NY 13021 315 253-1226

### Chautauqua

Co. Office for the Aging, Hall R. Clothier Bldg., Mayville, NY 14757 716 753-4471

### Chemung

Co. Office for the Aging, 425 Pennsylvania Ave., Elmira, NY 14904 607 737-5520

### Chenango

Area Agency on Aging, Co. Office Bldg., 5 Court St., Norwich, NY 13815 607 335-4624

### Clinton

Co. Office for the Aging, 137 Margaret St., Plattsburgh, NY 12901 518 565-4620

### Columbia

Co. Office for the Aging, 71 North 3rd St., Hudson, NY 12534 518 828-4258

### Cortland

Co. Office for the Aging, Co. Office Bldg., 60 Central Ave., PO Box 5590, Cortland, NY 13045 607 753-5060

### Delaware

Co. Office for the Aging, 6 Court St., Delhi, NY 13753 607 746-6333

### Dutchess

Co. Office for the Aging, 488 Main St., Poughkeepsie, NY 12601 914 431-2465

### Erie

Co. Dept. of Senior Services, 95 Franklin St., Erie Co. Office Bldg., Buffalo, NY 14202 716 846-6046

### Essex

Co. Office for the Aging, Elizabethtown, NY 12932 518 873-6301 Ext. 370

### Franklin

Co. Office for the Aging, Co. Court House, 63 Main St., Malone, NY 12953 518 483-6767

### Fulton

Co. Office for the Aging, 1 East Montgomery St., Johnstown, NY 12095 518 762-0650

### Genesee

Co. Office for the Aging, Batavia-Genesee Senior Center, 2 Bank St., Batavia, NY 14020 716 3433-1611

### Greene

Co. Dept. for the Aging, 19 S. Jefferson Ave., PO Box 392, Catskill, NY 12414 518 943-5332

### Hamilton

See Warren/Hamilton

### Herkimer

Co. Office for the Aging, Co. Office Bldg., Mary St., Herkimer, NY 13350 315 867-1121

### Jefferson

Co. Office for the Aging, 1240 Coffeen St. (Lower Level), Watertown, NY 13601 315 782-1075

### Lewis

Co. Office for the Aging, Lewis Co. Office Bldg., PO Box 408, wville, NY 13367 315 376-5313

### Livingston

Co. Office for the Aging, Livingston Co. Campus, Bldg 1, Mt. Morris, NY 14510 716 658-2881 Ext. 18, 29, 41

### Madison

Co. Office for the Aging, Box 250, Rt. 20, Morrisville, NY 13408 315 684-9424

### Monroe

Co. Office for the Aging, 375 Westfall Rd., Rochester, NY 14620 716 274-7800

**Montgomery**

Co. Office for the Aging, PO Box 191, Amsterdam, NY 12010 518 483-2300

**Nassau**

Co. Dept. of Senior Citizen Affairs, 222 Willis Ave., Mineola, NY 11501 516 535-5814

**Niagara**

Co. Office for the Aging, Switzer Bldg., 100 Davison Rd., Lockport, NY 14094 716 439-6044

**Oneida**

Co. Office for the Aging, Co. Office Bldg., 800 Park Ave., Utica, NY 13501 315 798-5771

**Onondaga**

Metropolitan Commission on Aging, Ciic Center, 19th Flr., 421 Montgomery St., Syracuse, NY 13202 315 425-2362

**Ontario**

Co. Office for the Aging, 120 N. Main St., Canandaigua, NY 14424 716 396-4041

**Orange**

Co. Office for the Aging, 60 Erie St., 3rd Flr., Goshen, NY 10924 914 294-5151 Ext. 1560

**Orleans**

Co. Office for the Aging, Orleans Co. Admin. Bldg., 14016 Rte 31, Albion, NY 14411 716 589-5673 or 7004 Ext. 191

**Oswego**

Co. Office for the Aging, Co. Office Complex, 70 Brunner St., PO Box 3080, Oswego, NY 13126 315 349-3231

