



New Community Opportunities Center at ILRU Presents...

ABCs of Nursing Home Transition

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Purpose of the Project

This presentation is part of a series of trainings and other activities provided to the IL field by the New Community Opportunities Center at ILRU. The project's purpose is to assist CILs in developing self-sustaining programs that support community alternatives to institutionalization for individuals of any age, and youth transition from school to post-secondary education, employment, and community living.

Community Alternatives Project Team



ILRU's partners and collaborators in the community alternatives activities include

- Utah State University, Center for Persons with Disabilities
- National Council on Independent Living
- Suzanne Crisp, national community alternatives expert
- Association of Programs for Rural Independent Living
- Michele Martin, Social Media Consultant



Trainer Introductions

Jane Schiele

Director, Satellite Offices
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Bruce Darling

President/CEO, Center for Disability Rights
and ADAPT Organizer

Participant Introductions and Expectations



- Who are you?
- What experience have you had with nursing facility transition?
- What do you want to most learn from this training?

Overview of Training

- Assisting someone in reclaiming their life and moving into the community is a fundamental to Independent Living
- The Independent Living Philosophy answers many of your questions and guides you through the process





Overview of Training, cont'd.

Over the next two-and-a-half days, we will:

- Share our experience
- Provide information on effectively assisting in transition
- Answer questions on the transition process

Feel free to ask questions!

Policy Framework

Nursing Facility Transition work is based on the Americans with Disabilities Act.

- Title II: State and Local Government Programs and Services
- The most integrated setting is defined as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”

ADA (28 C.F.R. pt. 35, App. A, p. 450)

Policy Framework, cont'd.

The Supreme Court's Olmstead Decision

- Lois Curtis and Elaine Wilson against the State of Georgia
- On June 22, 1999, the United States Supreme Court held in *Olmstead vs. L.C.* that “unjustified isolation is properly regarded as discrimination based on disability.”

Policy Framework, cont'd. 2

The Supreme Court's Olmstead Decision

The Court wrote that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life."

Policy Framework, cont'd. 3

The Supreme Court's Olmstead Decision

The Court also wrote that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Implications of Current Issues for Nursing Facility Transition



We live in very interesting times.

- State Budget Issues
- Aging and Disability Resource Centers
- Expansion of Managed Care
- Community First Choice Option
- Definition of "Community"



Current Issues: State Budget Issues

States are facing serious budget problems, but that doesn't eliminate the expectation that they comply with Olmstead.

HCBS is generally more cost-effective than institutional placement.

Current Issues: Aging and Disability Resource Centers



Some states are developing Aging and Disability Resource Centers, with varying degrees of involvement of Independent Living.

Centers need to determine the best type of relationship they will have with the ADRCs in their area.

Current Issues: Managed Care



Some states are bringing in managed care (others have had it). It's how states pay for services, but it doesn't mean folks have lost their rights under Olmstead.

Managed care may be more interested in HCBS because it is cost effective; they may contract with CILs to promote transition.

Current Issues: Community First Choice Option



Some states are considering selecting the Community First Choice Option.

First State Plan Amendment which is:

- Cross-disability/cross generational
- All types of assistance
- Expanded Opportunities for Self Direction

Selecting the option, alone, doesn't eliminate all of the barriers to community living.

Current Issues: Definition of “Community”



Some states are trying to argue that the following are community:

- Living on the grounds of a nursing facility or hospital campus
- Living on the grounds of a private institution
- Living in a setting that is only persons with the same kind of disability

Current Issues: Definition of “Community”



These states* argue that we shouldn't be denied choice to live in such settings by limiting the use of HCBS funding.

Advocates need to be vigilant and monitor state policy.

*Alaska, California, Hawaii, Illinois, Louisiana, Maine, Maryland, Michigan, Missouri, Nevada, Rhode Island, Tennessee, Washington, and Wisconsin

What is successful transition?

Successful transition is much more than someone changing where they live.

- Increasing sense of self-direction and decision-making
- Becoming a full participant in community life
- Developing and using informal supports as well as formal supports and services.



Role of Transition Facilitator

Facilitator ~ A person who aids or assists in a process, especially by encouraging people to find their own solutions to problems or tasks



Role of Transition Facilitator, cont'd.

Know that the consumer will often feel:

Frustration,
Desperation and
Isolation...



Role of Transition Facilitator, cont'd. 2



1. UNDERSTAND what brought the person to the nursing home
2. RECOGNIZE that the individual's emotions of fear, anger, and anxiety are real
3. KNOW the types of supports and services available in the community and how to access them
4. PROVIDE accurate information in a timely manner
5. EXPLORE options with the person

Components that Contribute to Successful Transition



- Developing a trusting relationship
- Having a comprehensive assessment that clearly reflects needs, concerns, and priorities
- Developing and implementing a Transition Plan/Independent Living Plan that addresses the individual's needs
- Follow-up and post-transition support

Assessment



Let's look at some guiding principles to
assessment for nursing facility
transition.



