

ABCs of Nursing Home Transition

An Orientation Manual for *New* Transition Facilitators

Authors:

Judith Holt, Ph.D.
Darrell L. Jones, M.A.
Richard E. Petty, M.B.A.
Helen Roth, M.A.
Heather Christensen, M.S.

**A Publication of the IL Net National Training and Technical Assistance
Program at Independent Living Research Utilization**

**Developed in Collaboration with Utah State University
Center for Persons with Disabilities**

© February 2006 by ILRU
This is a publication of the IL Net.

The IL Net is a collaborative project of Independent Living Research Utilization (ILRU) and the National Council on Independent Living (NCIL), with funding from the Rehabilitation Services Administration. The IL Net provides training, technical assistance and publications supporting the work of centers for independent living and statewide independent living councils.

ILRU is a program of The Institute for Rehabilitation and Research, a part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities.

ILRU Program
2323 S. Shepherd, Suite 1000
Houston, TX 77019
713.520.0232 (Voice and TTY)
713.520.5785 (Fax)
<http://www.ilru.org>

Lex Frieden
ILRU Director

Richard Petty
ILRU Program Director
IL Net Director

Publications Staff: Laurel Richards, Darrell Jones, Dawn Heinsohn, Sharon Finney, Marisa Demaya, and Rose Shepard

Permission is granted for duplication of any portion of this manual, providing that the authors, ILRU and the IL Net are credited:

Holt, J., Jones, D., Petty, R., Roth, H., Christensen, H. (Authors). (2006). ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators. Houston, Texas: ILRU and the IL Net.

Substantial support for development of this publication was provided by the Rehabilitation Services Administration, U.S. Department of Education, Agreement No. H132A020004. No official endorsement of the Department of Education should be inferred.

Table of Contents

TABLE OF CONTENTS	II
ACKNOWLEDGEMENTS	VI
ABCs OF NURSING HOME TRANSITION	1
FACILITATING TRANSITION TO THE COMMUNITY: MODULE 1	1
Introduction	1
Meet Chelsea.....	1
Meet John	1
Purpose of the Manual.....	2
Setting the Stage: the ADA and the Olmstead Decision	3
The ADA (Americans with Disabilities Act).....	3
For Application and Discussion.....	3
The Olmstead Decision	3
LOIS and ELAINE.....	3
Interview with Lois and Elaine.....	5
For Application and Discussion.....	7
What the Decision Says	7
What the Decision Means.....	7
What is Successful Transition?.....	8
The Role of the Transition Facilitator.....	8
Critical Components of Transition that Contribute to Success	8
For Application and Discussion.....	9
ASSESSMENT: MODULE 2	11
Topics to Be Covered	11
Objectives	12
Guiding Principles	12
The Purpose and the Components of the Assessment	14
What is the Purpose of the Assessment?	14
What Are the Important Components of Assessment?	14
Health Services.....	14
Social Supports.....	14
Housing.....	14
Transportation.....	14
Volunteering/Employment	14
Advocacy	16
Financial Resources	16
The Assessment: Getting Started.....	16
How Do I Conduct the Initial Interview?	17
For Application and Discussion.....	18
HIPAA	18
Successful Interviewing Steps	20
Activity.....	21
Building Relationships with Nursing Homes, Family, and Other Supports	24
How Do I Establish a Relationship with the Nursing Home?.....	24
How Do I Work with Family Members and Other Support People?	24
What Do I Do About Confidentiality and Informed Consent?	25
What Kind of Notes Should I Keep?	25
How Do I Review Medical Records?	25
What Do the Medical Records Contain?	26
What is the Medication Administration Record (MAR)?	26
For Discussion and Application.....	27
How Is Your Progress?	27
Summary of Module on the Assessment Process	29

Key Terms Used in this Module	29
TRANSITION PLANNING: MODULE 3	31
Topics to Be Covered	31
Objectives of the Module on Transition	32
Transition Planning	32
What Do We Mean by Transition Planning?	32
What is Individual Self-Direction?	33
What Is Person Directed Planning?	34
For Application and Discussion	35
Activity	35
Transition Plan Components	36
Housing:	36
Personal Assistance:	36
Assistive Technology:	37
Health Care:	38
Mental Health Supports:	38
Addiction Supports:	38
Transportation:	39
Volunteering/Employment:	39
Family and Friends Support:	40
Social, Faith, and Recreation:	40
Community Integration:	41
Advocacy:	41
Finances:	41
Transition Schedule and Check List	42
For Discussion and Application	42
Chelsea Update	42
John Update	43
How is Your Progress?	44
Summary of Module on Transition Planning	45
Key Terms	45
POST TRANSITION: LIVING IN THE COMMUNITY: MODULE 4	47
Topics to Be Covered	47
Chelsea Update	47
John Update	47
Objectives of the Module on Post Transition	48
Post Transition Responsibilities	48
Housing	50
Personal Assistance	50
Assistive Technology	50
Health Care	51
Mental Health Supports	51
Transportation	51
Employment	51
Family and Friends Support	52
Social, Faith, and Recreation	53
Community Integration	53
Advocacy	53
Finances	54
Celebration	54
Post Transition Checklist	54
For Discussion and Application	54
Chelsea Update	55
John Update	56
How is Your Progress?	58
Summary of Module on Post Transition	59

Key Terms.....	59
APPENDIX A: THE ADA AND OTHER EXAMPLES OF MAJOR FEDERAL LEGISLATION THAT CONTAIN THE DISABILITY POLICY FRAMEWORK	61
The ADA recognizes the history of treatment of people with disabilities	61
The ADA states the four goals of disability policy.....	61
The ADA reflects the new paradigm that disability is a natural part of human experience, and the solution is to fix the environment, not the person	62
Other Examples of Major Federal Legislation.....	62
APPENDIX B: EXAMPLE ASSESSMENT INSTRUMENT	65
Nursing Home Transition Needs Survey	65
APPENDIX C: TRANSITION PLANNING WORK SHEETS.....	71
Planning Work Sheet for Health	71
Planning Work Sheet for Housing.....	72
Planning Work Sheet for Daily Living	73
Planning Work Sheet for Financial Matters	74
Planning Work Sheet for Self-Determination.....	75
Planning Work Sheet for Social & Recreational Needs.....	76
Planning Work Sheet for Transportation.....	77
Planning Work Sheet for Employment.....	78
APPENDIX D: GENERAL GUIDELINES FOR NURSING FACILITY TRANSITION.....	79
Overview	79
Referral	79
I. General Planning Information.....	79
II. General Community Based Services and Supports	80
III. Actual Community-Based Services and Supports.....	81
IV. Discharge Meeting	84
V. Day of Discharge.....	84
VI. Follow-up.....	85
APPENDIX E TIMELINE OF ACTIVITIES FOR TRANSITION	87
A. Planning Activities	87
B. Health	88
C. Housing	88
D. Transportation	89
E. Daily Living	90
F. Personal Finance.....	91
G. Social/Recreation	91
H. Employment	92
NOTES.....	93
REFERENCES AND RESOURCES	93
MICROENTERPRISES.....	93

Acknowledgements

We gratefully acknowledge the insights provided by so many individuals from Centers for Independent Living and State agencies throughout the country over the past three years. These insights were of great value in envisioning a training manual for new transition facilitators. In particular we want to thank Tony Records for his assistance in the conceptual design of this material. And we are equally grateful to Kris Baldwin, Bruce Darling, Paul Ford, Tim Fuchs, Michele Jordan, Dan Kessler, Dawn Lambert, and Jane Schiele for reviewing the manual and giving feedback on its usefulness and completeness. Many of their suggestions have been incorporated into this final version. Finally, we want to express our deep gratitude to the countless numbers of individuals we have met who have transitioned out of nursing homes and so generously shared their experiences and ideas with us. It is to them, and those still waiting to make their transition, that we dedicate this manual.

ABCs of Nursing Home Transition

Facilitating Transition to the Community Module 1

“Growth means change and change involves risk, stepping from the known to the unknown.” ~Author Unknown

Introduction

Meet Chelsea

“I need help. I don’t want to live here, in this nursing home any more, but nobody seems to be listening. It’s been ten long miserable years since I had a ‘normal life’ in the community. I want the freedom to be on my own again and to do things with my friends. All of the kids I was in high school with now have jobs and families of their own, and lives! I know since the accident, I’ve lost a lot of my ability to get around on my own, but I know I could make it in the community!”

Meet Chelsea, age 27, who lives in Valley Haven, a for-profit nursing facility, where over 250 people live.

“I want my life back. I want to be around people my own age. I still have a lot of living to do. If someone could help me escape this place, and help me get a job, I want to live in my own apartment.”

Meet John

John is a resident of another nursing home, Happy Acres, in the same city. He has been in and out of nursing homes in several states over the past 20 years. John is 51 and was a construction worker from the time he left school at 15 until a violent physical assault resulted in severe traumatic brain injury. After leaving outpatient rehabilitation, he tried

to return to work but he was not able to manage the physical demands of his construction job. John was incarcerated several times for domestic violence and public intoxication. His wife and children moved to another state and John was homeless with an increasing dependence on drugs and alcohol. He was placed in a nursing home for continued “rehabilitation” since there were no community supports available and he didn’t want to do serious jail time.

Throughout this training manual you will “meet” individuals such as “Chelsea” and “John” who are engaged in a transition planning process. These are stories of real people that the authors have formed into composite scenarios without using the actual name of any particular person.

Chelsea and John’s situations and level of frustration are common among thousands of people with disabilities in nursing facilities in your state and across the country. Many people in nursing facilities express feelings of desperation, deprivation, and isolation; and, most of all, frustration with knowing that they can live successfully in the community but feeling that no one is listening.

You are going to be Chelsea and John’s transition facilitator (actually a peer mentor). As you read and work throughout the modules, you are going to follow each of their situations from beginning transition to successfully living

in the community. The experience of Chelsea and John will be examples to keep in mind as you have the opportunity to complete your own assignments, hopefully, along with an experienced facilitator. This manual is filled with experienced facilitators' valuable knowledge, the best ideas, and examples of tools to use when facilitating a transition.

Purpose of the Manual

The Supreme Court decision known as *Olmstead vs. L.C.*, has changed the landscape for disability advocates. It provides the framework for advocacy to support persons with disabilities to transition out of nursing homes and other institutions into the community. *Olmstead* also supports persons with disabilities to remain in the community and not be placed in institutions.

In order to make the manual more concise and in order to avoid repetition, we find it necessary to use the general term, "people with disabilities," as defined by the ADA, which says,

An individual with a disability is a person who:

1. has a physical or mental impairment that substantially limits one or more major life activities;
2. has a record of such an impairment; or
3. is regarded as having such an impairment.

We will use this term to encompass all people in any kind of situation or with any condition and or disability, which could lead them to live in a nursing home. People who are, or at risk to be, in nursing homes may have disabilities as a result of genetic, chronic, traumatic

or aging conditions. Therefore when we use the term "people with disabilities," we mean any adults with one (or more) of the above conditions as defined by the ADA, and (or) any minors whose families support transition; and we do not mean to state that one individual or situation is like another.

This manual is a "work in progress" and will be updated over time to reflect the recommendations of users. It is offered as a self-study guide for new transition facilitators, with material that was developed with input from Centers for Independent Living and a variety of other organizations and agencies. The manual is to help new facilitators understand and apply the principles and the resources that successful transition facilitators have used.

A facilitator is somebody who aids or assists in a process, especially by encouraging people to find their own solutions to problems or tasks.¹ In the case of this manual, a facilitator partners with someone with disabilities who wishes to live in the community and requires community-based supports and services. A facilitator provides support and is a peer mentor. The facilitator is providing this service when he or she assists any person with disabilities to live in the community. The primary use* of the manual is:

- To provide a framework and a discussion guide for more experienced facilitators to mentor new facilitators.
- To serve as a resource for new facilitators as they begin the important task of supporting individual's with disabilities to

successfully transition from nursing homes to the community.

- To provide resource material to new (less experienced) facilitators.
- To enrich community education opportunities.

*Note: This manual is not a detailed step-by-step guide for new facilitators. It must be supplemented with the appropriate training, forms, procedures, and policies used by your agency or organization as well as the provision of sustained mentoring and support from experienced facilitators.

Setting the Stage: the ADA and the Olmstead Decision

As you begin the process of supporting individuals to move from nursing homes to the community, it is important that you understand some of the laws and Supreme Court decisions that have established a national legal framework for what you do.

The ADA (Americans with Disabilities Act)

The Americans with Disabilities Act (ADA) was a huge breakthrough for persons with disabilities. The *Olmstead* decision was based on the ADA. In 1990, President George H. W. Bush signed the ADA into law. Title II of the ADA prohibits state and local governments from discriminating against people with disabilities in the provision of public benefits and services (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

The regulations implementing the ADA state that a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.²

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”.³

Advocates were able to use the Americans with Disabilities Act to challenge states that only provide extensive care and supports in institutions. This meant that the only option for people with disabilities was to live in segregated settings. Advocates argued that states were not following the law because they were only providing services in segregated settings. One of these challenges—*Olmstead vs. L.C.*—went all the way to the Supreme Court.

For Application and Discussion

1. If “segregate” is the opposite of “integrate,” what does “segregate” mean? How are people who are segregated viewed (valued) by society? By communities?
2. Discuss situations in which people with disabilities have been segregated. Have you ever experienced any type of segregation? How does “segregation” feel?

The Olmstead Decision

LOIS and ELAINE

Now that you better understand how the ADA made the *Olmstead* decision possible, we will give you the background and the story of the Supreme Court’s decision on *Olmstead*.

In the next segment of the module, you will be able to read the transcript of an interview with Lois Curtis and Elaine Wilson. In order to gain a better understanding of the interview, first read their biography.

Biography

Lois Curtis and Elaine Wilson, two women with disabilities who lived in a Georgia state hospital, asked state officials to allow them to move into their own homes in the community. After the state's refusal, Atlanta Legal Aid attorney Susan Jamieson filed a lawsuit on behalf of Ms. Wilson and Ms. Curtis. In the lawsuit, they again sought to have the State of Georgia allow the two hospital residents to live in the community. After appeals, the U.S. Supreme Court heard the case.

The two Georgia women with disabilities (mental retardation and mental illness) claimed that living in a nursing home deprived them of their rights under the Americans with Disabilities Act (ADA) to live in an integrated community setting. *[For more information on the ADA see Appendix A: The ADA and Other Examples of Major Federal Legislation that Contain the Disability Policy Framework.]*

Lois and Elaine argued that they had a right to receive services in a community-based setting under Title II of the ADA.

The law requires public entities to provide their services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities... [that] enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."

The state argued that Lois and Elaine were placed in state-run institutions to obtain needed services. Physicians for the women disagreed, stating they could receive appropriate services while living in the community.

In July 1999, the Supreme Court issued the *Olmstead vs. L.C.* decision. The Court ruled in favor of Lois and Elaine, affirming that where individuals live must be appropriate to their needs and can include home and community-based arrangements. The Court noted that institutionalizing a person with a disability, who wants to live in the community and can benefit from it, is discriminatory.

Interview

The "Interview with Lois Curtis and Elaine Wilson" was conducted in July 2000 by Richard Petty in Atlanta, Georgia. The transcription of the interview, which follows, contains a few items that were not understandable.

Interview with Lois Curtis & Elaine Wilson

Richard Petty: We're talking with Lois Curtis and Elaine Wilson. And Elaine, what is it like to live in your own home now?

Elaine: To live in my own home, well I feel very grateful to all the people who helped me to get my own home and I feel very good about my home. I have a great life and I can make my own decisions. And I can handle my own business, and I feel good about myself.