**Otsego**

Co. Office for the Aging, Co. Office Bldg., Cooperstown, NY 13326 607 547-4233

**Putnam**

Co. Office for the Aging, 110 Old Rte. 6 Bldg. A. Carmel, NY 10512 914 225-1034

**Rensselaer**

Co. Dept. for the Aging, 1700 7th Ave., Troy, NY 12180 518 270-2730

**Rockland**

Co. Office for the Aging, Bldg. B, Health & Social Services Complex, Pomona, NY 10970 914 354-0200 Ext. 2100

**St. Lawrence**

Co. Office for the Aging, Co. Office Bldg., Canton, NY 13617 315 379-2204

**Saratoga**

Co. Office for the Aging, South Street School, Ballston Spa, NY 12020 518 885-2212

**Schenectady**

Co. Office for the Aging, 117 Nott Terrace, Schenectady, NY 12308 518 382-8481

**Schoharie**

Co. Office for the Aging, 122 E. Main St., Cobleskill, NY 12043 518 234-4219

**Schuyler**

Co. Office for the Aging, 336-338 W. Main St., Montour Falls, NY 14865 607 535-7108

**Seneca**

Co. Office for the Aging, PO Box 480, Seneca Falls, NY 13148 315 568-5893

**Steuben**

Co. Office for the Aging, County Rte. 113, Bath, NY 14810 607 776-7651

**Suffolk**

Co. Office for the Aging, 65 Jetson Lane, Central Islip, NY 11722 516 348-5313

**Sullivan**

Co. Office for the Aging, 100 North St., New Co. Government Ctr., Monticello, NY 12701 914 794-3000

**Tioga**

Co. Office for the Aging, 231 Main St., Owego, NY 13827 607 687-4120

**Tompkins**

Co. Office for the Aging, 320 N. Tioga St., Ithaca, NY 14850 607 272-2825

**Ulster**

Co. Office for the Aging, 240-244 Fair St., PO Box 1800, Kingston, NY 12401 914 331-9300 Ext. 578

**Warren/Hamilton**

Counties Office for the Aging, Warren Co. Municipal Ctr., Lake George, NY 12845 518 761-6347

**Washington**

Co. Office for the Aging, PO Box 58,  
Whitehall, NY 12887 518 499-2468

**Wayne**

Co. Office for the Aging, PO Box 7336, Rte.  
31, W. Lyons, NY 14489 315 946-5624

**Westchester**

Co. Office for the Aging, 214 Central Ave.,  
White Plains, NY 10606 914682-3000

**Wyoming**

Co. Office for the Aging, 76 N. Main St.,  
Warsaw, NY 14569 716 786-8833

**Yates**

Co. Area Agency on Aging, 5 Collins Ave.,  
Penn Yan, NY 14527 315 536-2368

**New York City**

Dept. for the Aging, 2 Lafayette St., New  
York, NY 10007 212 577-0848

**St. Regis-Mohawk**

Office for the Aging, St. Regis-Mohawk  
Indian Reservation, Hogansburg, NY 13655 518  
358-2272

**Seneca Nation of Indians**

Office for the Aging, 1500 Rte. 438, Irving,  
NY 14081 716 532-577838, Irving, NY 14081 716  
532

## Resources

### Books on Aging and Disability

#### *Aging and Developmental Disabilities: Issues and Approaches*

by Matthew Janicki and Henry Wisniewski.

This extensive text, containing 26 chapters by various experts in the field, covers various aging and biological processes, legal and advocacy considerations, epidemiology, research and planning, service issues and practices, and residential and day programming, and family concerns (427pp). It is available from Paul H. Brookes Publishing (PO Box 10624, Baltimore, MD 21285 or call 800 638-3775).

#### *Aging and Mental Handicap*

by James Hogg, Steve Moss and Diana Cooke.

The authors present a review of and ageing and mental handicap literature from a British perspective. Chapters cover background issues, epidemiology, medical and psychiatric issues, intelligence and adaptive behavior, work and retirement, interventions for changing behavior, residential issues, and informal supports (411pp). It is available from Routledge Chapman and Hall, Inc. (29 West 35th Street, New York, NY 10001).

