

*Illinois Department on Aging*  
**Illinois Long-Term Care Ombudsman Program  
Supplemental Training Curriculum**

**Supplemental Module #15  
Residents in Intermediate Care Facilities for the  
Developmentally Disabled (ICFDD):  
Best Practices for Visiting Residents and  
Assuring Their Rights**

**Pre-publication Edition I**

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## **PROCESS FOR USING THIS MODULE**

The supplemental modules for ombudsmen have been developed to accommodate different learning styles and are based on research about how most people learn. The premise on which this module is based is the idea that new information is learned best when there is an opportunity for discussion and to ask questions. This module incorporates individual reading, group discussion, questions on what is not clear to you and an evaluation of what you have learned.

After the reading of the module and participating in group discussion, you will be asked to:

1. Work as a group to identify at least three kinds of behaviors that persons who have developmental disabilities might display and list the strategy (ies) the ombudsman would use to improve communication with them, depending on the type of disability.
2. Individually
  - (a) Write a paragraph or two (or as long as you would like) to your supervisor, saying why you would or would not like to visit residents in an intermediate care facility for residents with developmental disabilities (ICFDD),
  - (b) Include whether or not you feel that you are trained sufficiently to protect ICFDD residents, either through this training or your own personal experiences with this population, and
  - (c) Include what additional training is needed for you to visit residents who have developmental disabilities.

## **PURPOSE OF THE MODULE**

The purpose of this module is to

- Inform the ombudsman about the federal and state laws and regulations concerning ICFDD facilities.
- Inform the ombudsman on the survey process for these facilities, which is separate from other long-term care facilities.
- Inform the ombudsman about the behaviors of vulnerable residents with developmental disabilities, and how to cope with common developmental disability behaviors.
- Inform the ombudsman about how to protect residents with developmental disabilities.

**SUPPLEMENTAL MODULE #15**  
**Residents in Intermediate Care Facilities for the**  
**Developmentally Disabled (ICFDD):**  
**Best Practices for Visiting Residents and Assuring Their Rights**  
By Margaret Niederer

**I. INTRODUCTION**

The resident population and setting of Intermediate Care Facilities for the Developmentally Disabled (ICFDD) is quite different from the nursing home setting with which most ombudsmen are familiar. The residents in ICFDD facilities (sometimes referred to as ICF/MR facilities—intermediate care facilities for the mentally retarded) have had one or more disabling conditions since an early age and are in active treatment programs to acquire or maintain behaviors that will lead to independence.

Some ombudsmen may fear potential abnormal or unpredictable behaviors of persons with developmental disabilities and avoid visits to the ICFDD homes. However, with knowledge and some experience, ombudsmen have no reason to feel apprehensive about visiting ICFDD homes. Ombudsmen who regularly visit ICFDD facilities find that the residents are most appreciative of having someone visit them. Two volunteer ombudsmen share their experiences:

- “ICFDD facility residents are a genuine group of people. They wear their hearts of their sleeves and are delightful to visit.”
- “In one large ICFDD facility, there is one resident who plays the piano by ear—all the old songs and many religious songs. Another resident has several oil paintings to his credit. Taking an interest in his paintings can produce delightful responses. The residents at the facility I visit love company and love to be active, no matter what their age.”

**A. ICFDD FACILITIES IN ILLINOIS**

Currently (2002), there are approximately 340 ICFDD facilities in Illinois. Approximately 256 ICFDD facilities have populations of 16 beds or less. Thirty-two facilities have large resident populations, up to 300 beds.

To qualify for ICFDD placement, an individual must be screened by an Illinois PASARR (Pre-Admission Screening and Resident Review) agency and determined to

1. Have mental retardation—“significantly subaverage general intellectual functioning (IQ of 70 or below) with deficits in adaptive behavior. The mental retardation must have manifested before the age of 22;

OR,

2. Have a related condition that meets all of the following conditions:
  - Attributable to Cerebral palsy, Epilepsy, Autism, or any other condition found to be closely related to mental retardation that requires treatment or services;
  - Manifested before age 22;
  - Likely to continue indefinitely;
  - Results in functional limitations in at least three of the following major life activities:
    - Self-care
    - Language
    - Learning
    - Mobility
    - Self-direction
    - Capacity for independent living (***Procedures Manual for DD PAS Agencies***, 500.20).

The PASARR program is under the auspices of the Department of Human Services, but the actual work is contracted out to not-for-profit agencies, which are located in the Department of Human Services regions throughout the state.

*The philosophy of ICFDD facilities is to provide housing for persons with developmental disabilities, as well as training in the development, acquisition and maintenance of life skills to move residents closer to independence.*

In order for a person to be admitted to an ICFDD, he/she must have the need for “active treatment.” Active treatment “includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services that is directed toward

1. Acquiring behaviors necessary for the client to function with as much self-determination and independence as possible; and
2. Preventing or decelerating regression or loss of current optimal functional status” (***State Operations Manual***, Appendix J, w196).