Richard: How long did you live in the institution?

Elaine: Oh, I was in there 37 times. I was in the Georgia Regional Center 37 times. But that once when my mother called Sue--that was the best call she ever made. Because she filed a complaint, Sue did.

Richard: How is it different?

Elaine:Well, I can go out when I want to. I can date when I want to. I can go home when I want to. I can go out to eat with my workers when I want to. And I can go to dialysis, and that's about it.

Richard: How does your worker help you?

Elaine: How does she help me? She was the one that got this home.... Angela and Harriet, and Nancy was the one, and Wendy was the one that got this home for me. And this is really, the only person that lives there is me and Nancy. And the way it was different is when I first went there, I didn't think it was going to work out. I thought we were going to have to move me again. But I was wrong. It worked out. And now I'm really and truly happy the way my life is now. That's the difference.

Richard: That's a big difference.

Richard: Lois, how long were you in the institution?

Lois: 30...35 years. I was in the hospital.

Richard: And do you live in your own house now?

Lois: I love it here....You can cook, eat breakfast in the morning, get up and go around. I smoke a cigarette in the morning. And then I do my other stuff. And then I say..."where's my tennis shoes...I got to play basketball." And then after lunch...we do the test, and then come back here, and then go to the store. Go to the store on Friday, and we watch a movie...do that after lunch.

Richard: Elaine, what do you want to do now?

Elaine: Well, I'm going to be going to a job-training program.

Richard: What kind of job are you thinking about?

Elaine: Well, they prepare you for a job... and they train you for a job. And they ask you what job you want. And I want housekeeping. That's what I want.

Richard: Have you ever worked before?

Elaine: Uh-huh, I worked in a nursing home as a kitchen helper. And I worked there eight years.

Richard: Was that while you were in the institution?

Elaine: No, I was out of the institution. I was out, I had my own apartment.

Richard: When you first met Sue, do you remember that?

Elaine: Yeah, I remember that.

Richard: What did you tell her when you first met her?

Elaine: She asked me questions, and I answered them. And I shared with her, how they were wanting to discharge me to the streets. To make me homeless, put me in a homeless shelter.

Richard: They were going to put you in a homeless shelter?

Elaine: Uh-huh. And then one time they were going to release me to the streets. And Sue stopped it.

Richard: Is there anything that either of you would like to say?

Elaine: I would tell them to get a lawyer, and if they can't pay the lawyer, then ask if the state could pay the lawyer, and I would also tell them that it's a long process, a real, real long process. I would also tell them, it's hard to sue a hospital, but, but, you can do it. Because I did it and Lois did.

For Application and Discussion

1. Do you know people like Lois and Elaine in your community? Where do they live? What could happen that would “push” them into a nursing home.
2. Are there enough services and supports in your community to keep people from being placed in nursing homes? If no, what other services and supports are needed

[Elaine Wilson passed away on December 5, 2004.]

What the Decision Says

On June 22, 1999, the United States Supreme Court held in *Olmstead vs. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities. Information listed below shows how the decision benefits people with disabilities.

The decision is a victory because it upheld the mandate that state programs should be conducted in the most integrated settings appropriate to the needs of individuals with disabilities. Using the ADA as its basis, the decision also found that unjustified isolation is considered discrimination. The *Olmstead* decision focused on the importance of community living opportunities for people with disabilities and further extended the earlier efforts of the ADA as well as the

Developmental Disabilities Act and Rehabilitation Act.

What the Decision Means

According to ADAPT (American Disabled for Attendant Programs Today), a grassroots advocacy organization, the *Olmstead* decision changed the debate from “should people with disabilities live in the community?” to “how do we integrate people with disabilities into the community?” The decision means that freedom and independence are possible.

This is what the *Olmstead* decision means according to Advancing Independence Modernizing Medicare and Medicaid (AIMMM):

In 1999 the U.S. Supreme Court found the ADA forbids states from institutionalizing people with disabilities of any age if they can live in the community with the right mix of cost efficient community living services.⁴

Yes, freedom and independence are possible, but advocating can be hard work. The ADA and the *Olmstead* decision set the guidelines and opportunities for community living, but making it happen for people with disabilities is still an uphill battle. Most states are lagging behind in implementing the *Olmstead* decision and funding for health care and supports in the community is often limited.

What is Successful Transition?

It is crucial to remember that successful transition is much more than someone changing where they live. The move from a nursing home to a residence in the community is much more than a physical change. It includes an increasing sense of self-direction and decision-making on the part of the individual who is transitioning. It often means not only living where one chooses, but also becoming a full participant in community activities. Living in the community also means developing and using informal supports as well as the more formal supports and services. As a transition facilitator, you are not solely responsible for the success of the transition. You do have a critical role, but success is also dependent on the individual themselves and their willingness to take a proactive role in the process and commitment to change.

The Role of the Transition Facilitator

As a transition facilitator, you will have multiple roles. Although this is not an exhaustive list, it should give a sense of the complexity of what facilitators do.

Be an effective peer mentor. You are supporting someone as they reclaim their life. Remember, it is their life, not yours and they need to be directing what happens.

- Understand what brought the person to the nursing home. The same things that brought them there may be barriers to a successful transition to the community.

- Be a good listener who hears both words and feelings.
- Recognize that the individual's emotions of fear, anger, and anxiety are real. Name them and discuss them.
- Be knowledgeable about the possible types of supports and services available in the community and how to access them.
- Provide accurate information in a timely manner. Don't over promise.
- Explore options with the person, don't just push what you think is best.

Critical Components of Transition that Contribute to Success

The critical components that contribute to the success of the transition include: developing a trusting relationship and having a comprehensive assessment that clearly reflects needs, concerns, and priorities; developing and implementing a Transition Plan that addresses the individual's needs; and critical follow-up and post-transition activities.

Each of these components will be discussed in more detail in the following sections.

For Application and Discussion

In order to better understand the challenges and feelings of an individual who is moving from a nursing home to the community, let's talk about this in terms of your own life. Remember a time when you made a huge transition. Moving to a new city? Changing jobs? Moving away from your childhood home? Making a long-term commitment to a partner? Quitting a job? What were the emotions that you went through at this time?

An individual transitioning from a nursing home to the community is making a monumental change and you, as the transition facilitator, need to understand and acknowledge this. Discussing these fears, doubts and

anxieties with the individual is absolutely critical. Emotions are powerful!

1. Find the laws and regulations that your state has supporting nursing home transition and make note of them. These will be helpful in supporting future transitions.
2. Find an experienced facilitator whom you may assist in an individual's transition. This is a most important step for your learning. Not only will you be able to follow Chelsea's example, but you will also be performing all of the steps necessary in assisting an individual's transition.
3. Write down the name of the person you are assisting with the transition.

Assessment Module 2

“If we do our jobs well, at the end of the transition journey, there will be a worthwhile outcome called community freedom.” ~Centers for Independent Living, Arkansas

Topics to Be Covered

- Self-determination and dignity of risk
- Components of assessment
- Getting started
- Establishing a relationship with the nursing home
- Conducting the initial interview
- Interviewing tips
- Working with families and other support people
- Keeping notes
- Confidentiality and informed consent
- Reviewing medical records

Chelsea

In the first module you learned about Chelsea who is a resident of the Valley Haven nursing home. Let's say that you are a transition facilitator at the local Center for Independent Living and you just received a phone call from her. She sounded desperate, saying that she has been “stuck” in this nursing facility for 10 years, since a serious automobile accident. Chelsea said she has told the nursing home staff at every planning meeting that she wants to live on her own and all they do is write her request in the “discharge plan summary.”

You scheduled an appointment with Chelsea and told her you would like to meet with her right away. She sounded appreciative, but highly anxious. Chelsea also said her family understands her request to leave, but “buys into” the nursing facility staff’s

assertion that she needs a nursing “level of care.”

Obviously Chelsea is frustrated with her situation and has gotten to the point where she has little trust in anyone. Take a moment to read and talk about the following questions.

1. How would you approach your first meeting with the staff at the Valley Haven nursing home?
2. How would you work with Chelsea around her desperation about being “stuck” in Valley Haven for the past 10 years?
3. How would you plan to work with Chelsea’s family members?
4. What are the implications of Chelsea’s age at the time of her institutionalization?

John

John has called you four times in the past two days to see how soon you can come to get him out. Each time you tell him that you will help him develop a plan and assist him in accessing the supports and services that he needs. Then he will call you a little later and ask the same questions again. Each time he tells you that the staff is plotting against him to “make him disappear.” He also says that the staff talk about him behind his back. You are concerned that he may have serious emotional problems or that he is just trying to aggravate you.

1. How would you handle the multiple phone calls from John?
2. How would you approach his concerns about the staff?

Objectives

The above questions can be difficult to answer. The goal of this manual is to help people like Chelsea and John to obtain the supports and services that they need in the community and not be forced to stay in a nursing home. After understanding the guiding principles in this module you should be able to answer the previous questions as well as be able to:

- Discuss the importance of self-determination and dignity of risk.
- Define the purpose of the assessment process and list the important parts of an assessment.
- Conduct an initial interview with an individual wishing to transition to the community.
- Through a process, complete a comprehensive assessment.
- Develop a relationship with the nursing home, and work with families and other support people.
- Develop an assessment plan, keep organized notes, obtain informed consent, and review medical records.

Guiding Principles

Before we begin discussing the assessment process, there are two important principles to keep in mind throughout the transition process. If the process of the individual returning to the community is not guided by these two principles, then the move may well be

just a *different place to live* not a full life in the community. These principles are: self-determination and dignity of risk.

“Self-Determination is the ability or right to make your own decisions without interference from others.”⁵

Self-determination includes such basic rights as a person making his own decisions about his future, the supports and services that he wants, where he would like to live, how to spend his money, and what he wants to do on a daily basis. Self-determination also implies that an individual can make choices from various options. A critical aspect of self-determination is the individual’s responsibility for the choices that he makes.

A nursing home environment provides little opportunity or encouragement for self-determination. Choices are made for the individual in the form of routines (when to get up, when to eat, what to eat, when to shower, when to go to bed) and an individual’s wishes and preferences may be ignored. It is sometimes challenging for an individual who has not been allowed to make decisions for many years, to suddenly be told that he is in charge. As with most things, self-determination is a process and as a transition facilitator, you will need to support the individual in this process as he retakes control of his life.

Dignity of Risk means making choices about new experiences and possibilities. The concept of dignity of risk is critical to human development. We grow by making choices even if sometimes the results are not what we wanted. We learn by successes as well

as failures. If individuals make choices and try different activities, their potential to live a productive self-determined life is significantly enhanced. In order to support this, you (the transition facilitator) must understand that taking risks is part of our lives, and discussions of risks and rewards as well as making plans with contingencies are also important aspects of this concept.

In nursing homes and other residential settings, safety and protection are of paramount importance and individuals with disabilities are “protected.”⁶ Perske discusses dignity of risk in this way:

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 hopes and expectations, and strip them of their dignity.

Overprotection can keep people from becoming all they could become.

Many of our best achievements came the hard way: We took risks, fell flat, suffered, picked ourselves up, and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try. Persons with special needs need these chances, too.

Of course, we are talking about prudent risks. People should not be expected to blindly face challenges that, without a doubt, will explode in their faces. Knowing which chances are prudent and which are not - this is a new skill that needs to be acquired.

On the other hand, a risk is really only when it is not known beforehand whether a person can succeed....

The real world is not always safe, secure, and predictable. It does not always say ‘please,’ ‘excuse me,’ or ‘I’m sorry.’ Every day we face the possibility of being thrown into situations where we will have to risk everything....

In the past, we found clever ways to build avoidance of risk into the lives of persons living with disabilities. Now we must work equally hard to help find the proper amount of risk these people have the right to take. We have learned that there can be healthy development in risk taking... and there can be crippling indignity in safety!⁷

With these two principles to guide your interactions and your assessment and transition activities as you support the individual moving to the community, the long-term ability of the individual to stay in the community is strengthened.

The Purpose and the Components of the Assessment

What is the Purpose of the Assessment?

One of the first steps in the transition process is conducting the assessment. An assessment is not a single meeting, but rather a series of meetings that allow the nursing home resident to develop a sense of trust in the transition facilitator and the transition process. The purpose of the assessment is to identify the individual's strengths, abilities, and wishes in order to ensure that the return to the community is consistent with what they want. During the assessment, we get to know the individual and gather as much information as possible about the person as it relates to their pending transition to the community. The assessment process also provides an opportunity to identify additional issues which need to be addressed such as alcohol or substance abuse, mental illness, or criminal record. Information gathered during the assessment process is one of the key components in developing the written plan for the person's transition to the community. This is frequently called a community living Transition Plan.

The philosophy of Independent Living and the direct experience of many Centers for Independent Living and community service providers throughout the nation is that the level of community supports available to the individual, *not the type or severity of disability*, is the key factor in successful community integration. The goal of assessment is not to determine IF the individual has

the capacity to transition to the community, but rather to identify specific service needs and begin to build a support system. This philosophy clearly specifies that transition is not a matter of "readiness" but rather the assumption that individuals can live successfully in the community with appropriate supports and services.

What Are the Important Components of Assessment?

The assessment process generally includes seven key components. These are:

1. Health Services
2. Social Supports
3. Housing
4. Transportation
5. Volunteering/Employment
6. Advocacy
7. Financial resources

Each component is described more fully below:

Health Services: People are often in nursing facilities due to health-related conditions. The needs related to these conditions should be itemized within the individual assessment. For each need there should be a documented strategy for supporting the individual in addressing the need in the community. This strategy may include staff support, technology assistance or natural supports in the community. Assessments for people who wish to transition out of a nursing home should be developed in a "setting-neutral" fashion, or one that describes a need, support or service regardless of the setting in which the service will be provided. Assessments for each service should specifically describe the type of

service necessary and the required frequency and/or intensity as well as the purpose of the service. For example, if the person requires supports from a nurse, the term “24-hour nursing services” is not considered setting-neutral because it is too broad and suggests that a nurse be present with the person all of the time. Instead, an assessment may state that a person needs a specific type of nursing support, such as IV therapy assistance or vital signs documentation and the frequency of such a support (e.g., two times per day). This will allow planners to structure a specific service and offer the service in the most integrated setting.

An area that is often overlooked is the possible need for community mental health supports. Many individuals who reside in nursing homes have a previous history of mental illness and/or are currently receiving medications to address psychiatric issues, but they are hesitant to disclose it. The transition facilitator needs to be aware of this possibility and carefully determine if this may be an area that will require community support. These supports could include psychiatric services, peer counseling, crisis-intervention and medication assistance. In some instances, people would also need addiction management supports, such as a 12-step program or counseling. These interventions should be considered with equal importance as other health interventions.

Social Supports: Often, people living in nursing facilities have lost contact with many of their friends, family, and neighbors. The assessment needs to include the most important people

currently connected with the individual as well as those with whom the individual was previously connected. Another important step is to identify the social activities that the individual values. Social activities may include religious events, recreation activities, social clubs, traditional family activities and leisure time preferences. Many times, former friends and family can be reconnected with during the person’s transition to the community. It is critical to identify family members, old friends and significant others during the assessment process. A question such as: “Who used to be involved in your life?” can be very useful in discovering prior contacts and relationships.

Housing: The availability of safe, accessible and affordable housing is a major obstacle to community living. This problem has been cited as one of the major barriers to successful nursing home transition around the country. The housing component of the assessment should fully describe all housing needs, including location, safety, accessibility, size and type of neighborhood. This assessment should also include financial resources as well as potential eligibility for different types of housing benefits.