#### *Aging and Mental Retardation: Extending the Continuum*

by Marsha M. Seltzer and Marty Wyngaarden Krauss.

This American Association on Mental Retardation monograph includes a review of community and institutional-based day and residential programs currently in operation, and provides specific details of services models that appear to be particularly effective, as well as information on the role and structure of informal support networks (187pp). It is available from AAMR, (1719 Kalorama Road NW, Washington, DC 20009 or call 800-424-3688).

#### *Expanding Options for Older Adults with Developmental Disabilities: Practical Guide to Achieving Community Access*

by Marion Stroud, Evelyn Sutton and Ruth Roberts.

This book is based upon the experiences of Dr. Roberts and her colleagues with Project ACCESS in Ohio (251pp). It contains background information on aging, the developmental disabilities, the needs of elderly persons with a disability, community organization, and treatment planning and implementation. A companion book, *Activities Handbook and Instructor's Guide*, is also available (255pp). The Handbook contains helpful information on specific program activities. Both are available from Paul H. Brookes Publishing (PO Box 10624, Baltimore, MD 21285 or call 800 638-3775).

## Other Useful Publications

### ***All of Us: Strategies and Activity Ideas for Integrating Older Adults with Developmental Disabilities into Senior Centers***

by Eunice Thurman.

This 109pp monograph covers a variety of activity suggestions for involving seniors in the day-to-day program of a senior center. The activities are presented within a means to evaluate the seniors potential for participation. It is available from Senior Center Integration Project, Kent Client Services, 1225 Lake Drive, S.E., Grand Rapids, MI 40506

### ***Aging and Disabilities: The Intersection of Needs and Resources***

Developed at the University of Maryland, this is a training manual for workers in aging and developmental disabilities agencies that covers a variety of topic areas useful in the implementation of integration efforts. Copies of the training manual are available from the Center on Aging, University of Maryland (College Park, MD 20742-2611 or call 301 454-5856).

### ***Aging and Lifelong Disability: Partnership for the 21st Century***

by Edward F. Ansello and Thomas Rose.

This is a summary of an invitational conference held at the Wingspread Conference Center in Racine, Wisconsin in June, 1987. Discussion summaries provide overviews of the relevant issues facing the states as they work toward integrating older Americans with developmental disabilities within mainstream aging network programs (82pp). It contains a series of recommendations for action and social policy to aid in affecting integration. It is available from the University of Maryland's Center on Aging (College Park, MD 20742-2611 or call 301 454-5856).

### ***An Orientation Manual to the Older Americans Act***

by Susan Coombs Ficke.

This publication details the history and various provisions of the Older Americans Act (as amended up to 1985). While not containing the provisions in the 1987 amendments, it is nevertheless an excellent compendium of easily retrievable information about the Act (122pp). It is available from the National Association of State Units on Aging (2033 K Street, N.W., Washington, DC 20006 or call 202 785-0707).

### ***Barriers and Strategies: Barriers to and Strategies for the Integration of Older Persons with Developmental Disabilities Within Aging Network Programs***

Developed and issued by the New York State Office for the Aging, this 36 page monograph outlines the preliminary aspects of the State Office's Aging and Developmental Disabilities Integration Feasibility Demonstration Project, identifying the problems localities may encounter as they implement integration projects of their own. The report outlines key actions at the state level and strategies to be employed at the local level to implement integration activities. This report is available from the State Office for the Aging, (2 Empire State Plaza, Albany, NY 12223-0001 or call 518 486-2727).

***Developing Adult Day Care: An Approach to Maintaining Independence for Impaired Older Persons***

by Helen Padula.

This publication offers helpful information on setting up and operating a social model adult day care center (118pp). It is available from the National Council on the Aging, Inc., (600 Maryland Avenue, S.W., West Wing, Washington, DC 20024 or call 800 424-9046)

***The Role of Adult Day Care in New York State's Long Term Care Service Continuum***

by the New York State Long Term Care Policy Coordinating Council.