*Functional status, or level of functioning, is categorized as **mild, moderate, severe, or profound** according to results of an **intelligence assessment** completed by a qualified professional.*

(See Appendix A)

If the person cannot benefit from active treatment, then he/she should go to a nursing home as his/her needs do not fit with the program’s philosophy of training and improvement. It costs the State of Illinois less to care for a person in a nursing home.

Most persons who are classified as developmentally disabled are eligible for Medicaid. Very few are private pay residents.

Although the Department of Public Health does not require that persons with like-kinds of disabling conditions be housed together, in practice, a facility may accept residents with similar characteristics, such as:

- Type of behavior,
- Medical involvement,
- Age of residents, and
- Level of functioning.

ICFDD facilities currently have more lower functioning residents than ten years ago. The current trend is to provide more nursing care in ICFDD facilities to address physical health conditions. With appropriate nursing care, ICFDD residents should be able to stay in their facility until they die; even hospice care can be available within the facility. Ombudsmen should advocate for hospice care, if resident/designated representative prefers. This may require more effort by the ombudsman, depending on the facility's willingness to retain the resident at the end of life.

If a person enters an ICFDD and needs more medical services than are currently provided, the facility can obtain a "medical add on" and receive additional dollars from the Department of Public Aid for the resident being provided that medical service. A "medical add on" must address a condition that requires more than a nurse consultant, as all ICFDD facilities are required to employ a nurse consultant.

Most, if not all residents have a guardian. However, some sign their own consent forms for medical treatment. The guardianship papers should specify what the resident is able to approve.

### ***B. State Facilities, CILA's and CLF's***

The ombudsman may have inquiries concerning types of long-term care facilities for persons with developmental disabilities other than state-licensed ICFDD's. State-operated developmental centers (SODC's), CILA's (Community Independent Living Arrangements) and CLF's (Community Living Facilities) all provide services for a resident population with developmental disabilities.

The CLF's were designed to be homes for transition to the community for residents close to being independent. CILA's were designed to meet the needs of certain residents who are higher functioning in a smaller home-like setting. The differences in resident populations between the ICFDD and the CILA's/CLF's are not always readily apparent. In practice, there is little difference between the populations of ICFDD's, CILA's and CLF's, except they are regulated by different rules and agencies.

Residents of state facilities (SODC's) most often have more severe and complex disabilities than residents who live in community residential facilities (ICFDD's, CILA's and CLF's).

The Department of Public Health is responsible for oversight and licensure but does not federally certify CLF facilities. The Department of Human Services is responsible for oversight and licensure of CILA facilities.

The ombudsman program does not have laws or regulations that permit access, representation, or indemnification to serve residents of CILA's, CLF's or state facilities.

### **C. THE OMBUDSMAN PROGRAM AND ICFDD FACILITIES**

The Long Term Care Ombudsman Program is only responsible for visiting facilities that have residents 60 years old and older. The ombudsman program has no responsibility for other residents of ICFDD facilities, but an ombudsman can take a complaint from a younger resident as long as it does not diminish the services provided to eligible residents. Oversight for the ICFDD residents under 60 years old is provided through the Department of Public Health surveys and complaint hotline.

Ombudsman visits to ICFDD facilities are required according to the regional plan, but ombudsmen are encouraged to visit once a month. Sometimes changes in behavior or demeanor are the only indicators of problems for residents who cannot communicate. Only with regular visits can an ombudsman get to know the residents well enough to notice such changes.

In facilities that have one or more residents who are at least 60 years old, the ombudsman may choose to visit with only those residents for which the program is responsible or with all the residents. It is important to understand how all residents are being treated, as it may impact the care of residents who are at least 60 years old.

## **II. FEDERAL AND STATE REQUIREMENTS**

All ICFDD facilities must meet the Life Health Safety Code Requirements, the same as for all long term care facilities.

The regulations for the ICFDD facilities are separate from those for nursing facilities that govern skilled and intermediate facilities. The state requirements for the program are found in the state regulations, **77 Illinois Administrative Code 350, Intermediate Care for the Developmentally Disabled Facilities Code**. These regulations are authorized by the Nursing Home Care Act (210 ILCS 45).

The federal requirements for surveyors of ICFDD facilities are in Appendix J of the **State Operations Manual**. Deficiencies are categorized according to the program standards specified in regulation. These regulations are indicated by W Tags. (F Tags identify program standards for nursing homes.)

### ***Residents' Advisory Council***

State regulations require each facility to establish a residents' advisory council, which consists of at least five resident members. If there are not five residents capable of functioning on an advisory council, the residents' representatives shall take the place of the required number of residents (77 Illinois Administrative Code, Section 350.650).

The facility must designate a member of the staff to coordinate the establishment of and provide assistance to the council; however, no employee or affiliate of any facility shall be a member of the council. The council must meet at least once each month. A record of the council meetings must be maintained in the office of the administrator. The council is required to review procedures for implementing resident's rights and may present complaints on behalf of a resident to the Department of Public Health or to any other person it considers appropriate.