Transportation: An inventory of transportation needs is also critical in transition planning. A thorough review of where the person wants to go on a regular and/or intermittent basis needs to occur along with determining what type of vehicle is necessary and any specialized transportation needs.

Volunteering/Employment: Another part of the assessment process is – What is the individual going to do

during the day after transition to the community? For some adults, volunteer activities and perhaps employment should be considered if the individual indicates that this is a priority. If it is meaningful, the assessment may include a volunteer or a work component including an inventory of the individual's interests, vocational skills and past experience in working or volunteering. If and when a person indicates a desire for additional training or employment, a referral to the state vocational rehabilitation office may be suggested and support provided to the individual through the application process. Regular meaningful activities in the community are essential.

Advocacy: One of the most important roles of the transition facilitator is to encourage and support the individual in advocating for herself. The individual in the nursing home should fully participate in her transition to the community. This provides an important opportunity for an individual who may have not felt like her personal concerns were heard and acted upon by the nursing home staff, to begin speaking for herself, gain confidence, and start using advocacy skills. A successful life in the community often requires self-advocacy skills. It is important to re-emphasize that the individual's preferences should be respected during the assessment process.

Financial resources: This is a critical part of the assessment process. It is important that as a new transition facilitator you have assistance from a more experienced staff member during this phase to ensure that any information that is collected regarding social security benefits, Medicaid,

Medicare, personal assets, trusts, etc is current and accurate.

For Application and Discussion

1. What are the purposes of conducting an assessment? For the transition facilitator? For the individual?
2. What are the seven components of an assessment and why are they important?
3. What component would be the most challenging for you?

The Assessment: Getting Started

Becoming a transition facilitator is a significant commitment of your time and energy. Make sure that you can fulfill your obligation before you accept the challenge of supporting an individual through the transition process. It is important that you have an adequate amount of time and energy to successfully support an individual transitioning from a nursing home. If you feel that you cannot support the number of individuals that you are working with, please talk with your supervisor and see if other staff can provide additional assistance such as following through with locating housing, contacting potential community supports, getting utilities turned on, etc. If you are overwhelmed, it is not helpful to you or to the individual who is transitioning.

The first step in the assessment process is an initial interview with the individual. The collection of any other information or discussions about the individual with others should not occur until you have conducted the initial

interview and gathered basic information. The initial interview may often take more than one appointment. Some people may lose focus or become overly fatigued after 30-45 minutes. Others may become emotionally upset the first time and a second or third interview may result in more deliberate and accurate responses. Do not rush the process; it is difficult for people to share their dreams with someone they do not know well.

How Do I Conduct the Initial Interview?

Below are some important guidelines for conducting the initial interview.

Let the Individual Lead: It is critical that the individual should, at all times, be the “leader” in the assessment process. “One thing to always remember is to involve the person whom you are working with in everything.”⁸ This is discussed in more detail later. Sample assessment instruments are included in Appendix B (which is also useful as a planning instrument) and under the title *Resources* at the end of this module.

Listen and Assist the Individual in Expressing Desires: During the initial interview, the transition facilitator should begin to learn about the individual’s life. Much of the first visit may consist of listening to what the person wants and doesn’t want. You may need to encourage her to express her desires, wishes, and preferences. Sometimes people living in nursing homes have had limited opportunities to express their choices and have adopted the behaviors of “learned helplessness.” This is when people may have lost skills

or are no longer using their skills to assert their preferences.

Take Time: It is important not to rush the individual, even if you don’t get all the information you need in the first visit. It’s better to go back again to ensure that the person feels comfortable with the process rather than trying to get all the forms filled out and signed on the initial visit. Rushing through all the forms can be intimidating to someone who has just begun thinking about wanting to move back to the community. She may be hesitant to move from the place she has called home for several years. This is a time for listening and an opportunity to learn how long the person has been in the nursing home, how she got there, and how the family feels about her moving.

Answer these Questions: What activities of daily living does the person need/want assistance with? Who are the most important people in the person’s life now and in the past? Are they still connected? What caused the person to move to the nursing home? During the day, what is the person involved in at the nursing home? Does she enjoy these activities? What are the person’s favorite activities? The transition facilitator should also be looking for information about what the person would like to do once in the community. What are the priorities for action? What needs to be done before other less important issues? Finding answers to these and other questions will help you get to know the individual and be aware of the issues which need to be addressed during the transition process.

Accomplish the Following:

- Become acquainted with the person so that each of you can work comfortably together throughout the assessment and transition process.
- Explain and discuss an overall strategy for conducting the assessment, including the identification of other friends, family or significant others who the individual may want to be involved.
- As stated previously, the goal for the transition facilitator is to support the individual in being the leader throughout the entire transition process. It is critical that the individual actively participate in the assessment process. Sometimes the person himself will conduct his own assessment, called a self-assessment. At other times, the transition facilitator will need to assume the role of gathering the information. In all instances, the transition facilitator and the individual will review all the information together to make sure that the assessment provides a thorough understanding of the individual's preferences, desires and needs.
- Discuss the transition process and determine an overall schedule of tasks to be performed throughout the assessment process.
- Explain confidentiality and obtain the individual's verbal and written consent to obtain and review confidential information about the individual for the purpose of assessment and transition. This is called informed consent. Informed

Consent is a person's agreement to allow something to happen after the person has been informed of all the risks involved and the alternatives. An individual must give written consent before that specifically gives you permission to review her records in the nursing home. Your agency should have appropriate forms. [See the information on HIPAA on the next page.]

- Remember, the length of time that the assessment will take varies with each individual.

For Application and Discussion

1. Why is it important to "involve the person whom you are working with in everything?"
2. What is "learned helplessness" and how does it come about?
3. What is dignity of risk?
4. Read the section titled, "Successful Interviewing Steps" and proceed to the activity.

HIPAA

As a transition facilitator, it is essential to understand the federal Health Insurance Portability and Accountability Act (HIPAA) of 1996. The primary goal of the law was to make it easier for programs/agencies to ensure confidentiality and security of personally identifiable healthcare information.

Personally identifiable information referred to in this document as “personal information,” means any information that is identifiable to an individual (name, age, address, social security number, Medicaid/CHIP number, income or other financial information), including information regarding health care and treatment.

Privacy rights must be guaranteed by:

- obtaining written authorization from the individual before accessing any health care and/or other personally identifiable information;
- giving individuals (or legally designated guardians) clear, written explanations of how the individual’s personal information will be used; and
- respecting an individual’s request to restrict the uses and disclosures of his information.

The transition facilitator should ensure reasonable safeguards of personally identifiable information, for instance:

- avoid using names in offices, hallways and elevators, and post signs in the agency to remind employees to protect confidentiality;
- isolate or lock file cabinets or records rooms; and/or
- provide additional security, such as passwords, on computers maintaining personal information;
- fax information containing personally identifiable information *only* when the transition facilitator has determined that it is a secure (not available to the public) fax machine and that someone who has been authorized to receive the information is standing by; and
- limit how much protected personal information is used, disclosed, and requested for certain purposes.

Understand and carefully follow the HIPAA regulations because it is the law, and YOU, the nursing home staff, and other health care agencies are responsible for ensuring that all information is obtained and shared only with the full written agreement of the individual. By doing this and always handling all information in a confidential manner, you are modeling the key principle of self-determination. Self-determination means that an individual has control over the choices and decisions in his life including personal information. You are demonstrating the individual is in control of his personal information and may choose to disclose or not disclose it.

Successful Interviewing Steps

Transition facilitators should develop and/or possess the necessary skills to interview a person in a nursing facility. These 12 interview skills should convey an overall message of respect for the individual being interviewed as well as an appreciation for the individual's frustration with their current living situation. Some essential points in interviewing include the following:

Always be on time!

Start off by showing the proper respect by valuing the individual's time. Showing up late can increase the individual's anxiety and is often interpreted as a statement of disrespect. Also, try not to schedule the interview during mealtime or other scheduled activities. First thing in the morning may also be difficult depending on whether nursing facility staff are prompt in getting the person out of bed. Allow for up to 90 minutes, but not longer for the initial interview. The assessment process will take more than one visit.

Dress casually.

Don't overdress and look like a lawyer or an investigator. Wear something casual and non-controversial that is conducive to relaxed and candid communication.

Identify an appropriate interview location.

If at all possible, avoid conducting the interview in the bedroom. Offer to meet outside the facility if possible, but most important, ask the individual where he would like to meet.

Position yourself at eye level contact with the person.

Avoid hovering over the person if they are in bed or in a wheelchair. Position yourself so that your heads are at the same level and you have direct eye contact.

Take only essential notes.

To avoid distancing, take only a writing pad and not reams of paper. Take notes only on relevant and important information and not a transcript of the conversation. Explain to the individual that the notes are to make sure that you remember all of the information.

Respect personal space and equipment.

A person's wheelchair, prosthetic device or communication device should be treated as part of their body.

Interview the person alone.

The initial interview should be a one-on-one discussion unless the person specifically expresses otherwise. Do not include roommate or staff unless specifically requested by the individual.

Listen. Don't interrupt.

Exercise patience. It may take the person some time to open up and share personal pieces of their lives. Take time to establish rapport. Avoid acronyms or disability jargon. Often a person needs to tell their story. This often provides valuable insights that will assist you in being a more effective transition facilitator.

Do not make promises you cannot keep.

The individual often wants you to tell them how quickly they will move. Any

suggestion of a timeframe or schedule will be perceived as a commitment. Failure to meet this perceived or real commitment will undermine your credibility and can diminish the positive attitude of the individual.

Ask about activities in the nursing facility.

An understanding of the individual's favorite activities within the nursing facility may help shape activities in the transition planning process. It is also important to determine the individual's least favorite activities and why they are described that way.

Community and social connections.

Ask about their previous favorite community and social connection and what they would like when they return to the community. Reconnections are often made during the transition.

Schedule next appointment before you leave.

Continue building the relationship.

Activity:

1. When you read the following scenario, think about what you have learned in this module so far to see if you can identify the positive skills displayed in setting up and conducting the initial interview.

You met Chelsea at the nursing home in the lobby. You had asked her if she knew of a spot where you could speak alone without interruptions. She said that the activities room was empty now. As your visit began, you told her about yourself and she seemed to open up a little when she found out that you both had an interest in old movies. You then

began to talk about what your role would be throughout the process and that it was very important you both were honest with each other. You told her that she would need to be the leader in the process and make the decisions. She seemed a little hesitant but also pleased that you would allow her the freedom to do so.

The conversation turned to how she got in the nursing home and you found out that her family put her there because she couldn't get the services in the community that she needed. They also questioned her judgment for living independently because she had been drinking while driving the night of her accident. She said that she thought she would be able to direct and manage her own care, but also stated that she had never really lived on her own. She was in high school when she was injured in the accident and had planned on going to a technical school when she graduated from high school. When you asked what types of things she needed assistance with, she hesitated because she thought that you might also think she couldn't take care of herself. You assured her that everyone needs assistance at one time or another and she needed to be honest with you. Then you asked her about where she planned to live. She talked about sharing an apartment with an old friend—she said she had already spoken with the friend and she agreed that it would be a great idea. However, Chelsea had not asked if it was accessible. Her doctor said he thought she would probably be able to live in the community.

Chelsea seemed to be getting more energy as you spoke to each other. When you asked if she would mind

completing some forms with you, she didn't seem to mind. She understood about your needing to obtain her medical records. You asked her if she had talked to her family about moving to the community. Chelsea became somber and her eyes watered. She said she had tried to talk with her mom, but her mom dismissed the idea, saying that she shouldn't be silly. She had "just the care she needed" where she was. You suggested a meeting where the whole family and the both of you could be there to discuss the concerns and fears. You explained to her that the reason many families acted that way was because they were misinformed about living in the community and they were only trying to protect her. She was open to the family meeting and wondered if you would help her set it up. You agreed because you could see she had been trying so hard to get things moving on her own.

In the next few weeks Chelsea called her mother and set up the meeting. Her mother seemed reluctant and tired, but agreed that since Chelsea seemed set on the idea, that it might be good if everyone was there to be involved. You also went back to the nursing home and made contact with the social worker, and began to get acquainted. He started looking for supports in the community to assist with the transition. The social worker was actually more open to the idea of Chelsea's living in the community than other social workers you had met in other situations.

2. Again, thinking about what you have learned so far, read the following scenario to see if you can identify some areas that could be improved. What things should a transition

facilitator do to make this a more positive experience for the individual?

After repeated calls from John, you set a first meeting with him. Because of his somewhat erratic behavior in your phone conversations and because you do not know John, you felt more comfortable arranging to meet him in a busy area of the nursing home. The only day you could meet was a very busy one, but you wanted to get this meeting over with so John would quit calling you.

On the day of the interview you are running late because of an important meeting with some community leaders. John had been nervous about the meeting and he thought that you would be there by 9 am. He skipped some of the morning activities to meet with you and was sure that you were deliberately making him wait. He also skipped breakfast because he felt very anxious and was afraid that you wouldn't take him seriously.

You arrive 20 minutes late and realize that you are still dressed in a high power suit from your earlier meeting, but you just don't have time to change. You rush into the room where you were to meet John and asked several people before you locate him.

Dialogue:

TF: Hi, I'm sorry I'm late. You must be John.

J: (Sounding startled) Oh yeah. Are you the person who is going to get me out? Can we leave now?

TF: I am here to help you but we need to talk about some things first. Shall we get started?

J: Uh, sure. I am a little worried and I have some questions....

TF: Great! But I'm in sort of a hurry. My last meeting knocked me off schedule. Do you mind if I move this checkerboard so I can use this table to write?

J: Oh, yeah. I was just playing with my friend. Would you like to meet him?

TF: Not now. I really have a lot to do and we need to get started now. Here is a paper to sign so I can look at all of your confidential records. Just sign it there and we can start to work to "get you out of here," ok?

J: Well...I, what is your name again? Have I talked with you before? Well anyway, I want to be able to live on my own and also want to find some kind of employment. I am really good at construction.

TF: Yeah, well, that's a tough one. Look, I have another really important meeting and I need to get going. I just wanted you to sign this paper anyway.

You listen impatiently for a couple of minutes as John rambles about his family and how he doesn't know where they are. You check your watch and then say that you have to leave right now but will check back sometime. John is almost in tears and just sits in his chair looking confused and bewildered.

3. Find someone with whom to practice the following scenario. Take turns role-playing the transition facilitator

and Darren. Practice setting up the interview over the phone, describe what you will do to prepare for the interview and role-play the interview. Make sure to talk about activities in the community, friends and family, where he would like to live, his financial situation, etc. Keep in mind all of the steps in a successful interviewing process.

You are a transition facilitator and have received a phone call from Darren, a 36 year-old man who has developmental disabilities and has to maintain his surroundings in a certain way. He is very concerned if something has been moved or if he can't check and recheck turning off the lights, washing and rewashing his hands, and taking exactly the same number of steps to the lunchroom each day. He is able to function on his own in all areas of self-care. His family had placed him in a nursing home 10 years ago, when his parents died, because they were worried he would get hurt living on his own or let other people take advantage of him. He is frustrated and wants to be independent. He heard about you through one of his friends that used to live in the nursing home, but now lives in the community.

Building Relationships with Nursing Homes, Family, and Other Supports

Now that you have a general idea of how to conduct an initial interview and have had the opportunity to practice some interviewing skills, here are some other vital things to remember in the process of conducting an assessment: Establish a relationship with the nursing home, work with family and other support people, keep notes, obtain informed consent to review confidential information, and review medical records.