This 66 page monograph is a report of the Long Term Care Policy Coordinating Council on the various issues related to adult day in New York. It is useful reading in order to understand the political and policy climate for expanding adult day care services in New York. Copies are available from the State Office for the Aging, Building Two, Empire State Plaza, Albany, NY 12223-0001.

***Working with Developmentally Disabled Older Adults: A Training and Resource Manual***

by Margaret F. Sailer and Scott Jay Selkowitz.

A "how to" oriented manual on introducing and using a range of activities in programs specifically designed for older adults with developmental disabilities (73pp). Available from the Southeastern Pennsylvania Rehabilitation Center (SEPRC) of Elwyn Institutes, (Baltimore Pike and Elwyn Road, Elwyn, PA 19063).

***Age Pages***

issued by the National Institute on Aging.

This booklet is a compilation of fact sheets, the *Age Page*, published by the National Institute on Aging. These fact sheets offer practical advice on health promotion and related topics. Available from the National Institute on Aging (NIA) Information Center, (2209 Distribution Circle, Silver Spring, MD 20910 or call 301 495-3455).

***Contemporary Issues in the Aging of Persons with Mental Retardation and Other Developmental Disabilities***

by Matthew P. Janicki, Marsha Mailick Seltzer and Mary Wyngaarden Krauss

This 43 page monograph contains material that is useful as background. Areas covered include definition concerns; estimates of size; and demographic, health and functional, and family/social support characteristics. The monograph also contains an extensive bibliography. Available from National Rehabilitation Information Center, (8455 Colesville Rd., Suite 935, Silver Spring, MD 20910 or call 800 346-2742).

## **Videos**

### ***Aging... A Shared Experience***

This 20 minute video, developed and distributed by the New York State Office of Mental Retardation and Developmental Disabilities explores the twin themes of the effective community integration and friendships among older persons who are developmental disabled. It is equally appropriate for public education and staff training sessions. The videocassette (VHS format) is available from the Bureau of Aging Services, NYS OMRDD, 44 Holland Avenue, Albany, NY 12229-0001 (518 473-7855).

## **Reports on Aging and Developmental Disabilities**

### ***New Directions for Seniors: Senior Day Program Demonstrations***

Developed and issued by the New York State Office of Mental Retardation and Developmental Disabilities, this 20 pp report is available from the Bureau of Aging Services, NYS OMRDD, 44 Holland Avenue, Albany, NY 12229-0001 (518 473-7855).

### ***Program Resources Directory for Older Persons with Developmental Disabilities, 1989***

Developed and issued by the New York State Office of Mental Retardation and Developmental Disabilities, this 315 page report is available from the Bureau of Aging Services, NYS OMRDD, 44 Holland Avenue, Albany, NY 12229-0001 (518 473-7855).

### ***Report of the Committee on Aging and Developmental Disabilities***

Developed and issued by the New York State Office of Mental Retardation and Developmental Disabilities, this 85 page report is available from the Bureau of Aging Services, NYS OMRDD, 44 Holland Avenue, Albany, NY 12229-0001 (518 473-7855).

### ***The Newest Minority: The Aging MR/DD Population in Oneida County***

Developed and issued by the Oneida County MR/DD Task Force, this 30 page report is available from the Institute of Gerontology, Utica College, Burrstone Road, Utica, NY 13502 (315 792-3129)

## Basic Rights of Older Persons With Developmental Disabilities

Dr. Paul Cotten, a leader in the area of work with older persons with developmental disabilities, has proposed in the book, *Aging and Rehabilitation: Advances in the State of the Art* (Springer, 1985), that States consider the following Bill of Rights:

The right to an adequate standard of living, economic security, and protective work.

The right to humane services designed to help one reach his or her fullest potential.

The right to live as independently as one is capable and reside in the community of one's choice, in as normal a manner as is possible.

The right to an array of services that is generally available to other older persons.

The right to retire "to something" rather than "from something."

The right to participate as a member of the community, having reciprocal interdependency.

