

# OSSUP

ONLINE SUPPLEMENTAL SUPPORT PROGRAM FOR ICF/IID  
THE STUDENT MANUAL – JUNE 2011 edition (revised May 2013)





## Revision History

Revision	Effective Date	Author	Description of Change
1.0.0	05/21/2014	Jasmine Powell	Although this course has previously occurred, this is the first offering to be recorded under the CMS version control policy. This documents the baseline version for purposes of document control but was issued 2011 as stated. Released for the class offering beginning August 18-22, 2014.



**OSSUP:  
ONLINE SUPPLEMENTAL SUPPORT PROGRAM FOR ICF/IID  
STUDENT MANUAL – JUNE 2011 edition**

**Table of Contents**

<b><u>Module 1</u>: Promoting Dignity</b>	Page 3
<b><u>Module 2</u>: Promoting Dreams &amp; Meaningful Lives</b>	Page 29
<b><u>Module 3</u>: Promoting Independence</b>	Page 59
<b><u>Module 4</u>: Promoting Assistive Technology and Environmental Adaptations</b>	Page 83
<b><u>Module 5</u>: Surveying for Positive Behavioral Support</b>	Page 109
<b><u>Module 6</u>: Promoting Community as a Way of Life</b>	Page 145



*What should move us to action is human dignity:  
the inalienable dignity of the oppressed, but  
also the dignity of each of us. We lose dignity  
if we tolerate the intolerable...*

*Anonymous*

*The only kind of dignity which is genuine is that which  
is not diminished by the indifference of others.*

*Dag Hammarskjold  
UN Secretary*

## ***Module 1: Promoting Dignity Participant Version***

*Remember this...that there is a proper dignity and proportion to be observed in the  
performance of every act of life. Emperor Marcus Aurelius*

***R-E-S-P-E-C-T***

***Aretha Franklin***

***Songstress***

***(More than just a song title)***

*Always do right.  
This will gratify some people  
and astonish the rest.*

*Mark Twain, Author*

## **Module 1 Promoting Dignity**

1. Introduction and Objectives
2. People First
  - Talk the Talk and Walk the Walk
  - People First Alternatives
  - Wheelchairs, Cases & Tube Feeders ARE NOT People
  - More about Language
3. CMS-2567 Language Sensitivity Activity
  - Activity 1 – Language Sensitivity
  - Activity 1 Discussion
4. Body Language and Tone
  - Tone
  - Body Language
  - Etiquette for Talking to a Person with a Disability
5. Dignity and Respect
  - Dignity and Respect During Observation, Interview & Record Review
  - “Don’t” Picture Examples
6. Surveyor Behavior Activity
  - Activity 2 – Surveyor Behavior
7. Behaviors and Values
  - Be Aware of Your Actions/Words – Informal Activity
  - Provider Expectations
  - Dignity of Risk Resource – Examples of Dignity Situations and Tags
8. CMS-2567 Sensitivity Activity Revisited
  - Activity 3 – CMS-2567 Sensitivity Revisited: Poor Practices
  - A Better Practices Example
9. Sample CMS-2567 for Tag W189
10. Dignity Activity 4
  - Activity 4 - Matching Tags to Dignity Situations
  - Module Conclusion
11. For More Information – References for Module 1

## Section 1

### Introduction

Has your husband, wife, boss or colleague ever asked you questions in a way or tone of voice that was accusatory? Did he or she then make light of your answers? Over time what happened? How did you feel? Did this automatically put you on the defensive with that person? Were you anxious to talk with that person? Or did you start to avoid him or her? Did you feel good about yourself or your work? Were you inclined to volunteer or help him or her out when needed?

For more years than human services professionals care to remember, many children and adults with developmental disabilities and, by proxy, their families and friends were dehumanized by language and attitudes, leading to lives marked by anguish and loneliness. Through much of the 20<sup>th</sup> century, children and adults with developmental disabilities were treated as outcasts:

“Some physicians and dentists refused to treat (them).

Public schools closed their doors (to) them...

Police automatically placed them on suspect lists for unsolved neighborhood crimes.

Other parents ordered their children to stay away from them...

When (people) came into contact...they washed their hands afterward.

Community agencies offered no services and gave no support.

Clergy probed for the sins the parents of these odd ones must have committed.”  
(Perske, 1973, pg. 42)

For most of the 1900's, society expected that parents would institutionalize their family members with developmental disabilities and many did. However, the powerlessness that parents felt eventually resulted in them coming together in the 1950's in voluntary groups. The members of these associations “began talking back to physicians, educators, police, clergy, politicians, neighbors, and society in general” (Perske, 1973, pg. 42). One such organization is likely familiar to you, originally the National Association of Parents and Friends of Mentally Retarded Children, it renamed itself the National Association for Retarded Children (NARC), then the National Association for Retarded Citizens and is now known simply as “The Arc”. (Hickson, Blackman, Reis, 1995, pg 29).

Around the same time that parents began organizing, Charles Vail, the medical director of Minnesota's Department of Public Welfare, began holding workshops in “institutions” throughout the state of Minnesota. During the workshops, lists identifying the things that dehumanized prisoners, patients and residents were generated. Vail published a book, Dehumanization and the Institutional Career, in 1964, which detailed these lists

and the “principle of human dignity” in hopes he could change staff behavior in “institutions”. Although professionals largely ignored his work, volunteer associations such as NARC began making up their own lists of what gave dignity to people and what took it away. The language, attitudes and situations on these types of lists continue to drive advocacy groups to effect change today. (Perske, 1973)

Webster’s Dictionary (1996) defines dignity as the “quality or state of being worthy, honored or esteemed”. Over the past ten years, many researchers have explored dignity and care giving in various settings with people of different needs and the staff who are paid to help them. This research has revealed overlapping themes that further define dignity:

- Respect, as both humans and as individuals, as demonstrated by others’ courtesy, good communication (speaking and listening) and taking time
- Privacy, such as personal space, modesty and privacy in personal care as well as confidentiality of treatment and personal information
- Self-esteem and self worth, evidenced by clean and respectable appearance, pleasant environments and by choice
- Autonomy, the freedom to act and decide given clear, comprehensive information and the opportunity to participate. ([www.scie.org.uk](http://www.scie.org.uk), 2008)

The Regulations for Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) expect that staff at an ICF/IID will act and treat individuals with developmental disabilities with respect and that staff will enhance, develop, add to and support each person’s human dignity. That expectation is no different for surveyors. Surveyor actions during the entire survey – regardless of the situations – should not belittle, humiliate, demean or embarrass staff and/or individuals. This includes how observations are done, how questions are asked and how records are used. It includes every way information is obtained and conveyed, for example: words, tone of voice, body language and actions such as using manners and providing choices and respecting privacy.

In this training module, you will be asked to think about your role as a surveyor modeling human dignity and your role as a surveyor evaluating human dignity. Topics will be expanded that were previously introduced to you in ICF/IID Basic training.

### **Objectives for This Module**

Upon completion of this training module, you will be able to:

1. List at least ten things a surveyor can do to show or support human dignity while surveying.
2. Identify at least ten W-tags which relate to human dignity issues.

## Section 2

### **Talk the Talk and Walk the Walk**

You have, no doubt, heard a variation of the expression “you need to do more than talk the talk, you need to walk the walk”. In terms of human dignity, professionals (like you!) need to start by talking the talk and then following-up with the walk. The “talk” includes a number of things: the way a sentence is worded, the tone and volume in which it is delivered and the body language associated with it--as well as avoiding labels, being careful not to group and objectify people and changing expressions with the times.

Language plays a unique and significant role in human services. References made to people, how people are spoken to and spoken about, both reflect and shape the value placed on those people. As one speaks in a respectful manner to a person or about a person, the value and respect communicated in that language becomes more and more a part of that person to the speaker and to those listening. The United States government recognized this when it retitled “The Education for the Handicapped Act” as “The Individuals with Disabilities Education Act” (Malick, 1990) and when Public Law 95-602, “abandoned the use of categorical labels in defining persons with developmental disabilities”. (Perske, 1973, pg. 26)

More than just being “politically correct,” language that recognizes that an individual is a person first provides a continual reminder that people are seen as capable and “whole” persons. One of the initial uses of the people-first concept occurred when a former client of a state hospital was attending a meeting in 1974 to name a new advocacy group. She is quoted as saying: “We are tired of being seen as retarded. We want to be seen as people first!” The advocacy organization named itself “People First!” (Perske, 1973, pg. 25) and today has chapters throughout the United States.

When communicating, a people-first approach means that, whenever possible, you should mention the person first and follow with any necessary description. For example, say “the woman who is blind” instead of “the blind woman.” Or even better, say “the woman who uses the white cane to travel the neighborhood because her vision is not good enough to drive”. The latter reference goes a step further, de-emphasizing disability and emphasizing the individual and what she can do!

## People First Alternatives

<b>As a surveyor, instead of:</b>	<b>Use a “people-first” alternative:</b>
The handicapped or disabled	People with disabilities
The mentally retarded young woman	The young woman with an intellectual disability
The Behaviors live here	The men with behavioral issues live here
Workshop client	The individual who works at Jobs, Inc.
The Down’s client	He has Down syndrome
Dual eligibles get Medicare Part D	People must be eligible for both Medicaid and Medicare services to get Part D services
The deaf man	The man who wears two hearing aides
The wheelchairs	People who use wheelchairs
The tube feeders	People who take medications and nutrition by g-tube
The mentally ill	The women with mental health issues



These are wheelchairs – note the absence of humans.



Cases are used to move things from place to place-no people here either!



This is a “tube feeder”; it’s a thing, not a person.

As more and more professionals and ordinary citizens have become aware of people-first language, it has made them sensitive to whether they really need to use disabilities as labels in everyday conversation. Labels are fine for clinical use but when they become ways to categorize individuals in casual conversation, they take on a life of their own. Labels tend to objectify people, making it less easy to see strengths and more

easy to not see the person at all. If you were told your new neighbor was “schizophrenic”, would you take the time to learn anything else about him? Or would you just avoid him? In reality, he may have been taking medication for schizophrenia and not missed a dose or shown any unusual behaviors in a decade—which is far different from where the label “schizophrenia” might lead your thoughts about him.

Similarly, expressions change over the years. Words, such as crippled, afflicted with, confined, invalid, victim of, handicapped and special all came into vogue and are now out of favor or rapidly losing favor. These terms reflected the now outdated philosophy that a person with disabilities was a patient. It was once state of the art to be intelligence tested and categorized as an “idiot”. Profoundly mentally retarded, then profoundly developmentally disabled replaced that diagnosis. (Beirne-Smith, Patton, Kim, 2006, pg. 70) Today a reference to the level of support the person needs is the state of the art, as in: John needs support with his self care. (Beirne-Smith, Patton, Kim, 2006) There will likely be something new in five years! Although government may lag, in your conversation you should try to model that which is most current. You can probably think of terminology in government regulations that will eventually disappear—one bet is the term “handicapped parking space”!

In the ICF/IID Regulations, which were promulgated in 1988 and composed earlier than that, terms like “client”, “for the mentally retarded”, “unit” and “patient” have become outdated. As a surveyor, this puts you in an awkward spot because you must use the language of the regulations and guidance when writing your 2567 reports or when quoting regulation in presentations BUT otherwise YOU SHOULD ATTEMPT TO MODEL THAT WHICH IS MOST CURRENT. The following Activity will give you an opportunity to practice identifying current versus out-of-favor terminology.

### Section 3

#### **Activity 1- CMS-2567 Language Sensitivity Activity**

Save this activity, you will use it during your preceptor call and again later in this training module.

**Directions: Using the following CMS-2567 for ICF/IID tag W120, find and highlight in yellow ten uses of insensitive language.**

Please Note: At this time the ICF/IID regulations use the reference “client”, so it is necessary to use this language in a CMS-2567 citation.

**W 120 Based on observation, interview and record review, the facility failed to ensure that 1 of 5 clients in the sample (Client B) and 5 clients who were not in the sample received transportation as scheduled to the All-U-Can-B Day Program for implementation of individual support plans.**

#### **Findings:**

- 1. Review of the client’s residential record on X/29/09, revealed Client B is a profoundly retarded, 29-year-old woman who is handicapped by cerebral palsy and confined to a wheelchair. According to the I-Luv-U Home’s Activity Schedule dated X/10/09, she attends the All-U-Can-B Day Program from 9am to 4pm Monday through Friday except Holidays. According to this same schedule, which was also posted on the kitchen refrigerator, All U-Can-B provides her transportation in a wheelchair bus.**
- 2. On X/28/09, the surveyor observed Client B in the enclosed sun porch of the Home from 8:05am to 9:10am. During this time, Client B and 5 other nonambulatory people sat in winter coats, hats, scarves and mittens. Residential Services Aide (Aide) 4 chatted with them and periodically called someone on the phone. An unsampled client began to cry and complained she was going to miss making coffee for snack time. Another client began kicking the wheel of the quad’s wheelchair next to him; Aide 4 asked him to stop three times during the hour. At 9:10am, a bus arrived with All-U-Can-B printed on the side in huge red letters. Client B and the other nonambs were loaded and, at 9:25am, left for All-U-Can-B Day Program. The bus driver apologized to Aide 4 and the clients, mentioning that “(name) had been causing problems again”. Aide 4 commented that it was a shame everyone had to be late again because “(name) knew what he was doing even if he was a Downs”.**
- 3. At 9:35 am on X/28/09, the surveyor asked Aide 4 if this was the normal morning routine. Aide 4 replied that it was not supposed to be but that it**

had been for the past 2 months despite her complaints to the bus driver and Qualified Intellectual Disabilities Professional (QIDP) 1. Aide 4 explained that the bus was supposed to arrive at 8 am but would arrive anywhere between 8:30am and 9:30 am. Aide 4 stated that the phone calls she had made earlier were to the driver's cell phone, her children and the I-Luv-U Home's Administrator. Aide 4 stated that the QIDP and Administrator "put up with this" outside service because All-U-Can-B was "the only program in town" that would handle people who were tubefeeders and nonambs. She said Client B and 3 others had g-tubes. Aide 4 said the only program she implemented while the clients were waiting was the behavior plan for the client kicking the wheelchair.

4. At 11am on X/28/09, the surveyor interviewed QIDP 1. QIDP 1 explained that the reason the bus was late was a "new" client from another facility who was having problems, so QIDP 1 had agreed he should get on the bus first in order to settle down before I-Luv-U's clients got on the bus. The surveyor pointed out that the bus had been 30-60 minutes late for 2 months according to the Home's 2009 Occurrence Log. QIDP 1 replied: "I guess I should have noticed that was the reason Client B's day programs had no data". When asked if it was possible that extra leeway was being provided to this outside service because they were the only ones to deal with multiply handicapped, the QIDP said: "yes, that's partly true".
5. Review of Client B's day program and residential records on X/29/09 showed that data was missing for several objectives implemented at All-U-Can-B for Months V, 2009 and W, 2009, due to the reason "bus was late".
6. On X/29/09, the I-Luv-U Home Administrator was interviewed at 9am. He said he was familiar with the situation and expected the behavior problem from the other facility would adjust soon, thus resolving the situation. When asked if he realized that clients from I-Luv-U were having behavioral reactions to the late bus and that objectives were not being implemented at All-U-Can-B due to the late hour of arrival of the bus, he said he did not. He admitted that it would be hard to find another transportation or day service which would handle his kind of people.

End CMS-2567 Insensitive Example

## Section 4

### Tone

Now that you have given some thought to the words involved in talking the talk, let's think about how the "talk" is delivered. All of us remember hearing "Young lady/man don't you use that tone of voice with me!" as we were growing up. And even today tone often gives away whether someone is really serious or just joking. Tone of voice has everything to do with showing respect and maintaining a person's dignity. The tone of voice that is used when speaking to others is an indication of how that individual is perceived. The wrong tone or inflection used by a surveyor asking "Is this all you have?" could make or break the situation. Surveyors need to control their tone/inflection and volume when talking to staff and speaking with individuals. There is almost nothing more disrespectful and demeaning than a surveyor's tone of voice indicating an adult individual is viewed as a child rather than an adult. Except maybe speaking loudly and slowly because the person is developmentally disabled. Either view is outmoded philosophy. Yelling, on the other hand, (except in an emergency or sports event) is just plain rude and has no place in an ICF or during the survey process.

The way we word things goes a long way in getting a receptive, on point answer to a query. For example: "Why did you decide to do it this way? What are your policies on absenteeism?" Instead: "How was it decided to do it this way? What are the facility's policies on absenteeism?" These latter phrasings depersonalize the questions, getting to the same answers without pointing fingers. Surveyors need to be careful how they phrase questions and statements. It may take a little more effort but it is typically worth it.

### Body Language

It is not news to anyone that body language goes hand-in-hand with verbal language. Paying attention to body language while talking is important especially during the survey process. Observing with your arms crossed in front of your chest does not give the impression of acceptance, openness or willingness to see any good things that may be happening. Looking any where but at the person you are talking to during interviews or information solicitation indicates you're not that interested in the conversation. Shaking your head back and forth and "tsking" or sighing while reading a person's record adds unnecessary stress to the already stressful situation.

Similarly, patting people on their heads or other areas of their bodies when approaching them or talking to them indicates a condescending attitude. In our society unrelated adults do not greet each other in this manner. The rule of thumb for a surveyor is treat people as you would like to be treated which includes tone and volume of voice, how you ask questions, body language and types of physical contact.

## **Yelling and pointing is for football games, not surveying**



### **Talking Etiquette**

Take a moment now to read an adapted synopsis from the (CMS) Basic Training ICF/IID Surveyor Training manual called “Etiquette for Talking to a Person with a Disability” (Malick, 1990). The tips in this reading are virtually timeless in their application. When you think about it, many are just “good manners”.

**ETIQUETTE FOR TALKING TO A PERSON WITH A DISABILITY**  
**(Adapted Synopsis taken from WATCH WHAT YOU SAY, by Ron Malik, 1990)**

1. When introduced to a person with a disability, it is appropriate to offer to shake hands. Even people with limited hand use or who wear an artificial limb can shake hands.
2. Treat adults as adults. Address people who have disabilities by first name only when calling everyone present by first name.
3. When talking with a person who has a disability, speak directly to that person rather than through a companion who may be along. This includes individuals who are deaf and using the services of an interpreter.
4. Don't be embarrassed if you happen to use words that seem to relate to a disability. ("See you later," "walk this way," or "got to be running along" are common expressions everyone uses.)
5. If you offer to help, wait until the offer is accepted, then listen to or ask for instructions.
6. When speaking with a person who has severe vision loss, always identify yourself and introduce anyone else who might be present first.
7. When approaching an individual who is blind and has a guide dog with them, acknowledge the individual first. Do not attempt to play with the dog. The animal is on duty and should not be made to confuse play time with work time.
8. When talking to a person who uses a wheelchair, do not lean on the chair. The chair is a part of that person's body space.
9. When talking to a person in a wheelchair for longer than a few minutes, place yourself at that person's eye level to avoid stiff necks. When speaking with a person with a hearing disability, don't block your mouth.
10. When talking to a person with a disability do not use terms of affection or endearment. Also avoid childish greetings, questions and actions such as "Hi honey", "How are you baby?", "You're sure a pretty looking thing" and "What's up Junior?"
11. If the person seems to have difficulty understanding, rephrase, slowdown or repeat the information.
12. Don't pretend to understand if you don't. Ask for more information or ask them to say it in a different way.

## Section 5

### Dignity and Respect during Observation, Interview and Record Review

Now that you have refreshed yourself on these tips, let's think about more things surveyors can do to communicate dignity and respect as they perform three major survey tasks: Observations, Interviews and Record Reviews.

	<b>OBSERVATIONS</b>	<b>INTERVIEWS</b>	<b>RECORD REVIEWS</b>
Body language	Sitting if people are sitting; standing if people are standing. Washing your hands in private. Calmly reacting to inappropriate behavior by others. Taking notes unobtrusively.	Making eye contact. Calmly reacting to inappropriate behavior by others.	Quietly reading records.
Choice	Would you prefer me to stand here or over there?	Would you rather talk at your home or someplace else? Is this a convenient time to talk?	Where is the best place to read through this record?
Manners	Knocking on doors and WAITING for a reply before acting. Turning your cell phone off.	Letting the person answer the question before you ask the next one. Explaining why you have to take notes. Turning your cell phone off.	Asking if you need to sign the record out and heeding the answer. Asking staff to explain record organization so you don't need to continually interrupt them.
Privacy	Only observing personal care activities if absolutely needed.	Finding a place where no one can hear your conversation with someone and being aware of how your voice carries	Reading records where others cannot see what you are reading
Discreet actions	Offering to shake hands-acts to circumvent hugging. Timely and unobtrusive reporting of inappropriate behavior of individuals to staff or of staff to administration	Introducing yourself and explaining what you need and why you are there in user friendly language. Use conversational volume and rate rather than talking loudly and slowly.	Putting papers back where you found them
Assistive technology	Asking permission before examining a person's assistive/supportive devices such as lap trays, walkers, wheelchairs	Acknowledging and using the communication method that the person uses such as pocket wallet, language boards, electronic devices, picture boards	Treating computerized records no different/y than paper records

**The following pictures demonstrate what a surveyor shouldn't do.**

**This surveyor's conspicuous notes convey an unnecessary "gotcha" attitude.**



**Even with inappropriate sunglasses and posture to hide behind, this surveyor failed to discretely cover her shock.**



**It's rude to point. And ruder still to slouch disinterestedly and point.**



## Section 6

### Activity 2 - SURVEYOR BEHAVIOR ACTIVITY

**Directions:** From the following list of behaviors, identify with a checkmark the surveyor behaviors that you think convey respect of individuals and staff. Save this document for your preceptor discussion telephone call. The correct number of “do’s” is: 8

- Asking staff to point out people in a room
- Refusing to touch anything for fear of germs
- Slowly nodding while listening to someone
- Using hand cleaner in front of someone as soon as you shake hands
- Using a red pen and grand gestures to cross out things in notes
- Watching someone else while talking.
- Asking the individual permission to observe medication administration
- Not laughing or shrieking when an individual streaks by
- Pointing to someone who is pouring their milk in their lap
- Asking permission to sit in a chair
- Not answering questions
- Taking notes at the kitchen table while others are eating breakfast there
- Addressing someone as Mr. or Ms.
- Drumming your fingers or tapping your toes while observing activity in a living room
- Using please and thank you
- Knocking on a bathroom door before entering
- Wiping your hands on your pants immediately after touching a board game piece
- Asking the QIDP to go to the kitchen to discuss John
- Shaking your head from side to side and rolling your eyes
- Showing disgust at someone’s actions
- Acting afraid
- Telling people you’re the Feds

## Section 7

### **Informal Activity**

In the coming month, make it a point to become more aware of your own behavior, replace words and actions as necessary and elicit your coworkers' assistance in identifying things you may have missed.

### **Provider Expectations**

Just as important as surveyor behavior is provider behavior. Just what is a surveyor "looking for" while surveying a provider when it comes to dignity and self respect? Will you know it when you see it or, even more importantly, when you don't?

### **The Dignity of Risk**

You first saw the following reading, "Dignity of Risk, What if?" in the BASIC ICF/IID Surveyor Training manual. (From Changing Expectations/Planning for the Future: A Parent Advocacy Manual, by Dorothy Sauber, published by the Association for Retarded Citizens, Minnesota, Minneapolis, MN)

We would like you to take another look at it now that you have had training on specific ICF/IID Regulations. With experience, a surveyor's critical thinking should kick in as soon as facility practices (such as outlined in this reading) are seen or heard. If you are not familiar with the tag referenced, please take a moment to look it up in Appendix J of your ICF/IID Field Resource Guide. Think about how/when the tag could relate to the dignity issue mentioned.

**Please Note: The W-tags referenced are commonly used. They are, by no means, all inclusive. Please discuss with your preceptor any tags you don't understand or that you would add.**

**THE DIGNITY OF RISK  
WHAT IF....**

**WHAT IF...you never got to make a mistake? (W189, W190, W227, W268, W269)**

**WHAT IF...your money was always kept in an envelope where you couldn't get to it?  
(W124, W126, W137)**

**WHAT IF...you (are an adult and) were always treated like a child? (W189)**

**WHAT IF...your only chance to be with people different from you was with your own  
family? (W136, W246)**

**WHAT IF...the job you did was not useful? (W225)**

**WHAT IF...you never got to make a decision? (W247)**

**WHAT IF...the only risky thing you could do was act out? (W191, W193, W214, W239)**

**WHAT IF...you couldn't go outside because the last time you went out, it rained? (W137,  
W246)**

**WHAT IF...you took the wrong bus once and now you can't take another one? (W189,  
W214/W224, W268)**

**WHAT IF...you got into trouble and were sent away and you couldn't come back because  
they always remember your "trouble"? (W136, W147)**

**WHAT IF...you worked and got paid 46 cents an hour? (W132, W225)**

**WHAT IF...you had to wear your winter coat when it rained because it was all you had?  
(W137)**

**WHAT IF...you had no privacy? (W129, W130, W133, W134)**

**WHAT IF...you could do part of the grocery shopping but you weren't allowed to do any  
because you weren't able to do all the shopping? (W190, W227)**

**WHAT IF...you spent three hours a day just waiting? (W186, W194, W196, W240, W249,  
W250)**

**WHAT IF...you grew old and never knew adulthood? (W194, W211, W213, W214, W227,  
W232, W240, W268, W269)**

**WHAT IF...you never got a chance? (The tags immediately above and W196, W195!!!!)**

In an ICF/IID it is important to maintain a world that reflects some basic values. It is critical to respect the dignity of people who live and work in an ICF. Respect is reflected in language, concern with privacy, promotion of choice and independence, individualization, support of basic human rights and freedom. People with disabilities should be treated as would any other person of the same age, culture and gender. Materials used for teaching, technology and adaptations, clothing, home decorations, and other aspects of life should reflect the person's status as a "normal" member of his or her community. What a person with a disability does should be the same as what anyone else does. Each person supported in an ICF/IID must be thought of as a capable, whole person, not as a "client," not a "person with a disability", but rather as a person who can and will learn and who is far more like others than different—someone who deserves the same respect, dignity, opportunity, and encouragement as any other person.

## Section 8

### **Activity 3 – CMS-2567 Sensitivity Activity Revisited**

**Directions:** You previously identified insensitive language in this W120 tag. This time look only at findings 1 and 2. Identify and highlight in pink four "practices" employed by the facility/facility staff which do NOT promote dignity. After you have completed the activity, save the document for discussion at your preceptor telephone call.

Please Note: At this time the ICF/IID regulations use the reference "client", so it is necessary to use this language in a 2567 citation.

**W 120** Based on observation, interview and record review, the facility failed to ensure that 1 of 5 clients in the sample (Client B) and 5 clients who were not in the sample received transportation as scheduled to the All-U-Can-B Day Program for implementation of individual support plans.

#### **Findings:**

1. Review of the client's residential record on X/29/09, revealed Client B is a profoundly retarded, 29-year-old woman who is handicapped by cerebral palsy and confined to a wheelchair. According to the I-Luv-U Home's Activity Schedule dated X/10/09, she attends the All-U-Can-B Day Program from 9am to 4pm Monday through Friday except Holidays. According to this same schedule, which was also posted on the kitchen refrigerator, All U-Can-B provides her transportation in a wheelchair bus.

2. On X/28/09, the surveyor observed Client B in the enclosed sun porch of the Home from 8:05am to 9:10am. During this time, Client B and 5 other nonambulatory people sat in winter coats, hats, scarves and mittens. Residential Services Aide (Aide) 4 chatted with them and periodically called someone on the phone. An unsampled client began to cry and complained she was going to miss making coffee for snack time. Another client began kicking the wheel of the quad's wheelchair next to him; Aide 4 asked him to stop three times during the

hour. At 9:10am, a bus arrived with All-U-Can-B printed on the side in huge red letters. Client B and the other nonambs were loaded and, at 9:25am, left for All-U-Can-B Day Program. The bus driver apologized to Aide 4 and the clients, mentioning that “(name) had been causing problems again”. Aide 4 commented that it was a shame everyone had to be late again because “(name) knew what he was doing even if he was a Downs”.

### **End CMS-2567 Citation of W120 (Poor Example)**

As a comparison to the above “poor” example of the W120 citation, consider this scenario:

On a recent survey at Happy Acres, an ICF/IID, the administrator was observed as he visited the house. He spoke to people by name, pulled one man off to the side, and had a private discussion with him. Staff entered the living room and asked one of the people served, Mr. Smith, when he would like to have their help washing his clothes that day. He chose to wash his clothes after the evening meal, a time when others had scheduled a trip to the grocery store. Hearing this, the administrator volunteered to assist with the grocery shopping trip, so that Mr. Smith’s favorite staff could help him with his laundry. Staff asked Mr. Smith if he would mind telling the visitor about his progress in learning to do his laundry. With Mr. Smith’s approval, staff helped him explain that he was learning to put his clothes in the washer and had already learned to gather up his dirty clothes. The surveyors could see that people from the top to the bottom of this organization shared values of choice, dignity, and independence.

## **Section 9**

### **Sample CMS-2567 of Tag W189**

There are many tags in the ICF/IID Regulations which support dignity. When you cannot find a specific tag for a situation you witness (for example W129, lack of privacy during treatment), you should consider one of the staff training tags (W189-W194) or one of the staff-individual conduct policy/procedure and implementation tags (W267-W270). For example:

**W189 Based on observation and interviews, the facility failed to ensure that staff performed duties in ways that demonstrated respect for 3 of 5 clients in the sample (Clients 3, 5 and 12) and two clients not in the sample.**

### **Findings:**

**1. During breakfast at 11/5/xx, beginning at 8:35 am, the following observations were made: Direct Care Aide (DCA) A pulled Client 5 out of a chair in which he had been seated in the living room and guided him to sit in a chair at the dining room table. Although Client 5 was blind, DCA A did not speak to him before she pulled him up from his chair to let him know what was going to happen or where she was taking him. When the staff member sat him down, she did not tell him**

what foods were on his plate or where the food items were located on his plate. She did not assist him in locating his plate, cup or utensils. When Client 5 finished his breakfast, DCA B remarked "He does real well to be a blind, doesn't he?" Staff members were asked if they had received any special training to address Client 5's visual impairments. Both staff said they had general orientation class and had been told to apply it to anyone in their group, so they applied it to Client 5. The staff members said that they had not had any training that was specifically designed to meet client 5's needs.

2. On 11/5/xx, at 8:45 am, Client 3 was observed in the living room after breakfast. He intermittently made a loud, short, vocal sound approximately 16 times within three minutes. DCA B was present and said they referred to Client 3's vocal sound as "barking". She went to Client 3 and encouraged him to shave as she plugged an electric razor into a wall outlet in the living room. DCA B repeatedly asked client 3 to shave; however, he refused and continued making the vocal sound. DCA F, also in the living room, stated loudly "(Name-Client 3) is passing some wicked gas. Your bowels moved good this morning." DCA B on the far side of the room agreed. There were two clients present during the observation.

3. Also on 11/5/xx, at 9 am, Client 2 entered the living room carrying a purse. Her name was written on the outside of the purse in neat block lettering. Examples of Client 2's handwriting were in evidence on the wall behind her where she had signed in name on several drawings. These signatures contained numerous letter reversals and repetition of letters. DCA F indicated that the client had signed the pictures with staff assistance.

4. On 11/6/xx, at 10 am, the Qualified Intellectual Disabilities Professional (QIDP) confirmed that the printing of the client's name on the outside of the purse appeared to be an effort by staff to assure another client would not take her purse. The QIDP agreed the lettering could have been put inside the purse for the same effect.

End CMS-2567 W189 Citation Example

## Section 10

### Activity 4 – Matching Tags to Dignity Situations

**Directions:** The next activity offers you the chance to determine for yourself where you might cite situations which reflect failures to promote dignity.

**W104**      **W129**      **W247**  
**W112**      **W137**      **W249**  
**W125**      **W189**      **W269**  
**W130**      **W190**      **W425**  
**W135**      **W191**      **W435**

Pick one of the W-tags above which best fits the situation described below.

Save your answers for your preceptor for discussion on your next call.

- \_\_\_ Everyone is wearing a shirt with his name visible on the back below the collar.
- \_\_\_ People are only told “no”, with no examples of reinforcement or encouragement seen.
- \_\_\_ Bob complained that he was never allowed to be by himself in his bedroom.
- \_\_\_ There was nothing to do after supper except watch TV.
- \_\_\_ People shared toothpaste and shampoo.
- \_\_\_ A living room chair smelled of urine; the upholstery of another was torn.
- \_\_\_ No one could use the porch swing without a staff person beside them.
- \_\_\_ There was no choice of juice or cereal.
- \_\_\_ Trish was wearing only a shirt on her way to the nurse’s office for medications.
- \_\_\_ The three women who are retired each ate from a plate with a nursery rhyme on it.
- \_\_\_ A person repeatedly missed work because the van needed gas.
- \_\_\_ The phone was permanently plugged into a socket in the TV room.
- \_\_\_ The bathroom used by four people had no shower curtain or partition around the roll-in shower or toilet.
- \_\_\_ Regardless of circumstance, the schedule was followed.

\_\_\_\_ Taylor's eating program was laminated and taped to the dining room table.

### **In Conclusion**

There are times that supporting a person's dignity may involve some risk. Here's an example. Imagine you are a surveyor watching staff in this decision-making scenario:

**It's about 6:30 p.m. at the Maple Lane Home. It's a very cold Tuesday, and a new snow has fallen during the afternoon. The radio says that traffic is snarled and crawling. Several of the residents normally go to the local shopping mall on Tuesday evenings to join a small group of people there who regularly walk for exercise and window shop. It will take much longer than usual to get to the mall today because of the weather and traffic. What will staff do? (a) not mention the mall and hope everyone forgets, (b) get out the leisure materials and get people involved in their designated "alternative activities," (c) plow on ahead to the mall, for the schedule must proceed as the QIDP planned last week, or (d) ask the people who live at the house if they want to brave the weather and go to the mall or stay home tonight (which means staff will probably spend the rest of the evening refereeing an argument between the two most outspoken people living in the house)? What will staff say and do?**

Regardless of what is decided, the surveyor needs to determine if, in fact, the staff at the Maple Lane Home made the decision that best took into consideration the individuals expectations, needs, and choices while still considering their role in assuring safety. Was the risk of the activity explained fairly and equitably? Were potential hazards minimized? Were alternatives offered equal and compelling? Was the adventure worth the risk? In this example, as in many others a surveyor will come across, there is probably no exact right or wrong answer; however, rest assured, if the surveyor does not add respect, choice and dignity of risk into the equation needed to get to an answer, the answer won't be the best one.