How Do I Establish a Relationship with the Nursing Home?

One of the first things in planning for the initial interview is to establish a relationship with the nursing home. What is the best way to accomplish this? The Centers for Independent Living, Arkansas⁹ found one of their best strategies was to involve the nursing home staff from the beginning. The response has not always been positive but not involving them ensures, “at the very least, a lack of cooperation and at the worst, sabotage against your efforts.” They found the nursing home social workers to be one of their greatest assets. Social workers helped the individual to fill out required applications, switch social security payments to the individual, go shopping for necessities, find a local doctor, and ensure they received their medications and personal belongings from the nursing home before leaving. The Centers found that establishing a working relationship with the nursing

home staff significantly reduced their workload.

Other groups have suggested offering training from the local Center for Independent Living to the nursing home as a way to establish a positive relationship. In some instances, the nursing home staff may not be receptive to having you visit with someone in the nursing home. However, under the federal Older Americans Act, every state is required to have an Ombudsman Program to help address complaints in the long-term care system. An ombudsman is an advocate for residents of nursing homes and can assist residents in resolving quality of care complaints. Make use of these advocates as they are already in the nursing homes and they know people who want to get out.

How Do I Work with Family Members and Other Support People?

Most people in nursing homes have families and friends and it is important to work as closely as possible with them, again with the consent and direction of the individual making the transition. Some people lose contact with their family and friends and often they become reconnected during the transition process. If possible, it is important to get families and friends involved in the transition process as early as possible. A good support system will add to the likelihood of a successful transition. However, some families may actually oppose the move to the community. Sometimes family members opposed to the move do not change their minds prior to the move. Keeping the family informed as progress is made, having them attend the planning meetings and even visiting

the housing as it is identified have been found to be good ways to help families feel more comfortable with the move.

What Do I Do About Confidentiality and Informed Consent?

We have previously discussed confidentiality and informed consent; however, these topics are of such importance that we will cover them a bit further here. Sometimes people need to develop more trust in you and in the process before they are comfortable giving written consent.

Many people with disabilities or other health conditions are concerned that information about themselves will be used against them. This concern comes from negative experiences when their private information was improperly shared with others. You can help overcome these fears by explaining how you will use the information you obtain. The person has the right to limit the information that you can see in his/her file. It is critical for you to set a high standard regarding the use of confidential information. You need to watch your own conduct with regard to confidentiality in both the nursing home and in your agency. If there is a legal guardian or surrogate decision-maker, then separate consent will be necessary.

A note of caution here: Do not allow confidentiality laws to be used as an obstacle to working with an individual in a nursing home. The person has a right to give written consent to share her information with whomever she chooses.

What Kind of Notes Should I Keep?

During the interview and assessment process, you will want to take notes about the information you are collecting. Notes should be complete but do not have to be extensive. Do not duplicate information that is easily obtainable by going back to the records should you need to. Keep track of follow-up actions that are needed as you proceed through the assessment process. Include contact information for relevant people you may need to reach at a later time. Maintain your notes in an organized file. Be aware that your notes could be subject to subpoena in any future court action. Do not include personal opinions that have no purpose in supporting transition. This includes your personal opinions of the person being helped, the nursing home staff, family members, etc. Your notes must be based on facts, not your perceptions.

How Do I Review Medical Records?

Every person in a nursing home has a medical record. For most people, this is an important resource for their transition to the community. The medical records can help the transition facilitator better understand the individual's needs. The transition facilitator's role is not to evaluate the quality of the record, but to extract the information most useful in the transition to the community. A major purpose of the medical record is as a communication tool to enable different health care professionals in the community to ensure continuity of care. As such, the medical record is an important tool in ensuring a safe and effective transition to the community.

Many medical records contain extensive amounts of information about the

individual. For our purposes, we will want to concentrate on the most current and factual information in the record. Remember, a written permission will be needed in order to review this record. You may find that the individual is unsure if he is receiving the medication that is listed. Always be sure to verify with the nurse if the current medication and the dosages listed are correct. The transition facilitator's review should be done with the individual if possible. If not, the facilitator should summarize the review with the individual to determine that nothing is missing. If notes are needed from the record, it is preferable to make copies of a page rather than to make extensive notes. Supplemental records may be located in other locations and should be obtained if necessary. An excellent directory of medical abbreviations is available from Med League Support Services [<http://www.medleague.com>].

What Do the Medical Records Contain?

The medical record contains information about the health of an individual recorded by a doctor or other health care professionals. The medical record will contain information to identify the individual's needs. It will describe and specify the person's medical and health problems. The prescribed treatment will be specified as well as the actual treatments received.

In order to ensure continuity of health supports, a medical record is required to contain the following:

- A complete list of medical diagnoses
- Allergies and adverse reactions to medications prominently displayed
- Appropriate past medical history
- Social History
- Plans of action/treatment consistent with the diagnoses
- Care that is demonstrated to be medically appropriate
- Health insurance and financial status
- Basic identifying information
- Special reports and other records
- Order sheets and physician notes
- Nursing notes, vital signs & record of diagnoses
- Medical history and physical examination
- Medication Administration Record (MAR)
- Laboratory reports
- Minimum Data Set
- Working diagnoses consistent with the diagnostic findings
- Clinical records

What is the Medication Administration Record (MAR)?

Frequently, for people moving out of nursing homes, the Medication Administration Record (MAR) is of great importance. If the transition facilitator understands the basics of the Medication Record, it will facilitate the transition process. A copy of the current Medication Record will be needed on the day of transition from the nursing home.

The MAR typically contains the following:

- List of all medications (brand and generic name)
- Purpose of medication

- Frequency and time of day to be administered
- Stop and start dates
- Prescribing physician and supplying pharmacy
- Several months of the MAR, but not current month
- Contraindications and side effects
- Current month usually maintained in a place convenient to nurses who administer medications
- May also include prescription plan if one exists.

The medical records need to be reviewed carefully and can play an important role in a successful transition to the community. However, the medical records may not tell us about the services needed in the community nor the person's preferences and desires. Specifically the transition facilitator must be sure that needed medication and treatments will be available in the community.

How Is Your Progress?

In the first module you wrote down the name of someone that you and an experienced transition facilitator would assist to live in the community. This module has given you important information on completing an assessment. You should have already practiced the interview tips for the initial interview and read points on how to develop support relationships, as well as keeping notes, obtaining informed consent, and reviewing medical records in order to complete the assessment. You should now be ready to assist an experienced transition facilitator in the assessment process.

At the end of this module under the title "Resources," assessment instruments are listed which you will find useful in identifying the needs of the person you are assisting to move to the community. Appendices B and C, at the end of the manual are questionnaires that are also used to assess an individual's needs. Reviewing each of these resources will help you assist the person in determining the supports and services he will need in the community.

For Discussion and Application

1. How can the transition facilitator, most effectively support and encourage the individual to participate actively in the transition process?
2. How does the Independent Living philosophy (especially self-determination) underlie and support the transition process?
3. What are the most effective methods to learn about the individual and what they want?
4. Why is it important to establish a relationship with the nursing home and family members or support person?
5. Why is it absolutely required to obtain informed consent?

Summary of Module on the Assessment Process

In this module on the assessment process, we have learned that the individual in the nursing home takes the lead in planning for the transition as the transition facilitator provides the level of support needed. Families play an important role in transition and it is helpful to meet with them and answer questions they will have. Reviewing medical records is also an important part of conducting the assessment. The

assessment process should be part of the overall person directed planning.

Key Terms Used in this Module

assessment:

the process of systematically gathering information about the strengths, needs, desires, and preferences of an individual.

informed consent:

verbal and written agreement to share private information about the person after achieving a full understanding of how the information will be used.

Transition Planning Module 3

“Freedom is not merely the opportunity to do as one pleases; neither is it merely the opportunity to choose between set alternatives. Freedom is, first of all, the chance to formulate the available choices, to argue over them and then, the opportunity to choose.”~ C Wright Mills

Topics to Be Covered

- Transition Planning
- Person Directed Planning
- Transition Plan Components
- Transition Schedule and Checklists

Chelsea

As discussed in Module 2, the assessment process has gone well with Chelsea and she is more comfortable talking about what she wants in her life. Chelsea has also been able to discuss more of her fears and hopes for moving into the community.

Chelsea wants to “get down to business” and begin planning the actual transition. She is excited but also afraid that this planning process will fall through and then she will be disappointed “one more time.” Clearly Chelsea has some mixed feelings. You decide to spend some additional time visiting with her about these feelings and continue to listen carefully to her fears and hopes.

Chelsea is also getting negative comments from family members as she has begun talking with them about moving out of the nursing home. The meeting with her family will give them the chance to voice their fears and opinions and hear from Chelsea about what she wants in life.

John

The assessment process has been challenging. After your initial interview with John, you spoke with your supervisor about how upset you were with John because he just didn't seem to “get it.” Your supervisor had you tell him exactly what you said and did. He then talked with you about the key principles of interviewing and establishing a relationship. You realized that you had really messed up and spent the next several visits with John trying to repair the damage and develop a good relationship. John talked a lot about his life before the accident--his job and family--but when you asked about the other nursing homes and how he liked them, he seemed vague. You felt that perhaps he just didn't want to tell you the truth. Although John continues to tell you that he wants to leave, he does not follow through with things he says he will do. If you come to see him in the afternoon, he seems really tired and can't help you much.

With John's written permission, you are reviewing his medical records. As you do this you discover that the accident John had several decades ago resulted in severe traumatic brain injury (TBI). You have permission from John to discuss this with the medical staff at Happy Acres. The charge nurse takes almost an hour to talk with you about TBI and how it may impact the cognitive planning function, memory, and social

skills. She also mentions that John's fatigue is another part of TBI and that the fatigue is very real. As you leave, she gives you several references so you can learn more about TBI.

Chelsea and John's situations are similar to many others who are transitioning. As you think about the process for this module, take a moment to answer these questions:

1. How could you most effectively support Chelsea and John to be in control of the transition planning process?
2. How could Chelsea's age at the time of the accident be a factor in planning the move?
3. How can you support Chelsea in acknowledging her fear and anxiety and dealing with these feelings?
4. How can you help John with his memory loss?
5. How can you involve the family and friends in the planning process?
6. How can you enhance community integration for Chelsea or other individuals moving?
7. What will be some of the challenges for John to become integrated into the community?

Objectives of the Module on Transition

Each of the above questions is about transition planning. These are important aspects to understand and think about. The material in this module is designed

to provide the critical steps in transition planning:

- Assisting the individual to plan for his or her transition to the community.
- Identifying and locating supports necessary to live in the community.
- Conducting Transition Plan meetings.
- Working with family members and other support networks.
- Establishing timelines for the move to the community.
- Supporting the individual as he advocates for himself.

Transition Planning

Important aspects of transition planning are described in this module within a framework of person directed planning.

What Do We Mean by Transition Planning?

The assessment process, identifying the individual's strengths, abilities, wishes, and the supports needed to enable the person to return to life in the community, should have been completed at this stage. Transition planning is the process of identifying how each of the supports needed, can be provided in the community. Frequently called a "community transition plan," its development often involves a planning team. The plan addresses support for living in the community, such as housing, health care and social networks. These will be addressed in detail later in this module.

Frequently, the transition facilitator will focus on obtaining needed services, but another helpful strategy is to help the

person envision what she will be doing on a daily basis before she leaves the facility. Other examples include: having the person list exactly what kind of attendant services she will need throughout the day. That way the person starts to envision the detail she will need to know in the community. Or the person can envision what she will do in a morning and afternoon once she is out; listing the specifics of doing such and what she will need in order to accomplish it. This discussion can minimize any unpleasant surprises when the person transitions out. There may also be activities that the individual can engage in prior to moving that take the envisioning process to a more practical level, such as taking the bus to meet the transition facilitator in the community. (Of course this would depend on the individual and his/her circumstances.)

What is Individual Self-Direction?

The goal for the transition facilitator is to support the individual to remain in charge and have control to the maximum extent possible during the entire transition process. Self-direction is one of the fundamental goals of the Independent Living philosophy, and requires that persons with disabilities be given the opportunities and tools to maximize their own decision-making and control of their own lives.

The transition facilitator can support self-direction through several steps.

1. Make sure that the individual is not just included in every meeting and decision during the transition process, but leads the process to the extent possible.

2. Explain each step of the transition process to the person moving. It can take significant time and effort to assist the individual to prepare for the planning meetings so that he or she can participate fully.
3. Direct questions and decision-making back to the person moving using questions such as: "what do you think?" This action will support the individual to make his own decisions and choices. It may also help nursing home staff to see the individual as a more capable decision-maker. Frequently, the nursing home staff will defer to the transition facilitator and leave the person out of the decision-making process.
4. Assist the individual to clarify his goals and personal choices. If an individual wants to live near public transportation, but also wants to have a lawn and garden, determine which is most important through discussion with the individual.
5. Encourage/expect the person moving to do as much of the work as possible involved in planning the move to the community, e.g., call the phone company and ask about rates.
6. Support the person in managing the extensive amount of paperwork that will be created during the transition process. Many papers will come directly to the person from community agencies. Some will require responses within deadlines in order to take advantage of potential community resources.

What Is Person Directed Planning?

The goal for individuals who want to move out of a nursing home is to regain control and be in charge of their own lives. It is critical for the person moving to be in charge, to the extent possible, of all the steps and decisions during the transition to living in the community. This may be difficult for people who have been living in nursing homes for a long time who felt that their preferences were not acknowledged. Many people

living in nursing homes, or their family members, have been told and come to believe they no longer have the ability or the right to be in charge of their own life. This occurs because the institution takes over making choices about the person's care and often, all the decisions about their life. Over time, by not making their own choices and decisions, the individual may become passive and look to others to make decisions. This is described as "learned helplessness."

Person-directed planning focuses on what people can and want to do in their lives, not on what their deficits are and what needs to be fixed in a person's life. Person-directed planning focuses on the strengths and gifts of an individual and puts the person in charge of defining the direction of their lives. While the planning process addresses the person's support preferences and needs, a focus on person-directed planning assures that the individual's strengths and dreams are the key elements and foundation of the planning process.

Some individuals may require additional support to take the lead in planning meetings. If this is the case, do not automatically take charge, but rather encourage the individual to be an active participant in the process. As the individual gains confidence, gradually step back. The individual should not ever feel as though they were in the transition process without support.

This transition planning process consists of several elements that are significantly different from the typical discharge planning meeting from a nursing home. These critical planning elements are:

1. *The person moving must attend all meetings.* A planning meeting cannot be held without the person in attendance and able to participate fully.
2. *The person moving chooses who shall attend the meetings.* Anyone not invited by the person moving is not allowed to attend the meetings. This may result in excluding family members or professionals who are accustomed to attending all such meetings in the past.
3. *Meetings are held in the community as often as possible.* This is to remind everyone of the goal of being

a part of the community. However, do not let facility rules against this be a barrier to assisting the person in transitioning.

4. *Non-paid people who care about the individual from the community, family, prior friends, and others attend the planning meetings when requested by the individual.* This is to begin to generate the personal support system that the person will need once living in the community.
5. *Either the individual or someone selected by the individual leads the meetings and helps to include all the members of the planning team and makes sure everyone's voice is heard.*

For Application and Discussion

1. How is person-directed planning different from a typical discharge planning meeting from the nursing home?
2. What are some of the challenges to having a “real” person-centered planning meeting?

3. What does individual self-direction mean for Chelsea who has lived either with her parents or in a nursing home, but never been “on her own?” For John, who has no real idea about what he wants except to get out of the nursing home?
4. How can you help Chelsea understand self-determination? To prepare to direct the planning meeting?
5. How can you help John understand the importance of planning? With the nature of his memory, how can you best support John in taking a leadership role in his transition?