The right to be considered a person and not merely "elderly" or "retarded."

The right to protected well-being, and to a qualified guardian, when required.

The right to be involved in setting one's own goals and making one's own decisions; and the right to fail if necessary.

The right to a positive future, having enough involvement with life to prevent a preoccupation with death.

The right to be romantic, not asexual.

The right to sufficient activity and attention to permit continued integrity of self, individual identity, and purpose.

The right to an interesting environment and lifestyle, with availability of sufficient mobility to provide a variety of surroundings.

The right to live and die with dignity.

## **Some Basic Assumptions**

The New York State constitution affords all elderly people an equal opportunity to participate in the activities in which they chose to be involved. A person with a disability has the right to decide whether he or she wants to participate in any program. The choice should always be left to the individual. But if the person is not given a chance, never knows about the choice, then that individual has no real choice.

The elderly person with a developmental disability has a right to be integrated. Any form of segregation tends to harm both those who are segregated and those who segregate them. The lives of both groups are richer if everyone is free to participate in the programs that interest him or her and is not barred from them because of such factors as physical or mental handicaps.

The elderly person with a developmental disability has the right to participate in programs for the aging. The lack of such an opportunity can mean there is no opportunity to participate in social or recreational programs at all.

Each individual should be accorded full legal and human rights without regard to age or disability. Each individual has a right to receive services in the least restrictive environment, and in a way that recognizes that individual's ability to benefit from participation. The services should be provided in a manner that is flexible, accessible, and appropriate, and that promotes the dignity of the individual.

# Memorandum of Understanding Between the Administration on Aging and the Administration on Developmental Disabilities

## Introduction

The Administration on Aging (AoA) was created under the Older Americans Act of 1965 and is the only Federal agency devoted exclusively to the concerns and potential of America's older population. AoA serves as the visible advocate on behalf of the elderly within the Department of Health and Human Services and other Federal agencies and national organizations administering programs affecting older people. The major goal of the Administration on Aging is to help older people live more meaningful, independent, and dignified lives in their own homes and communities for as long as possible.

The Administration on Developmental Disabilities (ADD) is the lead agency within the Department of Health and Human Services responsible for planning and carrying out programs which promote the self-sufficiency and protect the rights of the nearly four million Americans with developmental disabilities. The major goal of the Administration on Developmental Disabilities is to work in partnership with State governments, local communities and the private sector to increase the social and economic integration of individuals with developmental disabilities into the fabric of society.

The purpose of this agreement is to improve the coordination of programs administered by the Administration on Aging and the Administration on Developmental Disabilities which relate to the welfare of older persons with developmental disabilities.

## Background

It is estimated that two out of every 1,000 older adults have a developmental disability. The total number of elderly persons in the United States who are developmentally disabled is estimated to be as high as one-half million persons. These older persons are in double jeopardy. Their problems are complicated by long-standing physical or mental impairments and they frequently need individualized housing, day-care, and other supportive services. Assistance, through the provision of appropriate services, to this priority older population can be made available and accessible within the community through a comprehensive, coordinated, community-based service system. This system of services should be designed to enable older persons with developmental disabilities to attain and maintain emotional well being and independent living.

The Older Americans Act now contains many requirements for services to elderly disabled people and cooperation with agencies and organizations regarding the developmentally disabled. For example, the Act requires the State Agency on Aging to establish and operate an Office of the State Long Term Care Ombudsman. This Office is required to coordinate ombudsman services with the protection and advocacy systems for individuals with developmental disabilities and mental illness established under Part A of the Developmental Disabilities Assistance and Bill of Rights Act and under the Protection and Advocacy for Mentally Ill Individuals Act of 1986.

With respect to the needs of elderly persons with severe disabilities, the Act requires State plan assurances for the coordination of planning, identification, assessment of needs, and services with State agencies primarily responsible for disabled, including severely disabled,

persons. The State plan must also contain an assurance that the State will work with these agencies to develop collaborative programs to meet the needs of older individuals with disabilities.