Consumer Control

Dignity of Risk – We grow by making choices even if sometimes the results are not what we wanted...



Consumer Control, cont'd.

It is not a matter of *if* the person should transition into the community, but *how* can we work with the individual to get the correct supports in place for a successful transition back to the community.



Consumer Control, cont'd. 2

"Self Determination is the... right to make your own decisions without the interference from others."

Consumer Control, cont'd. 3

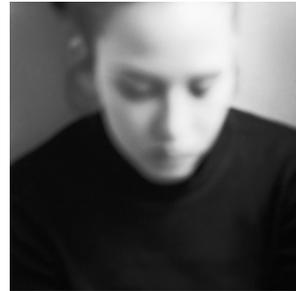
“Overprotection may appear on the surface to be kind, but it can be really evil. An oversupply can smother people emotionally, squeeze the life out of their hope and expectations and strip them of their dignity”

ABC's of Nursing Home Transition (Pg. 13)

(What gets in the way of) Consumer Control



- Institutional Bias
- “Safety” Issues
- Fear





Consumer Control, cont'd. 4

Remember:

You are the co-pilot, not the pilot.

- Show respect by allowing the consumers to take the reins of their lives back.
- Follow their lead

Outreach - Initial Outreach Strategies



- Review your consumer lists
- Ask your consumers
- Ask other people
- Ask people who got out



Additional Outreach Strategies

- Contact the local nursing home ombudsman program
- Ask for referrals from a friendly nurse or resident doctor who works at the local hospital or clinic
- Ask attendants (Many work in nursing facilities!)
- Write a letter to the editor or editorial
- Talk to support groups

Building Relationships With the Consumer



- Be positive! Have a CAN DO attitude!
- You are not a gatekeeper!
- Give examples of what you do.
- Be on time!
- Dress casually
- Identify an appropriate interview location

Building Relationships With the Consumer, cont'd. 2



- Position yourself at eye level contact
- Take only essential notes
- Respect personal space and equipment
- Interview the person alone
- Listen - Don't interrupt

Building Relationships With the Consumer, cont'd. 3



- Do not make promises you cannot keep
- Ask about activities in the nursing facility
- Ask about any community and social connections
- Schedule next appointment before you leave

Building Relationships With the Nursing Facility



- Start by involving the nursing facility staff from the beginning when possible
- Involving the facility staff helps them buy into the idea of transition and provides much-needed help with the process.

Building Relationships With the Nursing Facility, cont'd.



Facility staff can:

- Help the individual to fill out required applications
- Switch social security payments to the individual
- Assist with the transition to a community doctor
- Ensure they received their medications and personal belongings from the facility

Building Relationships With the Nursing Facility, cont'd. 2



When a nursing facility isn't cooperative...

- Try to figure out why by listening to the staff
- Offer training from your Center and include folks who have successfully transitioned
- Educate facilities on the law (including ADA/Olmstead and CRIPA)
- Contact the Ombudsperson Program

Building Relationships With Family and Other Significant People

- It is important to work as closely as possible with families and friends too
- Supportive ones can make a successful transition more likely
- Unsupportive folks can derail the plan



Building Relationships With Family and Other Significant People, cont'd. 2

Getting unsupportive folks on board:

- Start by assuming good will
- Listen to and acknowledge their concerns
- Educate them on services that can support community living
- Explain how the new situation will be different
- Keep them informed of progress

Building Relationships With Family and Other Significant People, cont'd. 3

If unsupportive family and friends don't change their mind...

Move on... but don't slam the door.



Conducting the Initial Interview

- Introduce yourselves and get acquainted
- Explain your role as the Nursing Facility Transition Coordinator
- Discuss Independent Living philosophy
- Educate the consumer about the *Olmstead* decision and the rights under the Americans with Disabilities Act.



Initial Interview: Set Expectations

- Distinguish between transition assistance and the Ombudsman program
- Explain that this process takes time, particularly if you need to secure housing

Initial Interview: Talk about Truth and Honesty



- The nursing facility transition process involves a whole lot of both!
- Honesty is particularly important because valuable time can be lost if you do not know the whole truth
- Disclosing information will not cause problems for the transition

Initial Interview: Obtain Demographic Information



- Get the required reporting data
- Age and disability type will help you determine what services the consumer is eligible for

Initial Interview: Get Background Information



- Ask the consumer how they ended up in the nursing facility. The answer to this question will provide insight into what the focus of your work will be
- Identify potential barriers for the transition process, including:
 - experiences with home care agencies
 - credit problems



Initial Interview: Tough Conversations

- You may need to ask some direct questions.
- Make sure that you explain why you are asking these questions
- You are not being nosy, but you need to know the answers in order for you to help the person make informed choices about services and supports

Initial Interview: Questions during initial planning stage



- How long have you been here?
- How did you end up here?
- How is your nursing facility stay being paid for?
- Are you able to direct and manage your own care?