Activity

Take turns role playing the transition facilitator, the individual transitioning, nursing staff, and family member or friend. Following the principle in step number 3, under the heading *What is Individual Self-Direction?* Role play discussions with Chelsea and John about self-determination and person-directed planning.

Transition Plan Components (Adapted from *Transition to Freedom and Transition Guide*)

The Transition Plan will outline in detail how the transition will be implemented. This includes how supports and services will be put into place, the timeline for doing so, and who will take responsibility for each activity. The plan must be very concrete and it is the responsibility of the transition facilitator to ensure that each of the following areas is addressed, as appropriate:

- Housing
- Personal Assistance
- Assistive Technology
- Health Care
- Mental Health/Addiction Supports
- Transportation
- Volunteering/Employment
- Roles of Family and Friends
- Social, Faith, and Recreation
- Community Integration
- Advocacy
- Finances

Each of these is discussed in detail below.

Housing:

Locating affordable, accessible, appropriate housing in the community is often one of the biggest barriers to leaving the nursing home. It is frequently the reason the person ended up in the nursing home in the first place. It is important to begin exploring available housing options in the community as soon as possible, even if the assessment process has not been completed. Most people living in nursing homes are eligible for rental assistance and/or subsidized housing which can

substantially lower the amount of money that needs to be spent on housing.

There are local housing specialists who are aware of the existing rules and regulations at the local Center for Independent Living or the local housing authority. However there is often a long waiting list and this often delays the move. That is why it is important to get started as soon as possible on locating potential housing resources in the community. Neighbors, friends, family and church members can often help find housing in the community. Other alternatives are bartering room and board in exchange for support or home sharing with someone who has similar needs.

Some other things to consider when discussing housing and the move are:

- Living arrangements.
- A realistic budget. Generally, one third of the person's income is a guideline for housing expenses.
- Obtaining furnishings.
- Moving expenses.
- Security and utility deposits, telephone connection, and requirements for paying the first (and sometimes last) month's rent "up front." There may be governmental programs in your state to assist with security deposits and incidental moving expenses.
- Housing modifications, such as widening of doors, lowering of kitchen cabinets, etc.

Personal Assistance:

The assessment process will have determined how much personal assistance (daily living activities) the

person may need. A personal assistant is someone who helps with eating, bathing, toileting, positioning, etc. It has been found that “a big part of the success or failure of an attendant [assistant] is usually related to how well the two people involved interact with one another.”⁸ PAs may be “aides” or “homemakers” provided by a home health care agency or the local Center for Independent Living. There may be specialized local attendant care programs in your geographical area. Many people in nursing homes have never had personal care assistance services and may need help in learning how to manage this service appropriately. The person moving may need to learn these new skills as a part of transition to the community. Many Centers for Independent Living offer classes on such issues. There are also excellent attendant care training manuals that may be helpful (See References and Resources section).

Assistive Technology:

(adapted from Wisconsin Assistive Technology Initiative): The Assistive Technology Act of 1998 defines assistive technology as “...products, devices or equipment, whether acquired commercially, modified or customized, that are used to maintain, increase or improve the functional capabilities of individuals with disabilities....”

Assistive technology (AT) can enable people with disabilities to accomplish daily living tasks; and assist in communication, education, work or recreation activities. AT is used to gain greater independence and an enhanced quality of life. AT items which may be helpful in moving to the community include such items as:

- Hearing aids and other amplification devices for individuals with hearing loss
- Devices that operate lamps, radios, and other appliances through a remote control switching device, that might be attached to a person's wheelchair
- Toilets and showers equipped with grab bars for persons who require supports
- Door levers instead of knobs

AT services support people with disabilities or their caregivers to help them select, acquire, or use adaptive devices. Such services include functional evaluations, training on devices, product demonstration, and equipment purchasing or leasing. Most Centers for Independent Living have AT centers. Every state has an Assistive Technology Project responsible for improving access to AT (See References and Resources section).

Another thing to consider when thinking about AT, is low-tech solutions, i.e., inexpensive, simple adaptations that can sometimes make the difference for someone to live independently, or to perform tasks independently. It can be something as simple as a pencil holder constructed out of PVC pipe for Jenny, who has difficulty grasping her pencil to write because of spastic muscles in her fingers; or even a tray or tabletop for a wheelchair, which was what Jerry needed to be able to edit papers from his home. Some people have adapted helmets in order to hold pointers for keyboards. One can also make handles to assist individuals in getting in and out of the bath. With a little bit of creativity

and some scrap material the possibilities are endless. [Go to <http://nhassistivetechology.org> or call (603) 226-2900 to order the new book: *Assistive Technology Solutions in Minutes* by Therese Willkomm, Ph.D.]

Health Care:

Everyone has health needs. Generally, people living in nursing homes have increased health needs. If the person moving has significant medical considerations, it means that these issues need to be extensively planned for and addressed by community medical professionals. The fear of not receiving proper medical care can be a major reason why nursing home staff and even families think that a person cannot live in the community. It is important to realize that for every person living in a nursing home, there are many more people living safely in the community with the very same health conditions.

Many people moving out of nursing homes do not have significant medical needs other than regular follow-up care. Other individuals have complex medical needs. It is imperative that physicians and other medical professionals are identified in the community, have agreed to have the individual as a patient, and scheduled appointments prior to the transition. Durable medical equipment such as transfer benches, wheelchairs, commodes, etc. can be ordered by the nursing home shortly before the actual move. However, it is always a good idea also to know where these items can be obtained in the community. Often the Centers for Independent Living have donated items that are useful.

Mental Health Supports:

Mental health supports are often overlooked or minimized during the assessment process. Sometimes individuals return to nursing homes after transitioning, not because of physical factors, but because of emotional or psychological ones.

The transition facilitator should be particularly attentive to medication prescribed for mental health conditions, notes in the chart indicating mental illness, or concerns expressed by the individual. If it appears that the individual either currently has a significant psychiatric disability and/or has had a history of mental illness, the transition facilitator should discuss this further with the individual to determine what type of supports may be needed in the community. These supports could include psychiatric services, peer counseling, crisis-intervention, and medication. If needed, all of these supports should be identified and put in place prior to the move to the community.

Addiction Supports:

Transition facilitators who have extensive experience in assisting people to move back to the community have indicated that one of the most challenging issues is substance abuse. The substance abuse may have been a significant factor in pushing the individual into the nursing home. For instance abusing drugs or alcohol may lead to behaviors that will put someone out of public housing and onto the streets. Families sometimes feel that if the person were in a nursing home, he would be unable to continue his addictive behaviors. Addiction to prescription drugs (such as pain

medication) may be particularly problematic and common because it appears that the individual needs the medication for a physical problem and it is difficult to determine if the person is actually abusing the drug. Regardless of the reason, if an individual in the nursing home has addictive behaviors that are not evident because of the lack of access to illicit drugs or alcohol, movement to the community may be challenging. Again, it is important for the transition facilitator to directly discuss these issues with the individual and determine strategies for accessing substance abuse treatments and supports, a 12-step program, or counseling in the transition plan.

Transportation:

Accessible transportation is dependent on the community, and sometimes even the area in a community, where an individual chooses to live. Most urban areas have local para-transit systems, but not everyone who meets the requirements to live in a nursing home also meets the eligibility requirements for the transportation service. In rural areas, transportation options are more limited and may only be available through volunteer services. Transportation, or the lack of it, often drives the location of the housing selected and the health services required.

Volunteering/Employment:

Most people work in our culture and society. The majority of people with disabilities do not. The unemployment rate for people with disabilities is approximately 60%. Employment, training to obtain job skills, and volunteer activities are all means to achieve income and/or a sense of worth

and value in our society. People who move out of nursing homes may experience isolation and dissatisfaction with their new life because they have nothing meaningful to do during the day. However, many individuals who transition out of nursing homes are not ready either physically or emotionally to handle the day-to-day expectations in a work setting. Volunteering is one option, and you can offer to support the person in pursuing this choice when the person is ready. In a volunteer setting, the individual will have a chance to get used to the flow of being around people. Successful volunteer experiences build a foundation of confidence and competence and are natural first steps in applying for and getting a job. Both volunteer work and employment lead to being out in the community, building a sense of self-reliance, and connecting with others socially.

With the growth of technology, “work, even for individuals with the most significant disabilities, is possible. Working from home or ‘telecommuting’ for part or all of a job is a real option”¹⁰. Alternative modes of employment have been developing in recent years to overcome the seemingly intractable high rates of unemployment for people with disabilities. With the goal of producing income to wholly support and/or supplement government benefits, many people with disabilities are successfully pursuing self-employment and the development of their own single person businesses called microenterprises. Additional information about microenterprises can be found in the resource section.

Family and Friends Support:

Having family and friends is important to everyone. People moving back to the community may experience a sense of isolation after the move occurs. A good support system can help with the significant adjustment from institutional to community living. Experience has shown that the planning process provides excellent opportunities to gain the involvement of family and friends. Even families and friends who have grown disconnected over the years can become reacquainted when they are asked to become part of the planning process. Having family and friends involved adds to the likelihood of a successful transition.

Sometimes families may oppose the move from the nursing home to the community. This is usually due to their fears of what might happen. They may be concerned that the person will not have 24/7 care and their needs will not be met. The opportunities for independence and risk (natural consequences) that they have allowed their other adult children, is difficult for them when their adult child, who has been “safe” in a nursing home, wants to move to the community.

Fortunately, this is changing as more and more people with disabilities are recognized as living successfully in the community. Strategies that have been helpful with families are:

- Developing relationships; the more contact, whether on the phone, by e-mail and particularly in person, the better.
- Keeping families informed along the way of the progress that is being made.

- Involving families as much as possible during the planning process.
- Being direct and honest. Admit where there is inherent risk in living in the community and compare this with its benefits rather than denying the family’s fears.
- As with all aspects of the transition process, making sure the individual is directing the communications that take place with family and friends and honoring the person’s wishes if he prefers not to have them involved.

Social, Faith, and Recreation:

Many people who moved out of nursing homes later comment on the importance of participating in their communities. “Loneliness, isolation, lack of contact, or interaction with people not paid to provide their care or supports can make living in the community seem very empty and depressing. Social interaction and recreation can be as important as getting your basic needs met.”¹¹

Many people find participating in organized religion a positive factor in their lives. If this is the case, it may be important to involve a community pastor, priest, or rabbi in the planning meetings as a means of kick-starting this connection. Religious leaders usually respond enthusiastically to supporting the individual in reintegrating into her local congregation.

Sometimes reconnections can be made to old friends during the transition phase. Interacting with friends can greatly decrease feelings of isolation and depression.

Recreational pursuits diminish during the years in a nursing home. Recreation has value in itself and/or as a means to finding friends. Frequently friendships form around common interests of clubs, associations, and recreational activities. It can be hard in the beginning to find recreational pursuits and/or to summon the interest and energy to participate. Feelings of discomfort in attending new events or meeting new people can surface. It is important to plan for and find a motivation to begin these pursuits.

Community Integration:

One of the major goals of the Independent Living movement is being a part of the community. While acknowledging the risk of community life, the values of independence, choice and control over one's own life are held as higher values to be pursued. People with disabilities have experienced centuries of being segregated in large scale institutions, long ago called "poor houses" and later "special schools" and more recently "nursing homes." Segregation has too often led to exclusion from most or all valued social roles, and the resulting isolation. The tenets of the Independent Living philosophy embrace integration and accept its accompanying risk, often called the "dignity of risk." The concept of transition facilitators is built upon these basic human and civil rights, and values inherent in human dignity for people with disabilities.

There are many strategies for increasing community integration and these have been covered above in the Transition Plan Components. However, it is important to underscore that there needs to be a *plan* for community

integration in order for the person moving to have a truly successful transition to the community.

Advocacy:

In disability work, advocacy is often defined as "representing the interests of the person as if they were your own." This is to say that the role of the advocate is not to determine what is best for the person but to pursue the interests of the person as he has defined them. As described previously, this includes supporting the individual in defining and clarifying his own goals and desires.

Advocacy is embedded in transition work. Some of the issues which transition facilitators encounter are:

1. resistance of nursing home staff to movement to the community because of concern over safety or medical treatment;
2. family (or guardian) concerns and/or opposition to community placement;
3. limited experience of the individual in living independently;
4. accessing housing with poor or no credit history; and
5. obtaining and maintaining utilities, food, and household goods, when the individual has limited financial resources or income.

Finances:

Having adequate income to live in the community is essential. The steps listed below describe some of the critical activities the individual and the transition facilitator need to accomplish.

1. Change of Address - Assist the individual in completing a change of address form for all income sources

and resources. (i.e., Social Security Administration, pensions, banks).

2. Income Source - If the individual has no income, assist him in applying for SSDI or SSI. If he has SSI, assist the individual in notifying SSA so that his SSI will go up after discharge (sometimes this cannot be done until the person is actually discharged).
3. Budgeting - If the person chooses, assist him in setting up a monthly budget.
4. Cash on Hand - Encourage the individual to budget for some cash on hand for the day of discharge. This is for any unforeseen expenses.
5. Community Medicaid - Make sure that, prior to the discharge, the person will be able to transfer his Medicaid into the community. If the person will need to set up a Supplemental Needs Trust, assist him in contacting a lawyer to establish this. If the person has a spend down, assist him in figuring out how he will meet his monthly spend down.
6. Food Stamps - If he qualifies, assist the person in applying for food stamps, including setting up an appointment.
7. Determine if the individual will have any financial support available from family members, trusts, workers, compensation, VA benefits, etc.

Transition Schedule and Checklist

Appendices C, D, and E provide detailed transition schedules and

checklists that can be used as guides to transition activities. These lists are used by successful transition facilitators throughout the country.

For Discussion and Application

1. This module presents 12 components for transition planning. Which might be the most challenging for Chelsea? For John? Why? Discuss ways to overcome these challenges with your colleagues.
2. Why was the term “dignity” used? What are the boundaries between acceptable risk and unacceptable risk? Who should determine what is unacceptable risk?

Chelsea Update

After numerous contacts and meetings with Chelsea and some meetings with the nursing home social worker, the assessment process was completed. The next step that Chelsea decided to take was meeting with her family to share her plans. Chelsea initially encountered silence and sarcasm from her family, but she didn't back down. She began to tell them exactly what she wanted and she knew how to get it. She told them about nightmares of living in the nursing home and that she knew she could live a better life and give to the community.

After Chelsea spoke she asked her family for their response. All of them voiced their fears and their opinions. They were not only worried about Chelsea and her safety; they were worried about the responsibility that would fall on them. They had their own children to take care of, without the responsibility of another “child.” There was anger, frustrations, and

accusations. It seemed the family had not communicated this openly for sometime.

Chelsea said that she was exhausted at this point, but wanted to meet again to talk to them about their concerns and fears and also admitted that she was afraid too. At the next family meeting, Chelsea asked you, the transition facilitator, to talk about your experiences with families and transition. You said that their fears were not uncommon and it was normal to have these feelings. Change is scary because of the unknown. But, you also assured them that to make this kind of change required the kind of detailed planning that was taking place. Chelsea then read through her assessment and began telling them of the plans that she had made. The social worker had helped to secure medical services in the community and Chelsea and you were actively looking for housing and personal assistance services.

The family listened quietly and a couple of the members seemed more open to the idea of Chelsea being on her own, though it still frightened them. Chelsea's oldest brother and his wife even volunteered to take Chelsea to church on Sundays and to a social gathering once a month. However, other members of her family did not volunteer.