A closing thought for this module is an Arc sponsored video clip entitled ***Another Kind of R Word***. On your computer, go to:

[http://www.youtube.com/watch?v=NHwOu8\\_qjRc](http://www.youtube.com/watch?v=NHwOu8_qjRc)

## Section 11

### For More Information - References for Module 1

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#### **Activity 4 – Matching Tags to Dignity Situations Answers**

**W189** Everyone is wearing a shirt with his name visible on the back below the collar.

**W191** People are only told “no”, with no examples of reinforcement or encouragement seen.

**W129** Bob complained that he was never allowed to be by himself in his bedroom.

**W190** There was nothing to do after supper except watch TV.

**W137** People shared toothpaste and shampoo.

**W104** A living room chair smelled of urine; the upholstery of another was torn.

**W125** No one could use the porch swing without a staff person beside them.

**W247** There was no choice of juice or cereal.

**W130** Trish was wearing only a shirt on her way to the nurse’s office for medications.

**W435** The three women who are retired each ate from a plate with a nursery rhyme on it.

**W249** A person repeatedly missed work because the van needed gas.

**W135** The phone was permanently plugged into a socket in the TV room.

**W425** The bathroom used by four people had no shower curtain or partition around the roll-in shower or toilet.

**W269** Regardless of circumstance, the schedule was followed.

**W112** Taylor’s eating program was laminated and taped to the dining room table.



***We all live with the objective of being happy;  
our lives are all different and yet the same.  
Anne Frank, Writer***

***There is nothing like a dream to create the future.  
Victor Hugo, Writer***

***Module 2:  
Promoting Dreams & Meaningful  
Lives  
Participant Version***

***It is neither wealth nor splendor, but tranquility and occupation,  
which give happiness.***

***Thomas Jefferson  
Statesman***

***I have a dream.***

***Dr. Martin Luther King Jr.  
Activist***

***You'll find boredom where there is the absence of a good idea.  
Earl Nightingale  
Writer***

## Module 2 Promoting Dreams and Meaningful Lives

1. Introduction
  - Objectives and Introduction
  - A Visit to Whitehall
2. Surveyor Expectation One - Normalization
  - Definition
  - Thoughts to Ponder
  - Whitehall Revisited
3. Surveyor Expectation Two - Individualization
  - Definition
  - Thought to Ponder
  - Example and Discussion
  - Questions to Ask Yourself
  - Getting to the Meaning – The In-depth Interview
4. Surveyor Expectation Three – No Limit on Learning
  - Definition
  - Questions to Ask Yourself
5. Activity 1: Gaylord Way – Applying the Three Expectations
  - Activity
  - Discussion
6. Tags Representative of Each Expectation
  - Expectation One – Normalization
    - Keyword Age Appropriate
    - Keyword Normalization
    - Keyword Preferences
    - Keyword Choice
  - Expectation Two – Individualization
    - Keyword Individualize
    - Keyword (Assess or Meet) Needs
  - Expectation Three – No Limit on Learning
    - Keyword Teaching
    - Keyword Learning
    - Keyword Training
    - Keyword Assessing
  - Suggestion
7. Sample CMS-2567 for Tag W247
8. For More Information on Promoting Dreams and Meaningful Lives
  - Associations
  - References for Module 2

## Section 1

### Objectives for this module

Upon completion of this training module, you will be able to:

1. List three expectations that a surveyor needs to apply when conducting surveys in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID).
2. Explain the concepts of normalization and individualization.

### Introduction

The 1960s and 1970s were a time of widespread social activism in the United States (US). Political speeches, rallies, sit-ins, marches through cities, disruptions of services and photographic exposés were commonplace. Emotions were high. Results of efforts were mixed. Opposition to participation in the Viet Nam War resulted in US troop withdrawal and the fall of South Viet Nam. Courts and laws ended segregation in schools and other public places, although progress in eliminating housing and job discrimination remained elusive for years. The photographic exposés of large, barren, crowded institutions filled with half naked/naked, staring or pacing individuals helped focus lawmakers, the courts and the public on the needs of people with intellectual disabilities. That resulted in increases in federal and state funding of training and residences and inclusion of children with intellectual disabilities in public education (Taylor, *Mental Retardation Journal: Christmas in Purgatory: A Retrospective Look*, 2006). However, even today surveyors visit state licensed and federally certified facilities and homes and find people with developmental disabilities who are not receiving required services or supports. It is rarely the blatant situations seen in the 1960s and 1970s; but, they still exist.

### Time for a Reality Check

Webster's Dictionary describes "expectation" using phrases such as "the act or state of expecting" and "prospect of the future: anticipation" (Webster's Dictionary, 1996). Each of us experiences "expectations" multiple times a day. It may be the simplest thing: like thinking the family dog will be there to greet us when we open the front door upon arriving home, or something more complex: looking at the traffic out the office window at lunch time and suspecting it will take more than the allotted hour to get lunch at our favorite restaurant down the highway. Our expectations have the power to change our behavior(s). For instance, in the dog-at-the-door scenario, it might cause us to only carry one of the three bags of groceries in the car into the house—so that one hand is free to pet the dog, thus preventing him from jumping up and knocking the bags out of our arms. Or, if we remember the dog is out being groomed, we may try to juggle all three bags. Similarly with the lunch scenario: we may decide to grab a bite from the vendor in the lobby because we have a meeting with the boss in an hour, or, if the boss is away, we may just risk being late from lunch.

We each have expectations about all different kinds of people, including people with developmental disabilities. Read the following scenario and see what you think.

## **A Visit to 48 Whitehall**

**Directions: Please read and reflect on the following scenario.**

**Note:** Through interviews it has been determined the people living and working in this home prefer using first names to address each other.

The home at 48 Whitehall has four bedrooms and a two car garage. The living room area has two recliners, a three person couch, and a rocking chair. There is a throw rug underneath the coffee table which is against a wall. There is a pole light between the recliners and a hanging light over the couch. The curtains on the sliding glass doors have a rip which is held together with a clothespin. There is a corresponding tear in the sliding screen door.

It is 4:30pm and all five people who live there are at home. Jake is sitting in his wheelchair watching TV – *Law and Order*, Howard is rocking in the rocking chair facing the sliding glass doors and Martin is walking around the room between the furniture. One staff person is in the kitchen preparing dinner and another staff person is in the laundry room folding clean towels. Tom is in his bedroom sleeping and Roger is rearranging his dinosaurs on the top of his chest of drawers.

Roger leaves his bedroom and using his walker maneuvers down the hall where he patiently waits for Martin to pass by so he can head for the laundry room. Once he gets to the laundry room he plaintively says to Alice, the staff person, “No work.” She responds with, “I know, they don’t have any contracts. Go and sit down and dinner will be ready by 5:30pm.” Roger mumbles, “Not hungry” and goes to stand by Howard.

At 5:15pm, Jean, the staff person who had been fixing dinner, brings the food to the table and announces to everyone that it is time for dinner and “come sit down”. Roger goes to the hallway and hollers for Tom that dinner is ready and then takes a seat at the table. Without a word Alice (other staff person) pushes Jake over to the table. Jean serves everyone and puts Jake’s filled plate on his lap tray. Alice stands behind Jake and makes sure he is eating all his meal. About 15 minutes into the meal Jean goes back and gets Tom up and follows him to his place at the table where his food is already served. Howard gets up from the table and goes into the kitchen and gets the Tabasco sauce and puts it on his meatloaf and then returns it to the kitchen. Both Alice and Jean thank him for putting it back. Martin pushes his plate away and starts to stand up until Jean tells him he needs to finish his succotash before getting up. He does.

By 5:35pm, everyone had gotten up from the table and Jean, along with Alice, cleared the table and wiped off the plastic tablecloth. Jake rolled himself over to the TV and changed the channel; Roger went down the hall to the bathroom; Tom got his clean towels and took them to his bedroom; Howard returned to the rocking chair and Martin sat down on the couch. When Roger returned to the living room, Tom went to the bathroom to take a shower. Alice hollered to him to remind him that tonight was the night to wash his hair. He then came out and got a bottle of shampoo from her. Roger sat in one of the living room chairs and just looked around at things.

When the dishes were done, Alice brought a bunch of folded towels to Roger, Martin and Howard and told them to take them to their bedroom and put them in their closet. Each followed her instructions and returned to what they had been doing before. Alice took Jake's towels to his bedroom and put them away. She returned to the living room and told Howard he could go start his shower. Howard went to his room and collected his pajamas and towels then proceeded to the bathroom. Alice went to the kitchen where she began packing lunches. Jean was filling out the log at the dining room table.

Tom finished his shower and returned to his room where he sat on his bed and systematically ripped the pages out of a magazine one by one, wadded the page up and threw it in the waste can. Jean got up and went to check on Howard and then called to Alice that they needed to help Jake take his bath. Alice went over and rolled Jake to the bathroom while Jean got his pajamas and towels. They did a two person lift to get Jake into his shower chair and Jean returned to her record book. When Howard returned to the living room, he picked up the remote, changed the channel and sat down on the couch next to Martin, who then got up and went to get his shower. By 6:45pm, everyone had completed their showers and was back in the living room except for Tom, who stayed in his room.

Alice continued packing the lunches and Jean got up and bought the *Connect 4* game and a set of checkers to the dining room table. She reminded the men that the games were there and then went to check on Tom. She returned and asked if they wanted to watch *Entertainment Tonight* on the TV and, getting no definitive response, got the remote from Howard and changed the channel. Things stayed the same until about 8:00pm when Alice asked the men if they would like a cookie and milk before bed. Everyone, including Tom, went to the kitchen, where each was given a chocolate chip cookie and a plastic tumbler filled to the rim with milk, which they consumed and then went directly to their bedrooms where they went to bed.

## **End Visit to Whitehall Scenario**

### **Reflections on Your Visit to 48 Whitehall**

Your thoughts on the answers to the next questions will be discussed on your preceptor call.

So is it a good place to live? Are people healthy? Do staff try to ensure their safety and well-being? From what we know, probably yes, but that's not all there is to this. Regulations lead you to expect that a place be healthy and safe with caring staff, BUT each surveyor needs expectations that are further evolved.

How about these questions: Is this a place where you'd like your nephew without disabilities to live? Or how about your friend's eldest son (also without disabilities)? Now consider the age of your nephew or friend's son, are things happening in this home that you would expect to be happening in a home where the age range was young children? How about teenagers? Young men? Middle-aged men? Old men? Are

there things going on at the Whitehall home that you would *expect* to be going on in homes around America? Are members of *your* household waited on when it comes to things like serving their food and dressing when they know or need to learn how to do them? Is it common in most homes around the country for all the people living there to be home at 4:30pm, eating at the same time and the exact same food? Are there no disagreements about what to watch on TV? Are all men older than twelve bathed and in bed by 8:30pm?

So why is the home at Whitehall more descriptive of homes surveyors see than not? If expectations of surveyors, educators, regulatory bodies, family members and providers are simply that a place appears safe and healthy, then Whitehall looks good. ***That needs to change.*** It was never the intention of the ICF/IID Regulations to tolerate as sufficient, compliant or, even, exemplary a home like Whitehall.

With all this in mind, let's take a look at expectations that surveyors need to have.

## **Section 2**

### **Surveyor Expectation One – Normalization**

#### **Definition**

One of the underlying assumptions of the ICF/IID Regulations is that people's lives will be "normal" or "normalized". It is highly likely you have heard of or studied this concept; it is not a new one. In fact, it was already decades old when the ICF/IID Regulations were revised in 1988. You may associate the concept with Wolf Wolfensburger, but it first came to the United States from Scandinavia. Dr. Bengt Nirje, a past director of what was then called the Swedish Parents' Association for Mentally Retarded Children, offered a particularly comprehensive but short and fairly self-evident definition. He said "normalization" is:

- "A normal rhythm of the day
- A normal routine (e.g. work, school)
- A normal rhythm of the year (e.g. holidays)
- Normal developmental experiences
- The chance to make choices
- The right to live heterosexually (not segregated into men-only or women-only accommodations)
- A normal economic standard
- The right to live, work and play in normal conditions." (as quoted on pg 4, Walker and Rogan, 2007)

Sometimes "normalization" is described as "age-appropriate", but as you can see from Dr. Nirje's explanation, it is "age-appropriate" *and more*. Yes, it means that the life of a person with disabilities should reflect the "normal" life of any other person of the same age and gender in the local community. Yes, it means the materials used for teaching, supports and adaptations, clothing, home decorations and other aspects of life should reflect the person's status as a "normal" member of his/her community. But it also

means a person with disabilities should do the same things and receive the same respect, opportunity and encouragement as any one else. As you can see, dignity, a concept also discussed in this training series, also underlies this concept.

**Thoughts to ponder:**

- **Normalization did not gain widespread “attention” in the United States until the 1970s (Taylor, Richards & Brady, 2005, p. 22).**
- **It was not until 1975 that federal law extended free public education to all children with disabilities in the United States. Individualization of education programs for children with disabilities was included in this law. (Beirne-Smith, Patton & Kim, 2006)**
- **It was not until later years that federal laws emphasized the importance of vocational education and planning for transition from school to life after public school for children with disabilities. (Taylor et al., 2005)**
- **It was not until 1990, that the federal Americans with Disabilities Act provided “sweeping protection against discrimination against (all) individuals with disabilities” in areas such as accessibility, telecommunication and employment discrimination (Taylor et al., 2005, p. 27)**

**“As attitudes change, so do rights” (DiLeo, 2000, p. A-2)**

With this “normalization” concept in mind, let’s go through Whitehall home again, this time with new eyes and see what’s really there.

## **48 Whitehall Revisited**

1. The home at 48 Whitehall has four bedrooms and a two car garage. The living room area has two recliners, a three person couch, and a rocking chair. There is a throw rug underneath the coffee table which is against a wall. There is a pole light between the recliners and a hanging light over the couch. The curtains on the sliding glass doors have a rip which is held together with a clothespin. There is a corresponding tear in the sliding screen. **Does the organization of the living room furniture facilitate the things people would normally do there? Is it “homelike”?**

2. It is 4:30pm and all five people who live there are at home. **Why is everyone home at 4:30? Is this day a fluke compared to a more normal daily routine/rhythm of the day or is it an indication that school, work, volunteer or social activities are not occurring?** Jake is sitting in his wheelchair watching TV – *Law and Order*, Howard B. is rocking in the rocking chair facing the sliding glass doors and Martin. is walking around the room between the furniture. **Is there sufficient furniture in the living room, as described in the paragraph above, for five people plus staff if they all chose to be together?** One staff person is in the kitchen preparing dinner and another staff person is in the laundry room

folding clean towels. Why isn't anyone who lives there helping with or even totally responsible for routine dinner or laundry tasks? Do they know how to make dinner and fold clothes? Tom is in his bedroom sleeping and Roger is rearranging his dinosaurs on the top of his chest of drawers. Does Tom always take a nap? Why? Is this hobby age appropriate for Roger? What exposure has he had to other hobbies and activities?

3. Roger leaves his bedroom and using his walker maneuvers down the hall where he patiently waits for Martin to pass by so he can head for the laundry room. Once he gets to the laundry room, he plaintively says to Alice, the staff person, "No work." She responds with, "I know, they don't have any contracts. What job options have been considered so that he might have a normal work schedule and consistent earnings? Go and sit down and dinner will be ready by 5:30pm." Does everyone always eat at the same time? Roger mumbles, "Not hungry" and goes to stand by Howard. Will Roger be expected to eat even if he is not hungry?

4. At 5:15pm, Jean, the staff person who had been fixing dinner, brings the food to the table and announces to everyone that it is time for dinner and "come sit down". Does everyone have to eat at 5:15? Roger goes to the hallway and hollers for Tom that dinner is ready and then takes a seat at the table. Without a word, Alice (the other staff person) pushes Jake over to the table. Why not ask him if he is ready to go to dinner? Jean serves everyone and puts Jake's filled plate on his lap tray. Why is staff serving? Why isn't Jake using the table? Alice stands behind Jake and makes sure he is eating all his meal. Do people stand behind you when you are eating? Or do they sit at the table and talk to you? About 15 minutes into the meal Jean goes back and gets Tom up and follows him to his place at the table where his food is already served. Isn't it more normal for a plate to be filled by the person? Or to be filled when the person arrives at the table? Howard gets up from the table and goes into the kitchen and gets the Tabasco sauce and puts it on his meatloaf and then returns it to the kitchen. Why aren't condiments on the table? Both Alice and Jean thank him for putting it back. Martin pushes his plate away and starts to stand up but Jean tells him he needs to finish his succotash before getting up. He does. What if he doesn't like succotash?

5. By 5:35pm, everyone has gotten up from the table and Jean, along with Alice, cleared the table and wiped off the plastic tablecloth. Why didn't anyone stay behind to drink coffee or talk? Again, no one is helping staff or asked to help. Jake rolled himself over to the TV and changed the channel; Roger went down the hall to the bathroom; Tom got his clean towels and took them to his bedroom; Howard returned to the rocking chair and Martin sat down on the couch. When Roger returned to the living room, Tom went to the bathroom to take a shower. Alice hollered to him to remind him that tonight was the night to wash his hair. What if he wants to wash his hair a different time or day? Is this scheduled for some reason? He then came out and got a bottle of shampoo from her. Why doesn't he have his own shampoo? Roger sat in one of the living room chairs and just looked around at things. What's with Roger sleeping and sitting so much?

6. When the dishes were done, Alice brought a bunch of folded towels to Roger, Martin and Howard and told them to take them to their bedroom and put them in their closet. Each followed her instructions and returned to what they had been doing before. *If they were watching TV, why is staff telling them to do something else right that minute? Aren't manners part of everyday expectations?* Alice took Jake's towels to his bedroom and put them away. *Why didn't Alice have Jake put his towels away?* She returned to the living room and told Howard he could go start his shower. *Is showering scheduled or a function of personal choice? Maybe he'd rather take his shower in the morning to avoid "bedhead".* Howard went to his room and collected his pajamas and towels then proceeded to the bathroom. Alice went to the kitchen where she began packing lunches. *Again, why is no one helping? Or being asked what they want?* Jean was filling out the log at the dining room table. *Why not plan, provide or support evening activities other than eating and showering and do the log later?*

7. Tom finished his shower and returned to his room where he sat on his bed and systematically ripped the pages out of a magazine one by one, wadded the page up and threw it in the waste can. *Is this a typical hobby?* Jean got up and went to check on Howard and then called to Alice that they needed to help Jake take his bath. Alice went over and rolled Jake to the bathroom while Jean got his pajamas and towels. *Again, why aren't they asking him?* They did a two person lift to get Jake into his shower chair and Jean returned to her record book. *Are there usually two staff who are female in an all-male home, especially if someone is not independent in hygiene?* When Howard returned to the living room, he picked up the remote, changed the channel and sat down on the couch next to Martin, who then got up and went to get his shower. By 6:45pm, everyone had completed their showers and was back in the living room except for Tom, who stayed in his room. *Is this consistent with each person's preferences? With school/work/activity schedules? Is it normal for their ages, culture, sex, economic station?*

8. Alice continued packing the lunches and Jean got up and bought the *Connect 4* game and a set of checkers to the dining room table. She reminded everyone in the living room that the games were there and then went to check on Tom. She returned and asked if they wanted to watch *Entertainment Tonight* on the TV and, getting no definitive response, got the remote from Howard and changed the channel. *Again, what's up with the limited evening activity options? Why does no one care what is on TV, when that is the "evening activity"?* Things stayed the same until about 8:00pm when Alice asked the men if they would like a cookie and milk before bed. Everyone, including Tom, went to the kitchen, where each was given a chocolate chip cookie and a plastic tumbler filled to the rim with milk, which they consumed and then went directly to their bedrooms where they went to bed. *What about variety/choice? What about serving themselves? Are plastic tumblers normal for this setting/age group?*

### **End Revisit to Whitehall**

These are the kind of questions surveyors should have when they are entering any sized home, any time of the year, whether men or women, boys or girls live there. Did

these questions about 48 Whitehall help you better understand the intent of ICF/IID Regulations? The next expectation may also.

### Section 3

## Surveyor Expectation Two - Individualization

### Definition

If “normalization” was the only concept surveyors applied to congregate living settings, there would still be an opening for a “what’s good for one is good for everyone” mentality that once characterized most large institutions. For instance, everyone should shower at the same time, everyone should go to work/classes between 9am and 3pm, everyone should go on the facility bus at the same time, everyone should receive M&M’s as reinforcers. This is also *not* the intent of the regulations. The ICF/IID Appendix J Survey Procedures and Regulations are very clear that ***each person is an individual***. Add this concept to normalization and in a five person home you might find five different things going on during an observational time period—for example, a person who works at the neighborhood convenience store on split shift, someone who works in an enclave at the rubber plant, another who attends programs at the YMCA, a fourth who folds, collates, counts and stacks church bulletins, women’s worship newsletters and Sunday school fliers, while the fifth person goes to a day center to learn to use his electric wheelchair, an electronic communication device and other activities of daily living as they occur across the day.

### ***Thought to Ponder:***

***Supporting people as individuals requires individualized supports rather than group supports. When one person requires significantly more structure than others in a group, the same restriction is placed on the group, which results in a lowering of opportunities for the other individuals. (DiLeo, 2000)***

The ICF/IID Regulations require service providers to look at a person’s strengths and preferences, needs, including specific assessments, and to devise with that person an “individualized program plan”. The format for these tasks is not, however, prescribed except very generally. Consequently, there are many ways surveyors will see them handled. Some ways, unfortunately, being mediocre and less effective than others. The best providers are able to use what energizes the person, what motivates the person and the people who are important to support the person in planning and accomplishing activities with meaning.

**For example**, Joan does not have enough control of her upper body to be able to sit independently. She does not use language and is dependent on others to move from place to place. She cannot use her hands to pick up most objects and in the past has been unsuccessful in learning to use a motorized wheelchair. When she first moved to her current home she cried several times a day for no apparent physical reason. The intensity of the crying was so great, it was considered a behavior management issue. Through assessment, which included using staff and family members who have known

her for years as informants, it was recognized that Joan loves to be outdoors; apparently the warmth of the sunshine and feel of the breeze are very important to Joan. Joan is frequently seen looking out the windows in her living room. Several Individual Program Plans (IPP) ago Joan and those close to her as well as others who meet her needs, determined that Joan has a personal goal of being able to go outside. They agreed to watch for Joan's window gaze and ask her if she wants to go outside whenever she is looking outside. The next IPP meeting, they set up a regular schedule to ask her, based on the times when Joan most frequently has been observed looking outside in the past. At another IPP update meeting, staff and others decided to find or record videos of outdoor scenes that Joan may push a button to play during inclement weather. Further, they attempt to find peers who would be equally interested in accompanying Joan outside to sit, garden or play lawn games. Recently a neighbor who is a Master Gardener helped Joan select a plant that would grow in a sunny window of the house. Joan seemed very interested in the care of the plant, and through assessment and questions asked about her preferences, a training objective was set up to teach Joan to signal when the houseplant needs to be watered. On occasion this neighbor takes Joan next door to her garden, talks to her while she is gardening and invites her to touch and smell leaves and flowers of various plants. She has also taken Joan as a guest to a Master Gardener container gardening class. Joan's favorite t-shirt has a local public garden pictured on it. Not surprisingly, the sheets that Joan picked out two years ago for her bed are powder blue with clouds on them. Joan has not cried in the past year, except for the day her finger was accidentally pinched by her wheelchair.

**Now that you have read about Joan once, look at the following example again. This time parts of the paragraph are high-lighted so you can see the instances identified where Joan's *individual* strengths and preferences were considered in planning and programming to meet her needs. REMEMBER, as a surveyor, you need to BELIEVE that people with disabilities have *individual* preferences and discern these through observations, interviews and record reviews.**

For example, Joan does not have enough control of her upper body to be able to sit independently. She does not use language and is dependent on others to move from place to place. She cannot use her hands to pick up most objects and in the past has been unsuccessful in learning to use a motorized wheelchair. When she first moved to her current home she cried several times a day for no apparent physical reason. The intensity of the crying was so great, it was considered a behavior management issue. Through assessment, which included using staff and family members who have known her for years as informants, it was recognized that Joan loves to be outdoors; apparently the warmth of the sunshine and feel of the breeze are very important to Joan. Joan is frequently seen looking out the windows in her living room. Several Individual Program Plans (IPP) ago Joan and those close to her as well as others who meet her needs, determined that Joan has a personal goal of being able to go outside. They agreed to watch for Joan's window gaze and ask her if she wants to go outside whenever she is looking outside. The next IPP meeting, they set up a regular schedule to ask her, based on the times when Joan most frequently has been observed looking

outside in the past. At another IPP update meeting, staff and others decided to find or record videos of outdoor scenes that Joan may push a button to play during inclement weather. Further, they attempt to find peers who would be equally interested in accompanying Joan outside to sit, garden or play lawn games. Recently a neighbor who is a Master Gardener helped Joan select a plant that would grow in a sunny window of the house. Joan seemed very interested in the care of the plant, and through assessment and questions asked about her preferences, a training objective was set up to teach Joan to signal when the houseplant needs to be watered. On occasion this neighbor takes Joan next door to her garden, talks to her while she is gardening and invites her to touch and smell leaves and flowers of various plants. She has also taken Joan as a guest to a Master Gardener container gardening class. Joan's favorite t-shirt has a local public garden pictured on it. Not surprisingly, the sheets that Joan picked out two years ago for her bed are powder blue with clouds on them. Joan has not cried in the past year, except for the day her finger was accidentally pinched by her wheelchair.

### **Discussion**

When normalization (expectation one) and individualization (expectation two) permeate the provider delivery system, you will see activities and opportunities occurring that are meaningful for each person in the ICF/IID. This is not to imply that basic skills training, such as closing a Velcro fastener on a shoe, is not expected; it is. But think how much more motivating it would be if you were a Philadelphia Eagles fan and the Velcro fasteners were on a pair of green and white sneakers that you planned to wear to a playoff game!! Or if your formal objective for grasping had you practicing with "built-up" cutlery at meals at home, the work cafeteria and your favorite restaurant, as well as with the grab bars and railings at home and in buses and stairways on your way to work and your favorite art museum and theater. Or what about an objective for identifying \$5 which is implemented during the purchase of \$5 items such as a movie ticket, snack at an event, deposit at the bank, offering at church and so on. Meaningful activities enhance lives and embrace each person's uniqueness.

### **Questions to Ask Yourself**

**If you observe:** People in a home doing things as a group rather than as individuals.

**Then ask yourself:** Is this due to lack of ideas or limited expectations? Is there lack of age-appropriate, ability-appropriate materials/activities? Was there lack of staff, lack of staff training? What about lack of assessment or training objectives? Or is it a combination? Find out and cite accordingly.

### **Getting to the Meaning**

In order to learn about the sample members that you are assigned to follow as a surveyor, the ICF/IID Survey Procedures (Appendix J, Part. VIII. C.) require you to conduct an “in-depth” interview with a prescribed number/per cent of your sample group (or their representatives). These interviews are to give you the opportunity to learn more about things such as each individual’s goals, choices and preferences. You should get a sense of how the provider is facilitating the people who live in the home to have meaningful lives—lives that count as contributing members of society, lives that have value for the individuals (and staff) and lives that allow and encourage individuals’ expectations and dreams.

## **Section 4**

### **Surveyor Expectation Three - No Limit on Learning**

#### **Definition**

Underlying the need for normalization and individualization as well as the ICF/IID Regulations is the belief that all people can learn no matter what their age, culture, sex, race or limitations. In the United States, all children are entitled to a free public education. For most children formal schooling lasts until twelfth grade. Some go on to college or technical school; many go to work. Either way, the majority of young adults eventually have a job and live on their own. This does not, however, signal the end of education. No matter who you are: ***There is no time limit on learning.*** It may occur in classroom settings, but it may also be incidental to everyday life. One may learn from his/her boss, spouse, spiritual advisor, brother, neighbor, the internet, etc. This ability of humans to learn throughout a lifetime is directly related to the ICF/IID regulation terminology “active treatment”.

The concept ***does not mean*** providers have a lifetime to train a particular skill or behavior. Rather, there is so much each individual needs to learn—an ocean rather than a puddle—that the regulations reflect this urgency. There is so much to get done that providers need to *prioritize* training goals and objectives so that safety, health and independence are addressed first. Why? Because these are things someone else has to do for you if you can’t do them. And let’s face it. Knowing and doing such things yourself makes you independent of the whims and availability of others. Promoting independence, promotes dignity. Promoting dignity, promotes dreams and meaningful lives.

The concept of no limit on learning ***also does not mean*** that the regulations require everything should be taught in a classroom. Far from it. It is recognized that people with intellectual disabilities, particularly those who are more severely disabled, learn better when places, situations and materials are authentic and where capable models and natural supports are available (Dileo, 2000). Some training will involve exposure to meaningful activities (“informal” in the language of the regulation, teachable moments in learning theory), while other training will be according to structured training methods each time the appropriate opportunity arises during the day/week (“formal” in the language of the regulation). In both cases, the team, including the person, will assess

and use strengths, needs and preferences to individualize and prioritize what, where and how the person will be taught. A trip to the bedroom closet maybe a teachable moment for one person and a formal objective for another, the same can be said about a trip to work and a trip to the bathroom.

In recent years it has become accepted that different people learn differently (Dileo, 2000). So despite the developmental learning continuums doctors, psychologists and educators theorized and studied for years, research shows human development **does not** always take place in a rigid, orderly progression (Taylor et al., 2005). As a surveyor, this means that you should carefully consider what is being said if you hear: “John needs to learn this before he can do that”. What were once considered developmental *prerequisites are not always necessary steps* to performing a task. For example, you may not need to crawl before you can walk. In fact, there are people with Down syndrome who are never able to crawl before they can walk. It is not necessary to recognize a coin before carrying or spending money. It is not necessary to prove yourself in a workshop before being matched to a job placement suited to your strengths, interests and needs. People with intellectual disabilities succeed everyday. They marry. They hold jobs. They parent. During incidental learning and formal instruction, it is as or more important to look at “the ultimate setting in which an individual is to function.” (Dileo, 2000, p. D-44).

The concept **also does not mean** that a formal training objective may run endlessly. Even with team review of the objective, method and reasons for lack of progress, there comes a moment when training an unchanging skill or behavior must be further reconsidered and reprioritized. Perhaps it is not physically possible at the time or not meaningful to the person. At that time the team decides, based on data, it is time to end an objective. It is always appropriate for a surveyor to question programs which have been running for a year or more.

If individuals are supported in their lives to learn relevant functional skills, live in a normalized environment, have control and choice in day to day activities and are trained and supported with respect and dignity, there is no reason for them not to dream. A dream might be: living alone, having a significant other, using a hot tub daily, playing on a winning athletic team or voting for the president.

### Questions to Ask Yourself

**If you observe:** The contents of a teenager’s or adult person’s pocket and it contains string, a ball of paper and two cigarette butts.

**Then ask yourself:** Why doesn’t he have a comb, nail clippers, billfold, handkerchief, key ring with a lucky charm, id card, debit card, gum/mints, cell phone or coins?

Normalization and individualization have to do with your whole life—what’s in your pockets, where you go, what you eat, how you make money, what you enjoy, how you get places, who your friends and neighbors are and so on.

## Section 5

The following Visit to 22 Gaylord Way is an example of how good life can be for someone with significant physical and mental disabilities. It was compiled from several real people's real lives.

### Activity 1 - A Visit to 22 Gaylord Way

**Directions:** Please read and reflect on the following scenario. During your next preceptor telephone call, be prepared to discuss how it relates to the three expectations for surveyors described in this module. You may wish to jot some notes on your copy.

1. It is early morning at 22 Gaylord Way and even though it is calm many things are happening. Someone is in the bathroom off the hallway; the TV in someone's bedroom is on to the *Today Show*; a fellow is in the kitchen looking for something and another is in the dining room setting clean placemats on the table. One of the placemats is a clear plastic, non-skid kind with magic marker lines across the top.

2. All of a sudden, a scooter comes down the hallway at a pretty good clip. The young man driving the scooter is dressed in a taupe uniform, has a backpack hooked around the back right side and is making unintelligible noises that obviously mean something. At about the same time a staff person comes out of a bedroom and comments to the driver, who is named Wen, "Slow down man –breakfast isn't going anywhere and you still have 40 minutes til the van comes." Wen laughs, but doesn't slow down much and heads to the kitchen. In the kitchen he gets a banana out of a fruit bowl, gets a serrated dinner knife out of the drawer and puts them both in a pocket attached to the inside of his scooter and tools out of the kitchen. He goes over to the dining room table, close to the marked placemat, and again makes some noises which receive an answer of, "Be right there." Sure enough, staff person Tim is there and helps move a dining room chair with only one side arm on it around to Wen's left side. Tim then asks Wen if he is ready to move and, after an affirmative nod from him, puts his arms under Wen's and pulls him to standing position. Both hesitate a moment and Tim asks "Ready?" Wen indicates "yes" and both men pivot to the right and Wen is in the dining room chair. Tim asks him if he wants to be pushed to the table and does so when Wen answers "yes". When viewed from a corner of the dining room, it is obvious that the dining room chair has been modified for Wen because it positions him at the appropriate height at the table and gives his right arm good support.

3. Just about then, a woman comes out of the kitchen, says "Good morning; sleep well last night?" Wen makes noises in the affirmative while this staff person, Julia, helps another fellow to his dining room chair. "So guys, what's your pleasure this morning? We have soft-boiled eggs, shredded wheat squares and, as a special bonus today, they are strawberry frosted (everyone laughs) and honey oat cheerios. Wen? I know - don't tell me – cheerios and a banana – right? I just knew it!" She snaps her fingers. "George, how about you? Eggs? One or two?" George holds up two fingers. "Tristan and I will get the stuff for you." At that moment a middle-aged man comes ambling

We have soft-boiled eggs, shredded wheat squares and, as a special bonus today, they are strawberry frosted (everyone laughs) and honey oat cheerios. Wen? I know - don't tell me - cheerios and a banana - right? I just knew it!" She snaps her fingers. "George, how about you? Eggs? One or two?" George holds up two fingers. "Tristan and I will get the stuff for you." At that moment a middle-aged man comes ambling down the hall and Julie tells him everyone is waiting on him and to "get a hitch in your gitty-up". Tristan's speed improves and he's off to the kitchen with Julie. Minutes later they reappear with two eggs and a bowl of cereal.

4. Tim comes over and helps Wen get his left arm up on the table, right at the edge of the placemat. He asks Wen if he is ready for his banana and when Wen nods "yes", Tim gets it from the scooter pocket, peels it and places it at the top of the placemat on top of the magic marker hatch marks. "OK now?" he asks. Again an affirmative answer and Wen begins moving.

5. Wen uses his right arm to get his left hand over one end of the banana. His left arm does not appear to have much independent movement. He gets his knife from his scooter pocket and then proceeds to cut his banana at each of the hatch marks. Once he has cut the entire banana, he puts the knife down and then puts all the pieces over his cereal. His cereal bowl has a lip that is closest to him and allows him to scoop his cereal, bananas and milk without much trouble. Twice during the meal he puts his spoon down and wipes his mouth. Julie is busy chatting away about the weather, the upcoming weekend and Tim's new car. The men periodically comment in their own way and keep the conversation going. All of a sudden Wen makes a sharp noise and motions to Julie. Julie looks around and says: "Oh, you forgot your coffee did you? Want me to get it for you?" and gets up to get Wen's coffee. She also asks Tristan and George if they want juice, milk or coffee. When Julie returns with everyone's drinks, she asks Wen if he wants some help with his sugar. He does and she proceeds to add two teaspoons of sugar to his coffee. His mug appears to have a non-tip layer glued on its bottom because Wen stirs his coffee with some pretty erratic movements without spilling it.