Initial Interview: Common Questions, cont'd.



- What types of things do you need help with?
- Another related question is, what types of things do you WANT help with?
- Were you receiving services while you were at home? Were you happy with your services? Why were they terminated?
- Do you have a home? What is it like? Is it accessible? (Ask specific questions.)

Initial Interview: Common Questions, cont'd. 2



- Where do you want to live?
- Are your family and friends supportive of you moving out?
- What does your doctor say about you moving out of the nursing facility?
- Would you like to talk with someone who has been through the nursing facility transition process?

Initial Interview

“I can’t possibly do this all in one visit!”

- You’re right!
- Take your time and handle the initial interview over a couple of visits

Assessment

The purpose of assessment is to work with the person to identify what is needed for a successful transition to the community. (See sample assessment tool in ABCs of Nursing Home Transition Appendix, page 69).



Assessment, cont'd.

Getting started at CDR, we filed complaints with the Health and Human Services Office for Civil Rights for every consumer.

This became our assessment process:

How people went in helped us determine what we needed to do to help them get out!

Assessment, cont'd. 3

Common ways people ended up in a nursing facility included:

- Hospital stay (home care withdrew services)
- Rehabilitation
- Adult protective

Assessment: How to Conduct

AVOID doing the assessment as if:

- you are going through a checklist
- you are interrogating the person
- you are playing twenty questions

Eventually you should get to a point where you can do the assessment in a casual, conversational manner

Assessment: Components

- Health Services, including personal assistance, mental health and addiction services
- Housing
- Social Supports
- Transportation
- Volunteering/Employment
- Financial Resources

Assessment: Health Services

- What Health Services does the individual need?
- Starting with the obvious things that we all (pretty much) need...
 - Doctor
 - Dentist
 - Medications



Assessment: Health Services, cont'd.

- Does the individual require services or supports related to health conditions?
- For example, does the person have diabetes?
 - If so how is it managed?
 - How could it be managed?



Assessment: Health Services, cont'd. 2

- What personal assistance services does the person need? Describe:
 - type of service needed
 - required frequency and/or intensity
 - purpose of the service
- Allows planners to structure a specific service for the individual in the most integrated setting

Assessment: Health Services, cont'd. 3



- Does the person require services and support related to a psychiatric disability or addiction?
- Supports could include:
 - peer counseling
 - crisis-intervention
 - medication assistance
 - 12-step program
 - counseling
- Folks may be hesitant to disclose this information

Assessment: Housing

- Where does the individual want to live? Describe:
 - Location
 - Size/space requirements
 - Accessibility needs
- This assessment should also consider financial resources as well as potential eligibility for different types of housing subsidies or benefits
- Avoid thinking about housing as linked to services

Assessment: Social Supports

- Identify social activities that the individual values, including:
 - religious events
 - recreation activities/social clubs
 - traditional family activities
 - leisure time preferences
- The question “Who used to be involved in your life?” can help identify connections that can be rebuilt.

Assessment: Transportation

- Where does the person want to go on a regular and/or intermittent basis?
- What type of transportation options do they have?
- Do they have specialized transportation needs? If so describe them.



Assessment: Education & Employment



What is the individual going to do after transition to the community?

- Volunteering?
- Pursuing education?
- Working?

Assessment: Education & Employment, cont'd.



- A referral to the state vocational rehabilitation office may be appropriate
- Don't worry if the person isn't immediately thinking about education, work or volunteering, but help the person identify things that they enjoy outside the home, including potentially coming to your center

Assessment: Advocacy

- Determine the individual's comfort level in advocating for him or herself
- Does the person express their desires and needs?
- Is the person intimidated by staff?
- What kind of support may be needed to help this individual develop any needed self-advocacy skills?



Assessment: Financial Resources

Gather accurate/complete information on:

- Social Security/SSI benefits
- Other income
- Medicaid and Medicare
- Personal assets
- Trusts
- etc.

New staff may have a more experienced staff member assist with this.



Assessment: Financial Management

- Does or did the individual manage their own money?
- Does or did the individual have a representative payee or someone who performed this function?
- Is there any indication that this may be an area that needs support?

End of Day One Questions and Answers



- Do you have any questions on the first day's topics?
- Give us feedback: How can we better meet your needs?
- Tomorrow
 - Confidentiality and HIPPA
 - Transition Planning





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