After the meeting, Chelsea said that she thought her family had come a long way and it was generally a positive meeting. At least she had support from two of her family members.

After a few more weeks of finding the necessary supports and resources, Chelsea's plan to move to the

community was complete. She arranged for a home health agency to have a personal assistant come in twice a day to help with bathing and dressing. She had talked with several people from the CIL who had set up their own microenterprise businesses and would help her if she were interested. She would manage her own financial matters. She was going to move into her friend's apartment so that someone would be there periodically in case of emergencies. She would pay her portion of the rent and had the PAs for personal assistance so she wouldn't have to rely on her friend for everything.

John Update

It is almost a year later and John is ready to transition. Each step has been challenging, but John's motivation spurred him to learn several ways to remember things and to maintain a daily schedule of what he needs to do. Although John had wanted to live in his own house, his finances were too limited, so John chose to live with his former roommate from the nursing home who had moved out almost five years ago. Juan Carlos had a spinal cord injury and John agreed to be his personal assistant. Juan Carlos could pay John and John was excited to be working again. Juan Carlos liked to have a beer in the evening and John worried that he would start drinking again. This stopped the actual move while John and Juan Carlos had several long discussions. Juan Carlos said that he would go the local bar to drink if he needed to and also volunteered to accompany John to his AA meetings. John was happy with the support. John had a lot of trouble trying to learn to budget his money. You told him about a peer support group at the CIL that was

Summary of Module on Transition Planning

This module has focused on successful transition planning, the components to consider, and the challenges that come with these areas.

Key Terms

transition planning:

the process of identifying how the supports and arrangements the individual needs and wants, can optimally be provided in the community.

person directed planning:

planning that enables the person moving to be in control of all the steps and decisions during the transition to living in the community.

assistive technology (AT):

an AT device is any item or piece of equipment that is used to increase, maintain or improve functional capabilities of individuals with disabilities. AT devices are tools and resources used by individuals with disabilities to help improve their quality of life.

advocacy:

The American Heritage Dictionary of the English Language defines advocacy as “the act of pleading or arguing in favor of something, such as a cause, idea, or policy; active support.”

Microenterprises:

the development of one's own single-person business.¹²

Post Transition: Living in the Community Module 4

"Change and growth take place when a person has risked himself and dares to become involved with experimenting with his own life." ~Herbert A. Otto

Topics to Be Covered

- Post Transition Follow up
- Community Integration
- Monitoring and Advocacy
- Follow-up Schedule and Checklists

Chelsea Update

Congratulations! Chelsea has moved out of the nursing facility and she is currently living in the community. She is happier now that plans have been carried through and you continue to stay in close touch with her.

One of Chelsea's personal assistants, Reva, seemed great the first two weeks. The third week, however, she showed up late in the morning and was a little bit cross when Chelsea asked her to modify the way she washed her (Chelsea's) hair. Chelsea shrugged it off as a bad day, but then it continued to happen a few more days that week. The next week Reva was continually cross with her. Chelsea was unsure of what to do because she knew she needed the assistance. Her roommate noticed that Reva was being rather rude and it bothered her to see her friend treated that way.

Chelsea was also having family problems. Although two of her family members seemed supportive and offered their assistance, they didn't ever come around and do what they said

they were going to do. It had been a whole month and she hadn't been to church yet. Her roommate wasn't of her faith and so she didn't want to impose on her.

Chelsea was frustrated with her computer. The mouse that she had was difficult to use and she enjoyed using her computer and staying in touch with several friends that had moved away. Although she was happy to be in the community, she was struggling with all of the new responsibilities and decisions.

John Update

Yea! John finally got out. It actually took almost 18 months before John felt that he was ready to leave. Each time he had left a nursing home before (or been kicked out of one) he had ended up on the streets and he did not want that to happen again. Although he had initially seemed eager to leave, in reality he was scared and needed to be sure everything was just right before he left. During the first month, John called you several times a day and you went by his place daily. He had asked Juan Carlos to get rid of the beer in the house and wanted to go to an AA meeting once a day. Juan Carlos felt that that was a bit much and refused to go more than once a week. One of the CIL staff volunteered to help John learn to ride the bus. This took several weeks, but John now can use three routes by

himself. He asked you to help him write a list of directions to get to the bus stop and what to do on the bus. Initially, he had just stood up and yelled "Stop!" when he wanted to get off. Juan Carlos helped John learn to use the washing machine in the building, but said that he didn't have the patience to teach John how to iron his shirts.

Two people he met at AA (one is his sponsor) have invited John to a movie a couple of times and they are talking about going fishing when the weather gets warmer.

It's been six months now and John pages rather than calls you now because he says that he knows you will get back to him as soon as you can. You are working with another person from a different nursing home and John offered to have lunch with you and the "new guy" if you can meet at a restaurant that is on one of his three bus routes. You are concerned because Juan Carlos's health is not good, and recognize that John may once more have changes in his life. John has tracked down his ex-wife (via the Internet) and she gave him the addresses of his grown children and also sent him a picture of them. He has written to them and checks the mail anxiously every day hoping to hear from them. His younger brother has visited him once and calls him now and then.

As a transition facilitator, your job is not complete after you have helped the individual transition to the community. Your role as a support is still crucial at this stage. This module will focus on important post transition issues. Take a moment to discuss the following questions with your colleagues.

How can you best support Chelsea and John during the first critical days, weeks, and months after their transition to the community?

How can you assist Chelsea and John in getting their basic needs met, solving everyday problems, and facing new challenges?

How can you support Chelsea and John in becoming integrated into the community?

Objectives of the Module on Post Transition

The questions above can be difficult to answer because situations are diverse. However, there are basic principles transition facilitators have followed in ensuring more successful and smoother transitions. After studying the material in this module you will be able to:

- Support the person following their actual move to the community.
- Provide follow-up during the community transition process.
- Pursue community integration supports and opportunities.
- Encourage the individual to become a self-advocate.

Post Transition Responsibilities

What needs to occur following the individual's move to the community?

Maintain frequent contact: If the individual agrees (some people choose to be left alone), it can be important to have frequent contact with her after she moves, particularly in the first weeks and months. In the nursing home, there were people around all the time (even if

they didn't interact much), and now the individual may be in an apartment alone or living with others who have more independent lives. It is essential to be with the individual during the actual transition and ensure that all of the household equipment and goods, medical supplies, food etc. are in the apartment/house. For the first few weeks, it is important to touch base with the person each day either in person or by telephone, to see how they are doing, if there are any problems, and to let her know that you are available. It is a lot easier to solve problems when they are small than to wait until they become big issues. Over time, the initial issues will be resolved and others may take their place. The frequency of contact should gradually decrease (but not disappear) depending on the level of support required by the individual.

Provide empathy for stress:

Transitioning to the community involves a tremendous amount of change and significant personal adjustments. It is helpful for both the individual and transition facilitator to acknowledge and discuss the high level of stress that is being experienced. Research into stress shows that it has a cumulative impact; the greater the change the higher the stress levels. A surprising finding of the research is that even positive change is stressful. During the transition, the individual will have changed her living situation, the staff providing supports, the food, the time she gets up and goes to sleep, daily activities, and recreational activities. Frequently, family relationships will change as well.

Be aware of and prepare for emotional challenges:

The first weeks and months following the move are a busy time of adjusting to a new home, new people, and new settings. Frequently, an emotional let down occurs following the move. What has been a busy time filled with the excitement of moving and having so many new things to be accomplished subsides. During this time, it is common to experience an emotional letdown, similar in many ways to mild depression. Many people who transition to the community also have difficult personal, emotional, and family problems. Many of these problems may not become clear until after the move to the community.

Assist the individual in looking to the future:

This post transition time is important for the person to begin their personal transition to thinking about their long-term goals, for example: "What happens now that I can do whatever I want to do as I no longer live in a nursing home that constricts my life options?" "What do I want to do with the rest of my life?"

Review and complete the Transition Plan:

The transition facilitator should review the transition plan. Is the person accessing everything that the plan indicated was needed? If not, does the individual feel that this service/support is it still needed? If still needed, what steps can the individual take to obtain it? (See the Advocacy Section that follows). Are there additional supports that are needed at the present time that the individual feels would help him to be successful in the community? Some questions to be considered in each of

the major areas of community living follow:

Housing

- Is the housing appropriate to the individual's needs?
- Have the needed modifications, such as widening of doors, lowering of kitchen cabinets, etc. all been completed and are they working properly?
- Are there additional modifications still needed that could help the individual live more comfortably in the community?
- Is the rent being paid? Has rental assistance and/or subsidies been obtained and are the payments working as expected?
- If there is a roommate, is this working out?
- Are additional furnishings needed?

For example, Rachael made the transition to her new apartment from a local nursing home and she needs assistance with a few tasks which she receives from a personal assistant who comes for two hours a day. She was pleased with the location of her apartment and her new roommate, but she began having difficulties with her roommate because the cupboard handles were difficult to grasp and she had to always ask her roommate to open them for her. The transition facilitator asked Rachael if she had any suggestions. She said that she had seen some handles that allowed people with limited upper body strength to open

doors and cupboards easily. The transition facilitator suggested that Rachael might want to call the community volunteer program to see if they could help. Rachael said that she would look up the number in the phone book and call the program.

Personal Assistance

- If the individual has personal assistants; how is this working out? Are the hours of assistance sufficient?
- Is the person able to provide adequate direction to the personal assistant? Does the individual need additional information on how to effectively manage personal assistants?

For example, Bruce had transitioned to his apartment where he lived alone. A personal assistant came for a few hours in the morning and a few hours in the evening to assist with meals and bathing. Bruce liked his personal assistant, who was nice and efficient. However, the personal assistant spoke little English and many times misunderstood Bruce's directions. The transition facilitator helped Bruce obtain an interpreter for a few weeks until the PA was familiar with Bruce's likes and dislikes. After that, the interpreter was available for phone calls if needed.

Assistive Technology

- Did the individual receive the assistive technology devices specified in the Transition Plan?
- Are the devices working properly and is there a plan for them to be serviced if needed?

- Is there additional assistive technology that might further support the individual to live in the community?

Health Care

- Have all medical needs been addressed by appropriate health care professionals?
- Have all health care appointments been made and kept?
- Has all durable medical equipment such as transfer benches, wheelchairs, commodes, etc. been obtained and are they working properly?

Mental Health Supports

- Are there any mental health needs and/or substance abuse needs that should be addressed?
- Does the individual acknowledge these needs and does she want assistance?
- How would the individual prefer to have these needs addressed?
- Are these needs being addressed?

Transportation

- Is accessible transportation available in the local area?
- Is the individual making use of what is available?
- Is there a need for training on how to use the transportation system?

For example, Amber loves to go to the library and loves to read. Because she cannot drive, she goes to work in a carpool; therefore she has not learned to use the local transit system. Her fear of a new experience kept her from using the system until the transition facilitator helped her find a family member to train her in using the system. She now not only goes to the library, but is able to go shopping and attend various civic and recreational activities as well.

Employment

- Does the individual want to be employed? Full-time? Part-time?
- Does the individual have a job?
- If not, what efforts is the individual making to find employment?
- Are other supports needed to assist the individual with his search for employment?

For example, Vern is now living in the community but had not obtained a job yet. He has a mental illness that involves social anxiety. He is on medication, but still was not comfortable with the type of jobs available because most of them require contact with the public. The transition facilitator suggested that Vern might apply for a job as a sanitation engineer. Vern applied for the job and works graveyard shifts at an office building. This way he can work when fewer people are around and he feels more at ease. The clients were so pleased with Vern's work that he got referrals to do more offices.

Family and Friends Support

- Have family and/or friends been involved in the individual's transition?
- What are some strategies that encourage the involvement of family/friends?
- Are family/friends being updated on the transition? By whom?

The transition navigator had, at Katrina's request, organized a transition plan meeting with Katrina and her family before she moved into the community. Katrina told the transition facilitator that her family was distant in their relationships with her; the exception was her mother and her mother was getting older. She had one brother and three sisters who were all older than she. Because of their lack of interest in her previously, she doubted that they would want to be involved in her life at all.

Katrina led the meeting and her transition facilitator supported her. First Katrina told them about her excitement to live in the community and to be able to have a life. She said that much of her life in the past eight years had been mostly meaningless days and she felt that now, with an apartment and perhaps even a job, she could give to others for the first time in her life. The transition facilitator suggested that the family may want to respond to Katrina's views.

Each family member took turns voicing his or her concerns: many had to do with Katrina being hurt—but surprisingly, the general response was

positive. All of them said that they never even thought to ask her what she wanted. Katrina told them that she was grateful they listened to her. She thought that they never cared before. The transition facilitator helped the family understand that in order to support Katrina in living as happy and safe a life as possible, that assistance was needed in providing Katrina rides to medical appointments or taking her to activities. Since Katrina could do some daily care tasks by herself, she only needed help from a personal assistant in the mornings and evenings. She also needed help finding social activities. As she went through the plan with the family, several of her siblings volunteered to assist in one way or another. One said she could take turns driving Katrina to the doctor. Another said she knew quite a few groups that met periodically, such as art lovers and book clubs—things that Katrina enjoyed and could be a part of. Other family members, although they were glad to have had this discussion, were still very concerned about Katrina living in the community and felt that it would eventually turn out to be the wrong decision.

In the next few months Katrina got to know some of her family members better although one brother who had said that he would help with transportation did not follow through and this concerned Katrina. Although Katrina realized her family members did care for her after all (even if not all of them agreed with her decision), she still remained uncomfortable in asking her family for assistance and was careful not to ask her family for what they might consider as "too much help."

Social, Faith, and Recreation

- What recreational activities or hobbies is the individual participating in or would like to be involved in?
- What support is the individual receiving for social, faith, and recreational activities?
- If he chooses, is the individual involved in the religion of his choice? Has the person been supported in reintegrating into a religious service of his choice?

For example, Chad moved into the community several months ago and is becoming increasingly lonely and depressed. His transition facilitator learned that Chad liked bowling and encouraged Chad to find out if there was a team in the community that he could join. Chad found a team and is now bowling on Friday nights.

Teresa also moved to the community recently. She had hoped to be able to attend a reading group at the community library but needed transportation. She didn't know whom to ask. The transition facilitator suggested that Theresa contact the para-transit service to see if she was eligible to use it. Theresa called and found that she was eligible. She immediately scheduled a ride to the library for the next reading group. To date, para-transit has provided transportation for Theresa but often arrives late and twice left her waiting for two hours at the library after the reading group was over.

Community Integration

- Housing: Is the individual living in a safe area with accessible

transportation and/or stores located nearby?

- Volunteering/employment: Does the individual want to volunteer or work? If yes, is the person volunteering or working in an integrated community setting?
- Transportation: Is the person using public transportation? Does he have any other means of transportation if needed?
- Recreation: Is the individual routinely participating in integrated social activities?

Ellen was excited about being in her new apartment and having a job. She was going to be a greeter at a local superstore and all she had to do was catch the 7:00 a.m. bus to get to her job on time. On the first day of work she left early to make sure she had plenty of time. When Ellen, a wheelchair user, went to get on the bus, she noticed the bus was not wheelchair accessible. "Sorry, Lady," the bus driver called to her, and shrugged his shoulders. Ellen was devastated and went back to her apartment. She might lose her job over this. How was she going to manage without transportation?

What should the transition facilitator do? This is where advocacy can play a crucial part in assisting people to live in the community. Read on to "Advocacy" to see how Ellen advocated.

Advocacy

- Are there supports and services that the individual needs but is not receiving at this time?