6. Two hours later, at a major home distribution center for auto parts, Wen is at work. For six hours a day Wen delivers and collects mail from a wagon hitched to his scooter. He appears every morning before 8 am at the mail room where mail is put in file boxes with cut out handles. Each box has a different colored stripe down one side. The business is in a huge warehouse with a permanent wall, floor to ceiling, separating the office space from the warehouse. The warehouse is automated by electronic robots that pick out parts according to codes entered at the order center. The business is considering making the mail system robotic too, but due to the decrease in snail mail orders and the increase of email/web based orders, does not think at this time this capital expenditure is a priority.

7. Wen can't read but is able to match things very well. At work he has a flip type wallet with pictures in it that he uses to communicate when needed. This wallet is rigged up to a small shelf that is on a metal rod which fits into a clamp on the right front part of his

scooter. One of the order clerks rigged it for him after getting frustrated watching Wen struggle to get the wallet in and out of his pocket. The office space is a two story area with hallways with doorways which lead to large cube farms. Each doorway has a very discreet stripe of paint on the baseboard. These paint stripes match the colors of the boxes in Wen's wagon. That's how he knows which mail goes where. At each office stop he leaves a box and picks up a box which he returns to the mailroom. He uses a freight elevator to go between floors. His morning route takes about 2.5 hours and his afternoon route about the same. In addition, once a day he delivers small packages to the offices. The mail room puts colored dots on those packages for Wen.

8. Wen has 30 minutes for paid lunch time. He eats his packed lunch in the lunch room with the other employees. Over the six years he has worked there he has developed friendships with some of the workers. The company had to modify a bathroom on each floor so Wen could use them independently. The person who modified them, Amando, has taken a keen interest in Wen's life and, in fact, now acts as his de facto guardian and advocate. They go fishing together and are working on an aquarium system for Wen's bedroom that Wen can access and take care of by himself. Wen has 7 days paid vacation and 6 paid holidays a year. He makes \$7 an hour with no benefits.

9. On Wen's way home, his van drops him off at the grocery store where Anna Marie (staff) and George meet him. All three proceed inside. Once inside, Anna Marie loops a canvas bag over the right side of the scooter. She then asks Wen if he will go pick out some bananas and other fruit and meet her and George at the deli counter. She and George then proceed to the meat section. Shortly thereafter, all arrive at a checkout area. Wen is supposed to be learning to use his debit card for some of his purchases but new machines have just been installed and he can't reach any of them. Anna Marie is perturbed because this means that Wen has to whisper his pin number to her so she can assist him. While George is loading the groceries in bags, Anna Marie discusses the situation with the Store Manager, who promises a lower debit machine at one of the wider checkout lanes by the next week.

10. Later Rob (also staff) and Wen plan for the weekend ahead and an upcoming trip. It is determined Wen needs to call for church pickup, to confirm with Manny that he will be ready for Meals on Wheels on Saturday and to check some details for the trip with his sister. Rob checks that Wen has all the telephone numbers in his communication wallet so Wen can make the calls on his own in the next day or so. Rob and Wen start a packing list for the trip and identify some clothes that need Velcro fasteners and some things that need to be purchased. For instance, Wen wants a smaller bathing suit.

11. Before bed, Wen goes to the kitchen and gets a green plastic lidded storage container. He takes it over to the area where Anna Marie has medications. Wen puts the container on the counter and indicates (in his own way) "medication". She hands him a blister pack and steadies the container with both hands. Wen slides the blister pack over a hole in the lid and pushes the pill through the foil, where it drops into the

container. She releases the container and he scoops the pill into his hand and slowly moves it towards his mouth, pops it in and follows it with a drink of water. Wen then scoots off down the hall to his bedroom.

12. At Wen's last annual planning meeting, Amando was there. Manny (he goes by this nickname) talked about the possibility of the mail job being phased out and leaving Wen unemployed. Wen expressed sadness at this thought, as did Manny. Manny suggested that Wen go to the community college to see if there was a beginning computer class that he might take. Manny didn't know if someone who couldn't read could learn to use a computer but he felt if Wen could tell time using a digital clock that maybe the resource people at the local college could teach him to read. Wen was beside himself with excitement about all this talk and ideas. Julia volunteered to go with Manny and Wen and check things out. At this same meeting, the new consulting speech therapist proposed that Wen try out a Voice Pod communication device. She demonstrated one at the meeting. Everyone was dually impressed, and since it cost under \$100, Wen could pay for it himself so if he needed more than one it wouldn't be a problem. Manny thought that maybe the more advanced Voice Pod (more memory) would be better for Wen and would encourage him to make faster progress. The speech therapist agreed to let Wen start out on her borrowed one and go from there. The home coordinator mentioned that the agency that owned this home qualified for free technology from the Cristina Foundation if things at the college worked out.

13. Wen's boss, Mr. Rodrick, commented that when he was approached by Wen's Vocational Rehab Counselor about a job, he thought it was a joke. How could someone who couldn't walk, talk and was labeled profoundly retarded, hold a job? He said he had since revised his expectations 180 degrees—that Wen was one of his most dependable employees. In fact, Mrs. Rodrick had encouraged a friend to hire a woman with similar disabilities for her small printing business.

## **End Activity 1**

### **Discussion**

If you survey an ICF/IID using the three expectations discussed in this module, normalization, individualization and lifelong learning, you will never consider people staring at a TV for hours as an acceptable level of provider service. You will not consider lengthy waits in hallways or doorways for meals, buses, etc. as okay. You will not consider sporadic availability of paid work for people who want to work as all right. You will not consider quarterly trips to favorite neighborhood places as adequate. You will not consider frequently cancelled activities as acceptable. You will not consider objectives on which people make no progress as training.

## Section 6

### Tags Representative of Each Expectation

The following tags are arranged by the three expectations discussed in this training module. They are further divided by topic areas within the expectation. The purpose of the listing is to provide surveyor direction as to where to find tags that might be suitable to a topic area.

The statements which follow each tag are excerpts from the regulation and/or the guidance to surveyors in Appendix J. This means the reader must go to Appendix J to read the entire regulation and guidance when determining whether to use the tag in a 2567 report.

### NORMALIZATION

#### Age Appropriate

- W137 - (12) Ensure that clients have the right to retain and use appropriate personal possessions and clothing
- W147 - Are outings age-appropriate?
- W196 - Are the activity and materials age-appropriate, adaptive and functional?
- W211 - Assessments address areas and active treatment needs which are relevant to the person's chronological age. The individual is given opportunities to participate in age-appropriate activities to assess the person's functioning in those activities or settings.
- W249 - Whether "structure" must be imposed by staff or whether the individual can direct his or her own activities for a period of time (without direct staff observation) is based on the individual's ability to engage in constructive, age-appropriate, adaptive behavior (without engaging in maladaptive behavior to self or others).

#### Normalization

- W104 – The governing body provides, monitors and revises, as necessary, the policies and operating directions which ensure the necessary staffing, training resources, equipment and environment to provide individuals with active treatment and to provide for their health and safety.
- W250 - The active treatment schedule reflects normal daily rhythms.
- W420 – Individuals with physical disabilities who live in a room are able to use the furniture.
- W421 – "Furniture" is to be distinguished from "furnishings" (such as plants, pictures, etc.), which though encouraged as being an appropriate and desirable aspect of a normalized living environment, cannot serve as a substitute for appropriate individual furniture that can be used by the individual alone.
- W459 – Individuals participate in normalized dining experiences appropriate to their functional abilities (e.g., using knives, family style meals, going to restaurants, etc.) and are being taught skills to do so.

- W486 – Staff monitor individuals who are able to dine independently in order to promote, support, reinforce and encourage individuals to eat in an appropriate and normalized manner (e.g., manners, social behaviors, etc.)
- W488 – Is family style dining made available to individuals who are able to participate?

Are individuals allowed to dine out at places like fast food restaurants, buffets, vendors at the park or beach?

Is the individual taught to use the most normal, least stigmatizing clothing protectors during mealtimes?

Do individuals take turns participating in setting their own tables? Serving their own meals? Preparing meals? Shopping for and putting food away?

### **Preferences**

- W213 - The individual's preferences, methods of coping/compensation, friendships and positive attributes are clearly described in functional terms in assessments.
- W420 - Individual preferences and program needs are considered in furniture selection.

### **Choice**

- W122 - Individual freedoms are promoted (e.g., individuals have choice and opportunities in their money management, community involvement, interpersonal relationships, daily routines, etc.).
- W125 - On what basis does the facility accept, or not accept, an individual's informed choice?
- W133 - Ensure clients the opportunity to communicate, associate and meet privately with individuals of their choice,
- W136 - Individuals are involved in various types of activities in the community (e.g., going to parks, movies, restaurants, church, community meetings and events) based on their interests and choices.
- W137 - Individuals have personal possessions and clothing which meet their needs, interests and choices.
- W147 - Can individuals choose not to participate?
- W195 - Individuals do not have opportunities to practice new or existing skills and to make choices in their daily routines;
- W196 - Individual's routines and environments are organized to facilitate acquisition of skills, appropriate behavior, greater independence and choice;
- W247 - Include opportunities for client choice and self-management.

Individuals are provided opportunities for choice, encouraged and taught to make choices, and to exercise control over themselves and their environment. Due to the basic underlying importance "choice" plays in the quality of one's life, the ICF/IID should maximize daily activities for its individuals in such a way that varying degrees of decision-making can be practiced as skills are acquired. Examples of some activities leading toward responsibility for one's own self-management include, but are not limited to, choosing housing or roommates, choosing clothing to purchase or wear, choosing what to eat, making and keeping appointments, and choosing from an array of

appropriate activities. Interview staff to determine how attitudes and activities of the team and consultants facilitate or impede individual choice.

Choices can be made by all individuals. The type of choices the person makes may vary from very simple to more complex, depending upon individual abilities. Look at choices in the context of the individuals served by the facility.

- W250 - Individuals should have opportunities to choose activities and to engage in them as independently and freely as possible. Staff routines and schedules should be supportive of this goal and result in the presence of reasonable choices by individuals.
- W251 - Are informal daily activities designed to promote choice, self-management, skill enhancement or reinforcement?
- W269 - Address the extent to which client choice will be accommodated in daily decision-making, emphasizing self-determination and self-management, to the extent possible;

Staff actively engage in practices which provide individuals with opportunities for choice, decision-making and self-management, promote participation in these opportunities and provide necessary supports as the individual becomes more independent.

Alternatives are available for individuals who do not choose to participate in a planned activity.

Individual's preferences and choices play a key role in daily decision-making.

- W270 - "Client conduct" refers to any behavior, choice, action, or activity in which an individual may choose to engage alone or with others.
- W436 – Furnish, maintain in good repair and teach clients to use and to make informed choices about the use of dentures, eyeglasses, hearing and other communications aids, braces, and other devices identified by the interdisciplinary team as needed by the client.
- W478 - Are individuals allowed to substitute menu items with their own choices (even though seemingly void in variety (e.g., an individual wishes to consume pizza 3 times per week, or on consecutive days) provided that the items contain the nutritive value comparable to the planned items on the menu?

## INDIVIDUALIZATION

### **Individualize**

- W195 - Individuals are not involved in activities which address their individualized priority needs;
- W230 - Completion dates are individualized (i.e., not all the same for all clients and all objectives).
- W232 - Objectives are individualized to take into consideration the individual's abilities and disabilities.
- W270 - The policy or "house rules" include(s), for example: allowable individual conduct (e.g., swearing or cursing, freedom of choice in religion, consumption of alcohol, smoking, sexual relations), reasonable locations where this conduct may or may not occur, and parameters for decision-making when an individual's choice conflicts with the group's choice (e.g., consensus, voting, taking turns, negotiation of differences).

- W318 - The Condition of Participation of Health Care Services is not met when individuals do not receive adequate health care monitoring and services, including appropriate and timely follow-up, based upon their individualized need for service.
- W322 - Medical services are provided as necessary to maintain an optimum level of health for each individual and to prevent disability.

### **Assess or Meet Individual Needs**

- W120 - The facility must assure that outside services meet the needs of each client.
- W164 - Each client must receive the professional program services needed to implement the active treatment program defined by each client's individual program plan.
- W186 - There are sufficient numbers of direct care staff over and above minimum ratios to meet individual's needs and to implement the active treatment program as defined in the IPP.
- W196 - Each individual's needs and strengths have been accurately assessed and relevant input has been obtained from team members; Each individual's IPP is based on assessed needs and strengths and addresses major life areas essential to increasing independence and ensuring rights; Identified priority needs are addressed formally and through activities which are relevant and responsive to individual need, interest and choice;
- W206 – (Standard: Individual program plan) Each client must have an individual program plan developed by an interdisciplinary team that represents the professions, disciplines or service areas that are relevant to- (i) Identifying the client's needs, as described by the comprehensive functional assessments; and (ii) Designing programs that meet the client's needs.
- W209 – (Standard: Individual program plan) Participation by the client, his or her parent (if the client is a minor), or the client's legal guardian is required unless the participation is unobtainable or inappropriate.
- W214 - Do the strengths and needs identified by the facility correspond to what you see individuals do or not do during observations?
- W233 – Are objectives and priorities based on each individual's needs?
- W331 - The facility must provide clients with nursing services in accordance with their needs.
- W344 - The facility must employ or arrange for licensed nursing services sufficient to care for clients' health needs including those clients with medical care plans.
- W356 – Dental care needed for relief of pain and infections, restoration of teeth, and maintenance of dental health. Are individuals' dental needs neglected until there is pain or other emergency?
- W435 – Provide sufficient space and equipment in dining, living, health services, recreation, and program areas (including adequately equipped and sound treated areas for hearing and other evaluations if they are conducted at the facility) to enable staff to provide clients with needed services as required by this subpart and as identified in each client's individual plan.

- W484 - Equip areas with tables, chairs, eating utensils, and dishes designed to meet the developmental needs of each client;

## LEARNING

### Teaching

- W126 - Allow individual clients to manage their financial affairs and teach them to do so to the extent of their capabilities;
- W190 - Staff are observed to demonstrate cross-cutting skills which are appropriate when training and interacting with any individual with developmental disabilities (e.g., shaping, breaking tasks into small steps, providing positive reinforcement, providing informal opportunities to practice skills, using appropriate materials, etc.).
- W191 - Staff are observed to demonstrate cross-cutting skills and interactions which are effective in addressing inappropriate behavior and in supporting appropriate behavior for any individual (e.g., teaching and reinforcing positive, adaptive or incompatible behaviors, diffusion strategies, environmental manipulation, differential reinforcement of other behaviors (DRO), differential reinforcement of incompatible behaviors (DRI), physical management techniques, etc.).
- W193 - When staff are unable to demonstrate how to correctly implement an intervention, or are unable to explain when and how the intervention is to be implemented, inadequate training is evident.
- W194 - Staff should be able to demonstrate in practice the results of training for the individuals for whom they are responsible.
- W234 - The training program provides clear directions to any staff person working with the individual on how to implement the teaching strategies.
- W239 - The training program provides specific information as to how to elicit or strengthen appropriate behavior and what behaviors to teach, reinforce or encourage which would reduce or replace the inappropriate behavior.
- W242 - There is documentation of consistent, appropriate attempts to teach individuals these skills, or specific evidence as to a medical condition which would preclude acquisition, prior to determination of developmental incapability.
- W266 - Individual programs and activities regularly include use of positive techniques, teaching strategies, and supports. Efforts are made to reduce and eliminate use of restrictive techniques with positive results;

Staff teach and reinforce appropriate behaviors, such as communication skills, social skills, independence and choice-making skills, coping skills, and leisure skills which serve as functional substitutes for inappropriate behaviors;

- W268 - Staff teach and encourage individuals to interact with each other in a socially acceptable manner.
- W288 - Any intervention used is tied to a specific active treatment program which addresses both the inappropriate behavior and mechanisms to teach, improve, support, or substitute appropriate behaviors.
- W289 - What specific appropriate behaviors are being taught, improved, supported or substituted for the maladaptive behavior?

- W340 - Training clients and staff as needed in appropriate health and hygiene methods;
- W371 - Clients are taught to administer their own medications if the interdisciplinary team determines that self-administration of medications is an appropriate objective, and if the physician does not specify otherwise;
- W423 - In the presence of an individual's personal storage space being locked by staff, the individual's program plan documents the necessity for limited access to his/her own possessions and includes provisions to teach the individual the necessary responsible behaviors.
- W436 - Furnish, maintain in good repair, and teach clients to use and to make informed choices about the use of dentures, eyeglasses, hearing and other communications aids, braces, and other devices identified by the interdisciplinary team as needed by the client.
- W482 - If an individual does not eat in the dining area, the physician has documented the medical necessity for, and/or the IPP documents the plan to teach the individual the physical and/or other skills necessary for inclusion.
- W488 – Individuals eating programs are implemented in accordance with their training objectives.

Is the individual encouraged, permitted and reinforced for being as independent as possible during meals?

### **Learning**

- W104 - The living arrangement promotes independence and learning for all individuals who reside there.
- W227 - Objectives may address services to be provided, learning/treatment needs, adaptive equipment, etc
- W229 - Each objective clearly states one expected learning result.
- W230 - Completion dates are based on the individual's rate of learning.
- W231 - The learning outcome is stated in a manner which enables all staff working with the individual to consistently identify the target behavior and to clearly identify when it is being displayed.
- W232 - For example, if the objective is to learn to put on shoes independently and the person does not have the manual dexterity to tie shoe laces, then the objective could include the use of slip-on shoes or shoes with velcro closures in order to facilitate the person learning this skill.
- W249 - The pattern of interactions observed supports the active treatment program (e.g., informal opportunities to reinforce learning or appropriate skill development are taken, needs are addressed as they present themselves).
- W406 - The environment promotes the health and safety, independence and learning of the individuals who reside there.
- W407 - The living arrangement promotes independence and learning for all individuals who reside there.

### **Training**

- W125 - Individuals are taught and encouraged to claim and exercise their rights

- W128 - The chronic use of restraints may indicate one or more of the following: the individual's developmental and/or behavioral needs are not being met and the appropriateness of placement should be questioned; staff behavior may be prompting behaviors in individuals which result in the chronic use of physical restraints and drugs to control behavior; staff may have inadequate training and/or experience to provide active treatment and employ preventive measures that reduce the levels of behaviors judged to require physical restraints and drugs to control behavior; and restraints may be applied to behaviors which are, in fact, not threatening to the health and welfare of the individual or other individuals and staff.
- W195 - Individuals receive continuous, competent training, supervision and support which promotes skills and independence;
- W196 - Each individual receives aggressive and consistent training, treatment, and services by trained staff in accordance with their needs and the IPP;
- W234 - The training program provides clear directions to any staff person working with the individual on how to implement the teaching strategies.
- W235 - The training program provides clear directions to any staff person working with the individual about when the strategies are to be implemented.
- W236 - The person who will monitor the program and ensure it is being implemented appropriately, is clearly identified on the written training program.
- W237 - The training program provides clear directions to any staff person working with the individual about the type of data to record, and the frequency which data is to be recorded.
- W238 - Any behaviors which would interfere with the individual's ability to function in, or benefit from the training program are identified.
- W239 - The training program provides specific information as to how to elicit or strengthen appropriate behavior and what behaviors to teach, reinforce or encourage which would reduce or replace the inappropriate behavior.
- W242 - Include, for those clients who lack them, training in personal skills essential for privacy and independence (including, but not limited to, toilet training, personal hygiene, dental hygiene, self-feeding, bathing, dressing, grooming, and communication of basic needs), until it has been demonstrated that the client is developmentally incapable of acquiring them.
- W249 - Each individual is receiving training and services consistent with the current IPP.
- W340 - Training clients and staff as needed in appropriate health and hygiene methods;
- W350 - The facility must provide education and training in the maintenance of oral health.
- W426 - In areas of the facility where clients who have not been trained to regulate water temperature are exposed to hot water, ensure that the temperature of the water does not exceed 110° Fahrenheit. Individuals must be under the direct supervision of staff while being trained to operate hot water temperature controls.
- W459 - Individuals do not receive training and supports which enable them to eat as independently and in as normalized manner as possible.

## **Assessing**

- W210 – 225 - All contain pertinent information about assessing individuals

## **End of Tags**

## **Section 7**

### **A Suggestion**

As you could see from the previous list of tags, there are many ICF/IID Regulations which support normalization, individualization and learning. When you cannot find a specific tag for a situation you witness, you should consider one of the staff training tags (W189-194) or the rather broad W247, promoting client choice and self-management. A sample citation of W247 follows.

### **Sample CMS-2567 for Tag W247**

#### **W247 483.440(c)(6)(vi) INDIVIDUAL PROGRAM PLAN**

This Standard is not met as evidenced by:

W247: Based on observation, interview and record review, the facility failed to provide opportunities for choice and self-management during dining and free-time for 3 of 4 clients in the sample (Clients 1, 2, 3).

#### **Findings:**

1. On 3/11/xx at 10:06 am, Client 2 was observed in the kitchen eating a snack of diced peaches. He was using a plastic spoon without assistance or prompting from staff present. On 3/11/xx at 5:40 pm, Client 2 was observed eating dinner in the home. He was prompted to sit at the dining room table, but did not require any prompts or assistance to eat his meal with the spoon provided. On 3/12/xx at 7:30 am, Client 2 was observed being fed his breakfast in the kitchen. Residential Support (RS) staff 5 was feeding Client 2 his oatmeal with a spoon. Client 2 did not participate other than to open his mouth for staff to feed him.
2. On 3/12/xx at 7:35 am, the two staff, RS 5 and RS 6, on duty at breakfast were interviewed. When asked why Client 2 was being fed, they stated they always fed him in the morning because he was “uncooperative and hyperactive when he woke up” and it made it difficult to get him to eat on his own.
3. On 3/12/xx at 4:45 pm, the Qualified Intellectual Disabilities Professional (QIDP) was asked about the morning shift difference in mealtime procedures for Client 2. The QIDP was unable to give any explanation for the difference in eating practices.

4. On 3/12/xx, Client 2's Residential Living Assessment of 7/10/yy was reviewed. It stated that he used a spoon independently.
5. On 3/12/xx at 9:45 am, Client 3 was observed seated at a table in the living room. RS 5 gave Client 3 an orange pencil to color a copy of a coloring book page. Client 3 colored with a back and forth motion as staff pointed to different areas of the picture for five minutes. At 9:50 am, RS 5 picked up a jar of colored pencils and selected a blue pencil and handed it to Client 3, who resumed coloring. Several minutes later, RS 5 selected a red pencil and gave it to Client 3 to use. Client 3 was never given a choice of colors or the opportunity to select colors independently.
6. On 3/12/xx at 4:45 pm, the QIDP was asked about Client 3's ability to identify colors. The QIDP verified that Client 3 could identify colors and that activities should promote choice.
7. On 3/12/xx, Client 3's Recreation Assessment dated 9/24/yy was reviewed. Client 3's assessment confirmed he identified colors.
8. On 3/12/xx at 3 pm, Client 1 asked to watch television in the front room. RS 7 told her she could not watch television because she "needed to do some active treatment". Client 1 was observed from 3:05 to 5:00 pm sitting on the sofa in the front room. During this time period Client 1 was not engaged in any activity, not engaged by staff or redirected to a training activity. The television was off the entire time.
9. On 3/12/xx at 4:45 pm, interview with the QIDP revealed she did not know why Client 1 was not allowed to watch television when other activities were not being encouraged or provided.
10. On 3/12/xx, a Recreation Assessment dated 8/22/yy noted 20 leisure activities Client 1 did alone or when prompted. The list included watching television.

**End CMS-2567 Example of W247**

## Section 8

### For More information on Promoting Dreams and Meaningful Days

#### **APSE -The Association for Persons in Supported Employment**

1627 Monument Avenue  
Richmond, VA 23220  
Phone: 804-278-9187  
Fax: 804-278-9377  
Email: [apse@apse.org](mailto:apse@apse.org)  
Website: [www.apse.org](http://www.apse.org)

#### **People First of California, Inc.**

1225 8th Street, Suite 360  
Sacramento, CA 95814  
Phone: 916-552-6625  
Fax: 916-441-3494  
Email; [info@peoplefirstca.org](mailto:info@peoplefirstca.org)  
**Website to setup a chapter:** <http://www.peoplefirstca.org/chapters.html>

#### **Self Advocates Becoming Empowered (SABE)**

P.O.Box 30142  
Kansas City, MO 64112  
[SABEnation@gmail.com](mailto:SABEnation@gmail.com)  
**Website:** [www.sabeuse.org](http://www.sabeuse.org)

#### **Speaking for Ourselves**

Speaking For Ourselves  
100 West Main Street, Suite 510  
Lansdale, PA 19446  
1-800-867-3330  
[info@speaking.org](mailto:info@speaking.org)  
**Website:** [www.speaking.org](http://www.speaking.org)

## References for Module 2

Beirne-Smith, Mary, Patton, James R., Kim, Shannon H. (2006) *Mental Retardation: An Introduction to Intellectual Disabilities, 7<sup>th</sup> Edition*. Upper Saddle River, NJ: Pearson Education Inc.

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Hickson, Linda, Blackman, Leonard S., Reis, Elizabeth M. (1995) *Mental Retardation: Foundations of Educational Programming*. Needham Heights, MA: Allyn and Bacon.

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Taylor, Steven J. (2006) *Mental Retardation Journal: Christmas in Purgatory: A Retrospective Look*, *Mental Retardation Journal*, 44 (2), 145-149.

[www.wisdomquotes.com](http://www.wisdomquotes.com)



The four cornerstones of character on which the structure of this nation was built are: Initiative, Imagination, Individuality and Independence.

Captain Edward Rickenbacker, Aviator and War Hero

***Module 3:***  
***Promoting Independence***  
***Participant Version***

Treat people as if they were what they ought to be and **you**  
help them to become what they are capable of being.

Johann Wolfgang von Goethe, Writer

Independence is happiness.

Susan B. Anthony, Activist

## **Module 3 Promoting Independence**

1. Introduction and Objectives
2. Potential Problem Indicators – Activity 1
  - Cues to Look Further
  - Activity 1
3. Interpreting Indicators
4. The Trifecta of Evidence
5. Observation
  - Stop, Look and Listen
  - Observation Example
6. Interview
  - You've Got Questions, They've Got Answers
  - Evidence Funnel
  - Clarification Interview and Example
  - In-depth Interview
7. Record Review
  - Seeing Is Believing
  - Record Review Example
8. Collaboration
9. Promoting Independence Scenario – Activity 2A
10. Sample CMS-2567 for Resources Not Available, W-249
11. Promoting Independence Scenario – Activity 2B
12. For More Information – References for Module 3

## Section 1

### Introduction

In Modules 1 and 2, values/concepts which underpin Regulations for Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) were discussed at length. They were dignity and respect, normalization, individualization and lifetime learning. You were shown what to look for and where you might cite concerns. In Modules 3 through 6, the focus will shift to outcomes expected for people who receive services. Consider this:

During a general observation when you first enter an ICF/IID home, YOU (the surveyor) notice:

Fourteen adults who are each eating lunch with only a spoon.

Eight men using wheelchairs that are all the same brand, size and color.

Staff dressing everyone in their coats and hats.

Do those three situations raise any red flags in your mind? Based on Module 1 and 2 values training you are probably saying: sure, there seem to be issues with normalization and individualization - and maybe even with beliefs about learning and dignity. Those are good answers, but now we'd like you to add another layer of concern to your observations and information gathering. What do these situations say about supporting and promoting individuals' quests for independence? Are YOU, as a surveyor, prepared to help ensure a better outcome for them?

### Objectives for this module

Upon completion of this training module, you will be able to:

1. List at least five potential problem indicators that surveyors may observe in an ICF/IID.
2. State three tags which relate to independence as an outcome.
3. Recognize when you have collected sufficient information from observation, interview and record review to support a deficient practice citation pertaining to these three tags.

### Independence as a Desired Outcome

According to the authors of Mental Retardation, An Introduction to Intellectual Disabilities, independence is one of the three categories of outcomes most commonly used by today's educators as measurements of educational success for people with severe intellectual disabilities. It is defined as "self-reliance and self-determination". "Self-reliance" refers to a person's ability to take care of himself or herself...from feeding one-self to living...alone." Whereas, "self determination refers to a person's ability to set and navigate his or her own life course", including "making choices, communicating preferences, setting achievable goals, and self-advocating." (Beirne-Smith, Patton & Kim, 2006, pg. 311).

Educators are not the only ones to use outcomes to measure success; Centers for Medicare and Medicaid (CMS) also does. In fact, in 1996, an "outcome-based" survey process was introduced

as a way of performing most ICF/IID surveys. In it, the surveyor focuses on 55 of the 379 ICF/IID tags. These 55 tags were identified as “outcomes” to determine compliance (as opposed to the others, most of which are considered structure and process tags). Not surprisingly, many of these 55 so-called “fundamental tags” address the development of independence (as in the above definition of self-reliance and/or self-determination). This “fundamental survey” is still used for the majority of ICF/IID recertification surveys today.

### **Narrowing the Focus**

In this module three commonly used outcome tags (regulations) will be the focus of evidence gathering related to promoting independence. They are:

(W242) 483.440 c. 6. (iii) Include, for those clients who lack them, training in personal skills essential for privacy and independence (including, but not limited to, toilet training, personal hygiene, dental hygiene, self-feeding, bathing, dressing, grooming, and communication of basic needs), until it has been demonstrated that the client is developmentally incapable of acquiring them.

And

(W247) 483.440 c. 6. (vi) Include opportunities for client choice and self-management.

And

(W249) 483.440 d. (1) As soon as the interdisciplinary team has formulated a client's individual program plan, each client must receive a continuous active treatment program consisting of needed interventions and services in sufficient number and frequency to support the achievement of the objectives identified in the individual program plan.

Simply put, W242 and W249 expect the provider to use **training** as the means to increase peoples’ independence, while W247 expects the provider to provide **opportunities** to experience and reinforce independence. As you can see in the regulation, W242 lists the personal skills (aka basic skills) that the provider must attempt to train people, while W249 focuses on the implementation of all training objectives (personal skills and others).

- With both W242 and W249, there is the expectation that there will be training objectives.
- With W249, the surveyor should also observe training occurring whenever the appropriate context arises for the objectives.
- W247, on the other hand, expects that opportunities for choice and self-management will be seen by the surveyor across the day, although written objectives in choice and self management may or may not exist.

Other *non-fundamental* tags (that will not be discussed in this Module) address how training/program objectives are written (W229-W232) and what the training program method must include (W234-239).

## Section 2

### Cues to Look Further

As a surveyor you have many things to examine in a short period of time. Because of this you must be organized and ready to survey “on arrival” to a location. You must also have a surveyor mindset. By this we mean you should have in mind the ICF/IID Regulations, values for the field of disabilities as well as some potential-problem indicators. While we don’t want you to assume the worst, we want you to be alert to indicators that people who live in an ICF/IID **may not be** being trained or supported towards independence, as in self reliance and self determination.

### Potential Problem Indicators - Activity 1

**Directions:** In the left hand column of the table you will find potential-problem indicators with two examples of each indicator in black type and, in red type, possible W tags related to the indicators. In the right hand column please write in the spaces provided why you think each indicator could possibly be a tip that a facility is NOT supporting individuals’ independence. Later, you will discuss this activity with your preceptor.

(Table on next page is activity)

**Potential Problem Indicators - Activity 1**

<b>POTENTIAL-PROBLEM INDICATORS with Examples</b>	<b>HOW might this indicator stand in the way of developing independence?</b>
<p><b>Everything is a group event. (W247)</b></p> <p>For example, everyone goes to the same workshop. Or, everyone goes to the same church service together.</p>	
<p><b>Staff do things for people who live there. (W242, 247)</b></p> <p>For example, staff put on everyone’s coats. Or, staff do all the shopping.</p>	
<p><b>Everyone does things the same way. (W242, 247)</b></p> <p>For example, everyone eats with a spoon. Or, everyone uses antiperspirant roll-on for men.</p>	
<p><b>People aren’t doing anything. (W242, W247, W249)</b></p> <p>For example, a person sits at a table without anything to do for long periods of time. OR, people constantly seem to be waiting for the next activity to occur.</p>	
<p><b>Resources are not available. (W242, W247, W249)</b></p> <p>For example, the physical therapist is on extended leave. OR, the van can’t be used because two seat belts are broken. OR, a person with no speech can’t reach his communication wallet.</p>	
<p><b>People have done the same things for years. (W242, W247, W249)</b></p> <p>For example, someone has worked on the same workshop contract for years. Or, someone has had the same training objective for years.</p>	

***Remember, these indicators are not regulations; they are cues to the surveyor to investigate further.***

### Section 3

#### **Interpreting Potential-Problem Indicators**

Well, you may be saying to yourself, those indicators are well and good but some people are at their highest level of independence when eating with a spoon and some people are as independent as they will ever be in the small community home in which they have lived for years. Guess what? You may be correct and that is why the ICF/IID survey process asks you to relate most of your general observations to specific people in the home, called “sample members”, and to collect evidence proving/disproving compliance with the regulations based on these sample members’ strengths, needs and preferences. We will now turn to that survey process.

#### **Reading**

Appendix J of the State Operations Manual, Survey Procedures for Intermediate Care Facilities for Individuals with Intellectual Disabilities, describes the tasks ICF/IID surveyors should perform during a survey. Take a few minutes to review it now, beginning at page J-6. Please pay particular attention to Parts VII. Task 3 - Individual Observations, VII.Task 4 - Required Interviews and XI. Task 7 - Record Review of Individuals in the Sample.

### Section 4

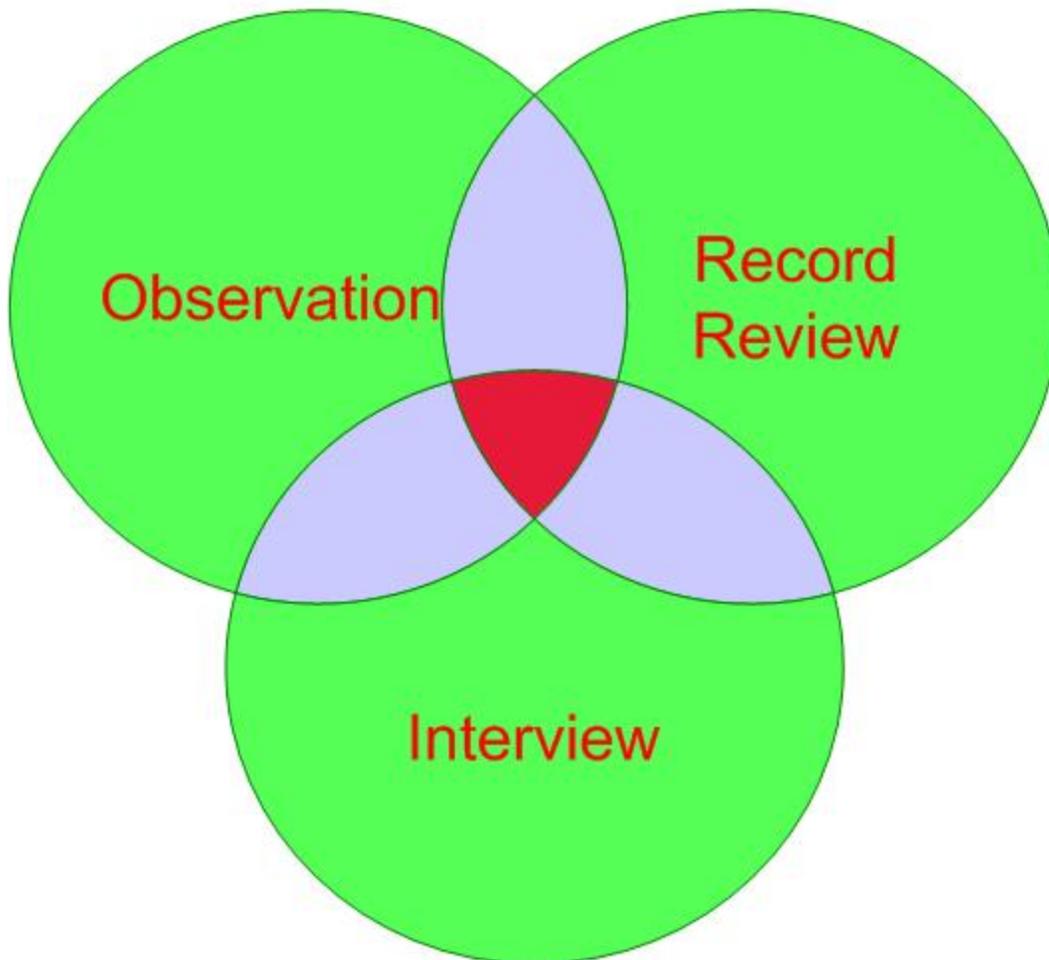
#### **The Trifecta of Evidence**

As you just read in Appendix J, when it comes to proving or disproving compliance with ICF/IID Regulations, evidence collection relies on three activities: observation, interview and record review. Some long-time surveyors jokingly refer to the three types of evidence collected by these methods as the “trifecta”. If you know someone who enjoys horseracing, you probably know this term refers to a type of betting in which the bettor must select the first three horses to finish a race in the exact order. What this has in common with ICF/IID surveying is not a joke and is not betting, rather it refers to collecting evidence in the order suggested in the State Operations Manual, Appendix J: observation, interview and record review. Obtaining all three types of evidence makes for a very strong case-it is what it is-and in that way is not unlike winning a trifecta bet. In legal circles, three types of evidence are also known as triangulation.