There is a need for the Administration on Aging and the Administration on Developmental Disabilities to undertake the development of collaborative activities to improve the coordination of programs administered by the Administration on Aging and the Administration on Developmental Disabilities which promote the independence and well-being of older persons with developmental disabilities.

### Scope of the Agreement

The immediate objective of this agreement is for the Administration on Aging and the Administration on Developmental Disabilities to discuss, and develop action plans for, joint initiatives which improve the coordination of the Administration on Aging and the Administration on Developmental Disabilities programs and activities in order to improve services to older persons with developmental disabilities, promote the integration of these individuals into the mainstream of society, and promote a better understanding of programs serving elderly and disabled persons between the National Network on Aging and the Developmental Disabilities Network.

Under this agreement, the Administration on Aging and the Administration on Developmental Disabilities agree to jointly develop and implement initiatives in support of the goals and objectives outlined below and to undertake the development of other collaborative activities which promote the independence and well-being of older persons with developmental disabilities.

### Goal I

Promote a better understanding of programs serving elderly and disabled persons between the National Network on Aging and the Developmental Disabilities Network.

### Objectives

1. To increase best practice and other information sharing/exchange between the Network on Aging and Developmental Disabilities Network.
2. To stimulate linkages between the Ombudsman and Protection and Advocacy Programs.
3. To explore potential linkages between the Aging Resource Centers and University Affiliated Programs.
4. To encourage the development of memoranda of understanding between the State Developmental Disabilities Councils and State Agencies on Aging.

### Goal II

To demonstrate a commitment at the national level between the Administration on Aging and the Administration for Developmental Disabilities regarding serving older persons with developmental disabilities.

### Objectives

1. To provide policy guidance to National Network on Aging and the Developmental Disabilities Network on serving older persons with developmental disabilities.

2.To promote training of Network on Aging and Developmental Disabilities staff and others regarding the abilities and unmet needs of older persons who are developmentally disabled.

3.To increase collaboration and linkages between national organizations and Federal, State, and local agencies serving the older persons who are developmentally disabled.

4.To jointly develop a priority area on elderly persons with developmental disabilities for the discretionary funds announcements.

### **Goal III**

Improve services to older persons with developmental disabilities.

#### **Objectives**

1.To identify the unmet needs of older persons with developmental disabilities.

2.To facilitate the provision of quality services in intermediate care facilities which meet the needs of older persons who are mentally retarded.

3.To promote training of health care professionals to provide services to older persons with developmental disabilities.

4.To promote training of family caregivers on how to care for older persons with developmental disabilities.

5.To promote the successful integration of older persons with developmental disabilities in aging network programs (mainstreaming those elderly persons who are developmentally disabled as participants and volunteers at senior centers and nutrition sites).

#### **Administration of Memorandum of Understanding**

The Administration on Aging and Administration on Developmental Disabilities jointly agree to:

1.Designate staff to be responsible for administering all aspects of this agreement; and

2.Designate staff of Administration on Aging and the Administration on Developmental Disabilities to meet regularly to review the progress of the joint agreement and to identify new joint initiatives.

#### **Period of Agreement**

This agreement is effective upon signature and shall continue in effect until terminated by either party.

#### **Authority**

The Economy Act of 1932, as amended (31 U.S.C. 1535)

**Modification or Cancellation Provision**

This agreement may be modified or amended by written agreement of both parties. Requires for modification and amendments to the agreement may be initiated by either party through written notification to either party.

**Costs**

To be determined upon the completion of specific action plans for dissemination activities and/or research and demonstration projects.

**Acceptance and Signature of Each Approving Party**

\_\_\_\_\_  
Joyce T. Berry, Ph.D.  
Acting Commissioner on Aging  
Administration on Aging  
U. S. Department of Health  
and Human Services

\_\_\_\_\_  
Will Wolstein  
Acting Commissioner  
Administration on Developmental  
Disabilities  
U. S. Department of Health  
and Human Services

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

**Memorandum of Understanding  
Relative to Older New Yorkers With a Developmental Disability  
Between the New York State Office for the Aging  
and  
The New York State Office of Mental Retardation  
and Developmental Disabilities**

This agreement is entered into by and between the New York State Office for the Aging (SOA) acting by and through the Director with Offices at 2 Empire State Plaza, Albany, NY 12223, and the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) acting by and through the Commissioner with offices at 44 Holland Avenue, Albany, NY 12229.