- What should the transition facilitator do? What should the individual do?

The transition facilitator knew Ellen's first day of work as a greeter at the local superstore was today. The transition facilitator called that evening to see how her job had gone and was concerned to hear Ellen crying and asked to come over to meet with her in person.

When the facilitator arrived he was surprised to hear that the bus was not accessible because other routes of the city system had accessible buses. He remembered that he had always transported Ellen in the Center's van and was upset with himself for not checking bus access out more thoroughly and even taking a practice trip with Ellen. However, he also recognized that this was an opportunity for Ellen to use her advocacy skills.

He made a game plan with Ellen. First Ellen would call into work and explain the situation and tell them she was working on a way to take care of it. Then tomorrow morning Ellen would call the city transportation department and make a complaint. The facilitator encouraged Ellen to remain calm and not accusatory so that the people would not be put on the defensive.

He waited for Ellen to contact the city transportation and speak with them on her own. He knew it would be good experience for her and hoped that it would be a positive one. It was important for Ellen to become more confident in advocating for herself.

Later he received a phone call from Ellen who was very excited. She had

called the city and they said they would take care of the problem. He volunteered to go with Ellen the next morning on the bus and Ellen was glad to have the support.

Finances

Living in the community means careful budgeting as well as obtaining the needed services and supports that are required. Do not assume that all of the plans regarding finances will work out perfectly. You will need to have regular discussions and perhaps problem-solving sessions to ensure that all of the financial issues are adequately addressed in the context of community life.

Celebration

One especially thoughtful way to support the individual who has moved to the community is to remember their birthday, holidays and especially the first anniversary of the day they moved out. A card, a telephone call and/or a first year anniversary party can make a big difference.

Post Transition Checklist

A post-transition checklist is provided in Appendix E.

For Discussion and Application

Read the following scenario, and discuss answers to the questions provided.

Scenario:

As a transition facilitator at Access Independence, the local Center for Independent Living, you helped Roger

transition from the Forest Haven nursing home to the community. Roger is 36 years old, uses a wheelchair and also has abused drugs and alcohol in the past. With your assistance, Roger moved from a nursing home of 180 people last month. He is now living in his own apartment using a Section 8 rent subsidy and on-going support from Access Independence, where you work.

Roger is elated to be living on his own but very nervous at the same time. He wonders, "Will I be successful? How will I manage all these new responsibilities? At the nursing home I didn't have to do anything and I did not have ready access to alcohol or drugs."

You are on your way to visit Roger in his fifth week of living in his new apartment. You were with him during the actual move and visited with him daily in the first two weeks following the move into his new apartment. Now, you are trying to help Roger think about the next few months and how to begin working on some longer-term hopes and challenges.

1. Roger's anxiety is real. As the transition facilitator, how will you address this? How could you have discussed Roger's anxiety prior to the move? Why is this so critical? How can you, the transition facilitator, most effectively support and encourage the individual to actively participate in the community?
2. How does the Independent Living philosophy (that people with disabilities should make decisions that affect their lives, become informed about their rights and responsibilities, and advocate for

themselves) underlie and support community integration?

3. What can you do to support the individual in addressing his addiction problems?
4. How can you best advocate for the person in getting what is needed for successful community life?

Chelsea Update

At the beginning of this module Chelsea was happy to be living in her new place and she had handled the challenges of working with Reva, her personal assistant, the members of her family backing out on their offers, and accessibility issues with her computer. You had called or visited her almost daily the first couple of weeks after moving and all seemed to be flowing smoothly and so you thought that you would wait to contact her again in another couple of weeks. Although you were familiar with the initial challenges Chelsea had faced, you were surprised that Chelsea was so upset when you contacted her again. She said that she was overwhelmed because her computer wasn't working and her family were not providing what they had agreed to. You immediately set up an appointment to see her the next day.

You arrived with a list of computer specialists that are familiar with accessibility that the local Center for Independent Living had provided. You asked her if she would be willing to call one of the specialists to help her with the program she was working on. She was happy to do so and would have done so before, but didn't know of anyone that could help her. You told her she was always welcome to call the

Center for Independent Living for any resources and gave her the phone number again.

She discussed her frustrations with her family and said that it really wasn't that big of a deal, but you were concerned that Chelsea was afraid to contact them and ask what was going on. You asked Chelsea if she wanted to call them while you were there. You said that it would be better if she contacted them since it was important for her to speak for herself.

When Chelsea called, her sister apologized when she realized who it was because she had forgotten that she had made the commitment to take her to church on Sundays. She said that she would make an appointment with the pastor to meet Chelsea and talk about some of the church activities as well. When Chelsea hung up with her sister she smiled and said that she would call her back as soon as she got hold of the pastor.

Her other sister was not nearly so friendly and got upset when Chelsea called. She ended the call quickly and Chelsea decided her sister was having a bad day and just needed more time to let her adjust to the idea of Chelsea living in the community—besides, her other sister seemed more than happy to help out.

Chelsea was afraid to take any action with regard to her personal assistant because Reva had been physically rough with her yesterday and Chelsea was afraid that Reva would really hurt her. You reminded Chelsea that she was in charge now. She wasn't in the nursing home anymore and she was

managing her own affairs. Reva wasn't worth paying if Chelsea wasn't happy with her. You asked her what she should do and she said that she probably needed to talk directly with Reva and tell Reva that she could change, or Chelsea could get another assistant. Chelsea asked if you would stay while she spoke with Reva. For the next hour while you waited for Reva to come, you went through a list of other home health agencies who provided personal assistants. You also explained that Chelsea could call the agency and let them know of her concerns. Chelsea said she felt more confident knowing that she had other options.

Six month update:

Five months later you threw an anniversary party for Chelsea. In the end Reva didn't work out and Chelsea selected an assistant named Sherrie. Sherrie has worked out really well, but will be relocating in three months so Chelsea will have another change. Chelsea has started a microenterprise in her home and sales have continued to slowly climb as her roommate's crafts have become more in demand. Chelsea's sister has been faithfully taking her to church and Chelsea is an assistant teacher in a children's Sunday school class. She also participates in a women's group every other Wednesday night.

John Update

John had already faced a lot of challenges in the first six months of living in the community. He referred to these as his "crisis of the week!" Budgeting has been a problem since John will spend money if it is in pocket. One of the staff at the CIL suggested

that when John cashes his check, he put the money in five different envelopes that are labeled food, rent, utilities, bus tokens, and fun stuff--movies or eating at the Chuck-a-rama. John is not sure if this will work, but thinks that it might be a good reminder about where the money should go.

John has been talking about having a beer in the evening just to see if he is cured of his alcoholism. You are concerned and suggest that he might want to talk with his AA sponsor about his idea. John writes this down on his list of what he needs to do this week. He is proud of all of the things that he has crossed off of the list and keeps all of his lists to show you.

Juan Carlos' health has gotten worse and John cannot take care of him alone. Juan Carlos may be eligible for home health services. John looks up the number and calls them. While Juan Carlos talks with them, he listens carefully and when Juan Carlos hangs up, John offers to go get the application since he can now ride eight different routes.

His brother has suggested that John come to visit him--maybe at Thanksgiving. One of John's sons has written him twice, but the other son hasn't. John really wants to see them and keeps talking about just getting on the bus. You suggest that he remember the label on his reminder book that says "Stop and think." He needs to think about the problems that could happen if he left the state and his son didn't want to see him.

John wants to do more than just help Juan Carlos, but his criminal record keeps him from a lot of volunteer activities. His AA buddies have suggested that he help with the reading program at the men's homeless shelter. One of them goes there twice a week and he said that John could come with him.

All in all, John says that life is better than he ever dreamed of and he is more than willing to talk with others who want to live in the community.

Summary of Module on Post Transition

In this module on Post Transition, we have described how to provide follow-up support to the individual after her actual move to the community has been made. We suggested questions to help the transition facilitator to determine if the individual's needs are being met. The importance of becoming integrated into the community and self-advocacy were also discussed.

Key Terms

transition stress:

a person going through transition experiences a large amount of stress because of all of the changes. During this time the individual may need extra support.

community integration:

full access and participation in the community with an emphasis on choice, and control over one's own life.

Appendix A

The ADA and Other Examples of Major Federal Legislation that Contain the Disability Policy Framework

The ADA (Americans with Disabilities Act), as mentioned in *Module 1*, is an example of a major piece of legislation that reflects the disability policy framework.

The ADA is a federal civil rights law designed to prevent discrimination and enable individuals with disabilities to participate fully in all aspects of society. The ADA was passed by Congress and signed by the President in July 1990.¹³
<http://www.usdoj.gov/crt/ada/pubs/ada.txt>

The ADA recognizes the history of treatment of people with disabilities

The first part, the *Findings and Purposes* section, states the reasons that Congress passed the law. This section describes problems that the law is intended to address.

For example:

“Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”¹⁴

It also states:

“Individuals with disabilities have been...subjected to a history of purposeful unequal treatment and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.”¹⁵

The ADA states the four goals of disability policy

The goals of the law are stated as follows:

“the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity
full participation
independent living, and
economic self-sufficiency for such individuals.”¹⁶

The ADA reflects the new paradigm that disability is a natural part of human experience, and the solution is to fix the environment, not the person

The law has five major sections that address 1) employment, 2) state and local government services, including public schools and public transportation, 3) public accommodations and services operated by private entities, 4) telecommunications, and 5) miscellaneous provisions.

Throughout the law, the focus is on how to “fix the environment” to eliminate discrimination and level the playing field to allow people with disabilities to participate in and contribute to society. The ADA relies on the concept of “reasonable accommodation” under the employment provisions (Title I), which is a legal term for fixing the environment.

To be protected by the ADA, a person must be a qualified person with a disability. For example, under the employment section, “a qualified employee or applicant with a disability is an individual who, with or without reasonable accommodation, can perform the essential functions of the job” in question. Reasonable accommodation may include, but is not limited to:

- Making existing facilities used by employees readily accessible to and usable by persons with disabilities.

- Job restructuring, modifying work schedules, reassignment to a vacant position.
- Acquiring or modifying equipment or devices, adjusting modifying examinations, training materials, or policies, and providing qualified readers or interpreters.

To read the full text of the ADA, visit the following website:

<http://www.access-board.gov/about/ADA%20Text.htm>

Other Examples of Major Federal Legislation

IDEA – Individuals with Disabilities Education Act of 1997

First enacted in 1975, this landmark legislation was needed to assure that students with disabilities receive free appropriate public education (FAPE) and the related services and support they need to achieve their educational goals. IDEA was created to help states and school districts meet their legal obligations to educate children with disabilities and to pay part of the extra expenses of doing so. Read it at: <http://www.ed.gov/offices/OSERS/Policy/IDEA/>

Rehabilitation Act of 1973 (amended in 1998)

Federal legislation that authorizes the formula grant programs of vocational rehabilitation, supported employment, independent living, and client assistance. It also authorizes a variety of training and service discretionary grants administered by the Rehabilitation Services Administration.

The Act authorizes research activities that are administered by the National Institute on Disability and Rehabilitation Research and the work of the National Council on Disability. The Act also includes a variety of provisions focused on rights, advocacy, and protections for individuals with disabilities. Find out more on the web at: <http://www.ed.gov/offices/OSERS/RSA/Policy/Legislation/narrative.html>.

Developmental Disabilities Assistance and Bill of Rights Act of 2000

A federal law that authorizes four programs: Developmental Disabilities Council State Grants, Protection and Advocacy Systems, University Centers for Excellence in Developmental Disabilities Education, Research and Service, and Projects of National Significance, all of which are programs aimed at assisting people with developmental disabilities. Find out more on the web at: <http://www.acf.dhhs.gov/programs/add/DD-ACT2.html>.

Technology Act of 1998

A federal law that affirms that technology is a valuable tool that can be used to improve the lives of Americans with disabilities. The law aims to increase access to, availability of, and funding for assistive technology through state efforts and national initiatives. All states are eligible to receive 10 years of federal funding for their state assistive technology program, and states that have completed 10 years may receive 3 additional years of federal funding. Find out more on the web at: <http://www.ncddr.org/relativeact/statetech/ata98.html>.

Appendix B

Example Assessment Instrument

Nursing Home Transition Needs Survey

Developed for Independence First by Julie Alexander, Independent Living Coordinator and Advocate

Transition Services

1. Do you feel that you are able to direct and manage your own care?
 - Have you previously managed your own care?
 - When and how long?
2. Which agencies, if any, have you chosen to assist you in this transition into the community?
3. Have you selected a company for home care supplies if needed? Please provide name and phone number:

Housing Services

1. Have you obtained a housing list from an Independent Living Coordinator?
2. Have you placed your name on a waiting list for a housing complex in which you would like to reside?
3. Do you need accessible housing?
4. Do you have funds to pay for housing?
5. Are you being evicted from your current living situation? If so, when?
6. What is your target date for moving?
7. What is the date of your lease?
8. Have you reviewed your lease?
9. What is the date housing was secured?
10. What date was the security deposit paid and rent paid?
11. What date is the move scheduled for?
12. What is the date you pick up your keys?

13. If needed, are duplicate key(s) and/or key cards made and obtained?

Utility Services

1. Have you scheduled an appointment for your telephone service to be installed?
2. Have you scheduled an appointment for your electricity to be turned on?
3. Have you scheduled an appointment for your gas service to be installed?
4. If you want cable television, have you made an appointment for installation?
5. Have you requested that the Post Office change your address?

Funding Resources

1. Do you think that you will need Community Options Program (COP) funding or Title 19 assistance as you deal with independent living issues?
 - If so, have you applied for these funds?
 - Are you on a waiting list for COP or Title 19?
 - When will you receive COP or Title 19?
2. If you have Title 19 funding, have you checked into whether or not this nursing home Title 19 can be transferred to independent living Title 19?
 - Have you initiated such a transfer?
 - What is the name and phone number of the Social Worker assisting you with this transfer
3. Will you be eligible for Veteran's Services?
4. Have you checked into the process of the transfer of SSI/SSDI income from the nursing home to the community?
 - Have you started the process of this transfer?

Personal Health Needs

1. Do you have your physician's approval for nursing home transition? Check any of the following activities you need assistance with:
 - Bathing in tub
 - Bathing in bed
 - Sponge bath

2. Do you need assistance with dressing? Check all that apply:
 - Lower extremities
 - Upper extremities
 - No assistance needed

3. Do you need assistance with toileting? Check all that apply:
 - With pads
 - Getting on and off the commode
 - No assistance needed

4. Do you need assistance with bowel care? Check all that apply:
 - Suppositories
 - Laxatives
 - Other
 - No assistance needed

5. Do you need assistance with bladder care? Check all that apply:
 - Catheter
 - Urinal
 - Other
 - No assistance needed

6. Do you need assistance eating? Check all that apply:
 - Feeding
 - Set up
 - Cutting Food
 - Clean up
 - Meal preparation

7. Do you need assistance with housekeeping? Check all that apply:
 - Dusting
 - Mopping
 - Vacuuming
 - General cleaning
 - Other
 - No assistance needed

8. Do you need assistance transferring from one place to another? Check all that apply:
 - Hoyer lift
 - Pivot lift
 - Need for worker to assist with equipment
 - Other
 - No assistance needed
9. Provide the names and phone numbers of supportive family members, friends or community advocates.

Personal Care Assistance Services

1. Do you need personal care assistance? If so, have you contacted:
PAS at IndependenceFirst
 - MA Program
 - Attendant Referral Program
2. Have you scheduled a needs assessment by these programs?
 - PAS at IndependenceFirst assessment
 - MA assessment
 - Attendant Referral Program assessment
 - COP worker assessment
3. What is the date assessments will be completed?
4. What is the target date for funding to be secured?
5. Have you recruited attendants and back up attendants?
6. Have you hired attendants?
7. Have you been orientated to the employer or employee manager role?
8. Have you made sure your attendant worker has received training and certification?
9. What is the date of certification?