While this module will discuss the importance of the collection of three types of evidence, it is recognized that, in reality, there are times when the nature of a regulation or citation does not lend itself to all three types of evidence. In these rare cases, multiple sources of evidence of two types are recommended, i.e. more than one person interviewed and more than one record review.

On the next page is a pictorial representation of the ways evidence may overlap.

## Triangulation of Evidence



### Observation, Interview and Record Review Picture

The red “trifecta” of evidence is highly desirable, but sometimes you’ll be “blue” because it’s the best you can do - or it is all the evidence available.

#### A Reminder

Observation, interview and record review are used by the surveyor to collect evidence for any type of concern related to the ICF/IID Regulations. Therefore, in the following paragraphs the *methods discussed will be universal* in their application. However, *the examples will be specific to the focus of this module on promoting independence*, identifying and proving/disproving concerns about training and supports which lead to independence.

### Section 5

## Observation – Stop, Look and Listen

Observation is like pulling up to an old fashioned railroad crossing sign. You, the surveyor, need to “Stop, Look and Listen” before you move onto something else. And although it may sound rude, in most situations you should also “sniff” and “feel” before moving on. For all observations: look, really look. What are people doing? Are people doing different things at different times or the same thing at the same time? Do people have assistive technology to help them? Do the materials in the room allow for individualization? Listen carefully. Are people being encouraged? Shown “how to”? Asked for an opinion? Offering opinions? Smell the smells – pleasant or noxious? Who is cooking? Cleaning? Check out how the place feels - too hot? too cold? sterile? uncomfortable? Who do you see controlling that? And don’t forget the non-verbal atmosphere – do people move about freely or does a look stop them in their tracks? Are people smiling and communicating with each other? Are you sensing the values we previously discussed? How about the potential problem indicators?

Usually the potential problem indicators discussed in Activity 1 will first come to light during observation. That is why it is essential to do observations across the day (early morning, afternoon and evening) and to include meals, home and out-of-home programs, drug pass. Opportunities for supporting and promoting independence should occur at all times of the day during all types of activities. Use various observations to form a picture in your mind of how independent your sample members are now and what they could become in the future.

Fine, you may be saying, but how do I get from the virtually unlimited and seemingly random input of observations to regulations? The general answer is to focus your note-taking.

- Make sure you note the basics: number of individuals and staff, names/identification of staff and sample members present, the activities observed, the date, start/stop time and place.
- For your sample members, record information specific to their training and supports. For instance: Did you observe training objectives implemented? Data collected? What personal goals and preferences did you observe? Are they respected? What supports (i.e. equipment, staff, services) are needed by this person? Are they provided?  
**REMEMBER, in the case of independence, when objectives are not identified or implemented OR supports are not present OR when personal goals and preferences are not elicited or supported, independence is not promoted.**
- Record consistencies and inconsistencies between observations. Is the level of independence the same between observations? For example, does a person always eat with a knife, fork and spoon? Are assistive devices available whenever needed? Do staff give the same type of assistance from shift to shift, location to location? Was an initial general observation of a meal similar to a later meal routine which included your sample member?
- Trust your gut, write down general things that don’t seem right, don’t make sense, look out of place or, particularly in the case of promoting independence, are related to one of the indicators previously listed.

## Observation Example



Woman not dressed appropriately -Skirt caught in waist band of underpants.

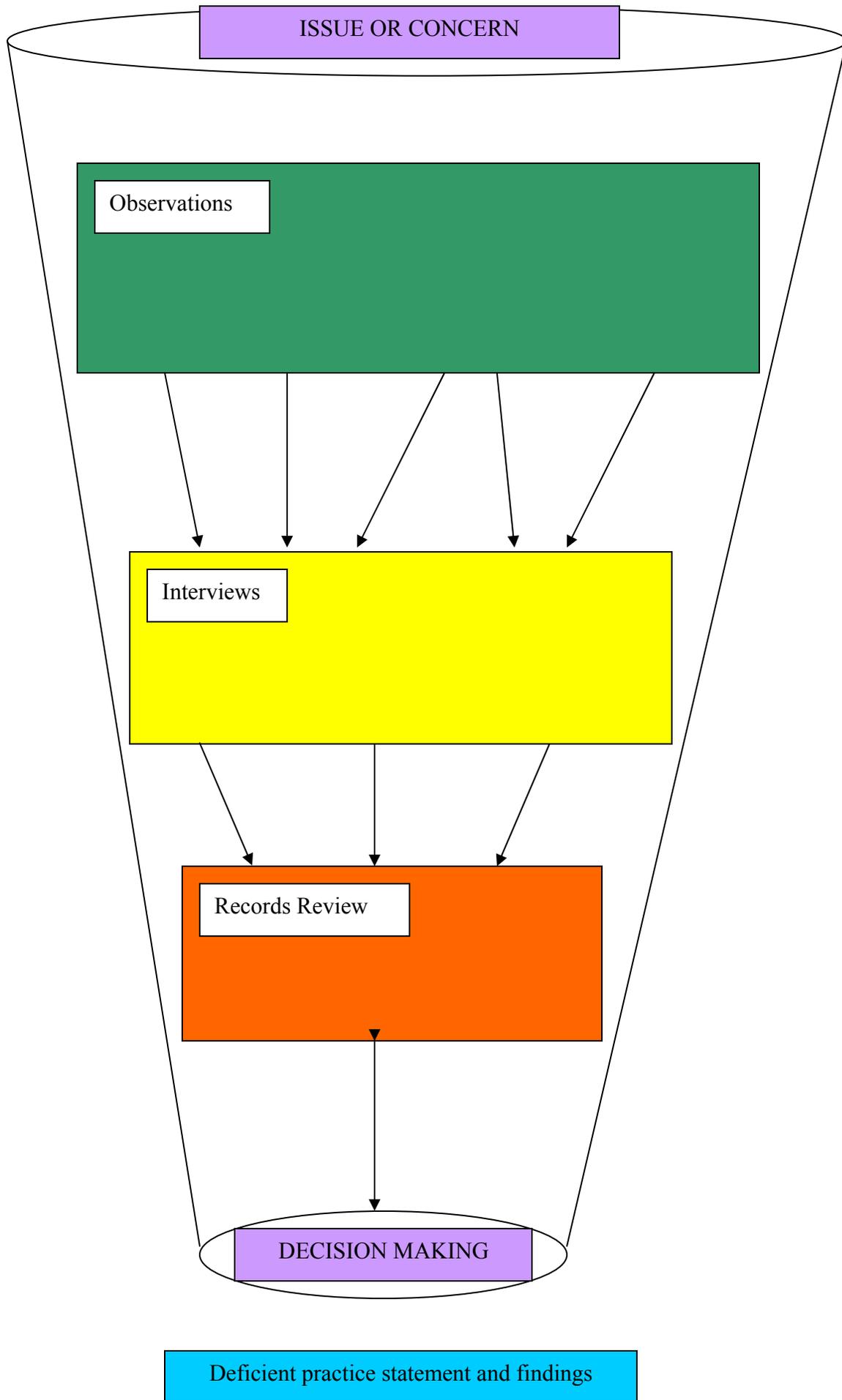
Look at what is right...what is wrong. Don't let what is right offset what is wrong...or at least not until you have examined what is wrong more fully. Shopping in the community can be a wonderful thing; public exposure is not; a careful observer sees and documents both these things.

## Section 6

### **Interview – You've Got Questions, They've Got Answers**

One way of verifying what you saw in an observation is to look for the same thing to occur in a similar situation or at the same time another day. Another approach is to clarify what you observed with a staff member. Seems simple enough but it is often given short shift! Which is unfortunate, because interviews are often a more time effective way to “funnel”, or narrow, the surveyor's areas of concern.

**Consider the following picture.** Each type of evidence has the potential of funneling the surveyor closer and closer to a final conclusion. Concerns will stop being concerns or continue being concerns as evidence of each type is gathered.



**Clarification Interview:** For ICF/IID surveyors, the most frequent interview should be the clarification interview. It is typically done immediately after an observation. It is short, a few questions about what was happening during the observation and why. The staff's name and verbal response, which should be written down, will usually allow the surveyor to immediately corroborate or contradict assumptions in the notes of the observation. Usually one asks questions specific to his/her sample member(s) with the objective of verifying things like: whether an activity was or was not part of a training objective, whether the routine was or was not "usual", what the person enjoys most, why an inconsistency was observed (i.e. person used a spoon here but was fed by staff elsewhere). A clarification interview is also the place to ask about red flags and potential problem indicators: why is everyone being helped with their underwear? why was the trip cancelled today?

During some observations staff are very busy and the surveyor may decide to skip asking questions. This is not a problem if you ascertain that the staff will be available later, but be careful to check as some staff may never be seen again (i.e. a nurse, classroom aide, direct care staff at change of shift).

**Remember, a clarification interview is a potential piece of evidence in a deficient practice finding and missing the interview may jeopardize the citation.**

#### Clarification Example:



#### Woman not dressed appropriately -Skirt caught in waist band of underpants.

Voice: Hi, I'm Susie Surveyor. I see you just got back from walking somewhere with Gina.

Staff: Yes, we just got back from looking for low-salt snacks at the grocery store. Susie:

What's with the back of her skirt? Staff: Ohhh, that's not good. She used the bathroom while we were out and must've missed looking in the mirror. We'll fix it now. Susie: Ok, I'll let you go. Thanks for the information.

**In-depth Interview:** After a number of observations and clarification interviews have occurred, it is time to hold the required in-depth interviews (See Appendix J for the minimum number calculation) with sample members, their guardians or family members or direct support staff who know the sample members best. Again, you will be corroborating or contradicting observations as well as other interviews regarding needs, preferences and services.

**Additional Interviews:** As the survey is drawing to a close, it is time to determine trends in your observations and interviews and to speak to selected professionals and supervisory/managerial staff who were not available during observations and to the Qualified Intellectual Disabilities Professional (QIDP) about inconsistencies, missing or confusing information, unmet needs and unmet preferences. When possible, compile all your questions and ask them in one interview. During these clarification interviews, many surveyors ask staff to bring the client record so that the interviewee may show documents supporting the answer to a question.

**Be prepared to follow-up any type of interview with other observations, interviews or record review.**

## Section 7

### Record Review – Seeing Is Believing

During this stage of evidence collection, the surveyor tries to further corroborate or contradict observation and interview information with records, either computerized or paper. Your notes of observations and interviews should lead you to the proper records. For instance, a training objective to put on socks that was explained during a clarification interview should be in the current individual program plan. The therapy discontinued until further notice might have been documented in a memo in the staff communication book. A person's preferred leisure activities should be the ones on their activity schedule. The training method that you observed staff following should be the method that you see in writing accompanied by the data specified.

**Keep in mind that it never hurts to spend a few minutes with a staff person who understands and can explain the facility's record keeping, especially when time is of the essence.**

### Record Review Example:



### Woman not dressed appropriately -Skirt caught in waist band of underpants.

The Individual Program Plan listed a goal to independently dress in pull-on pants and skirts. The objective to select such clothing for purchase was met as were pulling clothing over her underwear and pulling clothing up to her waist. The current objective is to adjust pull-on clothing so that her underwear is not exposed. The method says it is to be run whenever she dresses or uses the bathroom. Data had not been collected as specified for the past 2 weeks.

**Be prepared to follow-up record review with other observations and interviews if necessary.**

## Section 8

### Collaboration

Informal meetings with your team members provide the opportunity to discuss potential problem indicators and issues with your sample members to determine if they are “one-time” occurrences or systemic in nature.

### Collaboration Example:



[Woman not dressed appropriately -Skirt caught in waist band of underpants.](#)

Susie Surveyor’s other team members also substantiated that training on objectives for their sample members was not conducted. An interview with the QIDP was planned on the subject.

## Section 9

### Promoting Independence Scenario - Activity 2A

**Directions:** Please read the following scenario. You will be using it for Activity 2A and 2B.

#### GENERAL OBSERVATION (pre-sample assignment): Holloway Home

**OB-1:** *9am, March 6<sup>th</sup>* Five men sat in the living room dressed in jackets, hats and gloves. Three were on the couch and two were in their wheelchairs. One of the men who was in a wheelchair had a communication board sticking out of the backpack behind his seat. Tech Aide (TA) staff 1 and 2 were in the back of the home cleaning the bathrooms. The TV was off and no one said anything to any one for the 24 minutes before the workshop van arrived at which time they were escorted by TA 1 and 2 to the van.

#### OBSERVATIONS: Bengur Center

**OB-2A:** *11:15am, March 6<sup>th</sup>* Client 4 was putting colored tickets in containers according to color and size since there was no contract work that day. There were approximately 300 tickets to sort. When he completed sorting (about an hour), Workshop Supervisor (WS) 1 dumped all the

containers back into the original box and told him to keep sorting. Client 5 was weighing different objects (washers, small dowels, erasers) and at a certain weight put them in an envelope. Once all the items in front of him were weighed a staff person dumped out the envelopes and Client 5 started over. *End observation 12noon*

**OB-2B:** *12noon, March 6<sup>th</sup>* Clients 4 and 5 were getting ready for lunch. They had black lunch pails with the exact same lunch, ham/cheese sandwich with mayonnaise on white bread, Frito's, orange slices and lemonade. Client 4 traded his sandwich for one with PB&J. WS 1 smiled and said "he does that all the time". Client 5 ate his lunch and whatever else the guys at his table didn't eat in their lunch. Another staff person (WS 2) reminded him to ask first before he took anything. *End lunch 12:45pm* Since there were no contracts, everyone spent the afternoon playing Connect 4 and drinking sodas. *End observation 3:30pm.*

#### **CLARIFICATION INTERVIEW: Bengur Center**

**INT-1: *Workshop Supervisor 1*** *1:45pm, March 6<sup>th</sup>* Bengur Center WS 1 stated that in March and April work contracts from Teamie Nursery were very slow since the seeds they sold needed to be in the stores by January or February and the bulbs to be packaged for fall were just arriving. She said everyone at the Center sorted, weighed and packaged seeds and bulbs and everyone was paid piece rate. When asked about training goals, she said everyone had a goal to increase productivity but since they had all worked there for years their rates really didn't change much. She said data was only kept on seed or bulb packaging. She showed the surveyor sporadic data on daily earnings (**RR-1**) for Clients 4 and 5 from June of the previous year until January 20<sup>th</sup>.

#### **OBSERVATION: Holloway Home**

**OB-3:** *4:45pm, March 6<sup>th</sup>* Client 4 was in his bedroom watching TA 4 take his work boots off and collect his personal laundry. There was no conversation in the bedroom or as Client 4 followed TA 4 to the laundry room where he watched TA 4 put the clothes in the washing machine. Client 5 was in his bedroom watching Judge Judy. *5:15pm* Dinner was prepared and served by TA 5. Everyone got 5 fish sticks, 1 tablespoon of tartar sauce,  $\frac{3}{4}$  cup of beets, buttered roll, and  $\frac{3}{4}$  cup of yellow rice and a glass of iced tea. After everyone got done (less than 15 minutes), they all got  $\frac{3}{4}$  cup fruit cocktail. All 5 clients used built up utensils and partitioned built up plates. Dinner was finished in 20 minutes flat. No conversation went on because they

were all watching the World Series of Poker on TV. Client 4 tried to speak several times but everyone told him “ssshhh”.

### **CLARIFICATION INTERVIEW: Holloway Home**

**INT-2: *Tech Aide 4, 10am, March 7<sup>th</sup>*** When asked about staff doing all the laundry, meal prep and cleaning, TA 4 said they always did and he couldn't remember it ever being otherwise. He did think all of the men that lived there could do more things for themselves or could learn how to do things.

### **Excerpt from IN-DEPTH INTERVIEW: Holloway Home**

**INT-3: *Client 4 and Client 5, 8:10am, March 7<sup>th</sup>*** Both men preferred to talk to the surveyor together. When asked if there were things they would like to learn how to do, Client 5 said: “Shave like my brother.” He meant use an electric razor. He said staff used one to shave him and he thought he could learn how to do that. Client 4 wanted to earn more money so he could go to Reno to play Blackjack but admitted he didn't know how to play it. He did say that he owned some poker chips that his cousin had sent him for Christmas. He seemed quite intrigued with the idea that maybe he could learn how to play poker. Client 5 also thought that was a good idea. Both men thought they would live at Holloway Home and go to the workshop for the rest of their lives or as Client 4 said: “Til the good Lord takes me away.” Neither man had much knowledge about the community nor seemed interested in the goings on outside their home and work.

### **INTERVIEW: Holloway Home**

**INT-4: *QIDP, Mrs. Holloway, 10:45am, March 7<sup>th</sup>*** Said Clients 4 and 5 go to the local sheltered workshop operated by the county. She said all the men pretty much took care of their own needs and saw no reason for them to learn to prepare meals, handle money, clean house or do laundry since that's what staff were paid to do. Client 4 and 5 both earned about \$4 a week at the workshop when there was Teamie Nursery work; some months they didn't earn anything. She did not know if the men liked their work but in the 13 years she had been their QIDP she had never heard them complain. Her plan was that both would be at the Bengur Center until they retired. When asked if the men in the house talk with each other or the staff, she answered: “Of course, they're just shy with you folks being here.” The QIDP showed the surveyor a schedule

for March “outings” (**RR-2**) for all 5 men, but said that the home was waiting for a staff person to pass their chauffeur’s license exam before they could start going. The State requires a chauffeur’s license to transport more than 4 people for pay.

### **RECORD REVIEW:**

**Please note RR-1 and RR-2 are inserted in two different earlier interviews.**

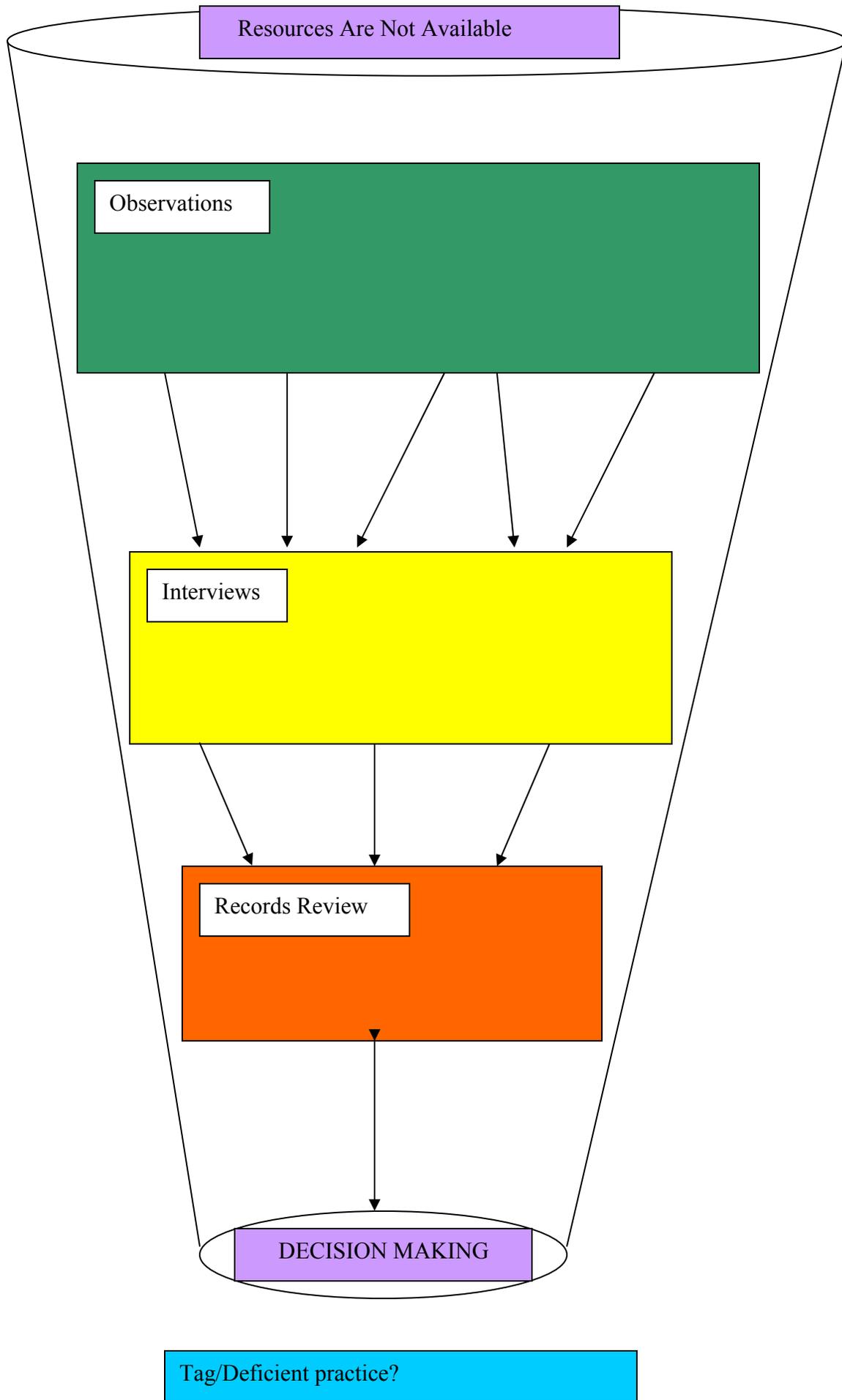
**RR-3: Holloway House 1:10pm, March 7<sup>th</sup>** Client 4’s and 5’s Individual Program Plan each contained 3 goals: Get up on time, at least on weekdays; lose 10lbs; and increase weekly wages to \$4.50. Client 4 takes drugs for high blood pressure and vitamins. Client 5 takes seizure medication, cholesterol drugs and vitamins. Both men have had the same vocational objective for 8 months: to earn \$4.25 for two weeks in a row. The Comprehensive Functional Assessment for both sample members had been updated for their annual team meeting. It did not address any vocational preferences, long range goals or needs in the area of Activities of Daily Living (ADLs). Each team discussed the need for each man to do more things in the community. The data from the Bengur Center filed at Holloway House showed time and attendance with no reference to productivity or wages.

### **End Activity Scenario**

**Activity 2A: Directions:** Now that you have finished reading the Activity 2 Scenario, you will complete a funnel diagram (next page) titled: **Resources are not available**.

- Using the indicator, **Resources are not available**, please go back through the scenario and identify examples in the observations – jot down the paragraph number and the issue and what clients were involved.
- Next go to the interviews and jot down any interview corroboration that the surveyor elicited, again using the paragraph number and a few key words. Also note if there are any new examples of unavailable resources.
- Do the same for record review which supported/contradicted observations or interviews, noting the paragraph and a few key words.
- Last, determine if you have enough evidence to present a cite of W242, W247 or W249 to your fellow team members.

Keep this completed activity. Questions will be answered during your Module 3 preceptor call.



### How Did You Do?

For technical reasons the **Resources Are Not Available** funnel answers are in a color-coordinated table. Please compare this table with your funnel answers. How did you do? Questions will be discussed during the preceptor call.

## Activity 2A Answers

<b>RESOURCES ARE NOT AVAILABLE</b>
<b>OBSERVATIONS</b> OB-1 - Communication board not available (non-sampled client) OB-2A - am - No subcontract work, redoing make-work – Clients 4 & 5 – all? OB-2B - pm - Playing games, no subcontracts – Everyone
<b>INTERVIEWS</b> INT-1 - WS 1- Nursery/contract work sporadic from January to April, productivity goals for all on nursery work INT-3 - Clients 4 & 5 would like to earn money to go to Reno INT 4- QIDP – Clients 4 & 5 earn about \$4 a week, some months when there is no nursery work, they earn nothing. No outings thus far in March for 5 men - no chauffeur.
<b>RECORD REVIEW</b> RR-1 - Sporadic wage data for Client 4 & 5 from June-Jan 20 at Bengur (remember, no data collected means no nursery/paid work) RR-3 - Clients 4 & 5 identical wage goals and for 8 months had the same objective to earn \$4.25 per week. No data at Home from Bengur.
<b>DEFICIENT PRACTICE?</b> Productivity training not implemented for Clients 4 & 5 because Teamie nursery work is not consistently available and this is what the objective (and data) is based upon. This practice may affect all sample members or all clients if they go to Bengur Center – conduct additional observation and interview.  Communication board? Determine through collaboration and/or additional observation and/or interview whether this represented a one-time occurrence or systemic practice.  No chauffeur for outings? Further investigation indicated.

## Section 10

### Sample W249-Resources Not Available

So what would the information in your funnel look like in your real surveyor world? The following is an example of what the CMS-2567 Citation of W249 might look like.

#### **W249 483.440(d)(1) PROGRAM IMPLEMENTATION**

As soon as the interdisciplinary team has formulated a client's individual program plan, each client must receive a continuous active treatment program consisting of needed interventions and services in sufficient number and frequency to support the achievement of the objectives identified in the individual program plan.

This STANDARD is not met as evidenced by:

Based on observation, interview and record review, the facility failed to consistently provide work and training to support the achievement of the vocational objectives to increase independence as identified in the individual program plans of 2 of 4 clients in the sample (Client 4, 5).

Findings include:

1a. Observation at Bengur Center workshop on 3/6/yy from 11:15 am to 12 pm, revealed Clients 4 and 5 performing make-work because there was no contract work. Client 4 sorted tickets by color and size. Client 5 weighed washers, small dowels and erasers and placed them in envelopes. Workshop Supervisor (WS) 1 was seen dumping the work and handing it back to them to redo. No instructions to Client 4 or 5 were witnessed.

1b. Further observation at Bengur Center on 3/6/yy from 12:45-3:30 pm, revealed no contract work. Clients 4 and 5 spent the time playing the game Connect 4 and drinking sodas.

2a. During an interview at Bengur Center on 3/6/yy at 1:45 pm, WS 1 was asked about training goals and contract work. She said everyone had a goal to increase productivity and that data was only kept on seed or bulb packaging. She explained that seeds needed to be in the stores in January or February and that bulbs started arriving in March and April.

2b. On 3/7/yy at 8:10 am, the surveyor interviewed Clients 4 and 5 together at their home. Client 4 stated he would like to earn more money to go to Reno. Client 5 agreed that was a good idea.

2c. During an interview at the home on 3/7/yy at 10:45 am, the Qualified Intellectual Disabilities Professional (QIDP) stated Client 4 and 5 earned \$4 a week but had months when there was no nursery work and they didn't earn anything.

3a. Record Review at Bengur Center during the interview with WS 1 on 3/6/yy at 1:45 pm, revealed that sporadic data was kept on Client 4's and 5's productivity from the previous June until 1/20/yy. There was no data from 1/21/yy to 3/6/yy.

3b. Record Review at Holloway Home on 3/7/yy at 1:10 pm, revealed that Client 4 and 5 had identical goals to increase weekly wages. For the past eight months, both Clients had the same objective to increase wages to \$4.25 a week.

**End CMS-2567 Example**

## Section 11

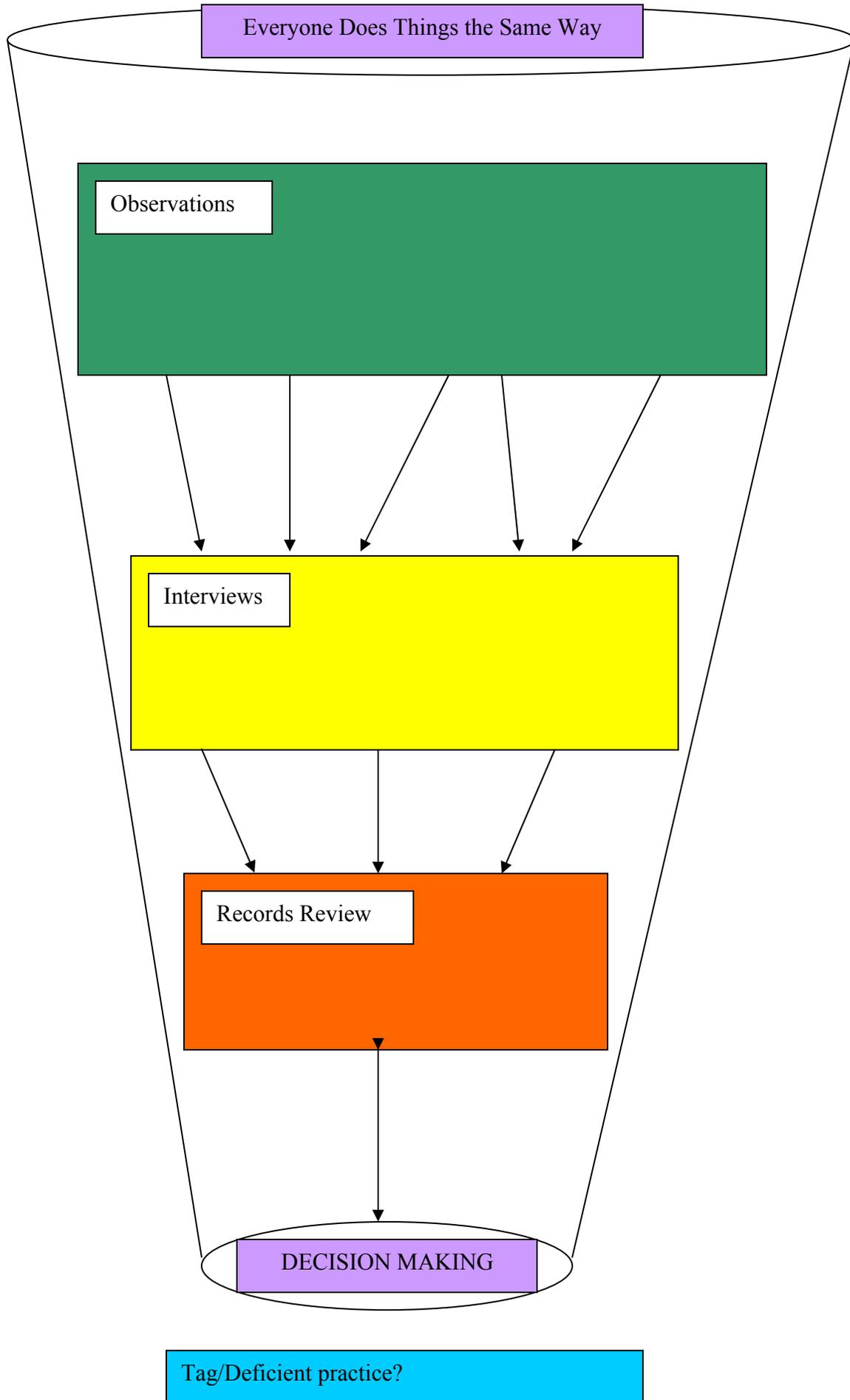
### **Promoting Independence Scenario-Activity 2**

**Directions:** For this activity you will reuse the Activity 2 Promoting Independence Scenario with a new funnel diagram titled: **Everyone does things the same way.**

- Using the indicator, **Everyone does things the same way**, please go back through the scenario and identify examples in the observations – for each example, jot down the paragraph number, the issue and what clients were involved.
- Next go to the interviews and jot down any interview corroboration that the surveyor elicited, again using the paragraph number and a few key words. Also note if there are any new examples of everyone doing things the same way.
- Do the same for record review which supported/contradicted observations or interviews, noting the paragraph and a few key words.
- Last, determine if you have enough evidence to present a citation of W242, W247 or W249 to your fellow team members.

Keep this completed activity. Questions will be answered during your Module 3 preceptor call.

Use the following funnel diagram as a worksheet.



## **Conclusion**

Although promoting independence is one of the cornerstones of the field of developmental disabilities, capturing the absence of it with the ICF/IID Regulations can be difficult. This is because one must use measures in the regulations such as W242, W247 and W249 which require the surveyor focus on the absence of training and opportunities to acquire independence. That does not mean that surveyors should not look for and identify those situations where people (aka clients, using the language of the regulations) have not been supported to become independent or self reliant. Surveyors should look. And this Module shows some ways to do just that. Others will be discussed in future modules.

## **Section 12**

**Beirne-Smith, Mary, Patton, James R., Kim, Shannon H. (2006) *Mental Retardation: An Introduction to Intellectual Disabilities, 7<sup>th</sup> Edition*. Upper Saddle River, NJ: Pearson Education Inc.**

**Edward Rickenbacker Quotes. (January, 2009) Available at: <http://www.quoteland.com>**

**Goethe Quotes. (December, 2008) Available at: <http://www.wisdomquotes.com>**

**Susan B. Anthony Quotes. (January, 2009) Available at: <http://www.brainyquotes.com>**



[With assistive technology] you're no longer a spectator in life,  
you're an active participant.  
Jim McGuire, Executive Director, Ann Storck Center

***Module 4:***  
***Promoting Assistive Technology  
and Environmental Adaptations***

***Participant Version***

## Module 4 Promoting Assistive Technology & Environmental Adaptations

1. Objectives and Introduction
2. Definitions
  - Assistive Technology
  - Environmental Adaptations (aka Accommodations)
3. Possibilities & Activity 1
  - Possibilities
  - Activity 1 – Tech Bingo
  - Activity 1 Discussion and More Pictures
4. Questions to Ask & Answer
5. Activity 2 – Tag Match
  - Activity 2 – Page 1: Tag Choices
  - Activity 2 – Page 2: Match the Situation to the Tag
6. Know What Evidence to Seek
  - Observation
  - Interview
  - Record Review
  - Collaboration
7. Sample CMS-2567 Tag Citations
  - W240
  - W436
8. Conclusion
9. For More Information – References for Module 4
10. Attachment: Key Notes article referred to in Section 2.