Advisory council meetings are open to participation by all residents and their representatives. The ombudsman may attend the advisory council meetings with any resident's approval.

### ***Family Councils***

The state regulations also require that each facility develop and implement a plan for interactions with local community groups and individuals (77 IL Admin. Code, Sec. 350.650). One of the ways to meet this requirement is the establishment of a family council, which is composed of families and friends who live in the community. (Some residents may not have families in the community.) The ombudsman should explore the possibility of a family council and encourage the formation of such a group.

The ombudsman should ask what the facility's plan is for assuring a liaison with the local community. Besides forming a family council, the facility can 1) include community members on the resident advisory council; 2) establish a separate community advisory group with persons of the residents' choosing; or 3) find a church or civic group to adopt the facility. The ombudsman should not be a member of any community advisory group, but should provide education and assistance to these groups about the rights of residents who are developmentally disabled.

## **III. STAFFING AND STAFF TRAINING REQUIREMENTS**

All staff of ICFDD facilities fit in one of the following categories:

1. Resident Services Director
2. Quality Mental Retardation Professional (QMRP)
3. Licensed Nurse
4. Direct Support Person (DSP)—also referred to as direct care staff, frontline worker, developmental disability aide, or rehabilitation aide (hab aide)
5. Cook
6. Other ancillary staff, such as custodian, secretary, etc.

The Resident Services Director is the administrator of the total facility operation. This director provides internal monitoring (e.g., upkeep of the facility and overall program), makes administrative decisions, and is a resource for facility staff. A resident services director may be responsible for several facilities, so he/she is not always on-site.

At least one Quality Mental Retardation Professional (QMRP) is assigned to each facility. QMRP's are responsible for the day-to-day supervision of the facility. A QMRP must have, at a minimum, a bachelor's degree in a human services field and must complete 40 hours of an Office of Developmental Disabilities approved basic training program. QMRP duties/training competency areas include

- Roles and Responsibilities
  - Causes of developmental disabilities
  - Values and principles of the developmental disabilities' support system (advocacy, choice/preference, rights, normalization, confidentiality, etc.)
- Leadership and Communication
  - Group dynamics
  - Active listening
- Assessing and Enhancing Quality Outcomes
  - Achieving quality for the individual may require changing the organizational processes and structures
  - Roles of direct support staff in providing opportunities for learning
- Planning
  - Assessment, planning, implementation, review/monitoring the active treatment/Individual Program Plan
- Record Keeping
- Community Relationships and Resources
  - Resident financial matters
  - Legal matters—guardianship, power of attorney, etc.
  - Crisis intervention
- Health and Safety
- Medical Issues
  - Basic information on medications
  - Physical assessment—weight, temperature, blood pressure, etc.
  - Positioning/transferring
  - Communicative and behavioral issues
  - Diet and nutrition
- Rules and Regulations

Twelve hours of continued training are required of QMRP's each year; however, neither the Department of Human Services, nor the Department of Public Health checks if the 12 hours have been completed yearly as required.

ICFDD homes have a licensed nurse available to provide nursing services to residents according to their individual program plans. Nurses attend annual staffings, depending

on the needs of the residents. A licensed nurse is only required to be on-site two hours per month, but must be onsite as required by the individual program plans. For facilities with a population of over 16, a nurse must be on duty 24 hours a day.

The persons providing the direct care to residents are called Direct Support Persons (DSP), or more commonly, “hab aides” (rehabilitation aides). Hab aides can be as young as sixteen years old. They are required to complete an approved training course consisting of 40 hours classroom and 80 hours on-the-job training. DSP duties/training competency areas include,

- Introduction to Developmental Disabilities
  - The agency’s values related to service provision.
  - Basic characteristics of developmental disabilities.
- Human Rights
  - Basic civil, legal, human and property rights and rights protection.
- Abuse and Neglect Prevention, Recognition and Intervention
  - The role a trust-producing, healthy, engaging environment plays in preventing abuse and neglect.
  - The forms of abuse (e.g., sexual, physical, verbal, and psychological).
  - The forms of neglect (e.g., medical, physical care, lack of needed supervision).
- Human Interaction and Communication
  - Different modes of nonverbal and verbal communication/interpersonal relationships with individuals receiving supports, family members and others.
  - Different types of assistive devices
- Service Plan development and Implementation
  - The process of person-centered planning and implementation with regards to his/her role.
- Basic Health and Safety
  - Injury prevention procedures

Upon successful completion of the training program and the Health Care Worker Background Check, hab aides are eligible to be placed on the Nurse Aide Registry, which is maintained by the Department of Public Health

Usually there are one or more hab aides assigned as “lead workers” or “group leaders.”