Whereas OMRDD is the state agency responsible for providing residential and community services for persons with a developmental disability in New York State, and

Whereas SOA is the state agency responsible for implementing and stimulating programs and policies both through the aging network and other state agencies on behalf of all older New Yorkers, and

Whereas aging network means agencies which receive monies administered by the SOA, and

Whereas the State and recent federal Older Americans Act amendments recognize the increasing number of older persons with a developmental disability, and

Whereas older New Yorkers with a developmental disability are eligible for aging network services, and

Whereas both agencies agree that the integration of capable older New Yorkers with a developmental disability within aging network programs is feasible and warranted, and

Whereas SOA and OMRDD believe a coordinated multi-agency approach can more effectively meet the needs of older New Yorkers with a developmental disability, SOA and OMRDD agree:

- to establish and maintain an interagency services coordination committee to address issues of common concern, coordinate planning and services, and resolve problems;
- to encourage local coordination of planning, needs identification, and development of services between local Offices for the Aging and OMRDD district offices and/or constituent provider agencies;
- to establish mechanisms for coordinating funding of services to older New Yorkers with a developmental disability including ensuring coverage of the additional costs stemming from provision of services such as supplemental staff assistance, transportation, or other activities within aging network services;
- to assist local Offices for the Aging and OMRDD district offices or its constituent agencies to develop arrangements for reimbursement of additional of aging network services;
- to establish mechanisms to cover services reporting and case record sharing requirements;
- to assist each other by sharing technical information, training resources, and providing cross-training to agencies providing services to older New Yorkers with a developmental disability within both networks; to cooperate on common projects involving grant or other external funding that would benefit older New Yorkers with a developmental disability; and
- to encourage New York's colleges and universities to address the issues of aging among New York's older population of persons with a developmental disability.

Therefore, SOA and OMRDD agree to the following:

*Office for the Aging agrees, only to the extent resources are available, to:*

- request the State's local Offices for the Aging to enter into a planning process with the relevant OMRDD district office on specific service projects, and such planning processes would include not only the local developmental disability and aging offices, but also older adults from the planning and service areas;
- share technical resources, such as videos, films and publications, free of charge, with OMRDD and its district offices;
- provide technical assistance in relevant areas to OMRDD, its district offices and constituent agencies;
- engage in advocacy activities on behalf of older New Yorkers with a developmental disability;
- facilitate the assimilation of disability agency senior programs into the local aging network;
- enter into cooperative endeavors that would benefit older New Yorkers with a developmental disability and their families; and
- request the state's colleges and university-based centers of aging or geriatric education centers to develop intramural and extramural activities related to aging and developmental disabilities.