## Section 1

### Objectives

Upon completion of this training module, you will be able to:

1. List at least 20 assistive devices or environmental adaptations.
2. Identify at least ten W-tags which relate to assistive technology and environmental adaptations.
3. Identify at least three places in the Individual Program Plan where assistive technology and environmental adaptations would be mentioned.

### Introduction

Consider the many reasons people with intellectual and physical disabilities use assistive technology and environmental adaptations. It:

1. ...enables them to exercise control over their own lives and to become more fully integrated into society.
2. ...extends the same options commonly available for people without disabilities to people with disabilities...making it a great equalizer.
3. ...can stretch mutual expectations for persons with disabilities and service providers.
4. ...is not based on mental age, intelligence quotient or physical limitations.
5. ...does not assume that a person should progress through preconceived stages of technology use.
6. ...can help maximize other services, devices or options.
7. ...can change as a person matures or transitions among multiple environments or as technology changes.
8. ...regards the consumer as the final decision-maker. (Adapted from: *SMART Moves Number 2: Technology, Removing the Shroud of Mystery*, July, 1990, pp 1-4.)

Now, picture in your mind a few of your recent visits to Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). Did you see people using assistive technology and environmental adaptations? Did the reasons correspond to the ones you just read? Did you wonder to yourself if others would have benefitted? Go to your computer and enter the website address below:

[http:// www.annstorckcenter.org/videos.html](http://www.annstorckcenter.org/videos.html)  
Click on "On the News CNN Launching of Gizmo House"  
for the Ann Storck Center CNN Interview (2000)

How did Gizmo House compare to the picture you had in your mind? Have you ever seen a home for people with intellectual and physical disabilities like Gizmo House? Why do you suppose you haven't? There is nothing in the regulations or the funding for ICF/IID that prevent a provider from establishing ICF/IID such as Gizmo House. So why don't we see more Gizmo Houses? One answer is that people just don't think about it. Another is that when they do, they think it is too expensive to put in place. The possible exception is homes in retirement communities, which nowadays routinely incorporate technology and adaptations such as

automatic door openers, lifts, ramps, lever door handles, grab bars, roll-in showers and high commodes, so that people with poor balance, little strength and limited range of motion can be independent.

To be clear – this module is NOT advocating that every ICF/IID look like a Gizmo House; however, what will be emphasized is what a surveyor can do to assure the assistive technology and environmental adaptations needed by individuals. It may surprise you to hear this, but these concepts are well-supported in ICF/IID Regulations. There are more than 20 ICF/IID standards/W-tags which support the use of assistive devices and adaptations in the environment to meet people's needs in the areas of:

- Mobility – i.e. canes, walkers, manual & power wheelchairs, scooters, joystick controllers, braces, gait belts, railings/grab bars, push gloves;
- Seating/Positioning – i.e. wheelchair & office chair inserts, anti-tippers, foot/leg rests, harnesses, lap trays, orthotics;
- Communication – i.e. letter, word, phrase or picture communication devices, boards or wallets, signing, electronic voice simulators;
- Activities of daily living – i.e. adapted cups, plates & silverware, anti-skid placemats, dentures, Velcro closures, shower/toilet chairs, reachers;
- Vision – i.e. glasses, wall tracks, audible closed captioning, large print & Braille, books on-tape & CD, white canes, seeing eye dogs, magnifiers;
- Hearing – i.e. hearing aids, headphones, text telephones, alarms w/ lights;
- Cognition – i.e. pocket calculators, talking clocks & alarm watches, computer instruction, games & visual hints, picture schedules, “real” money, events & supplies used in teaching;
- Controlling the environment – i.e. large button switches for appliances, voice activated phones, noise & motion activated switches;
- Independence (aka self reliance) – i.e. any needed assistive devices and adaptations;
- Work productivity – i.e. jigs for counting, packing, assembly, sorting, inspection & machine use, workstation adjustments, symbols/pictures to locate restrooms, stored items & timecards; and
- Community integration – i.e. ramps, automatic doors, wheelchair lifts, accessible event seating, mobility devices for uneven terrain.

## Section 2

### Definitions

Why is it that people in general (and providers in specific) don't think to use assistive technology and environmental adaptations? One reason may be that the legislated definitions use non-descript words like "devices", "items" and "product systems" to "increase" or "maintain functional capabilities" of "individuals with disabilities" which might seem to be addressing only physical disabilities (Individuals with Disabilities Education Act, 1998 & 2004; Technology-Related Assistance for Individuals with Disabilities Act, 1998 & 2004). Indeed, that view may not be surprising since much of the early technology was for seating, positioning and mobility. However, times have changed and as more and more technology has entered everyday lives, the colloquial definition of "assistive technology" has evolved to mean things that help, things that make life easier, things that allow people to be independent of others.

The same is true for "environmental adaptations" (which are also referred to as accommodations). Often considered a subpart of assistive technology, adaptations involve changes from "the norm" for someone with a disability. These adaptations change a setting (i.e. a room, furniture, vehicle, work station) or a way of doing things, so it is even less surprising that they should come to mean things that help, that make life easier, that make people independent. This module has chosen to treat environmental changes as a separate category of assistive technology to emphasize this aspect of ICF/IID Regulations.

For more about "assistive technology", please read the (attached) article titled: "What is assistive technology and what can it do for me or my family?" from a newsletter series called Key Notes published by The Access Group in 1998. (Reprinted with permission)

## Section 3

### The Possibilities

In order to survey effectively in ICF/IID, the surveyor must know what is available as well as the regulations pertaining to assistive technology and environmental adaptations.

Below is the address of a website which will introduce you to the wide range of assistive technology and environmental adaptations commercially available. Go to your computer and type in the following:

<http://www.abledata.com>

Go to the topic bar across the top of the home page and click on Products, which will bring up a list of topics, and then to click on the topics one at a time to view sub-lists and then click again on the samples of technology and adaptations

Note: If you would like to look at pictures of additional products, please go to the bibliography for Module 4 and type in the other product website references, one at a time, into your internet browser and look through them.

As you just saw, assistive technology may be as simple as substituting Velcro for a button or putting an adaptable handle on a regular toothbrush so someone with grip issues can hold the brush. It can be as complicated as a light pointer that enables a person to operate a communication aid. Environmental adaptations may also be as simple as using a lazy-susan revolving shelf in a deep cabinet or stackable cones to raise the height of a bed or chair, while more expensive adaptations include hands-free faucets and voice-activated telephones. If you are thinking: I don't know if I know which is which. It really *doesn't matter* what you call it, as long as you remember to look for it.

### Activity 1 - Tech Bingo

For a quick review of what you've just read and seen on [abledata.com](http://www.abledata.com), let's play bingo! Results will be reviewed with the preceptor. All verified winners will receive a free piece of technology. (Wahoo!)

**Participant Directions:** This activity consists of two pages. The first is directions and clues and the second page is a bingo card with pictures.

## Activity 1 TECH BINGO

This is just like regular Bingo except clues and pictures take the place of numbers. Your Bingo card is page two of this document. Print the Bingo card and then ----- play Bingo! Cross off each picture as you find it. Stop playing when you have BINGO. You'll check your answers with the preceptor to qualify for your prize.

### BINGO CLUES



OPEN SESAME



SOUPS ON



HOW DOES YOUR GARDEN GROW?



HELLO, HELLO – CAN YOU HEAR ME NOW?



UP AND OVER



TRAVELS WHEREVER YOU GO



CHECKMATE!



WHAT DID YOU SAY?

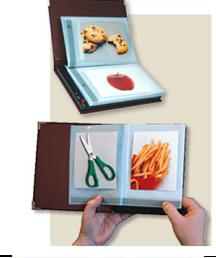


STRIKE!



FORE!

## TECH BINGO CARD

B	I	N	G	O
				
				
				
				
				

There is one last caveat before we leave the topic of “possibilities”. The pictures you looked at on the websites were *commercially* available assistive technology and environmental

adaptations. We showed these to you to emphasize the variety and the declining costs. However, when you survey, you will also see custom-made assistive technology and environmental adaptations. For example, long before there were commercially made wheelchairs, family members or local craftsmen made wheelchairs out of chairs and wood or metal wheels. Although we would not expect to see these in an ICF/IID, the tradition of hand-made items, adaptations of commercial items or using items in ways that were not originally intended, lives on today - particularly when a specific person needs assistance to do a specific task for which there is no commercially available item. The following examples were graciously provided by the production staff of the MARC Center in Mesa, Arizona.

(4 pictures follow)



**Caption one: Proper count is achieved by filling each “dent” in the carton**



**Caption two: With either of these jigs, a person with use of only one hand can fill a container & cap it**



**Caption three: Multiple coat hangers are stacked & straightened for recycling**



**Caption four: Pre-filled wood jigs slide onto the rails and increase the speed and safety of the heat sealer operator.**

#### Section 4

## Questions to Ask and Answer

So how do you as a surveyor determine when there is a need for, or a problem with, assistive technology or environmental adaptations? Ask and answer these questions as you are surveying:

1. **If someone can't do something**, has assistive technology or an environmental adaptation been addressed in the comprehensive functional assessment? This is particularly appropriate to ask when a skill appears physically impossible or physically exhausting, would take years to learn or was not learned after years of trying.
2. **If a person has an assistive device**, can she/he use it? Notice whether it is properly maintained by the person and staff. Does it “work” in all the settings and situations where it should be used? Is it always available to the person?
3. **Does the person's environment meet his/her needs?** If not, is it due to the lack of assistive technology, lack of environmental adaptation, lack of training or something else? Again, notice whether changes to the environment are properly maintained. Are changes safe? Are changes generalized across similar settings and situations? (See also #1)

These ways of thinking about people and when and where they might need devices or adaptations are consistent with the ICF/IID Regulations. They are cues that assessment, training or staff interventions pertinent to assistive technology or environmental adaptations need to be investigated. For example, a person who can communicate wants and needs effectively through hand gestures and sounds might not need technology or further training. He has (apparently) learned another way of communicating. However, if someone's method of communication is not universally understood (i.e. by cashiers, bus drivers, waiters, salespeople, surveyors/other visitors), this is considered a “functional deficit”. Identification of a “functional deficit”, such as not being able to communicate effectively with a variety of people, triggers the surveyor to look for training, intervention and assessment, including the involvement of relevant professionals.

## Section 5

### Activity 2 - Match the Situation to the Tag

**Directions to the participants:** The next activity offers you the chance to determine for yourself where you might cite situations which reflect needs for or problems with assistive technology and environmental adaptations.

W-Tags	Tag Summary <i>(Note: if you need more information about a tag, please read the tag in full in Appendix J of the ICF/IID Field Resource Guide):</i>
104	Governing Body exercises direction over the facility
108	Facility in compliance laws, regulations and codes pertaining to safety
120	Outside services meet the needs of clients
164	Client receives professional services needed to implement the IPP
215	Assessments identify services without regard to availability including devices/adaptations
218	Sensorimotor assessments address needs for devices/adaptations
220	Speech and language assessments address needs for devices/adaptations
223	Social assessments identify needs for devices/adaptations
225	Vocational assessments identify needs requiring devices/adaptations
240	IPP describes services and supports needed for relevant interventions
417	Bed of proper size, height
420	Functional furniture, appropriate to needs
421	Individual closet space in the bedroom accessible to client
422	Sufficient space in the bedroom for equipment used daily
423	Accessible storage space for personal possessions
424	Provide toilet and bathing facilities to meet the needs of clients
432	Nonabrasive carpet for client to lie/ambulate with body parts, no feet
433	Floor surfaces and coverings promote mobility
435	Sufficient space, equipment for dining, living, health, recreation programs
436	Furnish, teach clients to use dentures, eyeglasses, hearing and other communication aids, braces and other devices
484	Dining table and chairs, utensils and dishes meet client needs

### Activity 2 - Match the Situation to the Tag

**Participant Directions:** Pick the W-tag from this page which best fits the situation described on the next page (page 2) of Activity 2. Save your answers for discussion on the preceptor call.

The Tag Choices

Activity 2 Match the Situation to the Tag

Situation	Most likely tag
He can only wheel himself halfway up the ramp before he needs to ask for help	
A person's knees do not fit under the work table	
She cannot reach the closet rod in the shared closet	
A walker is stored in the living room at night	
No one can get out of the soft living room chairs without help	
The hall carpet runners are always bunched up	
Mary Sue left her rimmed dish at work and doesn't have one for dinner	
The grab bars in the home's bathroom prevent Betty from accessing the toilet in her scooter	
She requires staff assistance when using her cane; she has never been assessed for a walker	
A person expresses himself by throwing items; there is no speech-language assessment	
People who can't count to 10, can't do this job	
None of the assessments recommend adaptive equipment	
He goes to the bowling alley every Tuesday but can no longer plays since he got his wheelchair	
The wheelchair battery is not charged; the assessment says the client is physically unable	
Her IPP says she is independent in her use of her hearing aides, yet she is not wearing them at her cashier job and cannot hear questions	
He has macular degeneration and three months ago the team recommended an assessment for a low-vision device	
She can't reach her collection of teacups	
Without staff assistance, the backyard picnic tables are not accessible to those with mobility devices	
John complained that his twin sized bed was too short	
The facility was fined by OSHA for failure to provide a visual alarm for residents who are hearing impaired	
June's knees had brush burns from crawling across the carpet to her mat	

## Section 6

### Know what evidence to seek

During Activity 2, you may have noticed that W120, W240 and W436 were the only fundamental tags listed as possible choices on page 1. Does this mean that you would *not* cite one of the other, non-fundamental tags during a fundamental survey? *No!* You *do investigate and cite* non-fundamental tags any time you are “led to them”. For example, if you observe your sample member cannot reach his toothbrush from his dresser top, you have been “led” to that. Or, if during an interview, staff or your sample member tells you that your sample member cannot open the bathroom door on his own due to an automatic closer, you have been “led” to that. You would pursue these non-fundamental issues because you were *led to them*.

Another aspect of Activity 2 which might be misleading is how simple and straightforward some tags are. Do not be misled; you still need to attempt to obtain information through **observation, interview and record review** when evaluating tags involving assistive devices and environment. Here are some additional tips to help you focus on assistive technology and environmental adaptations:

### Observation

During general observations and sample member observations, **look, really look**.

- Are the incline and width of ramps, sidewalks and driveways accommodating the people with mobility devices or mobility issues?
- Are countertops in kitchens, bathrooms and laundry rooms accessible?
- Can everyone access the shelves in the refrigerator, stove, microwave, kitchen cabinets, laundry, family and training rooms as well as their personal closets, dressers, cabinets and lockers?
- Are floor surfaces nonskid both inside and out?
- Are the bathrooms modified so that individuals can use the toilet, sink and shower/tub safely and as independently as possible? (Remember the pictures of adapted soap dispensers, hands-free faucets and commodes?)
- Is furniture, including beds, chairs, and couches, the right size? Does it offer needed support?
- Do doors and drawers have handles (i.e. lever-types, enlarged knobs or pulls) that individuals’ can readily open? (Remember, the pictures of adapted handles for appliances?)
- Are wall switches, lamps and thermostats at heights and locations that allow individuals easy access?
- Can people move about their entire home – through doorways, including the yard- and through their program and work areas?
- Are tables, desks and workstations the right height for the people using them?
- Do vehicles (facility owned or contracted) facilitate entry/exit and accommodate needed mobility equipment?
- When applicable, do exit or other required signs include pictures or Braille?

The above list is not exhaustive but should be sufficient to give you, the surveyor, a heads-up as to potential (and common) concerns.

When observing, it is important to remember that while there are laws that address accessibility (such as the Americans with Disabilities Act), the requirements are often minimum levels of accessibility and, therefore, might not be sufficient to meet the environmental needs of some individuals living in ICF/IID. For example, measurements specified in law for the heights, widths or inclines of features in public buildings may still be too high, too narrow or too steep for the home of a given individual using his/her customized wheelchair or scooter. Remember Gizmo House?

### **Interview**

Interviewing in this topic is fairly straightforward. Try to ask open-ended questions and to avoid leading the person being interviewed. Sample issues and questions follow:

- Do the individuals and staff appear to know how/when to use technology and adaptations that you observe? **If not, ask the person and staff to explain what is being done and when.**
- Do you see (unmet) needs that might be amenable to technology or adaptations? **Ask the person and/or staff how these needs are addressed now and whether technology or adaptations were considered.**
- Does the person use the same technology and adaptations from place to place? **If not, how do the individual and staff explain that?**

In this day and age, surveyors should be very concerned if they hear any of the following responses to questions about assistive technology and environmental adaptations:

- She's not ready
- He'd rather be helped
- Trust me, it won't work
- Where will the money come from?
- It sounds risky
- It's stigmatizing
- You don't understand the problem
- He's too disabled
- It always breaks
- That would put me out of a job
- Medicaid won't buy it
- How do we do it?

### **Record Review**

As was discussed in Module 3, after you have made several observations, completed some clarification interviews and the in-depth interview (if required), you are ready to go to your sample member's record. Possible issues and suggested record review follow:

- Do you see technological devices and environmental adaptations? **Check the IPP for reference to them. If the Individual Program Plan (IPP) calls for them and they are not being used, interview further to determine how training and monitoring occurs.**
- Do the individuals and staff appear to know how/when to use assistive technology and adaptations that you observe? **Do training objective methods or staff intervention (aka service objectives) listings include instructions to staff on the person’s use of technology or adaptations? How is staff training on objectives and interventions documented? How is initial and continuing training of employees documented?**
- Do you see (unmet) needs that might be amenable to technology or adaptations? **Does assessment identify the same strengths and needs you have observed/heard about? Does the IPP document consideration of the need and discussion of technology/adaptation?**
- Does the person use the same technology and adaptations from place to place? **What does the record say about use in various locations? Examine the IPP including relevant training objectives or staff interventions for this information. If it is not present, determine whether assessment regarding usage is incomplete/missing.**

**There are several locations in the ICF/IID Regulations which explain to the surveyor and provider the expectations for assessment of assistive technology and environmental adaptations.**

- ❖ Tag **W214** asks providers to “Identify the client’s specific developmental and behavioral management needs”. The guidance probes: “Does the assessment reflect how the environment could be changed to support the person?”
- ❖ The following tag, **W215**, states: “Identify the client’s needs for services without regard to actual availability...include“ [the assessment areas listed in tags **W216-225**]. Guidance further explains: “Assessment of each area provides specific information about the person’s ability to function in different environments, specific skills or lack of skills, and how function can be improved, either through training, environmental adaptations, or provision of adaptive, assistive, supportive or prosthetic equipment.”
- ❖ Guidance for **W164** goes onto explain that the “initial comprehensive functional assessment [**W216-225**] should guide the team in deciding if a particular professional’s further involvement is necessary and, if so, to what extent.” **W164**, which reads: “each client must receive the professional...services needed to implement the...individual program plan”, then, is particularly relevant as the professionals identified in the guidance read like a “go-to” list for assistive technology and environmental adaptations. For example, occupational therapists, speech-language therapists, audiologists, dieticians, physical therapists, vision impairment specialists, work specialists, adaptive physical educators and psychiatrists are among the professionals who might provide services. If there is a functional deficit which needs to be assessed, a device or adaptation which needs to be obtained, maintained or trained, the surveyor should expect to find one or more of these persons involved in an “initial, temporary or ongoing” basis.

Earlier in this module, the term “functional deficit” was discussed along with the example of a person who could not communicate effectively in all the settings he visited. If your observation and interview exposes a similar functional deficit – a basic need which might be overcome by assistive technology or environmental adaptation and training, the surveyor should ask about and then look for an assessment which addresses the need. If there is no assessment, if the assessment is outdated, or if the assessment has failed to consider assistive technology or environmental adaptations, cite the tag of the area of assessment that is missing (**W216-W225**). If further assessment was recommended and has not happened in a timely fashion, **W164** would be considered, although the surveyor would also evaluate, and possibly cite instead, the role of policy, budget or operating directions (**W104**). For example, you notice a person cannot hear and you wonder if she/he would benefit from an aid(s). You find a hearing screening was completed by the physician as part of the annual update of the comprehensive functional assessment. The recommendation by the physician (and the team at the IPP meeting) was that the person sees an audiologist for further assessment of hearing loss and potential benefit from hearing aid(s). This has not occurred in the past three months; you investigate whether it is due to inability to obtain audiological services (**W164**), to policy/budget/operating issues (**W104**), or something else.

***When you are not certain which tag to use, consider all your evidence and then use the tag which fits best--makes the most impact and has the best chance of resulting in the needed correction.***

### **Collaboration**

Informal meetings with your team members provide the opportunity to discuss what you are seeing to determine whether they are one-time occurrences or systemic in nature. Glasses which are lost for one afternoon are different than glasses that are missing for three weeks; although if everyone’s glasses are lost sometime during a survey, something else is wrong. Using a transport wheelchair during a doctor’s appointment is different than never owning a wheelchair that fits you, but everyone using a transport wheelchair every time they leave the home suggests something else.

## Section 7

### Sample Tags

When it comes to assistive technology and environmental adaptations, two fundamental tags, W240 and W436, are commonly cited for issues of support, maintenance and training. Samples of the two follow. Do you understand why the findings were placed at one tag vs. the other?

**W240** The individual program plan must also: Describe relevant interventions to support the individual toward independence.

Based on observation, interview and record review, the facility failed to describe service objectives designed to promote client mobility and independence as specified by the Individual Support Plans for 2 of 3 clients in the sample (Clients 2, 4).

Findings Include:

### Velcro Guiding Strips

1. During observation in the home on 1/18/yy at 7:50am, Client 2, who is blind, was verbally prompted by Direct Support Aide (DSA) 4 to use Velcro strips on the hallway wall outside his bedroom to guide himself to the bathroom and back. He did so as staff watched. Later, at 5:15pm, DSA 6 verbally prompted Client 2 to come to dinner using a different set of Velcro lines to guide himself from the bedroom to the dining room. Client 2 did so as staff watched. After dinner, at 5:45pm, DSA 6 used sighted guide technique to take Client 2 to the bathroom and then to his bedroom. (Sighted guide is a technique where a sighted person leads a person who can't see. The person who can't see places his hand at the crook of the seeing person's elbow and follows slightly behind.)

2. On 1/19/yy at 7:15am, DSA 4 used sighted guide technique to take Client 2 from his bedroom to the dining room but then at 7:45am indicated Client 2 should use the Velcro strips attached to the hallway walls to guide himself between the dining room and bedroom. Client 2 did so. When asked why sighted guide was used one time and the Velcro strips the next, DSA 4 said it was at staff's discretion. Client 2 was never observed traveling independently around the home.

3. Record review was done on 1/19/yy. The Residential Skills Assessment dated 9/15/yy recommended a service objective to verbally prompt Client 2 to use Velcro guides whenever he was traveling within the home. A brief reference to the Velcro strips was found in the Individual Support Plan dated 10/1/yy but neither it nor other supporting documents explained when and how to utilize the Velcro guiding strips or sighted guide technique. Service objectives for personal hygiene tasks conducted in the bathroom contained no direction for staff to utilize the Velcro or any other self-guiding procedure to enable Client 2 to be independent of staff.

4. On 1/19/yy at 11:15am, the Qualified Intellectual Disabilities Professional (QIDP) was asked if the Velcro strips were still viable for increasing Client 2's independence. He indicated they were. When asked why there were no directions for staff to use the Velcro guiding strips, he replied that staff were familiar with Client 2 and knew how to use them. The QIDP was informed

that Client 2 was observed several times in 24 hours going to the bathroom and dining room via sighted guide technique and no one directed him to use the Velcro guides. The QIDP indicated that staff should have supported Client 2 to use the Velcro strips and that a service objective was “obviously needed”.

#### Power Wheelchair Battery

1. Observations on 1/18/yy from 8:40am – 10:30am and from 12:10pm – 1pm found Client 4, who has cerebral palsy, in a transport wheelchair. When asked about this at 12:15pm on 1/18/yy, Client 4 responded that no one had charged “his” wheelchair. DSA 4 confirmed this.
2. At 7pm on 1/18/yy, Client 4 was in his power wheelchair operating it by its joystick. However, from 9:40am – 11am on 1/19/yy, Client 4 was in the transport chair. Client 4 again reported no one had charged “his” wheelchair. DSA 4 said the charger was plugged in when he arrived at work but the battery was not fully charged. He said he suspected someone had forgotten to plug it in overnight and it hadn’t reached full charge yet.
3. Interview of Client 4’s Qualified Intellectual Disabilities Professional on 1/19/yy at 11:45am revealed that the wheelchair battery was still being charged and a purchase order had been submitted that morning for a back-up battery. The QIDP did not know what the problem was. When asked if Client 4 could charge his own battery, she explained he was physically unable. When asked if there was documentation of the procedure to maintain Client 4’s wheelchair battery, she did not produce one.
4. Review of Client 4’s record on 1/19/yy, revealed an Individual Support Plan dated 8/8/yy, with a service objective “To charge Client 4’s wheelchair battery after he retires at night”. No description was located in the record of who was responsible, how to charge it, what amount of time was necessary, whether there was a back-up battery, etc.

#### **W436**

The facility must—

Furnish, maintain in good repair, and teach clients to use and make informed choices about the use of dentures, eyeglasses, hearing and other communications aids, braces, and other devices identified by the interdisciplinary team as needed by the client.

Based on observation, interview and record review, the facility failed to furnish, maintain in good repair and/or ensure that each client was trained to use the adaptive devices described by the Individual Program Plan (IPP) for 2 of 4 clients in the sample who needed assistive devices (Clients 3, 5) out of the sample of 8.

Findings include:

#### Glasses

1. Observations of Client 3 throughout the facility at different times of the day from 5/3/yy to 5/6/yy, revealed she did not wear glasses at any time.

2. During an interview of Residential Aide (RA) 2 on 5/4/yy at 11am, RA 2 stated that Client 3 had a training goal to wear her glasses daily. The training also included glasses care. RA 2 reported he had not documented Client 3's glasses training because her glasses had been broken for about a week. He had also not documented check-writing training because she could not see well enough to write on the lines.

3. On 5/5/yy at 4:30pm, the Residential Manager said during interview that glasses repair normally took a week.

4. Review of Client 3's record on 5/6/yy found the words "broken glasses" written from 3/19 to 5/5/yy in training documents. An Optometry Report dated 11/3/yy indicated "glasses should be worn during waking hours".

#### Push Gloves

5. On 5/3/yy from 8:30am – 9:30am, Client 5 was observed wheeling his wheelchair through the dining room and the sun porch and down the exterior ramp. He and the wheelchair were loaded on a school system bus. Client 5's hands were bare. At 12:30pm, Client 5 was observed at his school sponsored mail delivery job wearing open finger wheelchair push gloves.

6. At 12:45pm on 5/3/yy, Client 5's Job Coach was asked about the gloves. The Job Coach replied that the skin on Client 5's hands broke down if he did not wear the gloves all the time. He explained that was because Client 5 was "energetic" and went places most other people in wheelchairs wouldn't try.

7. On 5/4/yy at 8:45am, Client 5 was again seen in his wheelchair outside with no gloves. The surveyor saw him brush his hands together as if knocking something off them; his right palm was slightly red. When asked where his gloves were, Client 5 said "school". RA 3 said "that shouldn't be" and that he would find a pair. After ten minutes RA 3 returned empty handed, but then he looked in the carryall bag on the back of the wheelchair and found a pair. The carryall bag was attached in a manner that Client 5 could not reach into it himself.

8. Review of the record on 5/4/yy, identified a copy of a detailed procedure initiated 1/21/yy to "ensure an available supply of lycra open finger wheelchair push gloves for school, work and home". An Annual Nursing Assessment dated 12/30/yy indicated that Client 5 wore the gloves to maintain skin integrity on his hands, particularly when using his wheelchair outside, on ramps or for distance. The assessment noted a significant decrease in scrapes, brush burns or imbedded dirt requiring medical attention on Client 5's palms since the gloves had been purchased the previous year. The Residential Living Assessment dated 9/29/yy, showed that Client 5 was independent in his use of wheelchair gloves. However, the school system reported in a Vocational Evaluation dated 9/2/yy, that he needed reminders to wear his wheelchair push gloves daily at work – both to protect his hands from injury and to help keep them clean. During review of facility incident reports on 5/3/yy, two reports for scrapes requiring medical attention on Client 5's palms were noted. Both incidents occurred while he was using his wheelchair on ramps, one on 12/5/yy and the other on 4/23/yy.

9. On 5/5/yy at 10am, the Qualified Intellectual Disabilities Professional (QIDP) was reminded of the two incident reports and provided the information that Client 5 was not wearing his gloves while outside at the bottom of the ramp waiting for the school bus the past two mornings. The QIDP said that it was not due to a shortage of gloves; he had 5 pairs according to the April 30<sup>th</sup> inventory. The QIDP admitted Client 5 could benefit from training to manage his gloves himself.

### **End Sample Tags**

## **Section 8**

### **Conclusion**

Technology is everywhere – for all kinds of people in all kinds of settings and situations. Because imagination is boundless, today’s ideas for assistive equipment and environmental adaptations will quickly be replaced by new ideas. Some will be better than others; therefore, surveyors will continue to play an important role in assuring the right assistive technology or adaptations for the right person. You will understand why we say that when you see the three pictures below!!!



Woman with umbrellas on her shoes. (A possible safety issue)



Woman with toilet paper roll on her head. (Just a small dignity issue!)



Woman with umbrella covering head to toe. (Another possible safety issue!)

## Section 9

### References for Module 4

Beirne-Smith, Mary, Patton, James R., Kim, Shannon H. (2006) *Mental Retardation: An Introduction to Intellectual Disabilities, 7<sup>th</sup> Edition*. Upper Saddle River, NJ: Pearson Education Inc.

Author unspecified. *SMART Moves Number 2: Technology, Removing the Shroud of Mystery*. (July, 1990)

Author unspecified. *Key Notes: What is assistive technology and what can it do for me or my family?* (1998) Atlanta, GA: The Access Group.

*Gizmo House: Celebrating the Tenth Anniversary of Its Opening*. (February, 2009)  
Available at: <http://www.annstorckcenter.org>.

The following web sites were used in the search for pictures of assistive technology and environmental adaptations:

<http://www.abledata.com>

<http://www.afb.org>

<http://www.assistivetech.com>

<http://www.ataccess.org>

<http://www.attainmentcompany.com>

<http://www.goldviolin.com>

<http://www.marccenter.com>

<http://www.rjcooper.com>

<http://www.specialkidszone.com>

<http://www.sammonspreston.com>

<http://www.wheelchairadaptedvehicles.co.uk>

<http://www.vankodesign.com:80>



# What is assistive technology and what can it do for me or my family?

## 🔑 A New Age....

This is the age of new technological advances. As new inventions and discoveries which were out of reach for most persons only a decade ago have become commonplace, we have seen the benefit in our daily lives. When we were children, we saw large expensive computers calculate numbers. Now we simply press a few buttons on our inexpensive home calculator and our answer quickly and accurately comes up. We have found that the exception a few years ago is now the rule. Technology in our lives has become commonplace. An example is the invention of "velcro" for the space program. Daily, velcro fastens and keeps things in place for us.

Technology assists many of us in our daily lives. The term "assistive technology" comes from the meaning of the word "assistive." The dictionary defines "assistive" as "giving help or aiding". For able-bodied people, the world is full of assistive devices that make life easier and more productive. Calculators help figure our grocery bills. We use our TV's remote controls to change channels while we sit on our sofas; and we use microwave ovens to cook our meals faster. Just as these and other modern "machines" help able-bodied people do things more quickly or more easily, they are used by people who have disabilities.

## 🔑 Technology for physically and mentally challenged individuals:

Technology has become essential to persons challenged by severe mental and/or physical disabilities. The world need not be a frustrating place for them. Personal and environmental limitations that created barriers and limited opportunities for these individuals to interact with nondisabled family members and friends, can now be overcome through the same simple

technology that people without disabilities use. (Assistive) Technology has increased access to new experiences, new activities, and new environments, bridging the gap imposed by a physical or mental disability. (Breaking Barriers, J. Levin, L. Scherfenberg, 1986)

## 🔑 High Tech or Low Tech

Many professionals have concentrated on more complicated technology--sometimes called "high tech," for "high technology." This includes computers, as well as augmentative communication devices, which speak for people who cannot be understood well by others. However, this type of equipment can be expensive and most people need training to use it.



Assistive technology also includes more simple equipment--sometimes called "low tech," or "low technology." These things make life easier, but are less expensive and require little or no training. A door lever makes it easier for a child in a wheelchair to open a door; elastic shoe laces help the child with poor motor skills put on his shoes; and a plate switch allows the child with mental disabilities to play with battery-powered toys by hitting the switch with his/her hand.

High tech or low tech, assistive technology opens up new opportunities for individuals

with disabilities to participate with family, friends, and peers in home, school, work, and community settings.

Assistive technology includes aids that:

- make things easier to turn on (for example, adaptive switches or large knobs)
- hold things steady or in place (for example, velcro or clamps)
- help a person get dressed, eat, or bathe (for example, bath chairs or built-up spoons)
- help a person learn (for example, tape recorders, computers, or "Talking Books")
- help a person play games or relax (for example, electronic card shufflers, page turners, or large dice)
- help a person get around more easily or quickly (for example, wheelchairs or walkers)
- help a person talk with other people (for example, electronic communication devices)
- help a person see or hear better (for example, magnifiers or hearing aids)
- help people control things at home or work (for example, remotes to turn on lights and talking computers)

Assistive technology is frequently overlooked because families do not realize all the implications for daily use. Simply taking an inventory of a child's daily activities may reveal activities or tasks in which an assistive device could be used:

- **frustration with communication...** can be helped with a device that can speak for the child so that everyone can understand
- **difficulty with bathing ...** can be helped with bath chairs, lifts, and other bathing aids
- **feeding and eating...** can be helped can be adaptive devices like built of spoons
- **helping make leisure and play activities independent...** can be aided with adapted toys and modified sport equipment

These and other examples may lead one to examine the child's home and school environment with assistive devices in mind. If the child has a need, there is probably an assistive device available which could help.

### **Finally....**

What is assistive technology? It comes in many colors, shapes, and sizes. It may cost a little, it may cost quite a bit. It may require continual training or no training at all.

The assistive technology needed for one family may be different from the technology needed by their neighbor or friend. But for most of us, technology will be a "fact of life" to help us as well as the child with disabilities.



**KEY NOTES** are created by **THE ACCESS GROUP** to provide information about assistive technology to the families of Vietnam veterans who have children with disabilities. **THE ACCESS GROUP** is jointly funded by the Agent Orange Class Assistance Program and United Cerebral Palsy Associations, Inc. If you are a family member or a professional working with families of Vietnam veterans, **THE ACCESS GROUP** can serve as a resource to you in your efforts to obtain assistive technology. This publication is also available on audiotape. For more information call: 1-800-821-8580, 1-404-888-9098 (TT).