#### **IV. ISSUES SPECIFIC TO ICFDD FACILITIES**

##### **A. THE INDIVIDUAL PROGRAM PLAN**

Much like Care Plans in nursing homes, each ICFDD resident must have an Individual Program Plan that delineates which active treatment program/services to maintain or improve his/her daily living skills and increase his/her independence. Goals are based on skills assessments and developed to assist the residents in enhancing or maintaining sufficient self-control, gross and fine motor skills, daily living skills, appropriate

behaviors, and the ability to accept assigned tasks. (Individual Program Plans may also be referred to as Individual Habilitation Plans, Treatment Plans, or Service Plans.)

Individual Program Plans are developed and modified during annual meetings called staffings. Residents should be offered the opportunity to attend the staffings, if appropriate, and participate in the development of their individual program plans. If the resident has a designated representative, that person must be invited to participate in the annual meeting.

It is important that the staff adapt each resident's goals to what the resident can reasonably achieve or maintain. Once developed and properly implemented, staff must monitor and document each resident's progress. If a resident is successful at obtaining his/her skills goal, the program plan should be modified to increase the level of difficulty or move to the next skills goal. This does not mean that previously learned skills should "fall by the way-side." Staff should encourage the resident to continue using and maintaining all skills he/she has previously learned.

*Staff should encourage the resident to continue using and maintaining all skills he/she has previously learned.*

State regulations require each resident be assessed to determine if they are making progress. If residents do not meet or they far exceed their individual program plan goals, the facility must reassess and modify the goals. If it does not update the goals, the home faces consequences from the state during the survey process. In the event a resident has not been successful at meeting a skills goal as listed in his/her program plan, staff should modify the plan, breaking down the skill into smaller, more manageable steps with which the resident can reasonably expect success.

One example of a daily living skill goal is understanding the use of money or the identification of money (e.g., a penny, nickel or dime). A resident may know that money has purchasing power, but has not learned the value of the monetary units. An example of objectives for the program plan goal may be:

- *Roberta will match the penny to the coin chart five times a month for four of six months.*  
For each goal there must be criteria for advancement. The staff may find that the resident is not able to meet the goal as written. In order to accommodate the resident's disability, the goal may be rewritten as follows:
- *Roberta will match the penny to the coin chart five times a month for four of six months with a physical prompt:*  
As Roberta achieves this goal, the goal will be re-written to include other prompts that will slowly increase difficulty until Roberta can identify money independently.

## **B. AGE AND DISABLING CONDITIONS**

Many of the older ICFDD residents have spent most of their lives in some type of institutional care. Some were housed in large state institutions and others were kept home until their parents became too old or disabled to care for them. In the 1980's, the state began to downsize the institutions and move residents into smaller, community residential facilities.

Age is not a factor in what activities residents are able to do. For the most part, there is no difference in programming for the older resident than for the younger ones. The home and workshop attempt to promote activities appropriate for the entire age range of most residents (18 years old and older).

If a resident who has reached normal retirement age decides he/she does not want to continue going to workshop, he/she can essentially retire. The goals of the program plan become recreation and leisure, as opposed to work and improvement. However, the resident must agree to continue using and maintaining life skills to stay in the facility. Because the philosophy of a developmental program is to acquire and maintain skills, a resident who is "retired" still needs to be in an active treatment program to maintain skills for daily living.

Not unlike the nursing home resident population, older ICFDD residents may experience increased health concerns. Older residents may experience medical problems such as decreases in vision, hearing, and mobility. Medication and diet become increasingly important. Older residents may require more hospitalizations and show an increased need for adaptive devices.

A person with medical concerns needs to be routinely evaluated and periodically observed by facility staff and medical professionals. Ombudsmen should be alert to residents' physical problems, alert staff, and follow-up with staff to assess if the appropriate medical attention and/or adaptive devices were given.

## **C. RESIDENTS AND MENTAL ILLNESS**

Some residents may have a mental illness; however, a mental illness cannot be the primary diagnosis of the resident to qualify for placement in an ICFDD facility. A person who has been assessed by a psychiatrist and diagnosed with a mental illness in addition to a primary diagnosis of developmental disability is considered to have a dual diagnosis.

The Department of Human Services provides mental health services through this network of facilitators to residents who live in ICFDD facilities to assure they receive certain assessments and "active treatment services."

Many antidepressant and anti-anxiety drugs, as opposed to sedatives and tranquilizers, tend to be used for residents with developmental disabilities. Antidepressant and anti-

anxiety drugs do make a positive difference in many residents' behavior. The following types of medications are typically used: Zoloft, Xanax, Paxil, and Prozac.

Some psychiatrists are experts in the care of the developmentally disabled population and work well with staff and others in providing and monitoring the medication that is of benefit to each person. The ombudsman program should identify a psychiatrist with DD expertise if there are questions or concerns about medications.

#### ***D. ASSESSMENT AND PLANNING FOR SEXUAL NEEDS***

Overt sexual behaviors, appropriate and inappropriate, are not uncommon in the ICFDD resident population. Each annual staffing should include an assessment and plan to address the residents' sexual needs.