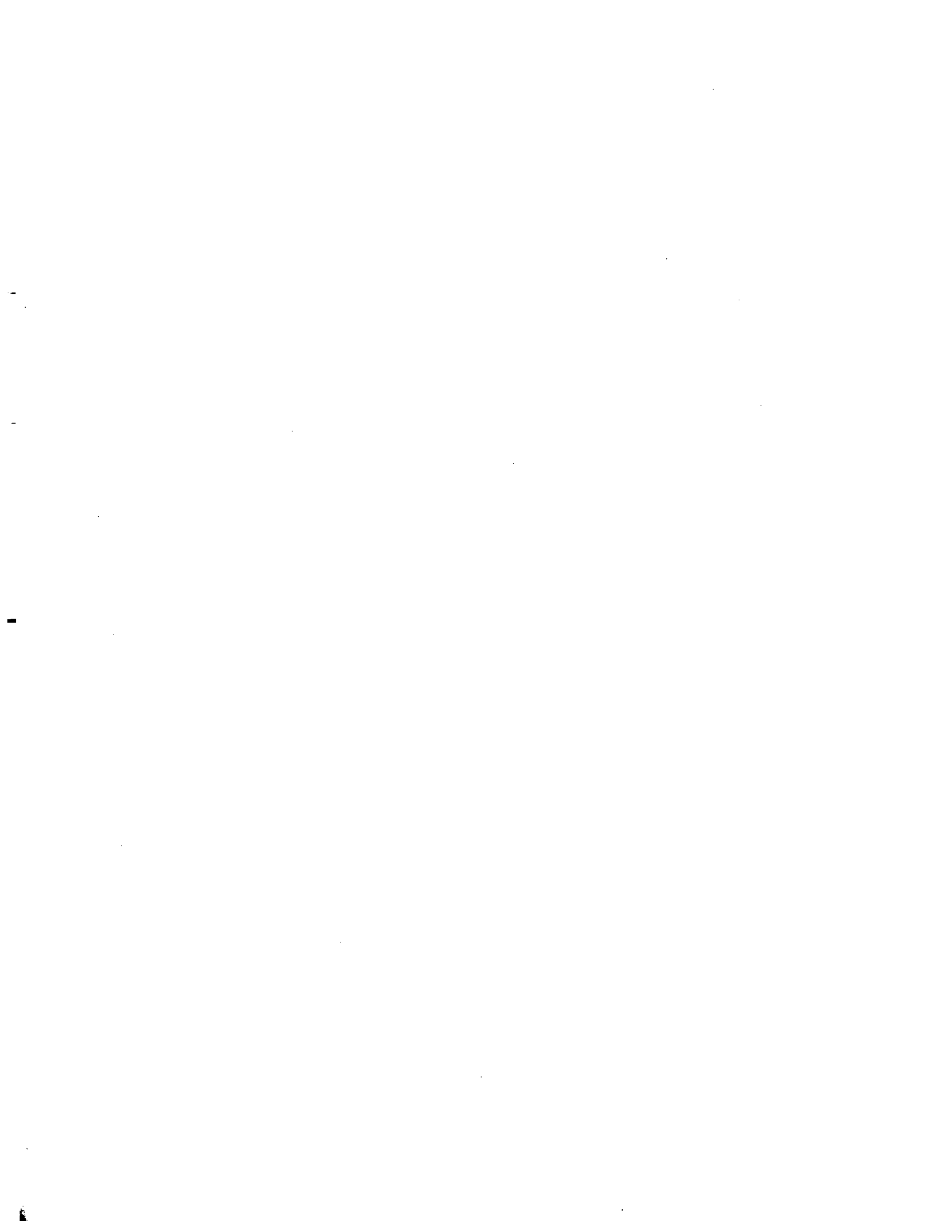
*OMRDD agrees, only to the extent resources are available, to:*

- request OMRDD district offices to enter into a planning process with the state's local Offices for the Aging on specific service projects;
- share technical resources, such as videos, films, and publications, free of charge, with SOA and the state's local Offices for the Aging;
- provide technical assistance in relevant areas to SOA and the state's local Offices for the Aging;
- engage in advocacy activities on behalf of older New Yorkers with a developmental disability;
- enter into cooperative endeavors that would benefit older New Yorkers with a developmental disability and their families;
- share information on available funding support to aging network programs specifically or individually serving older New Yorkers with a developmental disability;
- agree to assume the additional costs of providing services within aging network programs for older New Yorkers with a developmental disability;
- assume the responsibility of recordkeeping and reporting requirements, set by OMRDD, for older New Yorkers in aging network programs and services for whom such requirements apply; and
- to cooperate in cross-training endeavors directed toward local programs.

This memorandum of understanding is effective on the 31 day of JANUARY, 1990 and shall be in effect until terminated by mutual agreement.

  
by Jane G. Gould  
Director, State Office for the Aging

  
by Elin M. Howe  
Acting Commissioner, State Office of Mental Retardation  
and Developmental Disabilities





New York State  
Office for the Aging  
2 Empire State Plaza  
Albany, NY 12223-0001