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Action and reaction, ebb and flow, trial and error, change – this is  
the rhythm of living. Bruce Barton, Author

Behavior-human or otherwise-remains an extremely difficult  
subject matter. BF Skinner, Behaviorist/Scientist

***Module 5:***  
***Surveying***  
***for***  
***Positive Behavioral Support***  
  
***Participant Version***

*A moment's insight is sometimes worth a life's experience.*

*Oliver Wendell Holmes Jr., US Supreme Court Justice*

## **Module 5 Surveying for Positive Behavioral Support**

1. Introduction and Objectives
2. Identifying Behaviors
3. Activity 1 – Identifying Behaviors
  - Activity 1
  - Activity 1 Discussion
  - What Happens Next
4. Identifying Staff Responses
  - Identifying Staff Responses to Behavior
  - Activity 2
  - Sample CMS - 2567 for Tag W288
5. Applying Relevant Fundamental Regulations
  - Applying the Relevant Fundamental Regulations
  - Fundamental Survey Approach for Behavior which Elicits Staff Response
6. Modifying the Survey Approach
  - Modifying Your Survey Approach
  - Moving from Fundamental to Non-Fundamental Tags
7. Behavior- It's in All the Conditions
8. Supplemental Readings
  - 1 - Functional Assessment including W214 Samples
  - 2 - Function-based Objectives and Interventions including Informal Activity on Identifying Replacement Behavior
9. Conclusion
10. For More Information – References for Module 5
11. Attachment: Fundamental Tags List and Relevant Guidance (Paper Participants & Preceptor only)

## Section 1

**You will need a copy of Appendix J for parts of this module.**

### **Introduction**

In 2001, Rhoades and Altman examined the characteristics of people with intellectual disabilities who lived in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) and other State-licensed residential placements. At that time, nearly one half of the people had two or more behavioral issues. If for no reason but that, surveyors need to be able to identify the behaviors that interfere with people's lives and evaluate providers' responses to them using the appropriate ICF/IID Regulations.

The surveyor does not need to be a psychologist, a psychiatrist or a behavior analyst. However, the surveyor needs to be familiar with regulations/tags which address individuals' behaviors and with methods of evidence collection which facilitate comparison of providers' responses to behaviors to the applicable regulations/tags. When the provider and surveyor are both successful in their roles, it increases the likelihood that people living in ICF/IID will be taught about behavior in ways which promote independence, productivity and community integration (three major outcomes identified by educators for people with severe intellectual disabilities, Beirne-Smith et al., 2006).

### **Objectives for this module**

Upon completion of this training module, you will be able to:

1. Explain why "not normal" and "interfering" (when used as descriptors of behaviors) are cues to a surveyor that a client's observed or reported behavior is "important" to follow-up.
2. List at least 10 fundamental tags from the Conditions of Active Treatment and Client Behavior and Facility Practices that are relevant to behavior programming.
3. List at least 10 tags surveyors may be "led to" while following-up a provider's response to a client's behavior.

## Section 2

### Identifying Behaviors

Three forms of psychology came out of the 1800's: the Psychology of the Consciousness, the Psychology of the Unconsciousness, and the Psychology of Adaptation. The latter became Behaviorism, which some have called the most important development of twentieth century psychology (Leahey, 1980). John Watson is credited for conceiving the term around 1913. Since then many others have built upon his concept that a **stimulus** (an event in the environment) causes a **response**, which is either an observable muscular movement or a measurable physiological response (Kagan and Havemann, 1976). As you probably know, such a response is also known as a **behavior**.

Everyone displays behaviors. Some are genetically based. Some are reflexive. Some are age-related. Some reflect cultural expectations. Some are considered more appropriate to one sex than the other. Some are symptoms of mental health issues. Some annoy. Some hurt. Some prevent learning. Some are responses to the environment. Some need to be ignored. Some need to be changed; some don't. But which are which? Before you can evaluate a provider's actions, you must be able to identify behaviors which require reactions. Also, because **all** behavioral interventions, even "positive approaches", are intrusive to some degree, it is necessary for providers and surveyors to be able to determine if a behavior is "important" before concluding "this client needs a training plan to address "xyz" behavior".

Remember Module 2 and the many aspects of normalization? In that module we talked about the importance of daily routines, materials used for teaching, clothing, home decorations and other aspects of life reflecting the person's status as a "normal" member of his/her community. In this Module we would like you to think about normalization in a slightly different way, that is, what is "normal" behavior in a situation and what is not. Behaviors that are "not normal" to a context, such as the place, the time of day or year, or the person's age, sex, culture or economic standard, are the first cue to a surveyor to evaluate the provider's response to the behavior. What catches the eye is the type of behavior, the frequency with which it is occurring or the duration or intensity in a given context.

You have probably heard the behaviors we are talking about called "inappropriate behaviors", "maladaptive behaviors", "problem behaviors", "challenging behaviors" or even just "behaviors". At least one behaviorist, Todd Risley, has characterized the "challenging behaviors" which get attention as "dangerous, disgusting or disruptive" to "those who live and work with the consumer" (Koegel et al., 1996, pg. 426). While this may be an accurate description of many of the behaviors parents, providers or educators prioritize for change, it is an incomplete description of the behaviors that surveyors need to recognize as potentially "maladaptive" or "inappropriate" (to quote Regulation) and to follow-up.

When you survey, we ask you instead to "look, really look" for **behaviors which are not-normal to a context and by their presence interfere with the person's independence, productivity and community integration**. Using these cues ("not-normal" and "interfering"), *harm to self or others and destruction of others' property will always stand out as important to follow-up*. However, some other behaviors (i.e. a person's quirks, idiosyncrasies, certain choices or minor problems) may initially appear "important" to the provider and/or surveyor but are then ruled out by additional information. Conversely, sometimes quirks, choices, etc. may turn out to be "important" because they interfere with functioning--independence, productivity or community integration.

For example, Erin, who is thirty years old, is physically capable of controlling her bladder but does not do so during the day. Soiling her clothing gets attention, but probably not in a good way. It has the potential to quickly limit work, social and community experiences. Toileting, then, is "important" according to the "**not-normal**" and "**interfering**" definitions described earlier and, when surveying, you would expect to find evaluation/assessment of the cause of this behavior, strategies to address it and maybe even a behavior support plan. On the other hand, Arthur has the habit of repeatedly clearing his throat when he first encounters an anxiety-provoking situation. It doesn't happen every day and doesn't last more than a few minutes. There is no physical cause and his vocal chords are not damaged. Although it is not normal, he and his team feel it does not occur at a frequency that interferes with his daily life. As long as your observations as a surveyor are consistent with this assessment information, you would accept "throat clearing" as "unimportant". It is "**not-normal**" but it is "**not-interfering**". Assessment is indicated but "throat clearing" does not require behavior change programming **at this time**.

"**At this time**" is a key concept in surveyor evaluation of behavior. Frequency changes, intensity changes, co-occurring behaviors may develop. What is the case for a sample member during one survey is not necessarily the case during a future survey or for another person with a similar behavior. Therefore, each time you survey you need to use observation, interview and record review to identify behavior which is "not-normal" and may "interfere" with the person's functioning and quality of life. Each time you survey you will also make decisions about the provider's handling of current behavior. Each behavior needs to be evaluated as if it is the first time you have seen it.

#### ***Just a Reminder***

Your focus as a surveyor identifying behaviors is generally your own sample members. However, if, during the course of observations (including Task 6, Visit to Areas) or during record review (including Task 2), you become aware of another person's behavior harming or potentially harming others, you will need to bring this to the immediate attention of your fellow survey team members. Discussion might include: adding a client(s) to the sample for focused review, or, in the case of a person who is not a client, where to report the behavior, or, even, whether the situation rises to the level of a Condition citation or immediate jeopardy.

### Section 3

#### Activity 1- Identifying Behaviors for Follow-up

You will have the opportunity to discuss Activity 1 and any questions or comments you might have on your next preceptor call.

**Directions:** Imagine you are surveying in an ICF/IID and learn by observation and interview about the following behaviors. Think about each in terms of the cues “not-normal” and “interferes with independence, productivity or community integration”.

- ✓ If both cues apply, circle or underline “important”.
- ✓ If you are not certain whether both cues apply, circle or underline “evaluate further”.
- ✓ If neither cue applies, circle or underline, forget-about-it.

In each instance, indicate why you selected the answer you chose.

The questions for the first behavior have been completed as an example.

**1. (Example) Behavior:** Clara insists upon wearing something pink everyday.

**Important   Evaluate Further   Forget-about-it   Why?**

If Clara works at “Pink Beauty Salon” it may not only be normal, it may be required dress. However, if that is not the case, it would help to know “how much pink” as well as the age of the person. While it may be a temporary “stage” for a child or teenager (and of less concern in terms of community integration), for a person of any age it may still be interfering if it results in refusals to go places, tantrums, etc. when a pink item is not readily available to wear.

**2. Behavior:** George pushes others out of his way any time he walks in a hallway. Staff admit at least two people in the past year have fallen and bruised themselves as a result.

**Important   Evaluate Further   Forget-about-it   Why?**

**3. Behavior:** A teenager chews his finger nails.

**Important   Evaluate Further   Forget-about-it   Why?**

**4. Behavior:** A woman sucks on her lower lip; bruises are present.

**Important   Evaluate Further   Forget-about-it   Why?**

**5. Behavior:** Sarah constantly rubs her right hip and picks at the material in the same area of her right pants leg.

**Important   Evaluate Further   Forget-about-it   Why?**

**6. Behavior:** No one wants to be near Juanita because she frequently spits in her hands and wipes them on her jeans.

**Important   Evaluate Further   Forget-about-it   Why?**

**7. Behavior:** A 25 year old man seems obsessed with string. Hunts for it, plays with it, hides it.

**Important   Evaluate Further   Forget-about-it   Why?**

**8. Behavior:** After work, Bernard gets off the van and throws two dining chairs on his way to his bedroom.

**Important   Evaluate Further   Forget-about-it   Why?**

**9. Behavior:** A teenager is so afraid of the doctor she doesn't eat or sleep before appointments unless she takes Valium.

**Important   Evaluate Further   Forget-about-it   Why?**

**10. Behavior:** Peter, a 40 year old, holds hands with staff whenever he is outside.

**Important   Evaluate Further   Forget-about-it   Why?**

**11. Behavior:** Jim wakes up nearly everyday at 3am. He does not disturb anyone and, after making and drinking a warm glass of milk, goes back to sleep until 7am when he awakes rested.

**Important   Evaluate Further   Forget-about-it   Why?**

**12. Behavior:** Therese paces back and forth by the kitchen doorway while meal preparation is occurring. She does not do this any other time.

**Important   Evaluate Further   Forget-about-it   Why?**

## Activity 1 Discussion

The 12 behaviors in Activity 1 were selected to make you think. Separating normal behavior from not-normal is not as simple as you might expect. As you saw, even multiple observations of a behavior (those with descriptors such as “every day”, “constantly”, “whenever”), did not always assist you when you did not know the intensity or the reason for the behavior. Determining whether a behavior interfered with functioning and quality of life was even more likely to require additional information. A concept like harm to self or others was even difficult to apply (i.e. the example of Sarah who was rubbing and picking) without more information. Do not be deterred; the process of considering and identifying the importance of behaviors in a person’s life is not wasted time. The more observations you do and the more interview questions you ask as behaviors begin to reveal themselves, the easier it will be to gather **only** the evidence you need as you survey.

Sometimes you will hear staff talk about a behavior or will read about behavior during Task 2 or during record review but never personally observe it. As a surveyor **you will investigate these behaviors as if you saw them first hand**. You will determine their importance and, when appropriate, evaluate how the provider has responded to them. Generally your interview questions and record verifications will be no different than those you would do after witnessing behavior first hand.

## What Happens Next?

As you saw, most of the Activity 1 behaviors required **more information than the initial observation(s)** for the surveyor to decide whether the behavior was “not-normal” and “interfering” (aka “maladaptive” or “inappropriate” per the Regulations). Remember the discussion of observation, interview, record review and collaboration in Module 3? The same recommendations for evidence collection and note-taking apply to behaviors that you are evaluating. Consider the following tips when you need to learn more about a behavior.

- **Make sure your initial observation was sufficient.** For instance, you may need to observe a longer period of time or another shift or another location.
- **Ask the right question(s) to the right person** in order to “get the story”. For example, asking Clara, a family member, a favorite staff person or the QIDP to: “tell me about wearing pink”, should reveal whether this is/was a problem (i.e. w/ the employer, financially, due to teasing by others, adverse reactions by Clara, etc.) and, maybe even, if/how the provider addressed any problem. Or, as in another example, the case of the person with the bruised lip, asking “what happened that your (or the lip) is bruised? Or to staff holding Peter’s hand: “why are you holding hands?”
- Like any good detective, the surveyor would then **verify the answer(s) with another evidence source**—another observation, another staff person, Task 2 incident reports, Task 5 drug pass observation or even a part of the record such as progress/team notes, assessment, the Individual Program Plan (which should

include any objectives and strategies)- in order to make a decision about normal/not-normal and interfering or whether to continue evaluating.

- **Your verification(s) may lead you to “forget-about-it”** because the behavior has **already been successfully addressed** by the provider or the provider can demonstrate that the behavior **has not reached the not-normal or interfering level**. For example, in Clara’s case, the surveyor was told that past assessment and team discussion concluded there was no reason Clara’s preference for pink could not be supported at a reasonable level. Indeed, Clara had achieved objectives pertaining to selecting pink accessories (instead of totally pink outfits) and reducing tantrums about dressing to zero and there was no evidence to the contrary. The preference for pink and its related behavior, tantrums, were successfully addressed. In the case of the person with the bruising, the surveyor learned it was the result of a one-time accident and that the nurse was monitoring healing (and any negative impact that sucking might have). Both the nurse and QIDP thought what looked like “sucking” was just the person’s subconscious method of checking the injury site. The behavior had not reached a “not-normal” level.
- **The other possibility is that verification leads to the discovery that the surveyor thinks the behavior is important right-now.** Typically this would be because further information showed **the behavior is not-normal and is interfering** with independence, productivity or community integration but it can also be because the surveyor learns **the provider thinks the behavior is important**. Both reasons applied to the case of 40-year-old Peter; the surveyor learned that staff initiated hand holding off-the-record to prevent run-away behavior, restricting both Peter’s independence and his rights. Systematic interventions (on and of the record) are a signal that the provider thinks a behavior is important, as are assessments which say so. For instance, in the case of the man obsessed with string, this was identified as one of the symptoms of a psychiatric diagnosis for which he received medication.

## Section 4

### Identifying the Provider’s Response to Behavior

The last paragraph of the previous section spoke of the surveyor being “led to” behavior by observing systematic responses by the staff to the client. This is not as unusual as it might sound. The process of identifying behavior which is “not-normal” and “interfering” with a client’s functioning (aka maladaptive behavior in the language of the regulations) often overlaps the process of identifying the provider’s response to behavior and comparing it to the relevant ICF/IID Regulations. Let’s take a minute to look at some staff responses to “maladaptive” behavior. Would you have recognized them as staff responses? Would they have led you to identify a behavior that needed follow-up by applying the regulations? Please read Activity 2 now. **Directions:** Next to each observation, write a note to yourself about how/why staff might be using the item to manage behavior. Your thoughts will be discussed on your preceptor call.

Activity 2 - Coincidence or Cue?

<b>The surveyor OBSERVES:</b>	<b>HOW/WHY would staff be using this to manage behavior?</b>
<b>1. A toilet paper dispenser is repeatedly empty</b>	
<b>2. A lock on the fence gate near the front door</b>	
<b>3. Staff dispensing hard candy during an activity</b>	
<b>4. The lap tray is always on her wheelchair</b>	
<b>5. A child gate in a home for adults</b>	
<b>6. An empty dresser drawer in his bedroom</b>	
<b>7. She wears a leotard every day</b>	
<b>8. An empty room with a window into the hall</b>	
<b>9. A pill for behavior</b>	
<b>10. A mitten worn indoors</b>	
<b>11. Staff charging tokens</b>	
<b>12. A restraint chair</b>	
<b>13. Praise for helping</b>	
<b>14. Staff lock her wheelchair brakes before they leave the room</b>	

## Discussion of Activity 2

Of the 14 things observed by the surveyor in Activity 2, only two – praise and dispensing candy – likely fall in the realm of “positive approaches” to behavior. The rest, if employed in anticipation of or as a consequence of a client’s behavior, would be considered restrictive elements of programs or restrictive practices. When the surveyor sees restrictive programs or practices which affect both the person whose behavior led to the program or practice and those around him, everyone’s rights (and the appropriateness of the technique) must be considered when applying the regulations. When a person’s rights are restricted, the restriction and the method to teach the person to overcome it must always be included in the Individual Program Plan (IPP). In addition, positive or less intrusive techniques must be tried first and demonstrated ineffective (W278).

It is our hope that you see primarily “positive approaches” to behavior as this is the trend in the field of applied behavior; however, you need to be aware this may not be the case.

There will be times when you begin a survey that you will NOT observe a response by the provider’s staff to a behavior you think may be important. If the behavior was unsafe, ask clarifying questions. Otherwise, you may simply record what you observed for later use; the behavior may not turn out to be important. A pattern of staff failing to respond to “important” behavior will be discussed a bit later in this Module.

## Sample CMS-2567 for Tag W288

Because surveyors often find it challenging to write a CMS-2567 tag that talks about a provider’s inappropriate response to a behavior, it was decided to include one in this section. This sample citation of fundamental tag W288 demonstrates some of the concepts that were just discussed. Please note that W288 applies to the client with the maladaptive behavior (in this case pilfering) and not other clients whose rights might have been inadvertently restricted by the provider not thinking through a treatment decision. When other clients’ rights are also restricted by the provider’s response to a maladaptive behavior, that is cited at W125.

### W288

Based on observation, interview and record review, the facility used a restrictive technique to manage pilfering behavior as a substitute for active treatment programming affecting 1 of 4 clients in the sample (Client 5).

### Findings:

1. It was observed on 3/26/yy at 7:35 am that the refrigerator door in the kitchen of the home was locked with a hasp and padlock. During further observations on 3/26/yy and 3/27/yy, the refrigerator was locked and not accessible to Client 5.

2. On 3/26/yy at 7:35 am, Life Skills Instructor 2 explained that the refrigerator was locked because “We have some pilferers. I’m not sure who they are. I was just told to keep the door locked.”

3. On 3/26/yy at 7:42 am, the Shift Supervisor stated that Client 5 had a long history of taking food, usually cold cuts, from the refrigerator. The Supervisor explained that Client 5 did not have a training objective to address taking food from the refrigerator. The Supervisor did not know why Client 5 did not have a program.

4. In a review of Client 5’s treatment record on 3/27/yy at 8:30 am, there was no behavior support plan or other training objective found that addressed Client 5’s “pilfering”. The Individual Program Plan dated 7/10/yy did not contain documentation that Client 5 was receiving training to reduce or eliminate the need for the restrictive practice of locking the refrigerator door.

## Section 5

### Applying the Relevant Fundamental Regulations

Now that you have had an opportunity to think about identifying behaviors and responses to them, it is time to talk “Regulations”. Most of the relevant requirements are ***regulations in the Conditions of Active Treatment and Client Behavior and Facility Practices***, although tags in other Conditions (most often Client Protections and Facility Staffing) may apply.

### ***Thoughts to Ponder:***

- ICF/IID Regulation requires the provider to assess maladaptive behavior, address it in the Individual Program Plan, seek consent and, if necessary, specially constituted committee review of treatment/practices, implement objectives and interventions, document results and monitor and revise the steps of this process as necessary.
- Appendix J commits the surveyor to an observation-interview-record review format to collect evidence to evaluate the provider’s actions regarding that same maladaptive behavior.

Let’s take a look at one example of an approach by a surveyor. In this approach, the surveyor has identified the behavior as maladaptive and has seen staff respond to the

behavior. You will see W-tag numbers in parentheses which are fundamental regulatory expectations.

At the end of Module 5 there is a list of these fundamental tags with the applicable sections of the tags from Appendix J “Guidance to Surveyors”. The “Probes” found in the “Guidance” are useful questions to answer as the surveyor completes observations, interviews and record reviews.

## **Fundamental Survey Approach for Behavior which Elicits Staff Response**

The surveyor has been taking notes about his sample member and has identified “maladaptive” behavior “xyz”. Observation and interview have revealed that staff systematically respond to “xyz” behavior by doing “abc”. In this example, the surveyor proceeds as follows:

1. To clarify by interview whether staff response “abc” is based on a training objective and/or other intervention pertaining to “xyz” behavior. This includes asking staff to “show me” a copy along with the data pertaining to it.
2. a. To read the copy, noting whether:
  - it is current,
  - the objective/intervention and training program method/strategy addresses behavior “xyz” and previously observed staff response “abc” (W240, W249, W291),
  - it contains consent and SCC review for restrictive components including drugs to control behavior (W262, W263),
  - staff have recorded the data specified to be collected including restraint (W301-302).b. To clarify with the same staff (and note for further follow-up) the reason for any inconsistency or where missing information would be found.
3. To examine restraint devices (W285) and timeout rooms (W291, W293) for safeguards when applicable to that sample member. This will include follow-up of any safety concerns noted during Task 2.
4. a. To continue to observe the consistency of staff responses to “xyz” behavior with the method and data collection specified (in step 2) throughout the day and wherever the person goes. This may include Task 5 drug pass observation.  
b. To clarify (and note) the reason if inconsistency seen (W240, W249, W286-288).
5. To discuss the behavioral training objective and/or intervention —progress, concerns, consent/justification for treatment (W124, W209, W263, W313) as part of an in-depth interview w/ client, guardian, parent or direct care staff familiar w/ the sample member.
6. To review the record (Task 7) including:
  - The Individual Program Plan (IPP): for the current objective and/or intervention, progress/lack of progress in the past year (W256-257) and any components missing in step 2 or done differently during step 4 (W227, W240, W285-288, W291)
  - The Comprehensive Functional Assessment (CFA) for a functional analysis of the behavior - particularly if progress is not occurring (W256-257) and/or when drugs, restraint or timeout used, to verify consideration of less restrictive alternatives (W313-justify drugs).
  - Medical records for monitoring of drugs used for “control inappropriate behavior” (W314).
  - Task 2 results/documents for injury pertaining to restraint/timeout (W285, W293).

7. To review Specially Constituted Committee (SCC) minutes if consent/review for restrictive interventions is applicable and not found (W262, W263) during steps 2 or 6.
8. To discuss inconsistencies or missing documents from steps 1-7 with the Qualified Intellectual Disabilities Professional (QIDP) (W255-257), SCC Chairperson, behavior analyst or other knowledgeable supervisor, manager or professional.
9. Collaborate with team members as indicated.
10. Repeat steps 1-9 for additional behaviors and staff responses.

**To recap**, the 10 steps in “Fundamental Survey Approach...Response” will uncover common failures related to behavior that may occur during fundamental surveys. These issues are:

- ✓ Failure by staff to correctly implement (W240, W249, W301-302) and/or document results of a training program method/strategy for a behavioral objective/intervention (W257).
- ✓ Failure of staff to implement a training program method/strategy for a behavioral objective/intervention across areas the person visits (W249)
- ✓ Failure to design a training program method/strategy for progress (W209, W257, W302) and safety (W285, W293, W301, W313, W314).
- ✓ Failure by the QIDP to ensure needed changes in the objective/intervention or training program method/strategy (W255-257).
- ✓ Failure to seek consent for treatment (W124, W209, W313).
- ✓ Failure to obtain written consent when required (W124, W263)
- ✓ Failure to seek SCC review of restrictive plans/practices (W262-263, W285).
- ✓ Misuse of interventions by staff (W286-287, W293, W301-302).
- ✓ Failure to incorporate a training objective/intervention into the IPP (W227, W240, W288, W291).

As you would probably expect, sometimes steps 1-10 or certain tags referenced will **not** be applicable to a sample member during a fundamental survey. For example, if there are no restrictive components (ie. drugs, restraint, timeout or other rights restrictions) identified in a program or during observations, then steps and tags pertaining to consent for and SCC review of restrictive programs would not apply to the sample member.

There will also be times when citation of a fundamental tag appears imminent and evidence collection “leads” the surveyor to related non-fundamental tags as well as other fundamental tags. This will be discussed in the remaining sections of Module 5.

## Section 6

### Modifying Your Survey Approach

You have, no doubt, realized by now that the surveyor's approach will need to be modified for other fundamental survey scenarios. Let's take a look at another common scenario now-**behavior which elicits no staff response**.

The surveyor has decided "xyz" is an important "maladaptive" behavior for a sample member; however, thus far, a systematic staff response to behavior "xyz" has not been witnessed. This time the surveyor has some different issues to consider:

- ✓ Is the training program method/strategy to ignore the behavior while focusing on other tasks in the client's environment? (Proceed with Fundamental Survey Approach...Response)
- ✓ Did the individual or parent/guardian refuse to consent to a training plan method /strategy for behavior "xyz"? If so, what alternatives were offered? (W124, W227)
- ✓ Was the behavior the subject of an objective/strategy which was discontinued due to lack of progress? (non-fundamental assessment tags, W227, W240)
- ✓ Has the provider failed to recognize and assess a long-standing (perhaps cyclical) maladaptive behavior? (non-fundamental assessment tags)
- ✓ Has behavior "xyz" suddenly become not-normal or interfering? (non-fundamental assessment tags)
- ✓ Is the behavior undergoing assessment? (check timeliness)
- ✓ Is there a failure in staff training? (non-fundamental training tags)

Imagine for a moment that you are the surveyor. How would you modify the previous approach to address the possibilities just mentioned?

That's right! For all the issues mentioned, the interview in Step 1 would be modified slightly so that the surveyor is simply clarifying with staff whether there is a training objective and/or other intervention pertaining to "xyz" behavior.

- If the answer is yes, the surveyor would continue on with "Fundamental Survey Approach...Response", including "show me" a copy along with the data pertaining to it.
- If the answer is no, the surveyor would ask clarifying questions about the history of "xyz" behavior including whether it has been assessed and by whom and whether there has been previous programming. (This may not be necessary if this information was collected verifying the importance of the behavior to the person's functioning). Steps 2 and 3 would no longer be relevant; although steps 4 -10 would likely apply, some with modifications, others as they are written.

### Moving from Fundamental Tags to Non-Fundamental Tags

As you can see, the surveyor's approach to behavior flexes as necessary in a fundamental survey. As surveyors gain experience and confidence in identifying

behaviors for follow-up, the process discussed in this Module becomes less artificial and blends into the subsequent evidence collection steps necessary to evaluate the provider's response to an identified "maladaptive" behavior. It is not easy because the fundamental regulations related to behavior are intimately related to other fundamental and non-fundamental tags. For instance, in the "Fundamental Survey Approach...Response" that you just printed:

- If the surveyor learns in step 2 that the refrigerator is locked due to his client's behavior, the surveyor has been "led to" investigate fundamental tag W125, ensuring the rights of others to access the refrigerator, and non-fundamental tag W264, SCC review of practices related to inappropriate behavior.
- When no data is found in step 4 for a witnessed physical restraint, the surveyor is "led to" non-fundamental tag W303, record of restraint.
- If the surveyor does not find evidence of monitoring of drugs to control behavior in step 6 the surveyor may be "led to" question whether a plan is in place to reduce and withdraw drugs as per non-fundamental tags W312 and W316-317.
- When lack of progress is found during steps 2, 4 & 6, the surveyor is "led to" the details of the training program and behavioral assessment. Was a replacement behavior (non-fundamental tag W239) identified and taught?
- If the surveyor witnesses interventions in step 4 which are not listed in step 2 or the IPP in step 6, the surveyor is "led to" the non-fundamental tags W289 (systematic interventions), W295 (physical restraint) or W312 (drugs) which specify interventions must be incorporated in the IPP.

## Section 7

### **Behavior- It's in All the Conditions**

The fact of the matter is that the decision to provide a behavioral training objective or intervention for an individual who lives in an ICF/IID is so significant that requirements related to behavioral programming are found in every Condition. Here are just a few more examples:

#### Governing Body

W 120(F) - The facility must assure that outside services meet the needs of each client. Guideline reads: ...if the facility is implementing a behavior management program for the individual, it should be shared with and implemented as needed by the outside program.

#### Client Protections

W151 (NF) - The facility must not punish a client by withholding food or hydration that contributes to a nutritionally adequate diet.

#### Facility Staffing

W 193 (NF) – Staff must be able to demonstrate the skills and techniques necessary to administer interventions to manage the inappropriate behavior of clients.

### Active Treatment

W 214(NF) – The comprehensive functional assessment must include the client’s specific developmental and behavioral management needs. Guidelines include: Assessment of the behavior assumed to be maladaptive should include analyses of the potential causes...

### Health Care Services

W 363(NF) - The pharmacist must report any irregularities in clients’ drug regimens to the prescribing physician and interdisciplinary team. **Note:** Even though the Appendix N reference is not longer applicable as Appendix N has been deleted from the State Operations Manual, this requirement continues to include drugs used for control of inappropriate behavior.

### Physical Environment

W 407(NF) – The facility must not house clients of grossly different ages, developmental levels, and social needs in close proximity unless the housing is planned to promote the growth and development of all those housed together. Facility Practices include: The grouping...does not endanger the health, safety or development of any individual.

### Dietetic Services

W 465(NF) Foods proposed for use as a primary reinforcement of adaptive behavior are evaluated in light of the client’s nutritional status and needs.

Try not to be overwhelmed by the concept of “led to” when it comes to behavior. You will learn the relationships in time, particularly as you are required to apply all the regulations/tags in Full Surveys.

## Section 8

### Supplemental Readings

In this section of the module you will find a supplemental reading on functional assessment and another one on function-based objectives and interventions. We believe you will use these as you become comfortable looking beyond the fundamental tags. These are two concepts which are integral parts of behaviorism and the field of applied behavior analysis.

You may read this now or later. If you have questions, ask them on your preceptor call.

## Supplemental Reading 1

### Functional Assessment

There are more than 20 tags in the ICF/IID Regulations which deal with evaluation and assessment of the client. None of these tags are fundamental, yet on **any type of survey** when the surveyor identifies an unaddressed need, regression/loss of skills or an objective that is not making progress, questions about assessment are appropriate. These findings are just as likely to occur with behaviors as they are with cognitive abilities and physical status.

Take a moment to look at Appendix J tags W210 to W225, W164 and W259.

#### [The Language of Assessment](#)

***The comprehensive functional assessment (CFA) first referred to at W211 is NOT the same as the functional analysis of a behavior. The term “comprehensive functional assessment” refers to all assessment of the individual-whether synthesized from individual reports or presented as a series of reports. The CFA includes the functional analysis of a behavior, when it is required for “maladaptive behavior” (Guidance to Surveyors W214).***

The comprehensive functional assessment (CFA) is reviewed and updated annually by the interdisciplinary team-- unless changes occur in “the needs of the individual” which warrant an earlier update. Required “areas” of assessment are identified in tags W216 through W225.

The results of the CFA (W211-215) are used by the interdisciplinary team to prioritize needs and determine training objectives (W227), staff interventions and supports (W240, W289, W295, W312, W321) including, as discussed in Module 4, assistive technology and environmental adaptations. For this reason, many consider the CFA the cornerstone of provider programming.

The CFA is also the basis for involving, when necessary, professionals with specific expertise in assessment and programming (W164) who would not otherwise be interdisciplinary team members. For some providers, information in the CFA is the “jumping off point” for the team’s decision to request functional “analyses of the potential causes” of maladaptive behavior (Guidance To Surveyors W214) and behavior programming by a behavior specialist. For other providers, functional analysis of behavior (FAB) is a standard component in their CFA and a behavioral specialist is already a team member. If you don’t know which applies, ask!

As a surveyor, you should be aware that there is no “one” method or type of functional behavioral analysis/assessment. In part, this is because there are different ways to

conduct them. They include: **informal assessments**, such as questionnaires used with the client and people who know the client well; **probe assessments**, where the behavior analyst works directly with the person and manipulates environmental events; **descriptive analyses**, when data on events which occur before and after behavior is collected by one of several methods and analyzed graphically or statistically; and **experimental analysis**, where the clinician conducts experiments in controlled settings to test the reinforcers maintaining a problem behavior. **What is important is:** whatever the method, in the assessment the surveyor should expect to learn what the analyst thinks is the potential cause(s) for the behavior and what might change the behavior.

**Remember the tags you just read? The ICF/IID Regulations do not specify the “contents of assessments or particular assessments which must be used” (reference guidance in W210). However, assessments are required to identify strengths, needs and need for services, including assistive devices and adaptations to environment (reference W213-W215).**

After you have determined a behavior is important to a client’s functioning or, in some cases, when you are still questioning whether a behavior is important, ask yourself these three questions:

**1) Is there an evaluation of this specific behavior?**

- ✓ Although both adaptive and maladaptive or inappropriate behaviors may be the subject of programming, it is the “maladaptive” ones that require the provider to evaluate the “potential causes” of the behavior (as outlined in surveyor guidance at W214). Generally this is the tag of choice if no detailed assessment of “behavior assumed to be maladaptive” is found in the record.
- ✓ However, since the regulations do not specify the “contents of assessments or particular assessments which must be used” (reference guidance in W210), it is possible that you may find a facility which addresses these issues in the assessments prepared for W219 (affective development), W223 (social development) or W224 (adaptive behaviors), in which case you would cite that tag instead.
- ✓ Another choice (instead of W214, 219, 223, 224) might be W164 if a specialist such as a behavioral consultant or psychiatrist, is not on staff and must be brought in to provide behavioral assessment and programming services.  
**Remember Activity 1?** You may also find behavior observed/evaluated by medical or other personnel which the team “ruled-out” from requiring a more formal, written assessment report. You will need to think carefully about whether that was the correct decision.

**2) Is the assessment current?** Like other assessments, functional behavior analysis, when applicable, must be updated:

- ✓ within 30 days of beginning residence in the facility (W210),
- ✓ annually (W259) or

- ✓ when individual needs indicate (W259). This is a factor a surveyor would examine when a behavioral training objective is not progressing, i.e. does the behavior (intensity, duration, etc.) and plan to change it match the analysis in the assessment on record? If not, needs warrant an update. Or another situation, does the existing behavior plan and assessment address all the behaviors which are interfering with functioning? If not, time for an update.

**3) Is the assessment of the behavior sufficient?** Functional analysis of a behavior as described in W214 should not be confused with W212, which expects the comprehensive functional assessment to identify “presenting problems and disabilities and, where possible, their causes”. This is referring to diagnoses, which are “primarily medical”. Even when a person has a psychiatric diagnosis, further examination of the specific behaviors associated with it, aka symptoms, is expected (reference W312).

### **W214 Sample tags**

**First Example** – The surveyor was led to the maladaptive behavior by a potential rights restriction. Upon learning there were no training objectives, the surveyor looked for assessment – which would be the provider’s first step in developing objectives or interventions, determining if no action was unnecessary or deciding to request additional assessment.

Based on observation, interview and record review, the facility failed to assess the frequency, duration and causal factors of 1 of 1 client in the sample and 1 other client identified as having roaming behavior (Clients 2, 5).

### **Findings:**

1. On (date) at 8:15 am, it was observed that when the front door was opened a soft chime could be heard.
2. On (date) at 8:20 am, Direct Care Aide 2 said that the alarm was used to tell if clients went out the front door. In an interview on (date) at 4:30 pm, the Licensed Vocational Nurse (LVN) said the door was alarmed “in case a client walked out without staff supervision”. In the same interview, the LVN and Qualified Intellectual Disabilities Professional (QIDP) confirmed that the alarm was used to keep clients from leaving the building, not as a security device to keep people from coming in from outside. The LVN and the QIDP said that if the bell rang, staff would check and see if a client had left and, if they had, would go and bring the client back in the home. The LVN and QIDP identified Client 2 and 5 as having the potential to leave the home.
3. In a review of Client 2’s treatment record on (date), an assessment of Client 2’s roaming was not available. The record did not contain data on the frequency of roaming behavior. A Behavior Management Plan dated (date) did not indicate the roaming behavior as a targeted behavior.
4. In a review of Client 5’s record on (date), an assessment of Client 5’s roaming behavior was not available. The record did not contain data on the frequency of roaming behavior.