The ombudsman needs to be alert to sexual abuse issues. An example of sexual abuse is when one resident inappropriately talks to or touches another resident in a sexual manner.

If an ombudsman observes what he/she considers to be an inappropriate sexual behavior, such as masturbation in a public area, he/she should talk to the staff about the individual's assessment and program plan, and inquire about what interventions, if any, are in place.

If the ombudsman finds evidence of sexual abuse, he/she should contact the ombudsman supervisor about calling the Department of Public Health.

#### ***E. RELIGIOUS SERVICES***

Religious services vary from home to home depending on the residents' need for supervision. Each resident should be allowed to attend a religious service of his/her choice. A religious organization may bring services to the home, or may provide transportation to take residents to services.

#### ***F. THE DAILY ROUTINE OF THE WORKSHOP***

ICFDD residents attend workshop from approximately 8 a.m. to 3 p.m. every weekday and are transported to and from the workshop by bus or van. When there are residents who are unable to go outside the home, a workshop may be brought into the facility.

The workshop setting provides each resident with a day program that is appropriate to his/her needs. Many residents participate in a vocational activity during workshop, such as assembling small appliance parts for a local appliance factory. Residents may receive a small wage for the vocational tasks. Other residents of lower functioning status may participate in a craft or activity that builds gross and fine motor skills. The workshop goals should dovetail with the residents' goals as written in the individual program plan. The training at the workshop does not have to mirror the residents' program plans, but there should be consistency within the workshop and facility programs and the methods used to train the residents.

The Department of Public Health does not license nor survey the workshops. The Department of Human Services is responsible for oversight of the workshops.

### **G. COOPERATIVE PLANNING AMONG ICFDD FACILITIES**

Some of these homes cooperate with each other in planning for resident vacation outings, having bake sales, craft sales, and other community activities. Homes may have open houses for the community to visit and meet the residents. During holidays, the residents may decorate their home and invite the community to come to their open house.

## **V. VISITING ICFDD FACILITIES**

### **A. THE FACILITY IS THE RESIDENTS' HOME**

The term most often used by facility staff and residents is "group home." The residents refer to the facility as "my home" or "my house."

### **B. HOW THESE HOMES GENERALLY APPEAR**

ICFDD facilities are homelike and were designed in response to the institutional settings that were common for so many years. Most facilities are similarly designed with a common TV room, dining room, small kitchen, inconspicuous QMRP office and one or two wings with resident bedrooms. All residents are encouraged to participate in chores and facility upkeep, as they are able. In some homes, staff and residents interact almost like family and exhibit a sense of community.

The ombudsman may see the results of the ICFDD facilities of 16 beds or less have a more resident focused care approach than many nursing homes. The federal focus for the ICFDD's has been on resident-centered care and activities for many more years than for nursing homes. For example, some of the ICFDD's appear to have sufficient staff, more food preferences and better-prepared food (some residents qualify for food stamps) than larger facilities.

### **C. KNOW THE HOME'S SCHEDULE**

An ombudsman needs to know something about the schedule of the ICFDD facility to which he is assigned. Because most of the residents, including those who are over 60 years old, go to workshop each day, the best time to visit is late afternoon or evening. However, evening activities are often scheduled, so the ombudsman needs to know the evening schedule. Calendars are usually posted well in advance and there is ordinarily a routine to the evening schedule, except when there are special events, such as going to a local fair.

The hours before supper are fairly active and may not be the best time for ombudsmen to have a quality visit with residents.

*Always call the facility "a home."*

*Residents do not like to hear that the facility is called an intermediate care facility for the developmentally disabled. Residents who can talk will say that they live in a group home.*

## **Typical Schedule**

8 a.m. – 3:00 or 3:30 p.m.—Most residents go to a workshop.

3:00 p.m.— 5:00 p.m.—Bath time. Often the hygiene and grooming is done so residents can go out in the evening for activities.

4:00 p.m.—Medications are usually passed

5:00 or 6:00 p.m.—Evening meal.

6:30 – 9 p.m.—Evening Activities

## **D. COMMUNICATING WITH RESIDENTS**

Ombudsmen should be aware that some residents speak disjointedly. Do not be frustrated when a resident cannot stay on topic. Simply follow where the resident takes the conversation.

Some residents may use vulgar language or make disparaging remarks. Ombudsmen should not be offended, but the behavior is something to discuss with the QMRP. Ask staff if the behavior is common for the resident and if staff are taking steps to change the behavior. The ombudsman can ask how he/she should react when it occurs. It is important for ombudsmen not to take such language/comments personally.

When a resident is low functioning, and you cannot communicate with him/her, refer to the staff on how to approach the resident. Staff often have more rapport with the residents because they work with this population every day. Perhaps staff would be willing to accompany you as you meet with the resident. If the resident uses a communication board, ask the staff for instruction in its use.

For residents who cannot communicate at all, visiting regularly and learning more about individual residents will help ombudsmen notice signs of concern as evidenced in behavior and/or demeanor changes. The ombudsman must notice everything about the resident—posture, guttural sounds, and physical demeanor.

## **E. RESIDENTS' RIGHTS**

Residents' rights for persons with developmental disabilities are much like residents' rights in nursing homes. The document on rights, ***Residents' Rights for People in Intermediate Care Facilities for the Developmentally Disabled***, is available from regional ombudsmen or the Department on Aging.

Many residents cannot read any materials given to them about residents' rights and explaining an idea as abstract as "rights" can offer ombudsmen a challenge. To assess if residents' rights are being upheld, convert the rights statements into questions to use in your conversations with residents. Consider the following examples:

- Personal Property Rights
  - Do you have your own room? Who shares your room?
  - Do you have anything special that the staff keep for you?
  - How do you like to decorate your room?
  - Where do you keep your clothes? Jewelry? Money? CD's or tapes? Videos? Pictures? Magazines? etc.

- Have you ever lost your clothes, money, CD's, etc?
  - If you lost something, what did the people who work here do when it was lost?
  - Did you ever find it again?
  - Do you get to choose what clothes you wear every day?
- Right to Privacy
    - When you close the door to your room, do people knock before they come in?
    - What do you do, or where do you go, when family and friends come to visit?
- Right to Safety and Good Care
    - Who helps you when you're sick? What do they do for you?
    - Does someone come and clean the bathroom and floors every day?
    - Are you ever too cold or hot in your room?
    - Has anyone ever hurt your feelings here? Hit you? Said something mean to you? Bothered you when you didn't want to be bothered? What did they do that bothered you?
    - If someone bothered you, what did staff do?

If an ombudsman is speaking to a group of residents in a common meeting area, staff may help re-word questions so residents can better understand. Most of the time, residents enjoy talking with visitors and will answer questions honestly. If you notice a staff member correcting residents' answers or notice that residents seem afraid to answer, this may be a sign for concern.

#### **F. BE AWARE OF SOME BEHAVIORS**

Ombudsmen who have not had experience with the persons with developmental disabilities may notice some resident behaviors that seem unusual, but are not uncommon. Examples include body rocking or other repetitive movements, touching others, staring, repetitive speech, unusual vocalizations, etc. The facility may or may not have programs to decrease these behaviors included in residents' individual program plans. The facility may not formally address these types of behaviors because they are not detrimental to residents' daily lives. Ombudsmen can inquire if interventions for these behaviors are in place for particular residents, but the behaviors themselves are not necessarily overt signs of concern.

#### **G. NOTICE IF THERE IS EXCESSIVE CONTROL**

Having individual program plans that delineate active treatment does not imply that residents never have free time to relax and pursue their own activities. When residents are not at workshop or involved in planned activities, they should be allowed free choice of activity and not be regulated. A strict regimentation could imply excessive control, and should be questioned.

One time, an ombudsman noticed that when the residents arrived home, they went straight to their rooms. When the ombudsman asked to see one resident, the QMRP did not want to allow it. When the ombudsman persisted, she found the resident in his

room with nothing to do. In this case, the ombudsman contacted the company who owned the facility about this issue; ultimately the administrator was dismissed.

If the ombudsman suspects excessive control of residents, he/she should contact the ombudsman supervisor for assistance in handling this type of complaint.

#### **H. RESIDENT ACTIVITIES**

Besides going to workshop every weekday, residents have planned activities in the evenings and on weekends, such as making desserts, handball, walks, trips to the local shopping mall, attending a parade, watching videos, etc.

In some homes, hab aides function as group leaders. In order for all residents to have a choice in evening activity participation, more than one group leader is identified to accompany residents to different activities. For example, one group leader may take a group of residents to an activity outside the home, while another group leader remains with those who choose not to join that activity.

#### **I. VISITING THE WORKSHOP SETTING**

The ombudsman may want to visit the workshop setting as well as the group home. Though visits to the workshop are encouraged, if ombudsmen only visit residents in the workshop, ombudsmen may not know the living conditions and environment of the home in the evenings. Best ombudsman practice suggests regular visits to the home and periodic visits to the workshop. Ombudsmen do not have guaranteed access to workshops. A program explanation and a request to observe must be obtained from the workshop supervisor.

#### **J. SIGNS OF CONCERN**

Some resident behaviors exist that are of concern. Residents may exhibit aggression, self-injurious behavior, pica (ingestion of non-food items), yelling/screaming, etc. If ombudsmen learn of or observe this behavior from a resident, staff should be consulted to assess what interventions, if any, have been attempted, are in place, and the effectiveness of the interventions.

In the case of aggression, for your own safety,

- Ask staff if there are aggression problems of which you should be aware. If there is a known trigger for a resident's aggression, staff can instruct you on what to do and not to do with that resident.
- Do not make the resident feel cornered.
- Ask staff if any resident is agitated on the particular day of the visit.
- Ask staff to accompany you when visiting with an agitated resident or discontinue the visit with a resident if he/she becomes agitated.