**Next example** – Client 1: The surveyor was led to the maladaptive behavior during a Drug Pass Observation. Upon learning there might be confusion as to the role of two medications prescribed to control behavior, the surveyor looked for clarification in the Individual Program Plan and assessment. Client 3: The surveyor was led to question assessment by the first clarification interview – when staff implied the intervention strategy didn't always work as the cause for the behavior wasn't known.

Based on observation, interview and record review, the facility failed to complete a functional assessment of the maladaptive behaviors of 2 of 3 clients in the sample (Client 1, 3).

#### Findings:

##### Client 1

1. A review of Client 1's Medication Administration Record on (date) at 4 pm, indicated that Client 1 received Xanax as a sedative prior to his dialysis appointments and Risperdal for thought disorder.
2. In an interview with the Registered Nurse (RN) at the same time, the RN confirmed that Client 1 received Xanax as a sedation one hour before his dialysis appointment. The RN said that the sedation was given for Client 1's agitation in the van and at the dialysis center. He explained the agitation was hitting and scratching.
3. In an interview with the Qualified Intellectual Disabilities Professional on (date) at 5 pm, he stated that Client 1 received Risperdal for his maladaptive behaviors of hitting and scratching.
4. In a review of Client 1's records on (date), the Individual Program Plan (IPP) dated 6/14/yy had an objective "1-9-1" to address "hitting/scratching" but the relationship of drugs to the behaviors was not explained in the objective or the IPP. The records did not document that a functional analysis had been completed of Client 1's behaviors of hitting and scratching.

##### Client 3

1. During observations at the day program on (date) at 10 am, the Program Manager said that Client 3 would occasionally wet herself and that they were not sure if it was for attention or if she had no sensation of need to void. She said they had the practice of reminding her to go to the bathroom every hour.
2. During an interview at the residence on (date) at 9:30 am, the Registered Nurse was asked about Client 3's behavior of wetting herself and whether a functional assessment had been conducted. He said he had known Client 3 for ten years and she expressed anger by wetting herself. If she was really angry, she might also defecate in public. He said they had cut back the number of hours of day program thinking that the reason might be stress.
3. During record review for Client 3 on (date), there was no evidence found to indicate that an assessment of Client 3's behavior of wetting herself had been completed.
4. During an interview on (date) at 12:15 pm, the Qualified Intellectual Disabilities Professional (QIDP) was asked if a functional analysis of behavior had been

completed on Client 3's behavior of wetting herself to determine what might be causing her to do this. The QIDP said he would look in the Comprehensive Functional Assessment, Physician's Notes and Psychology Notes. He checked but could not find anything. He said, "That's all we've got."

**Next example** - The surveyor was led to the maladaptive behaviors after seeing a restraint chair while performing Task 6. Upon learning behavior was not addressed by a training objective, the surveyor was "led to" assessment, the provider's first step in developing objectives or interventions.

Based on observation, interview and record review, the facility failed to ensure that a functional assessment was completed for the behaviors of physical aggression and self-abuse that resulted in restraint use for one of two clients in the sample, Client 3.

#### Findings:

1. On 12/1/yy at 8:35 am, during observation at the residence, a black restraint chair with blue velcro straps on the arms and legs of the chair was present in the garage.
2. During an interview on the same date at 8:35 am, the House Manager (HM) said the restraint chair was there for use with Client 3 as an emergency restraint. The HM said that Client 3 had a behavior intervention program on verbal aggression in which he was learning to control his temper by calming himself, but he did not have a behavior intervention program for physical aggression or self-injurious behavior.
3. On 12/2/yy, the records of the use of emergency restraints with Client 3 were reviewed. The Time-Out /Restraint Form for 10/yy listed restraint use with Client 3 for physical aggression and self-abuse on 10/25/y at the following five times: 5:20 pm to 5:24 pm, physical hold; 5:24 pm to 5:50 pm, 4- point chair; 5:50 pm to 5:54 pm, physical hold; 5:54 pm to 7:03 pm, 4-point bed; 6:10 pm to 7:00 pm, protective mitts. The Time-Out/Restraint Form for the month of 11/yy listed the use of a physical hold for aggression twice on 11/4/yy: at 4:30 pm to 4:47 pm and again at 7:50 pm to 7:59 pm. It also listed restraint use for self abuse on 11/11/yy from 6:55 pm to 7:05 pm.
4. During an interview at 1 pm on 12/2/yy, the Qualified Intellectual Disabilities Professional said that a functional assessment addressing physical aggression and self-abuse for Client 3 had not been completed. She said that she knew Client 3 very well and that she knew how aggressive he could be. She further stated, "I didn't consider it for programmatic use because he probably will be fine for the next few months. I don't know when he might do it again. It is not in a plan of active treatment today".

**Next example** – The surveyor was led to a potential maladaptive behavior after seeing the person wearing a helmet, a potential rights restriction. The surveyor was led to assessment after staff gave inconsistent interview responses.

Based on observation, interview and record review, the facility failed to assess the specific developmental and behavioral management needs of one client added to the sample, Client 5.

Findings:

1. On 6/24/yy at 9:55 am, Client 5 was observed sitting at a work table in her day program. At the time of observation, she was involved in a sorting activity and wearing a helmet with fasteners on her head. When the instructor was asked about the reason for Client 5's helmet, she explained that it was due to Client 5's history of self injurious behavior (SIB).
2. At 12:00 pm on the same day, Client 5 was offered lunch and independently removed her helmet, placing it on a desk adjacent to her. When she finished eating lunch 20 minutes later, she put the helmet back on her head. At no time during the observational period of 9:55 am to 12:30 pm, did Client 5 exhibit any SIB.
3. In an interview with the Qualified Intellectual Disabilities Professional (QIDP) on 6/24/yy at 1:00 pm, she explained that the helmet was a protective device to the physician's concern about hydrocephaly and the potential of future damage due to Client 5's long standing history of SIB.
4. During observation in Client 5's home on 6/24/yy from 3:45 pm to 5:15 pm, Client 5 was again wearing a helmet. In an interview with Care Worker 4 at the same time, it was explained that Client 5 was expected to wear the helmet at all times to prevent self-injury and to protect her from other clients in the home.
5. In an interview on 6/25/yy at 9:00 am, the Home Manager, Nurse and Treatment Specialist were asked what their understanding was of the need for the helmet. All three explained and agreed that the helmet was used to prevent injury from SIB. In a follow-up interview with the QIDP and the Clinical Director on 6/25/yy at 10 am, the Clinical Director explained that the helmet was in response to SIB, while the QIDP reiterated her position that the helmet was a protective device. No one could produce policy on the use of helmets.
6. During record review for Client 5 on 6/25/yy, a physician consultation dated 10/28/yy stated "helmet in place while awake". A physical exam dated 4/23/yy noted, "SIB-Head: Helmet worn daily while awake to prevent injury". There was no documentation reflecting an interdisciplinary team decision on how the helmet was used-whether as a protective device or for behavioral purposes. There was no assessment or data collected which could be used to validate helmet use was based on Client 5's current functional needs.

**Next Example** – The behaviors were not witnessed by the surveyor but were identified during Task 2. The surveyor was “led to” question assessment by the current level of the harmful behaviors and learning that training objectives were in place but not protecting others.

Based on interview and record review, the facility failed to conduct a functional analysis of maladaptive behavior for 3 of 8 clients in the sample (Clients 1, 5, 7).

#### Findings:

1. On 11/4/yy, a review was conducted of the "Accident/Injury Report" documented from the period 11/1/yy to 11/4/yy. The review revealed 29 incidents of client-to-client aggression. All 29 incidents resulted in injuries to the victims. Client 1 was responsible for 10 incidents and Client 7 for 6 incidents. Client 5 was the victim in 14 of 29 incidents. The primary perpetrators of Client 5's assaults were Client 1 (5 incidents) and 7 (4 incidents).
2. On 11/4/yy, reviews of the records of Clients 1, 5 and 7 were conducted. The Behavior Support Plan (BSP) dated 1/12/yy, for Client 5, the primary victim of assaults, focused on staff prompts to avoid assaults by avoiding conflict with other clients. There was no functional analysis of behavior for Client 5. A BSP for Client 1 dated 9/17/yy, identified the behaviors of physical aggression, verbal aggression, self-abuse, hallucinations and non-cooperation. There was no functional analysis of behavior for Client 1. The BSP for Client 7 dated 3/15/yy, identified maladaptive behaviors of physical aggression including biting, kicking and hitting. There was no functional analysis of the behavior.
3. On 11/4/yy at 2:00pm, an interview was conducted with the Behavior Supervisor who served as the behavior specialist for the residence. He admitted that neither psychological assessments nor BSPs contained functional analysis of behaviors. This weakness had been identified recently and the new Chief Psychologist had set timelines to complete these-but they were not yet accomplished.

#### **End Supplemental Reading 1**

## Supplemental Reading 2

You may read this now or later. If you have questions, ask them on your preceptor call.

### Function-based Objectives and Interventions

If properly done, the functional analysis of a behavior allows the psychologist, psychiatrist, behavior analyst or other qualified professional to develop and recommend training objectives and interventions/supports which systematically alter the situation in which the important (aka inappropriate or maladaptive) behavior occurs, so that responses which promote independence, productivity or community integration can happen instead.

Training programs will often include things such as changes in the environment (noise level, temperature, new routines, increased availability of food or preferred activities), changes to the person (i.e. medical interventions, drugs) and changes in the consequences of behaviors (i.e. decrease in rewards for inappropriate behavior, increase in rewards for appropriate behavior) as well as functionally related **replacement behavior**.

Replacement behavior is discussed in W239 and surveyors should see a replacement behavior taught whenever an objective to decrease or eliminate a behavior is seen. For example, if Pablo has a target behavior to **decrease X**, then he should also have a target behavior to **increase Y**. This is also true when psychiatric symptoms are targeted for deceleration (W312). For example, Jill is to decrease her reports of A and increase her participation in B.

**Remember Activity 1?** It turned out that George was not being taught an alternative to pushing people out of his way and his pushing behavior was not decreasing. The idea behind a replacement behavior is that it teaches the person another way of handling him/herself, preferably one which gains positive attention and is naturally supported. If the person wants attention, the replacement behavior should gain attention. If the person does something inappropriate due to boredom, the replacement behavior should stimulate. If the person is anxious in a situation, a replacement behavior might provide opportunities to practice different, non-stressful activities in the same location. If the behavior allows the person to control a situation, another method of control should be substituted. Remember Clara? Her tantrums over her pink clothing choices disappeared after she was encouraged to use (and enjoy) pink accessories and to ensure her outfits were ready-to-go the evening before she planned to wear them.

## Identifying Replacement Behaviors

**Directions:** Just for fun, read through the following pairs of target behaviors from individuals' behavior support plans. After reading each set, pick the one which best represents a replacement behavior as required by W239.

- 1A. Within 2 minutes of being asked, Jack will stop rocking for 5 minutes...
- 1B. In the evening, Jack will play a game from his favorites list with at least one other person...
- 1C. Neither is a replacement behavior.
  
- 2A. Dora will not refuse to go to doctors' appointments...
- 2B. Dora will pick up a brochure at a doctor's office once a week...
- 2C. Neither is a replacement behavior.
  
- 3A. When asked, Anna will explain why she is angry...
- 3B. Anna will reduce incidents of aggression towards others from 4 to 2 times...
- 3C. Neither is a replacement behavior.
  
- 4A. Eloise will have no more than 8 episodes of crying per month...
- 4B. Eloise will be ready for work by 9am Monday through Friday...
- 4C. Neither is a replacement behavior.
  
- 5A. When told her voice is loud, Marta will ask to go to the break room...
- 5B. Marta will have incident free days 16 of 20 days...
- 5C. Neither is a replacement behavior.
  
- 6A. Alex will decrease the number of times he cuts himself from 3 to 0...
- 6B. When he appears upset, Alex will respond to the question "how is your day going?" with at least a two sentence explanation...
- 6C. Neither is a replacement behavior.
  
- 7A. Burt will have no more than 2 hallucinations per month...
- 7B. Burt will not sleep on the floor behind his bed...
- 7C. Neither is a replacement behavior.

## Answers to Replacement Behavior Activity

1B, 2B, 3A, 4B, 5A, 6B, 7C

## Discussion of Replacement Behavior Activity

In this activity you were asked to identify training objectives that appeared to be replacement behaviors. You should know that it is also an acceptable practice for providers to teach replacement behaviors as part of the training program method. If you are not certain which technique the provider is using, ask.

## End Supplemental Reading 2

### Section 9

#### Conclusion

It was not so long ago, in 1964, that the first scientific demonstration of a behavior change intervention for a person with a “challenging behavior” was published in *Behavior Research and Therapy* (Koegel et al., 1996, pg. 426). Shortly thereafter, in the 1970s and 1980s, there were “significant refinements in the strategies and procedures for implementing behavioral interventions”, the collection of “a large database of strategies effective for a wide variety of settings and conditions” and the realization that functional analysis was critical to selecting interventions (Koegel et al., 1996, pg. 115). Since then, evaluating the reasons for behavior, altering the environment to decrease behaviors and teaching skills to eliminate the need for behavior have collectively become known as “**positive behavioral support**” (Beirne-Smith et al., 2006, pg. 30). Although today’s commonly used terms - “behavior support”, “behavior support plan” and “positive approach” - are not incorporated in the 1988 ICF/IID Regulations and subsequent 1996 guidance, you have seen from the discussions in this module and previous modules, that the concepts underlying “positive behavioral support” are present.

Further refinements to applied behavior analysis will happen. It behooves the surveyor to be aware of such trends and, upon learning of them, to evaluate how they “fit” with Regulation. For example, in 1996, Koegel et al. reported trends “away from...crisis management toward... treatments” which “avert crises” before “the need for intrusive intervention arises” (pg. 165) and “general consensus” that behavior support technology needs to be “community-referenced” (pg. 166). A quick glance at the Regulations finds these two trends are consistent with requirements that the provider/facility identify the hierarchy of positive to intrusive interventions that it permits (W276-277) and that the staff use the least restrictive interventions first (W278). You can probably see what the benefit would be to use positive/less restrictive interventions which blend with the expectations of the community-at-large. We will talk more about community integration and the ICF/IID Regulations in Module 6.

## Section 10

### For More Information - References for Module 5

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O'Neill, Robert E., Horner, Robert H., Albin, Richard W., Sprague, Jeffrey R., Storey, Keith, Newton, J. Stephen. (1997) *Functional Assessment and Program Development for Problem Behavior: A Practical Handbook*. Pacific Grove, CA: Brooks/Cole Publishing Company.

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## Section 11

### Attachment: Fundamental Tags List and Relevant Guidance

(For Paper Participants) This list is referenced in Section 5. It corresponds with the tags shown in parentheses in the "Survey Approach" and contains (only) the sections of Appendix J "Guidance to Surveyors" applicable to the task at hand.

**FUNDAMENTAL REGULATIONS AND TAGS RELATED TO BEHAVIOR**  
**(The “Guidance for Surveyor” section of this document has been edited from Appendix J to contain the information most pertinent to the subject matter.)**

TAG	REGULATION	GUIDANCE FOR SURVEYOR
	The facility must ensure the rights of all clients. Therefore, the facility must- -	
W124	(2) Inform each client, parent (if the client is a minor), or legal guardian, of the client's medical condition, developmental and behavioral status, attendant risks of treatment, and of the right to refuse treatment;	<p><u>§483.420(a)(2) FACILITY PRACTICES:</u>  Individuals and their representatives, if applicable, are aware of the individual's medical condition and treatment, therapies, services and other treatment or prescribed approaches being received, the reason for their use, as well as any risks involved in those treatments or approaches.</p> <p>Individuals and their representatives, if applicable, understand the alternatives to proposed treatments, that they can refuse treatment, and the possible consequences/ alternatives to such refusal of treatment.</p> <p><u>§483.420(a)(2) GUIDELINES:</u>  The term "attendant risks of treatment" refers to <u>all</u> treatment, including medical treatment. An individual who refuses a particular treatment (e.g., a behavior control, seizure control medication or a particular intervention strategy) must be offered information about <u>acceptable</u> alternatives to the treatment being refused, if acceptable alternatives are available. The individual's preference about alternatives should be elicited and considered in deciding on the course of treatment. If the individual also refuses the alternative treatment, or if no alternative exists to the treatment refused, the facility must consider the effect this refusal may have on other individuals, the individual himself or herself and the facility, and if it can continue to treat the individual consistent with these regulations. Thus, every effort must be made to assist the individual to understand and cooperate in the legitimate exercise of the IPP.</p> <p><u>§483.420(a)(2) PROBES:</u></p> <p>Is there correspondence in the record informing the appropriate guardian of the individual's condition? Is there evidence of informed consent when needed?</p> <p>Is there evidence that appropriate people are informed of benefits and risks of treatments, including psychoactive drugs?</p>
W209	Participation by the client, his or her parent (if the client is a minor), or the client's legal guardian is required unless the participation is unobtainable or inappropriate.	<p><u>483.440(c)(2) GUIDELINES:</u>  Meetings should be scheduled and conducted to facilitate the participation of all members of the team, but <u>especially</u> the individual, unless he or she is clearly unable or unwilling, the individual's parents (except in the case of a competent adult who does not desire them to do so) or the individual's guardian or legal representative. The ICF/IID is expected to pursue aggressively the attendance of all relevant participants at the team meeting, (e.g., a conference call with a consultant during deliberations meets this requirement). Question routine "unscheduled" absences by individuals, guardians and particular disciplines or consultants, and determine the impact on effectiveness and responsiveness of the IPP to meet the individual's needs.</p>
W227	that states the specific objectives necessary to meet the client's needs, as identified by the comprehensive assessment required by paragraph (c)(3) of this section,	<p><u>§483.440(c)(4) FACILITY PRACTICES:</u>  The IPP contains a list of specific objectives based on needs identified in the CFA.</p> <p>There is a clear link between the specific objectives and the functional assessment data and recommendations.</p> <p>Objectives are developed for those needs that are observed to most likely impact on the individual's ability to function in daily life.</p>

		<p><u>§483.440(c)(4) GUIDELINES:</u>  The presence of a comprehensive list of behaviorally stated needs is acceptable for this portion of the requirement. "Comprehensive" means that objectives are stated for the needs identified in each domain included in the comprehensive functional assessment.</p> <p>Objectives may address services to be provided, learning/treatment needs, adaptive equipment, etc. "483.440(c)(4)(i)-(v) regulate requirements for current IPP <u>training</u> objectives (as opposed to staff, service, or long term objectives).</p> <p>Validate that the needs identified by the team are appropriate for the individual based upon review of the comprehensive functional assessment data, observations, and interviews with the individual and staff.</p> <p>Is there repetition and predictability of programming across individuals?</p>
	(6) The individual program plan must also:	
W240	(i) Describe relevant interventions to support the individual toward independence.	<p><u>§483.440(c)(6)(i) FACILITY PRACTICES:</u>  The IPP provides specific information to any staff person working with the individual about what services and supports they are to provide to assist the individual in functioning at a more independent level.</p>
W249	(1) As soon as the interdisciplinary team has formulated a client's individual program plan, each client must receive a continuous active treatment program consisting of needed interventions and services in sufficient number and frequency to support the achievement of the objectives identified in the individual program plan.	<p><u>§483.440(d)(1) FACILITY PRACTICES:</u>  Each individual is receiving training and services consistent with the current IPP.</p> <p>Staff use the adaptive equipment, assistive devices, environmental supports, materials, supplies, etc., specified in each individual's IPP to accomplish stated objectives.</p> <p>A consistent approach is being implemented in all environments.</p>
	(1) The individual program plan must be reviewed at least by the qualified intellectual disabilities professional and revised as necessary, including, but not limited to situations in which the client -	
W255	(i) Has successfully completed an objective or objectives identified in the individual program plan;	<p><u>§483.440(f)(1)(i)-(iv) FACILITY PRACTICES:</u>  The QIDP ensures the program has been modified or changed in response to the individual's specific accomplishments, need for new programs, or difficulties in acquiring or maintaining skills.</p>
W256	(ii) Is regressing or losing skills already gained;	<p><u>§483.440(f)(1)(i)-(iv) GUIDELINES:</u>  The interval within which IPP reviews are conducted is determined by the facility. However, the facility's review system must be sufficiently responsive to ensure that the IPP is reviewed <u>whenever</u> the conditions specified in "483.440(f)(1)(i-iv) occur. Information relevant to IPP changes should be recorded as changes occur.</p> <p><u>§483.440(f)(1)(i)-(iv) PROBES:</u>  Is there evidence that collected data are systematically recorded, analyzed, and used to make changes in programs?</p>
W257	(iii) Is failing to progress toward identified objectives after reasonable efforts have been made	
	The SCC must.....	
W262	(i) Review, approve, and monitor individual programs designed to manage inappropriate behavior and	<p><u>§483.440(f)(3)(i) FACILITY PRACTICES:</u>  Any programs which incorporate restrictive techniques (e.g., restraints, medication to manage behavior, restrictions on community access, etc.) have been reviewed and approved by the committee prior to implementation.</p>

	<p>other programs that, in the opinion of the committee, involve risks to client protection and rights;</p>	<p>The committee periodically monitors restrictive programs to determine if the restriction of rights or risk to protections remains justified.</p> <p><u>§483.440(f)(3)(i) GUIDELINES:</u>  Each individual program developed to decrease inappropriate behavior and which involves potential risk to rights and protections must be reviewed and approved by the committee prior to the program's implementation. Some examples of programs requiring review include, but are not limited to, programs incorporating usage of restraints, aversive conditioning, <u>any</u> medication used to modify behavior, contingent denial of any right or "earning" of a right as part of a behavior shaping strategy, and behavioral consequences involving issues of client dignity.</p> <p>The committee need not reapprove a program when revisions are made, as long as those revisions are in accordance with the approved plan. For example, if the physician changes the dosage of a medication in accordance with the drug treatment component of the active treatment plan to which the legally authorized person has given consent and which has already been approved by the committee, then there is no need for the committee or the legally authorized person to reapprove the plan. (See also W263.) Generally, this would also apply if the medication was changed to another within the same therapeutic class or family. Reapproval would be needed, however, if the reason for the change was the individual's strong untoward response to the original medication. Due to the differences in side effects and potential adverse response between drugs of a different class, reapproval would also be required if the new medication was from a different therapeutic class or family of drugs.</p>
W263	<p>(ii) Insure that these programs are conducted only with the written informed consent of the client, parents (if the client is a minor) or legal guardian; and</p>	<p><u>§483.440(f)(3)(ii) FACILITY PRACTICES:</u>  Written consent is present prior to implementation of any restrictive program.  Consent is given by the legally appropriate party.  The consent is for the <u>program</u> which incorporates the use of a restrictive technique, rather than the restrictive technique alone.  The consent is informed, i.e., the person giving consent is aware of the risks, benefits, alternatives, right to refuse and consequences.</p> <p><u>§483.440(f)(3)(ii) GUIDELINES:</u>  Informed consent consists of permission by the legally responsible party after having been informed of the specific issue, treatment or procedure; the individual's specific status with regard to the issue, treatment or procedure; the attendant risks and benefits; alternative forms of treatment; the right to refuse treatment and the consequences of that refusal. Informed consent implies that the person who is to give consent is <u>competent</u> to evaluate the decision requiring consent.</p> <p>For children up to the age of 18 the parent (<u>natural guardian</u>) or legally appointed guardian must give consent for him or her. At the age of 18, however, children become adults and are assumed to be competent unless otherwise determined by a court.</p> <p>For individuals who are minors or who are clearly incompetent, but have no appointed legal guardian, informed consent for use of restrictive programs, practices or procedures must be obtained from the legal guardian, parent or someone or some agency designated by the State, in accordance with State law, to act as the representative of the individual's interests. Become familiar with the statutes of the State in which the ICF/IID is located to determine who or what mechanism is designated to give informed consent in such circumstances. Verify whether or not consent was obtained in accordance with law. Additionally, under these circumstances, the facility is required to identify those individuals, and expected to advocate for them by demonstrating continuing efforts to obtain timely adjudication of the individual's legal status.</p>

		<p>The committee must ensure that the informed and voluntary consent of the individual, parent of a minor, legal guardian, or the person or organization designated by the State is obtained prior to each of the following circumstances: the involvement of the individual in research activities, or implementation of programs or practices that could abridge or involve risks to individual protections or rights.</p> <p>Informed consent should be specific, separate ("blanket" consents are not allowed), and in writing. In case of unplanned events requiring immediate action, verbal consent may be obtained, however, it should be authenticated in writing as soon as reasonably possible.</p>
W285	(2) Interventions to manage inappropriate client behavior must be employed with sufficient safeguards and supervision to ensure that the safety, welfare and civil and human rights of clients are adequately protected.	<p><u>§483.450(b)(2) FACILITY PRACTICES:</u></p> <p>Monitoring which is appropriate to the type of intervention being used, is in place to assure that the individual does not suffer unfavorable effects from the intervention.</p> <p><u>§483.450(b)(2) PROBES:</u>  What mechanism does the facility use to ensure that approval does not extend longer than warranted?</p> <p>Do the procedures deny requisite human needs, such as sleep, shelter, bedding, or use of bathroom facilities?</p> <p>Are rights denied in the absence of the required consent and approvals?</p> <p>Are drugs used to manage inappropriate behavior monitored for unfavorable side effects?</p>
	(3) Techniques to manage inappropriate client behavior must never be used	
W286	for disciplinary purposes,	<p><u>§483.450(b)(3) FACILITY PRACTICES:</u></p> <p>No technique, whether a part of a formal program or in informal situations, is used as retaliation or retribution.</p> <p><u>§483.450(b)(3) PROBES:</u>  Do these techniques continue to be implemented and/or authorized regardless of individual success on individual program plan objectives?</p> <p>Are restraints, time-out rooms or drugs used for environmental deficiencies (e.g., lack of staff, program structure)?</p>
W287	for the convenience of staff	<p><u>§483.450(b)(3) FACILITY PRACTICES:</u></p> <p>No technique, whether a part of a formal program or in informal situations, is used to compensate for lack of staff presence or competency.</p> <p><u>§483.450(b)(3) PROBES:</u>  Are the behaviors listed as problematic occurring only in certain situations, such as in living areas and on weekends, possibly indicative of understaffing? Are the problematic behaviors occurring during day programs, possibly indicative of inappropriate placement?</p> <p>Is there a systematic pattern showing restrictive technique usage occurring more frequently in units where staffing is not optimal? Where there is frequent staff turnover?</p> <p>Is usage tied directly to a carefully approved behavior reduction program? Or, is it in practice, a means of locking individuals at the convenience of staff or in the absence of effective programming?</p>
W288	or as a substitute for an active treatment program.	<p><u>§483.450(b)(3) FACILITY PRACTICES:</u></p> <p>Any intervention used is tied to a specific active treatment program which addresses both the inappropriate behavior and mechanisms to teach, improve, support, or substitute appropriate behaviors.</p>

		<p><u>§483.450(b)(3) PROBES:</u> Does the program to control inappropriate behavior actually address the problems identified, or is it, in fact, a behavior control/punishment program that does not result in desired behavior outcomes?</p>
W291	<p>(1) A client may be placed in a room from which egress is prevented only if the following conditions are met: (i) The placement is a part of an approved systematic time-out program as required by paragraph (b) of this section. (Thus, emergency placement of a client into a time-out room is not allowed.) (ii) The client is under the direct constant visual supervision of designated staff. (iii) The door to the room is held shut by staff or by a mechanism requiring constant physical pressure from a staff member to keep the mechanism engaged.</p>	<p><u>§483.450(c)(1) GUIDELINES:</u> The use of time-out rooms is effective only if the individual does not like to be removed from an activity or from people. Look for patterns of frequent, lengthy time-out usage which often indicates that the environment is not reinforcing to the individual (i.e., the activities in and of themselves are not engaging, and/or the scheduled activities are potentially engaging yet the schedule is not implemented). If the individual who is in a time-out room engages in self-abuse, becomes incontinent or shows other signs of illness, staff should immediately discontinue the procedure and intervene.</p> <p>Verify whether or not anyone standing or lying in any position, in any part of the time-out room can be seen.</p> <p>Key locks, latch locks, and doors that open inward without an inside doorknob are not devices or mechanisms which require constant physical pressure from a staff member to keep a door shut, and, therefore, are not permitted by the regulations.</p> <p>Pressure sensitive mechanisms must allow staff to enter the room at the moment the need arises.</p> <p><u>§483.450(c)(1) PROBES:</u> Is usage directly tied to a carefully approved behavior reduction program or is it in practice a means of locking individuals at the convenience of staff or in the absence of effective programming?</p>
W293	<p>(3) Clients placed in time-out rooms must be protected from hazardous conditions including, but not limited to, presence of sharp corners and objects, uncovered light fixtures, unprotected electrical outlets.</p>	<p><u>§483.450(c)(3) GUIDELINES:</u> A door that opens inward can potentially be held closed, either intentionally or inadvertently, by the individual in the room, thereby denying staff immediate access to the room.</p>
W301	<p>(4) A client placed in restraint must be checked at least every 30 minutes by staff trained in the use of restraints,</p>	<p><u>§483.450(d)(4) GUIDELINES:</u> The frequency of monitoring will vary according to the type and design of the device and the psychological and physical well-being of the individual. For example, an individual in four-point restraints might require constant monitoring while someone in soft mittens may require less frequent monitoring. It is also true that for some individuals, constant visual supervision would serve to reinforce the inappropriate behavior and thereby reduce the clinical effectiveness of using the restraint. However, in no case may the 30 minute time limit be extended.</p> <p>"As quickly as possible" means as soon as the individual is calm or no longer a danger to self or others.</p> <p><u>§483.450(d)(4) PROBES:</u> Is there a pattern that individuals are placed in restraints repeatedly for 2-hour consecutive applications during the entire restraint authorization period?</p> <p>Does the team decide whether constant or frequent monitoring is helpful or contraindicated for an individual? On what basis is this decision made?</p> <p>When staff apply restraints do they demonstrate proper usage per each</p>

		individual's program? Is the use of restraints well documented to present a clear picture of the events prior to, during, and following its use? Is this information reviewed by the IDT and addressed?
W302	released from the restraint as quickly as possible,	
W313	(3) Drugs used for control of inappropriate behavior must not be used until it can be justified that the harmful effects of the behavior clearly outweigh the potentially harmful effects of the drugs.	<u>§483.450(e)(3) FACILITY PRACTICES:</u> The risk(s) associated with the drug being used is consistent with the type and severity of the behavior/symptoms it is intended to affect.
W314	(i) Monitored closely,	
	in conjunction with the physician and the drug regimen review requirement at §483.460(j),	<u>§483.450(e)(4)(i) FACILITY PRACTICES:</u> The physician and the pharmacist regularly review use of medication for its effectiveness in changing the targeted behavior/symptoms, untoward side effects, contraindications for continued use, and communicate this information to relevant staff.

*Community is not a place but a way of life. Herb Lovett, Ph. D., Advocate & Author*

Your attitude just might be my biggest barrier [to inclusion].  
Kim Davis, Educational Consultant

***Module 6:  
Promoting Community  
as a  
Way of Life  
Participant Version***

...[instead of asking] “Why?” [ask] “Why not?” and Why not now?”...  
Dale L. Dutton, Parent, in the foreword of *Real Work for Real Pay*

**Module 6 Promoting Community as a Way of Life**

1. Introduction and Objectives
2. The Importance of Inclusion
3. Inclusion – Active or Passive?
  - Activity 1 More Inclusive or Less Inclusive?
  - Reflections on Activity 1
4. Moving Towards Inclusion for Everyone
  - Start with the Person
  - Sample CMS - 2567 for Tag W136
  - Activity 2 – Part 1 Identifying Inclusive Themes - Worksheet
  - Activity 2 – Part 2 Representative Tag Examples by Inclusive Keywords
  - Thoughts on Activity 2
5. The Language of Inclusion
  - More on Talking the Talk
6. Supported Employment
7. The Integration Mandate
8. The Era of Inclusive Support and Self-determination
9. For More Information – References for Module 6

## Section 1

### Introduction

In a speech in Dallas, Texas in 1996, Dr. Herb Lovett asked the audience to consider the idea that “community is not a place but a way of life”. He went on to explain that people with disabilities have the same rights as everyone else and should not be expected “to earn” their way into “ordinary” places--schools, homes and jobs. As he put it, “Rights are not privileges.” He believed that the long-accepted practice of readiness was “wrong” and that people with disabilities should not need to “prove” their worthiness for life in the community “to a team” (Dowling, 1998, pg 1). In the field of human services, this belief - that everyone should have access to and choices within the community - is known as **inclusion**. It is more than just physical integration; it is based on being “welcomed and embraced” as a “participating and contributing member” of society (Beirne et al., 2006, pg 362).

Take a moment to think about “community as a way of life” versus “community as a place”. Notice how it affects one’s mindset. A way of life has permanence to it; on the other hand, a place feels temporary – like you might visit and never go there again. A place sounds limited, whereas a way of life suggests opportunities – or, as vacation planners say, “it’s more than a location, it’s a destination”. A way of life implies long-term relationships, not just momentary encounters. A way of life says the person “belongs” instead of being a transient who stands out. A way of life hints at naturalness, of natural supports; community as a place suggests differences may exist in expectations or treatment depending on who you are. Community as a way of life is about the same rights and acceptance that others have - all the time.

Can you see how these two visions of community might result in very different services to people?

The ICF/IID (Intermediate Care Facilities for Individuals with Intellectual Disabilities) program and its regulations might be considered a bridge between the eras of institutionalization and inclusion. The program was conceived as a means to promote treatment (vs. custodianship) shortly after the population of large state institutions for people with intellectual disabilities peaked at 195,000 in 1967. Interest grew in the program as landmark rulings were made by courts (*Wyatt*, 1971, 1975, 1979; *Willowbrook*, 1973; *O’Connor*, 1974; *Halderman*, 1977) in favor of the “right to treatment” in facilities, culminating in states spending nearly a billion dollars for ICF/IID certification in the years 1978-1980. Since then “active treatment” provided by the ICF/IID coupled with increased options for supported community living have systematically reduced the numbers of ICF/IID and people in living in ICF/IID. For example, from 1993 to 2004, Charlie Lakin et al. (2005) reported a decline in ICF/IID population from 147,729 people to 104,526. In August of 2006, the Federal On-site Survey and Certification Automated Reporting System (OSCAR) revealed 98,479 people in 6,437 ICF/IID. In March 2010, OSCAR demographics found 109,449 people living in 6,434 ICF/IID.

You may be thinking “these numbers are high” but you need to know that the **percentage** of the population estimated to have intellectual disabilities and developmental disabilities has held steady – meaning that there has been no decrease in the number of people who might request services. Services are changing but not the people who may need them. You also need to know, ICF/IID ownership and size have changed over the years – now most are privately (vs. publicly) operated and the majority of facilities are 4 to 8 beds located in neighborhoods, not the out-lying locations that characterized state institutions in 1967 when hundreds and, in a few cases, thousands of people were segregated away from population centers.