**Physical Injury**—If there are signs of physical injury to a resident, discuss the injury with staff and contact the ombudsman supervisor. The ombudsman supervisor may determine that an Access to Incapable Residents' Records form is necessary to view documentation related to the injury. If the ombudsman suspects staff-to-resident or

resident-to-resident abuse, he/she should contact the ombudsman supervisor about calling the Department of Public Health hotline.

**Cleanliness**—The ombudsman should take action if he observes excessive dirty clothing, body odors, etc. For example, if a resident's clothing is soiled with food, ask staff what feeding intervention and/or assistive devices are appropriate for the particular resident.

**Signs or Complaints of Illness**—Report any signs of illness to facility staff and follow-up to see that appropriate medical attention was provided.

**Medication Issues**—If the residents appear to be over medicated and drowsy, speak with staff and possibly the nurse. Contact the ombudsman supervisor about how to proceed with this type of issue.

#### **K. SHOULD YOU HUG?**

Simply as a precaution, ombudsmen should check with staff about showing signs of affection to residents. Some homes encourage residents not to hug, but only to shake hands as part of teaching more appropriate social behaviors. Some residents may not be able to differentiate between situations in which hugs are appropriate and situations in which they are not. However, some residents are tactile deprived and can benefit from a friendly touch. The ombudsman should first ask staff if he/she can give residents a hug.

The ombudsman needs to be alert to some residents who touch in a sexual manner. If the ombudsman has checked with the facility staff about facility policy or appropriate actions for the resident, a welcome or goodbye hug is acceptable.

Any hugging should only be done in public areas of the facility for the sake of liability.

## **VI. THE FIRST VISIT**

- As with anyone's home, ring the doorbell before entering.
- If you have never visited the facility before, ask to speak with a staff member. Introduce yourself and explain the ombudsman program. Discuss which residents are sixty years old and older; what behaviors of residents, if any, to be aware; the facility routine and best times to visit; resident communication issues, etc.
- When visiting with residents, look them in the eye and offer a handshake. Eye contact is important.
- Introduce yourself: My name is \_\_\_\_\_. What is your name?
- Address them by the name they use on a daily basis, such as, "Hi Bob!"

- Explain to the residents why you have come to visit: “I’m here today to see if you like your home here and to help you if you have any problems.”
- Have a conversation with individual residents, or with a group of residents.
  - Did you go to work today?
  - What did you have for lunch?
  - Are you going anywhere else today?
  - Where is your favorite place to go?
  - **Use questions that relate to residents’ rights as listed in this module, pages 14-15.**
- Be aware that talking about family could be distressing for residents with no family or who miss their family. Ask staff about residents’ families before approaching this subject.
- Let residents approach you instead of you approaching them. You cannot force a resident to speak with you. Ask staff if there are residents who will not approach you at all.
- Do not rush residents when they are speaking.
- Do not underestimate the residents; this would be a disservice to them. Individually, they all have talent and skills. Even staff may never know when a resident will do something extraordinary.
- Every visit will not be the same. Staff may be different. Sometimes the same staff will have different energy levels. Residents may have different group and individual dynamics. The more you visit, the more you will know residents’ moods/behaviors and how residents and staff interact.

## **VII. THE DEPARTMENT OF PUBLIC HEALTH SURVEY PROCESS**

The survey process is somewhat the same as the process used for nursing homes. The Department of Public Health uses a different survey staff for ICFDD facility surveys than for nursing home surveys. Surveyors are either certified as a registered nurse or as a Qualified Mental Retardation Professional (QMRP).

As in the survey process of nursing homes, ICFDD surveyors perform an in-depth review of a random sample of residents. Surveyors interview the selected residents, observe their behaviors and analyze their records to verify the observations and interviews. The surveyors must include a proportionate number (at least one) of residents in the sample who are categorized by each of the following categories of retardation: mild, moderate, severe, and profound (See Appendix A). Additionally, they must include residents in the sample who are taking drugs to control behaviors. The

surveyors do not look at closed records per se, but look at records of residents, for which incident reports have been filed and are still in question. Any death of an ICFDD resident is considered an incident by the Department of Public Health and a report must be filed with that Department. (77 IL Admin. Code 350 700)

The major issues surveyors review are

1. residents' rights,
2. the major outcomes of residents' active treatment,
3. staff and resident interaction,
4. the safety of facility practices, and
5. safety of the home environment.

### **Incidence Reports**

The Department of Public Health must be notified of all incidents or accidents, which have or are "likely to have a significant effect on the health safety, or welfare of a resident or resident." (IL Admin. Code Section 350 700) This includes the death of any resident no matter how the death occurred. All incidence reports are reviewed during the annual survey if they have not been reviewed prior. If the incidence report was not filed, and a death occurred, the surveyors will investigate the circumstances of the death and determine whether or not the facility had violated any regulation.

Incidence reports submitted to the Department of Public Health are reviewed and complaint investigations are initiated per its protocols.

### **Survey Requirements Focus on Encouragement of Resident Choice**

Facility staff are expected to encourage residents to participate in daily activities and offer residents choices. The survey requirements regarding resident choice and encouragement are more detailed than those for residents of nursing homes.

ICFDD facility residents know what they like and do not like, but they may not understand that they have the right as a citizen to exercise the right of choice and autonomy. Therefore, they need encouragement to exercise their rights. For example, in the requirement for W Tag 136, the surveyors are to investigate whether the residents have the opportunity to participate in social, religious and community group activities. This includes investigating whether residents have the opportunity to use and are encouraged and trained to use age-appropriate materials.

Surveyors are not necessarily concerned if a resident has a toy or stuffed animal in his/her room, but are interested in whether the resident had a choice of age-appropriate items in which to decorate his/her room.

Assessment of residents during a survey includes detailed questions, such as:

- Are individuals dressed in their own clean, neat and attractive clothing?
- Is it the correct size and in good condition?
- Is the clothing appropriate for the weather and type of activity?

- Is there clothing for a variety of activities (e.g., clothing for church, casual social functions, sport events)?
- Are cords and pins used to keep pants up instead of belts?
- To what extent does the facility provide items of lesser quality or provide only one type of a particular item?
- Do colors, styles, and designs match and conform to community standards?
- Are individuals assisted in clothes selections, room decoration and other forms of self-expression?
- Are individuals satisfied with the access to and choice of the kinds and numbers of personal possessions they have?
- How frequently during the course of the day do you observe individuals using their personal possessions?
- Are individuals' personal decorative possessions displayed?
- Are individual possessions protected?

### **Role of the Ombudsman Program in Surveys**

The Department of Public Health sends a listing to the Department on Aging of what ICFDD surveys will occur during the next month. This information is distributed to Regional Ombudsman Programs. The surveyors may not always follow the schedule, so the Ombudsman Program cannot assume that because a facility is scheduled, the survey will occur. The ombudsman program must keep survey dates completely confidential whether or not the survey occurs on the date scheduled. If an ombudsman gives knowledge to a facility about a Department of Public Health survey or a complaint investigation, no matter how subtle, the ombudsman is subject to a fine of \$2000.

As part of the offsite preparation for the survey, the surveyor sends a letter to the state ombudsman asking the following questions:

- Are there any concerns about residents' rights (client protection, privacy, funds personal possessions) in the facility?
- Are there any concerns about resident rights related to choice and self-management in the facility?
- Are there any concerns about residents in the facility not receiving active treatment services?
- Are residents' needs being met in the area of healthcare services?
- Are residents' needs not being met due to lack of staff?

When the surveyors enter the facility, they ask if any resident is 60 years or older. If there are one or more residents who are sixty years old or older, the surveyor will call the ombudsman program to inform the program that surveyors are in the facility. The surveyors spend at least two days conducting the survey for each facility, and longer if necessary. They make certain that they visit the facility on every shift.

## **VIII. SUMMARY**

Despite behaviors of residents that may not be familiar to many ombudsmen, with an understanding of developmental disabilities and some experience, most ombudsmen have found that visiting ICFDD residents offers the uncommon satisfaction of knowing residents who display remarkable human traits of kindness, wit, consideration, joy and compassion. Each resident is an individual with his/her own needs, interests, and desires. An ombudsman dedicated to regular visits to his/her assigned facility is offered an opportunity to build relationships with the residents and staff. Knowing the residents and staff well enables an ombudsman to better identify issues and advocate on behalf of residents (especially residents unable to verbally communicate).

## **APPENDICES**

## Appendix A

### Illinois Department of Public Aid Department Approved Intelligence Assessments

Corresponding I.Q. range for tests with standard Deviations:

<b>LEVEL OF FUNCTIONING</b>	<u>15</u>	<u>16</u>
Mild	55-69	51-67
Moderate	40-54	36-51
Severe	25-39	20-25
Profound	Under 25	Under 20
	<b>Weschler-Adult</b>	<b>Stanford Binet</b>
Mild	55-69	52-67
Moderate	40-54	36-51
Severe	25-39	20-35
Profound	Under 25	Under 20

Department Approved Intelligence Assessments:

1. Weschler Revised for Adult and for Children
2. Stanford Binet
3. Leiter
4. Bayley Scales of Infant Development (for children)
5. Cattell (for Infants Only)

**89 ILLINOIS ADMINISTRATIVE CODE**

**CH. I.**

**§144. TABLE E**

**SUBCHAPTER d**

Section 144. TABLE E Standardized Adaptive Functional Assessment

Mental Age Level Equivalents with Level of Functioning

#### Adult MA Functional Age

Mild	8 years, 6 months to 10 years, 1 month
Moderate	6 years, 1 month to 8 years, 5 months
Severe	3 years, 9 months to 6 years, 0 months
Profound	Below 3 years, 9 months

(Source: Added at 14 Ill. Reg. 1-1988, effective October 29, 1990)