In this module, it will become evident what these trends have to do with the concept of **inclusion** and how surveyors can support inclusion.

### **Objectives for this module**

Upon completion of this training module, you will be able to:

1. List at least five reasons that “inclusion” is important.
2. List at least ten fundamental tags which support “inclusion”.

## **Section 2**

### **The Importance of Inclusion**

Research has shown that inclusion benefits both people with disabilities and people in general (Koegel et al., 1996, p. 127-128, 146 and 296). When people with disabilities participate in everyday activities, it alters the attitude of society because these people are no longer “unknown quantities”. Conversely a person with a disability who is part of the community benefits from increased opportunities for:

- Modeling. Typical people in typical places doing typical things can be observed and imitated.
- Exposure to the bigger “world around them”. Alternatives to what the person knows are demonstrated and become options to try or learn.
- Friendship. Proximity is one factor in developing social relationships.
- Communication. Language used in institutional settings is limited. New settings give reasons for people to initiate language and respond to it.

There are some theories that the “feeling of belonging” to the community may also make the difference between health and illness. Numerous studies, including a nine year study of 7000 people in California reported by Brent Hafen, Kathryn Frandsen and N. Lee Smith in 1996, showed people with more social supports were healthier and lived longer than those with few friends, family or organizational affiliations. The reasons were not clear. Perhaps it was the additional resources (i.e. financial, informational, physical assistance) that these supports provided or that the feeling of belonging improved the immune system. Regardless, social support correlates with still

other variables related to health and illness, such as reduction in amounts of medication, speedier recovery time and compliance with medical regimens (O'Brien and O'Brien 2002, pg. 105-6).

Not surprisingly, inclusion is cost effective. There is no need to have duplicate health facilities, recreational facilities, transportation systems, employment settings and residences for people with disabilities and people without disabilities. Also, as funding for alternatives to publicly funded facilities and services slows, friends, neighbors, employers and others can be supports instead of increasing numbers of paid professionals. Additionally, as is already demonstrated in England and Sweden, people with disabilities can change from tax beneficiaries into tax payers when concepts leading to inclusion are promoted (O'Brien and O'Brien, 2002).

Finally, and perhaps most important of all, are the many stories told by advocates, human service professionals and people with disabilities themselves. As opportunities for choice and inclusion increase, these stories report individuals' feelings of happiness, acceptance and value increase while isolation and behavioral issues decrease (O'Brien and O'Brien, 1998 & 2002).

**Photo of interlocking hands demonstrating "inclusion".**



### **Section 3**

#### **Inclusion - Active or Passive?**

If you think back to the definition provided in the introduction to this module, you will conclude that there is no such thing as passive inclusion. Inclusion by definition is active. To be "embraced", one must be "out and about"; to "participate" one must be "out and about"; to "contribute", one must be "out and about". But even "out and about" is not enough for some people with some disabilities. To the extent necessary, supports which facilitate social interactions with shop keepers, restaurant servers and cashiers, librarians, personal trainers, coaches, teachers, fellow shoppers, fellow diners, fellow students, fellow recreators, fellow club members, and so on are critical to

increasing the odds of being “embraced”, of fully participating and of contributing to the well-being of others.

Earlier in this module it was mentioned that inclusion in the community could change the lives of people with disabilities as well as the attitudes of people without disabilities. An example of this was recently featured on the ABC evening news ([www.abc.news.go.com](http://www.abc.news.go.com), October 16, 2009). A varsity cheerleader was inspired by Special Olympics to ask her high school squad to sponsor and train young women with intellectual disabilities to cheer with them at games. The Spartan Sparkles now practice and perform weekly – all in the same uniforms with the same enthusiasm as their mentors. Interviews revealed the pride of the varsity cheerleaders, their trainees and the fans and suggested new levels of participation, respect and friendship in that community for the young women with disabilities. A perfect example of what the right support in the right place can achieve!

The Spartan Sparkles story demonstrates why taking a van ride with one’s housemates from the ICF/IID which culminates in staff ordering food at a drive-in window **is not** inclusion. People in the van may be communicating but where are the opportunities to be “embraced”, to “participate” or, even, to “contribute”? A very different scenario is a person (let’s call him Mike) asking a friend from work or the neighborhood to go out – even if it was staff who encouraged Mike to extend the invitation. Maybe they meet and walk together, or take a bus or the friend (or staff) drives them to a restaurant of their choice. Mike orders, perhaps by responding to spoken choices or by pointing at pictures, continues to interact with his friend and the server and has the opportunity to watch or smile at other customers or even to pick up and return an item someone else drops. Mike may see something he wants to try for dessert or the next time he eats out. He might model other customers’ use of condiments, utensils or napkins. The table, booth or counter seat provides a comfortable vantage point. If Mike goes to that restaurant with some regularity, over time he will be recognized and restaurant staff may even ask if he wants his “usual” order or how his day went. And he might just gesture, sign or ask them about theirs. Which scenario would be a “way of life” to you? Which is just visiting a “place”? Which would be more satisfying?

As a surveyor you should expect to find through observation, interview and record review that your sample members participate in their local community. If they live in a large ICF/IID, the community is NOT activities which occur in non-residential buildings on the property. The community is the neighborhood - people and places - and resources which surround the grounds/property where the home is located. In rural, and even some city or suburban areas, commonly used community resources such as public libraries, educational or sports facilities and social organizations may be miles away. It is expected that the provider will support people in utilizing them, either to assess interest or explore the various aspects of someone’s known preferences and goals.

## Activity 1 - More Inclusive or Less Inclusive?

**Participant instructions:** Please read the standard and the guidance for tag W136 in Appendix J. Next, read through the following list of community related activities and identify with a checkmark those which would cause a surveyor to ask questions relevant to W136. In the margin, jot down a question you might ask to explore your concern. Save this document for your Preceptor discussion telephone call.

1. \_\_\_ Always being taken as a group to the community pool in the facility bus.
2. \_\_\_ Going to the local tavern on St. Patrick's Day to enjoy the music and dancing.
3. \_\_\_ Attending a surprise birthday party for the supervisor at McDonald's.
4. \_\_\_ Celebrating Halloween at a party for the residents of three group homes.
5. \_\_\_ Folding fliers at home for the Red Cross.
6. \_\_\_ Helping to carry supplies during the construction of a Habitat for Humanity home.
7. \_\_\_ Playing the maracas nearly every karaoke night at the local club.
8. \_\_\_ Attending chapel at 3 pm because that's when the minister can come to the facility.
9. \_\_\_ Ushering at the church a person's family attends using an electric scooter.
10. \_\_\_ Being taken to evening adult ed class despite asking to watch "Oprah" instead.
11. \_\_\_ Riding with the next door neighbor to volunteer at the local food bank.
12. \_\_\_ Meeting monthly with other birdwatchers at the clubhouse at the local preserve.
13. \_\_\_ Meeting monthly with an advocacy group for people with intellectual disabilities.
14. \_\_\_ Counting family vacations and family visits as a person's community activities.
15. \_\_\_ Attending Catholic church services when the stated preference is Lutheran.
16. \_\_\_ An adult volunteering as an assistant for a children's art class.
17. \_\_\_ All members of the sample going to identical activities for two months.

## Reflections on Activity 1

In Activity 1 you were asked to begin thinking about what made experiences more inclusive vs. less inclusive. The guidance for W136 points out that there are more variables than simply where one does an activity. Who else is there is a consideration. The surveyor is also guided by Appendix J to look at what the activity is. Is it age- and interest-appropriate? Are supports provided at the level needed? Is there variety? Meeting W136 is a matter of quantity and quality.

W136 does not say that every activity in a given month must be fully integrated, although that would be best practice. Rather, the surveyor must evaluate what observation, interview and record evidence relate about peoples' experiences and the above mentioned variables to determine whether the facility is meeting the intent of the regulation. If no one participates in activities held in the community, there is a problem. If events attended do not match assessed preferences, there is a problem. If there is no variety in activities, there is a problem. If people do not receive the support needed to participate regularly in activities, there is a problem. While surveyors must remember that there will be acceptable reasons for (occasional) exceptions to attending activities in the community (i.e. illness, extreme behavior, bad weather), it is important to remember the community is ripe with opportunities and the facility may just need to think outside the box.

Be aware that some community-based activities are related to other ICF/IID Regulations. Attending self-advocacy training (W125), counseling (W227/W240) and visits to family (W147) come to mind. This is not to say that the facility cannot count them as activities, rather that the surveyor needs to recognize them for what they are, one type of activity. More about W136 and the other tags which support inclusion will appear later in this module.

## Section 4

### **Moving Towards Inclusion for Everyone**

In Module 2, Promoting Dreams and Meaningful Lives, examples were given of activities in which people with intellectual disabilities might participate. While it is not your place as a surveyor to “make a list” for a facility, it is important to periodically think about the things adults and children typically do and then to consider how people with differing levels of intellectual disability might participate in their homes and in the community. This will help you ask pointed interview questions when you are evaluating compliance with regulations related to inclusion, particularly those related to community participation, client training and supports.

For example, think about the activities one might do related to a (free) public library. Now days, libraries have tapes, CDs, DVDs, books, books-on-tape, large print books, magazines, computers, reading groups, speakers on interest topics, readings by authors, tax and other forms. Many libraries allow you to select items via computer and then pick them up when they are available. For a person who likes movies, selecting and ordering DVDs on-line, picking them up and checking them out with a library card, watching them at home and returning them, might be the way to start learning library etiquette and to get to know staff and people who frequent the library. This could progress into making selections at the library from the physical inventory, attending speaker/reader/movie presentations and volunteering in some capacity, e.g., setting up chairs or passing out brochures for a presentation or a fundraiser. For another person, it might start with borrowing CDs, but you get the idea. It takes thinking; it takes planning. It takes training and supports. It probably takes trial and error – just as it would if it was you deciding whether you wanted to continue to participate in something or not. From the beginning to the end, it takes listening to the person.

### **Start with the Person**

During Basic ICF/IID Surveyor Training you are told when you survey to begin with the person, not his or her disability. What is important to him/her? Who is significant to him/her? What does the person want to do? What do other people his or her age do? What can the person do? How is the person supported? This is also the kind of information used by advocates of inclusion in “person centered planning”. Variations of person centered planning for people with disabilities include Individual Service Design, Circle of Friends, Essential Lifestyle Planning, Planning Alternative Tomorrows with Hope (PATH), Making Action Plans (MAPS), Personal Histories and Personal Futures Planning. In general, the protocols have in common listening and creative thinking. The focus is the person and the ways to implement the person’s choices and dreams. Self-determination is highly valued. (O’Brien & O’Brien, 1998; Wehman et al., 2007)

As a surveyor you should be aware that these planning protocols exist; you may hear about them or see individual program plan documents with names such as “My Personal Futures Plan” or “John Smith’s PATH”. Some advocates and human service professionals have maintained these protocols are inconsistent with ICF/IID Regulations; however, others have shown they can work in any setting (O’Brien and

O'Brien, 1998). As a surveyor, the critical thing to remember is that the ICF/IID standards on team construction, assessment, prioritization, objectives, interventions and so on need to be met and documented regardless of the means that the person's planning team used to get to them.

### **Sample Tag**

You may be wondering how you as a surveyor can address the quantity and quality of community activities. A sample tag follows.

W136 483.410 (A)(11) PROTECTION OF CLIENTS RIGHTS

The facility must ensure the rights of all clients. Therefore, the facility must ensure clients the opportunity to participate in social, religious and community group activities.

Based on observation, interview and record review, the facility failed to ensure 2 of 3 clients from the sample (#1, 3) had opportunities for community activities.

#### **Findings:**

1. On 11/3/yy at 10 am, the Vocational Aide stated that Client 1 went on evening van rides organized by staff almost weekly but that these rides did not include interacting with others in the community such as personnel in stores and restaurants. She acknowledged Client 1 enjoyed the rides and would probably like to go more often.
2. On 11/3/yy at 4:30 pm, Client 3 and Direct Support Aide (DSA) 2 were observed entering the side door of the home. DSA 2 volunteered they were just returning from a walk around the neighborhood. When asked what he did on the walk, Client 3 did not respond to the surveyor. DSA 2 reported that Client 3 was severely hearing impaired but enjoyed walking; therefore, his community outings involved walking in the local neighborhood or park. When asked about activities that might occur during the walks, DSA 2 stated "looking at the scenery". Shopping and eating out did not occur during walks.
3. On 11/4/yy, a review of Client 1's record including the Individual Program Plan (IPP) dated 5/19/yy, identified no data, interventions or objectives related to opportunities to participate in social, religious and community group activities. An objective to make a choice between options was present.
4. On 11/4/yy, a review of Client 3's record including the Individual Program Plan dated 8/28/yy found no objectives or data pertaining to opportunities to participate in social, religious and community group activities. The IPP included three interventions to be implemented by direct support staff by 9/30/yy, but the record did not indicate they had been completed. The first was to take Client 3 to a store to select a car magazine or to a car show or dealership due to an apparent interest in cars. In the second, Client 3 was to be taken to purchase CDs that produce strong vibrations as Client 3 listened to music via headphones and seemed to enjoy the vibrations. In the third, a consult was recommended with the Center for the Deaf for games or activities which provide sensory stimulation.

3. On 11/4/yy at 1:06 pm, an interview was held with Client 1's and 3's Qualified Intellectual Disabilities Professional. She acknowledged that the facility should use Client 1's rides and Client 3's walks to provide community integrating activities by ensuring opportunities to interact with personnel in stores and restaurants and other people in the community. She said Client 1 enjoyed food, so making choices in or about restaurants and stores in the community would be one way. She did not know how the three IPP recommendations for Client 3 had been overlooked but stated they would be integrated into his daily outings.

## **Activity 2**

Earlier in this module you were told that the ICF/IID Regulations might be considered a bridge between the eras of institutional custodianship and community inclusion. This was said because the ICF/IID Regulations do not require "full" inclusion (i.e. the use of only community health facilities, inclusive employment for all interested adults of working age or similar concepts) **but they do promote inclusion**. In the following Activity you will print and evaluate examples of regulation and guidance which promote inclusion.

## Activity 2

### Part 1 – Identifying Inclusive Themes Worksheet

**Directions:** You will use both Part 1 and 2 for this activity. Read through the list of representative tags which follows this worksheet. As you are doing this, decide which of the six following categories (or inclusive themes) each tag belongs to. Note the tag under that category.

1. The ICF/IID Regulations **promote inclusion** by permitting facilities to use community services and requiring coordination between the facility and the outside services or programs. Examples of tags that do this:
2. The ICF/IID Regulations **promote inclusion** by requiring leaves from the facility and participation in community activities. Examples of tags that do this:
3. The ICF/IID Regulations **promote inclusion** by requiring assessment and training designed to make people more independent. Examples of tags that do this:
4. The ICF/IID Regulations **promote inclusion** by requiring supports as needed. Examples of tags that do this:
5. The ICF/IID Regulations **promote inclusion** by asking facilities to use community expectations as a yardstick against practices they adopt and training and supports they provide. Examples of tags that do this:
6. The ICF/IID Regulations **promote inclusion** by requiring policy and processes which protect clients' rights as citizens. Examples of tags that do this:

### Part 2 – Module 6 Representative Tag Examples by Inclusive Keywords

The following tags are arranged by keywords related to inclusion as discussed in this training module. The purpose of the listing is to show the surveyor **some** of the many places in Appendix J that inclusion is addressed.

The statements which follow each W-tag number are excerpts from the regulation and/or the guidance to surveyors in Appendix J. This means the reader must go to Appendix J to read the entire regulation and guidance when determining whether to use the tag in a CMS-2567 report. The tags listed are both fundamental and non-fundamental.

## **Community**

- W122 – Individual freedoms are promoted (e.g. individuals have choices and opportunities in their money management, community involvement, interpersonal relationships, daily routines, etc.)
- W125 – As long as there are no decisions or circumstances which require action by a legally-appointed surrogate, a spokesperson or advocate could assist the individual in exercising his or her rights as a citizen of the United States and as a person residing in the facility. Some examples might include assisting the individual to express his/her needs, wants and interests, to utilize community resources or to file a complaint.
- W132 – “Prevailing wage” refers to the wage paid to non-disabled workers in nearby industry or the surrounding community for essentially the same type, quality and quantity of work or work requiring comparable skills.
- W136 – (11) Ensure clients the opportunity to participate in social, religious, and community group activities;  
Individuals are involved in various types of activities in the community (e.g., going to parks, movies, restaurants, church, community meetings and events) based on their interests and choices.  
Individuals are taught the skills and are provided with appropriate levels of support, commensurate with functional levels, for community participation.  
Does the facility arrange for individuals to participate in community integrated activities individually or in small groups (3 or less) at least part of the time?  
Does the facility arrange age and interest appropriate outside activities for individuals with the community (e.g., recreation centers, churches, social clubs)?
- W137 – Do colors, styles and designs match and conform with community standards?
- W195 – Individuals have developed increased skills and independence in functional life areas (e.g., communication, socialization, toileting, bathing, household tasks, use of community, etc.)
- W202 – Does the IPP reflect objectives preparing the individual for transfer or community placement?
- W224 – Assessment includes(s) adaptive behaviors or independent living skill necessary for the client to be able to function in the community.
- W228 – To organize objectives into a planned sequence the ICF/IID must consider the outcomes it projects for the individual in the long term. For example, if the long term objective is for the individual to travel independently in

the community, the planned sequence may involve training the individual to recognize traffic signs, cross a street safely, and to obtain help when needed if lost or an emergency arises.

- W246 – Is equipment available to provide access to community activities?
- W262 – Any programs which incorporate restrictive techniques (e.g., restraints, medication to manage behavior, restrictions on community access, etc.) have been reviewed and approved by the committee prior to implementation.
- W361 – The facility must provide or make arrangements for the provision of routine and emergency drugs and biologicals to its clients. Drugs and biologicals may be obtained from community or contract pharmacists or the facility may maintain a licensed pharmacy.

### **Church, Clubs, Recreation, Restaurants, Shopping, School, Vacations**

- W131 – Shared duties are common and appropriate. Included ...are:...food purchasing...shopping, including clothing.
- W136 - Individuals are involved in various types of activities in the community (e.g., going to parks, movies, restaurants, church, community meetings and events) based on their interests and choices.  
Does the facility arrange age and interest appropriate outside activities for individuals with the community (e.g., recreation centers, churches, social clubs)?
- W137 – As appropriate, each individual's active treatment program maximizes opportunities for choice and self-direction with regard to choosing and shopping for clothing which enhances his or her appearance, and selecting daily clothing in accordance with age, sex and cultural norms.
- W147 – The facility must promote frequent and informal leaves from the facility for visits, trips or vacations.
- W196 – The ICF/IID ensures that each individual receives active treatment daily regardless of whether or not an outside resource(s) is used for programming (e.g., public school, day habilitation services, senior day services program, sheltered workshop, supported employment).
- W374 – When individuals go out of a facility for home visits, or to attend workshops or school, drugs they are taking must be packaged and labeled in accordance with State law by a responsible person approved to administer medications.
- W459 – Individuals participate in normalized dining experiences appropriate to their functional abilities (e.g., using knives, family style meals, going to restaurants, etc.) and are being taught skills to do so.
- W468 – Mealtimes accommodate a variety of recreational activities (in and out of the facility) throughout the year, especially weekend and holiday activities.
- W488 – individuals learn skills in accordance with their functional levels including: ...ordering food in restaurants.  
Determine to what extent individuals are exposed to out-of- the home dining environments available to the general public (e.g., restaurants, fast-food establishments, picnics, parties, cafeterias, etc.)  
Are individuals allowed to dine out at places like fast food restaurants, buffets, vendors at the park or beach?

Do individuals take turns ...Shopping for and putting food away?

### **Integrated**

- W136 - Does the facility arrange for individuals to participate in community integrated activities individually or in small groups (3 or less) at least part of the time?
- W249 – Are active treatment activities integrated into a “normal daily rhythm”?

### **Least/Less Restrictive**

- W147 – It is not acceptable for a facility to sponsor or allow individuals to take a particular type of trip that is contraindicated. ...However, as with any right that may need to be modified or limited, the individual should be provided with the least restrictive and most appropriate alternative available.
- W488 – Mastery of the social skills involved in eating in a variety of dining areas and settings is another step to the individual’s independence beyond the health aspects of nutrition and the basic skills involved in eating independently. Achieving independence will further help the individual to live in less restrictive environments.

### **Outside, Outside Services/Resources, External Programs**

- W119 – (1) If a service required under this subpart is not provided directly, the facility must have a written agreement with an outside program, resource, or service to furnish the necessary service, including emergency and other health care.
- W120 – (3) The facility must ensure that outside services meet the needs of each client. Does the facility periodically observe services that are provided by the outside resource?
- W133 – Does the facility provide individuals with the opportunity to form individual relationships with others including opportunities to experience person relationships both within and outside the facility?
- W136 – Does the facility arrange age and interest appropriate outside activities for individuals with the community (e.g., recreation centers, churches, social clubs)?
- W159 – The QIDP ensures consistency among external and internal programs and disciplines.
- W196 – The ICF/IID ensures that each individual receives active treatment daily regardless of whether or not an outside resource(s) is used for programming (e.g., public school, day habilitation services, senior day services program, sheltered workshop, supported employment).
- W251 – The activities of the ICF/IID are coordinated with other habilitative and training activities in which the individual may participate outside of the ICF/IID, and vice versa.
- W252 – Are the data collected on objectives outside the facility also reviewed and analyzed to justify change in the objectives?

- W262 – The purpose (of the specially constituted committee) is to assure that each individual’s rights are protected through use of a group of outside individuals who are not invested in the maintenance of facility practices.
- W322 – Medical services, including sources for laboratory, radiology, and other medical and remedial services available to the individual must be provided if not provided in-house. There must be a written agreement that specifies the responsibilities of the facility and outside provider.
- W467 – It is the facility’s responsibility to ensure meals that are eaten regularly outside the facility are adequate...

### **Self-determination**

- W196 – (1) Each client must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services described in this subpart, that is directed toward-- (i) The acquisition of the behaviors necessary for the client to function with as much self-determination and independence as possible.
- W269 – Conduct towards clients. These policies and procedures must - (ii) Address the extent to which client choice will be accommodated in daily decision-making, emphasizing self-determination and self-management, to the extent possible;...

### **End Activity 2 – Part 2**

#### **Thoughts on Activity 2**

Were you one of the people who finished Activity 2 and said “I can think of tags/regulations that were not included”? You would be correct. There are quite a few other tags/regulations which facilitate inclusion in the ways discussed. Some do not include “keyword” language but nevertheless the intent is there. For example, guidance for W274-275 requires policy address the use of procedures/practices which would be “stigmatizing” if applied to “non-disabled peers”. Other tags were previously discussed in Module 3 on Independence, Module 4 on Technology and Adaptations and Module 5 on Behavior Support and the decision was made not to repeat them. Also not included was a theme considered self evident: **requirements that promote “social supports”**, an important component of inclusion. These tags/regulations would include keywords such as friends, family members, advocates and guardians. Did you think of any other inclusive themes?

## Section 5

### The Language of Inclusion

For more than two decades, advocates of inclusion and supports have been working diligently on a paradigm shift in what was once commonly called the field of intellectual disability. Their vision, a world which does not diagnose and label people or limit them to predetermined services, now appears in professional, educational, health and advocacy organizations and textbooks. This vision identifies supports (resources and strategies) which enable a person to function in the environments which are meaningful to them.

Perhaps the most obvious signal that this vision has taken hold is the frequent appearance of the words “intellectual disability” or “individual with an intellectual disability” in place of the words “mental retardation” and “mentally retarded”. Language converts include: the World Health Organization, Centers for Disease Control, the United States President’s Committee on Individuals with Intellectual Disabilities (was Mental Retardation) and the oldest and largest professional organization on intellectual disability, the American Association on Intellectual and Development Disabilities (AAIDD), formerly the American Association on Mental Retardation. Interestingly, as this module was being written, Rosa’s Law, a bill that would make those same language substitutions in federal education, health and labor laws was introduced in the United States Senate ([www.aaid.org](http://www.aaid.org), November 2009).

You may be wondering what this means to people with intellectual disabilities (or mental retardation) and to you as a surveyor. **Stay tuned!** At the moment, it is largely word substitution. The AAIDD website explains that the term “intellectual disability” is less offensive to people with disabilities, is internationally recognized and is a “heads-up” that the service model is changing from deficiency-based to support-based. ***Unless Rosa’s Law or a similar bill becomes federal law, “intellectual disability” is NOT the language of federal laws or regulations or CMS-2567 reports.*** However, that said, for those of you working in states such as Maryland which have already passed a law changing state terminology, there will be changes in language you use as you complete your state-related activities. For the rest of us, there is no harm in beginning to use “intellectual disability” when such a descriptor is required conversationally—or at least at times it will not confuse people using the current federal regulations.

### More on Talking the Talk

While we are on the topic of language, let’s talk for a moment about “deficiencies” and their place in inclusion and the ICF/IID Regulations. According to Appendix J of the ICF/IID Regulations, “deficiencies” are synonymous with citations. Advocates of inclusion are fine with that; their beef is when “deficiency” is synonymous with disability, specifically when a person is described by diagnostic labels or lists of things they can’t do. These are descriptors that work against inclusion because they emphasize how people are different rather than similar.

You will remember language and labeling people was discussed at length in Module 1, Promoting Dignity. Consider these additional thoughts on diagnostic labeling:

- As surveyors, we can recognize how labels separate people and use these types of words only in those infrequent situations which require them - for example, in CMS-3070G report forms which ask for characteristics of the facility's clients.
- When completing a citation in the CMS-2567 report form, use a diagnosis only when it is pertinent to making the case. For example, in a health related regulation, the relevant medical condition would be stated. It is not necessary to routinely describe or identify each member of the sample who appears in a citation by listing each of their mental or physical disabilities/diagnoses.
- When emphasizing that a skill should be addressed that is not being taught, consider presenting skills of similar complexity that the person already performs. For example, rather than use the descriptor "mild mental retardation" to imply what the person might learn, describe a skill that was witnessed or an objective that the person has accomplished, such as makes her own sandwich and makes change to \$5.

Remember what was said earlier in this module? Start with the person, not their disability! By thinking before we speak or write, it is possible to model descriptive language which is **not deficiency-based**. If it was about you, which would you prefer?

## Section 6

### Supported Employment

No discussion of community inclusion would be complete without mentioning supported employment, one of the most significant developments for people with severe disabilities in our time. First attempted in the early 1970's, it was finally included in the 1986 reauthorization (Public Law 99-506) of the federal Rehabilitation Act of 1973 (Wehman et al., 2007, pg. 38). The law defines supported employment as:

*Competitive work in integrated settings (A) for people with severe handicaps for whom competitive employment has not traditionally occurred, or (B) for individuals for whom competitive employment has been interrupted or intermittent as a result of a severe disability, and who, because of their handicap, need ongoing support services to perform such work.*

Why, you may be wondering, is this significant? Well, here's the story. For many years employment services were initiated through a state's Vocational Rehabilitation Services (VRS) program only as a person was being transferred out of a state institution or ICF/IID. While this worked for some people, it was not sufficient support for many others. Over time, laws and supported employment practices evolved. Now a person living in ICF/IID may hold a job which pays the same wage as his non-disabled co-workers through supported employment (VRS, facility or other sponsor) and still be considered appropriately placed in the ICF/IID. In fact, this type of job would be a best practice in terms of the concept of inclusion.

The facility is expected to provide vocational assessment (W225 - see Guidance for Surveyors for whom and how) which identifies needed services without regard to availability (W215). If the vocational assessment or the age, abilities and interests of your sample members indicate they should be working (and are not) or should be working at a different type of job, pursue why they are not. It may be failure to properly assess or update assessment, but it also may be that governing body has not done its job to develop resources (W104).

Additionally, as you saw in Activity 2, a facility may hire clients to work and pay them based on community prevailing wage (W132). Such work must be based on free choice/interest (W131). The type of activities the facility must pay clients to perform is discussed in Guidance for Surveyors for W131-132. If you have reason to question facility employment or payment practices, you should ask for records kept for the Department of Labor and, if your home office agrees that it is necessary, consult with wage and hour personnel at the state or federal level.

Supported employment has lasted through two recent recessions, 1990-92 and 2001-02 (Paul Wehman et al., 2007, pg.39), and there is no reason to believe it will not make it through the current fiscal crisis. Between 1988 and 2002, the number of people in supported employment grew faster than those in sheltered workshop and day programs. Yet, in 2002, 118,000 people were employed vs. 365,000 in sheltered workshops and day programs (Wehman et al., 2007, pg. 20). Think about it. Which do you think is more rewarding - financially and in terms of self esteem? Making crafts for your family in a day program? Earning less than minimum wage in a sheltered workshop? Or earning \$7.25/hour (or more) in an occupation which interests you? Proponents of supported employment believe there is a job which can be developed for everyone interested in working. Today's options even include telecommuting, temporary work or self-employment.

**Photo of person with Down syndrome holding folders in employment setting.**



## Section 7

### **The Integration Mandate**

In Modules 2, 4 and 6, federal laws were referenced which promote the inclusion of people with disabilities in education, employment and other aspects of everyday living. One of these laws, the Americans with Disabilities Act (ADA), contains Title II, a section popularly called the “integration mandate”. Title II prohibits discrimination on the basis of disability and, more specifically, as outlined in Department of Justice Regulation 28 CFR 35.130(d), requires that public agencies provide programs, activities and services in the most integrated setting appropriate to qualified individuals with disabilities. The most integrated setting is defined as the setting that ensures that the person with a disability will have *the greatest opportunity to interact with nondisabled persons*.

In 1999, ADA Title II was challenged by Georgia State Commissioner of Human Resources Tommy Olmstead before the U.S. Supreme Court in *Olmstead vs. L.C. and E.W.* In the resulting *Olmstead* decision (also known as the *Olmstead Act*), the court ruled that states were required to place persons with mental disabilities in community settings rather than in institutions when the state’s treatment professionals determined that community placement was appropriate, the person was not opposed and the placement could be reasonably accommodated, taking into account the state’s resources and the needs of others with mental disabilities.

Of note was that 19 of the 26 states that initially supported Georgia’s appeal withdrew when lobbied and educated by disability rights advocates and others. In the end, many states, organizations and the U.S. Solicitor General supported the right of people like L.C. and E.W., two women diagnosed with intellectual disabilities and psychiatric conditions, to move from the Georgia Regional Hospital in Atlanta to community based services after they had been determined capable by their treatment teams. During litigation, information was provided that demonstrated community services were less expensive than institutional ones.

Yet another sign of the times was the federal government’s response after the ruling. States were given guidance on the topic and encouraged to develop Olmstead implementation plans or strategies. President G. W. Bush expanded the ruling to all people with disabilities by Executive Order 13217 and he and, more recently, President Barack Obama established initiatives involving multiple federal agencies in support of Olmstead. Actions you may recognize include encouraging Home and Community-Based Services (HCBS) waiver applications and giving grants to states for programs such as “Money Follows the Person”.

As you can see from the description above, on one level, Olmstead is a planning and implementation concern of state and local leaders, policy-makers and legislators. On another level, “where the rubber meets the road” for people with disabilities, there are Olmstead-specific regulations (i.e. CFR 28) enforced by (other) authorities-having-jurisdiction, not ICF/IID surveyors. As a state surveyor, you may (or may not) be aware of Olmstead-based complaints investigated by federal agencies such as Department of

Justice (DoJ) Civil Rights Division or Health and Human Services' Office of Civil Rights (OCR) or a comparable state agency. If you have a state licensing role, your State Agency will tell you what it is. From the federal perspective, your role as a surveyor is to enforce the ICF/IID Regulations, remembering that training and supports make people more independent and more likely to be able to identify and realize their dreams in the community. Even now, more than 10 years after the Olmstead decision, there are many people in ICF/IID want to move to the community from which they came or wish for a home of their own. While they may or may not fall into the category of people covered by the "integration mandate", it is important to ensure they are given the tools and support ICF/IID Regulations require.

## **Section 8**

### **The Era of Inclusive Support and Self-determination**

According to Mary Beirne-Smith et al. (2006, pg. 26-36), the field of intellectual disability has been in a "Supports-Based Orientation" since 1985. Evidence cited includes federal legislation, new goals and themes adopted by national advocacy and professional organizations and the content of literature in the field - all of which address inclusion, choice and the use of supports "when needed". Others say "supports" gave way in the 1990's to "self-determination" as the hot topic (Wehman et al., 2007, pg. 117). No matter which you believe, the reality is that self-determination and supports are not mutually exclusive. As Wehman et al. (2007) explain it: self-determination is the philosophy and supported education, supported employment and supported living are the strategies.

There are signs that well-known and lesser known community organizations are recognizing the importance of inclusion and self-determination. For example, Special Olympics ([www.specialolympics.org](http://www.specialolympics.org), November 2009) which has sponsored local, state, national and international sports competitions for athletes with intellectual disabilities for years, recently launched "Unified Sports" and "Project Unify". Unified Sports teams are an equal mix of people with and without intellectual disabilities who train and compete on a variety of types of teams, ranging from youth teams to adult teams. Project Unify, on the other hand, is a school-based program designed to promote people with and without disabilities working together on projects such as Special Olympics.

Another example is the public and private sector partnerships that are increasing the employment of people with disabilities. Businesses include: Manpower, Bank of America, Medtronic, Pitney Bowes, Marriott International, CVS, Lowes, Safeway, SunTrust, Home Depot, IBM, Wells Fargo, Hyatt, Phillip Morris and Cincinnati Children's Hospital Medical Center (Wehman et al., 2007, pg. 284).

States such as Connecticut, Alaska and Oklahoma have more people with disabilities in competitive employment than in day or workshop programs (Wehman et al, 2007, pg 21). Published stories champion the conversions of services like Onondaga Community

Services, NY, and Jay Nolan Community Services, CA, from group-based residential and day programs to individualized living and inclusive community employment with personalized day services as needed (O'Brien and O'Brien, 2002, Chapter 27). Even state policy-makers in Alaska, Washington DC, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia have closed state institutions in favor of community-based homes (Lakin et al., 2004).

Inclusion has the power to eliminate or change the nature of organizations which were originally set-up to benefit people with disabilities. You may already know of local organizations such as workshops, mobile work forces and small businesses which were started to benefit people with disabilities but that now hire people from the local community who are not disabled and not human services workers to work along side the people who have disabilities. Consider this: the scales will have tipped to full inclusion when the proportion of people with intellectual disabilities in an organization are close to the 1-3% of the total population that experts believe mirror the natural prevalence in the total population.

## Section 9

### For More Information - References for Module 6

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[www.hhs.gov/ocr/civilrights/understanding/disability/serviceolmstead/index.html](http://www.hhs.gov/ocr/civilrights/understanding/disability/serviceolmstead/index.html) and <http://www.hhs.gov/news/press/2002pres/20020325.html> (referenced March 2010) Website of US Health and Human Services Office of Civil Rights and Press Office.

[www.justice.gov/crt](http://www.justice.gov/crt) (referenced March 2010) Website of the US Department of Justice, Civil Rights Division. Paste "Olmstead" in the site's search engine.

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