Assistive Technology/Devices Services

1. Do you need assistive technology or devices to assist you with your independent living needs?
2. Do you know what types of technology or devices you might like to use?
3. Would you like an assistive technology assessment?

4. If assistive technology/devices are required, have you ordered these pieces of equipment?
5. Have you worked out a plan of payment for this equipment?
 - Do you need funding assistance to purchase this equipment?
6. Have you worked out delivery plan for the equipment?
7. Do you need assistance in learning how to use the technology/devices or equipment?

Medical Services

1. Will your doctor follow you into the community?
 - If not, have you identified another doctor who is willing to accept you?
 - Have you scheduled an appointment within two weeks of transition?
2. What is the name and phone number of the pharmacy you have selected?
 - Does the pharmacy deliver?
3. Will your doctor write a prescription for a 30-day supply to meet your medication needs during transition?

Furnishings for Your New Home

1. Have you completed the attached transition checklist detailing what possessions you have and what possessions you will need to purchase before transition takes place?
 - Do you have money to make such purchases?
 - Are you aware of places which may donate furnishings?
2. Have you coordinated your move?
 - Do you need assistance moving?
 - Do you need assistance setting up?

Budgeting/Money Management Services

1. Have you established a monthly budget?
 - Do you need assistance with this task?
 - Have you written a "trial budget?"
 - Do you need training in the areas of budgeting and money management?
2. Do you need to make arrangements for direct deposit of your income at a bank?
3. Have you established a bank account?
 - Checking
 - Savings
4. Do you need a payee?

5. Do you need to apply for additional forms of identification?

Transportation Services

1. Are you able to take care of your transportation needs?
2. Do you need specialized transportation?
3. Are you approved for Title 19 or User Side subsidy transportation?
4. Do you know how to schedule appointments to use specialized transportation?

Meal Planning Services

1. Do you need independent living skills training in this area?
2. Have you coordinated a plan so that you can purchase, cook and eat meals?
3. Who will do the initial shopping for groceries and supplies?

Social and Leisure Activities

1. Are you able to geographically orient yourself to your new neighborhood?
2. Do you need assistance in meeting your new landlord and neighbors?
3. Do you need assistance in planning daily or weekly social activities?
4. Do you want independent living training to assist you with any of these activities?

Appendix C

Transition Planning Work Sheets

(Adapted from IL NET an ILRU/NCIL National Training and Technical Assistance
Project How to Free Our People: Real Life Solutions, A National Conference
Participant's Manual, May 21-23, 2003)

Planning Work Sheet for Health

Goal _____

Priorities and support needs

- medical supplies
- adaptive equipment
- Medicaid card
- preventative health care
- pain management
- exercise
- evaluations (O.T., hearing, etc.)
- pharmacy
- community doctor
- therapy
- dentist
- specialist
- specialist
- other
- other

Resources

- own equipment
- other
- other
- other
- other

Plan

- For each item, define
- What needs to be done?
- When it needs to be done
- Who will do it both on the short-term and for the long-term?

- Arrange for personal assistance
- Arrange for transportation
- Other.....

Planning Work Sheet for Housing

Goal _____

Priorities and support needs

- access to home
- utilities
- appliances
- access to rooms
- telephone
- furniture
- bathroom modifications
- change of address
- equipment
- kitchen modifications
- keys for care providers
- location
- subsidized housing
- pet accommodations
- independent housing
- shared housing

Resources

- Physical Disability Services
- Donated funds
- Own furniture
- Donated furniture

Plan

For each item, answer the questions

- What needs to be done?
- When?
- Who will do it? (Short-term & On-going).
- Change of address with appropriate agencies and institutions (e.g. post office, Social Security)
- Utilities
- Phone

Housing Resources

For each, list Source (name of agency), Contact Person, and Phone Number.

- Police
- Fire
- Center for Independent Living (CIL)
- Physical Disability Services
- Utilities
- Housing resource
- Kiwanis
- Landlord
- Other.....

Planning Work Sheet for Daily Living

Goal _____

Priorities and support needs

- personal assistance services
- housework
- IL skill training
- equipment
- personal items
- assistance with mobility
- taking medication
- meal preparation
- shopping
- pet care
- clothing
- food
- emergency procedures
- emergency contact list
- privacy needs
- Others....

Daily Living Resources

For each item, list the Source (agency), Contact Person, Phone Number and other contact information.

- CIL IL Specialist
- Home Care Agency
- Others....

Planning Work Sheet for Financial Matters

Goal _____

Priorities and support needs

- determine Social Security income
- bank account
- Medicaid eligibility
- direct deposit
- food stamps
- any current debts or bills

Resources

- SSI
- employment income
- pensions
- personal savings
- family support

Plan

For each item, answer the following questions:

- What needs to be done?
- When?
- Who will do it? (Short-term & On-going)
- Get from SSA "personal earning and benefits estimate" income information
- Develop a budget.
- Apply for food stamps

Financial Resources

For each item, list the source (agency), Contact Person and Telephone or other contact information.

- SSI
- Food Stamps
- Legal aid
- Others...

Planning Work Sheet for Self-Determination

Goal _____

Priorities and support needs

Assistance with:

- memory
- communication equipment
- emotional support
- organizing
- health care advocate
- support group
- decision-making
- legal advice
- money management
- living will
- record keeping
- other

Resources

(List Source, Contact Person, and Phone and other contact information.)

- Family
- Friends
- Church
- Social clubs
- Other Plan

For each item, answer the following questions

- What needs to be done?
- When?
- Who will do it? (Short-term & On-going)

Self-Determination Resources

(List Source, Contact Person, and Phone and other contact information.)

- CIL peer support
- Support groups
- Legal aid
- Protection and Advocacy
- Long Term Care Ombudsman
- Others...

Planning Work Sheet for Social & Recreational Needs

Goal _____

Priorities and support needs

- visits from friends and family
- phone calls
- peer support
- religious affiliation
- meet neighbors
- private time
- future events to plan for
- holiday & birthday traditions
- ethnic, cultural traditions
- join community groups
- others...

Resources

- family
- volunteer agencies
- friends
- volunteer opportunities
- place of worship
- CIL peer support
- others...

Plan

For each item, answer the following questions

- What needs to be done?
- When?
- Who will do it? Both Short-term & On-going

Social and Recreation Resources

(List Source, Contact Person, and Phone and other contact information.)

- Family
- Friends
- Place of worship
- CIL peer support
- neighborhood group

Planning Work Sheet for Transportation

Goal _____

Priorities and support needs

- personal transportation from Nursing Facility
- move belongings
- arrange specialized transportation.
- public transportation
- schedules
- transportation training

Resources

- Dial-a -ride
- own vehicle
- family
- friends
- volunteers
- others...

Plan

List:

- What needs to be done?
- When?
- Who will do it? Both Short-term & On-going

- Plan discharge transportation.
- Dial-a-ride application.
- Others...

Planning Work Sheet for Employment

Goal _____

Priorities and support needs

- assistive technology
- volunteer opportunities
- training
- education
- career planning
- assistance with job search
- assistance with accommodations
- assistance with resume writing
- others...

Resources

- friends
- MJC-RS
- family
- CIL
- place of worship
- organizations
- other
- other

Plan

List

- What needs to be done?
- When?
- Who will do it? Both Short-term & On-going

Employment Resources

(For each item list the Source, Contact Person, Telephone number, and other contact information.)

- CIL employment specialist
- Vocational Rehabilitation services
- United Way Volunteer services
- Others...

Appendix D

General Guidelines for Nursing Facility Transition

(Adapted from IL NET an ILRU/NCIL National Training and Technical Assistance
Project How to Free Our People: Real Life Solutions, A National Conference
Participant's Manual, May 21-23, 2003)

Overview

The following provides a general guide for nursing facility transition. It is broken down by subject area and tasks should be viewed as being done simultaneously, as opposed to being done in order. Nursing facility transition is an ever-changing process and much of the work is based on an individual's needs, choices, and preferences. The guide does not specify which activities should be completed by the consumer, advocate, or other interested parties. During the nursing facility transition process, the consumer, yourself, and other interested parties should share responsibilities for the activities.

All of these are general considerations in the nursing facility transition process. The most important thing to remember is that you need to be thorough and make sure that all community services and supports are in place prior to discharge. Don't overlook the simple things! (e.g. how will the person get groceries?)

Referral

When you receive a referral, schedule an appointment to meet with the person at the nursing home. Make sure you obtain the individual's name, address, and phone number in case this appointment must be rescheduled. If you are familiar with the nursing home, encourage the person to include their Social Worker in the meeting. The Social Worker can be very helpful with many of the activities that need to be completed and can also act as a liaison between the consumer and medical professionals. Also, make sure the person knows that they can include any family or friends in any of the meetings.

I. General Planning Information

A. Education

The initial meeting provides both the advocate and the consumer with a chance to discuss goals, services, and rights. This is a chance for you to explain your role as a Nursing Facility Transition Coordinator, explain Independent Living Philosophy as it pertains to consumer control and consumer choice, and explain the *Olmstead* decision and an individual's rights under the ADA.

B. Demographic Information and Background

When you initially begin working with the consumer, make sure you obtain their demographic information, including their age and type of disability. This is very important because some community services are age or disability type specific. This information should be obtained once the person has decided that they want to pursue nursing facility discharge. Also ask how they ended up in the nursing home. The answer to this question will provide insight into what the focus of your discharge planning will be.

C. Social Worker

If the Social Worker is not at the initial meeting, ask the individual if he/she has advised the Social Worker that they want to leave the nursing home. If you have had positive experiences with the Social Worker, encourage the individual to let the Social Worker know that he/she wants to leave and ask the individual to invite the Social Worker to a meeting. If the individual tells you that the Social Worker is opposed to them being discharged, wait until you and the consumer have developed a list of needed supports before speaking to the Social Worker. Experience indicates that the Social Worker can play a very valuable role in the discharge process by both assisting with discharge plans and acting as a liaison with medical staff at the nursing home.

D. Establish Ground Rules

Advise the individual that you both must be honest with each other at all times during this process. The nursing facility transition process is really based on trust, and dishonesty can cause difficulties which can impede the entire process. Emphasize to the individual that your role is to help them get out of the nursing home, and you are not there to judge them.

II. General Community Based Services and Supports

A. Payer Source

Ask the person about a payer source. If it is Medicaid, make sure that it can be transferred from the nursing home into the community. Discuss ways to get community-based Medicaid (i.e. spend downs, Supplemental Needs Trusts). If necessary, assist the individual in contacting an attorney to establish a Supplemental Needs Trust.

B. General Community-Based Services and Supports

Discuss all of the community-based services and supports with the consumer. Make sure you explain to the consumer all of the options (i.e. home health care vs. personal care assistance vs. consumer directed personal assistance). The consumer should then choose whatever community-based services and supports they will need.

C. List of Community-Based Services and Supports

You and the individual should develop a list (from your previous discussion of community-based services and supports) of the community-based services and supports that will be necessary. If the Social Worker is involved at this point, include him/her in this activity. If the Social Worker is not involved at this point, ask the consumer to schedule a meeting with you, the consumer, and the Social Worker to discuss this list.

D. To-Do Lists

Create to do lists to delegate responsibilities between yourself, the consumer, and the Social Worker (if involved).

E. Potential Barriers

Discuss any potential barriers to community living (i.e. outstanding bills, credit problems, criminal history, previous problems with home care agencies).

III. Actual Community-Based Services and Supports

A. Housing

1. Finding housing

You first want to find out if the consumer has accessible housing to return to. If the consumer does not have accessible housing, you will want to work with the consumer to obtain accessible, affordable housing. The following are some of the activities that must be done prior to discharge:

- Review type of housing, location, and other preferences
- Locate housing
- Assist in clearing up credit if necessary
- Get on waiting lists
- Save money for security deposit
- Sign lease and get keys
- Put in change of address
- Discuss how the consumer will physically be paying rent and assist the person in setting this up if needed (i.e. representative payee, friend, attendant, etc.)

2. Utilities

- Make arrangements to pay any unpaid utility bills or advocate to get them waived
- Set up appointments for phone, electric, and gas to be turned on
- Buy a telephone if needed

3. Household items

- Make a list of items needed

- Contact churches, friends, or civic groups for donations if needed
 - Arrange to have belongings moved
4. Home modifications
If the person has existing housing that needs modifications, assist the person in applying for funding for modifications and/or finding someone to do the modifications.

B. Personal Finance

1. Change of address
Assist the individual in completing a change of address form for all income sources and resources. (i.e. Social Security Administration, pensions, banks)
2. Income source
If the individual has no income, assist the individual in applying for SSDI or SSI. If the individual has SSI, assist the individual in notifying SSA so that their SSI will go up after discharge (this may not be able to be done until the person is actually discharged.)
3. Budgeting
If the person chooses, assist them in setting up a monthly budget
4. Cash on Hand
Encourage the individual to budget for some cash on hand for the day of discharge. This is for any unforeseen expenses.

C. Public Benefits

1. Community Medicaid
Make sure that, prior to the discharge, the person will be able to transfer their Medicaid into the community. If the person will need to set up a Supplemental Needs Trust, assist the person in contacting a lawyer to establish this. If the person has a spend down, assist the person in figuring out how they will meet their monthly spend down.
2. Food Stamps
If qualified, assist the person in applying for food stamps, including setting up an appointment.

D. Transportation

1. Medicaid transportation
If the person is eligible for Medicaid, assist them in applying for Medicaid transportation. If the person is not eligible for Medicaid, discuss how the person will be getting to medical appointments and assist them in setting up arrangements.

2. Non-medical transportation

Assist the person in applying for transit or para-transit services. If para-transit, educate the person on how to go about setting up rides.

E. Personal Care Assistance

Discuss with the person what type of personal care assistance is needed and the options that are available. Issues that should be addressed include assistance with feeding, meal preparation, bladder care, bowel care, toileting, transferring, and dressing. Other issues such as grocery shopping, housekeeping, and laundry should also be addressed.

Make sure that a referral is made to the appropriate home care agency and advocate for adequate coverage. Make sure that approval is secured and that the actual hours of coverage are adequate.

For Consumer Directed Personal Assistance services, make sure that the consumer has recruited and hired attendants and back-up attendants and that they are approved to start working. If the consumer is responsible for training the attendants, arrange this with the nursing home. Assist the person with setting up schedules and lists of responsibilities.

F. Therapy

Discuss with the consumer any physical, occupational, or speech therapy that will be needed. Make sure that referrals and appointments are set up for these therapies.

G. Medicaid Waiver Services

Make referrals as appropriate and make sure that services are approved prior to discharge.

H. Durable Medicaid Equipment/Assistive Technology

Determine what equipment/technology will be needed and obtain approvals as appropriate. Ensure that funding is available for this equipment. Make arrangements for delivery of equipment and assistance in learning how to use the equipment.

I. Supplies/Medications

Make a list of what supplies will be needed upon discharge. Make sure that prescriptions have been made and determine how the person will obtain these supplies/medications upon discharge. Determine if the nursing home will give the person at least a week's supply of supplies upon discharge.

J. Doctors

Help the person to obtain a primary care doctor in the community. Assist with setting up the first appointment after discharge, as well as transportation to the appointment. Assist the consumer in setting up other doctor's appointments (i.e. specialists, dental, eye, mental health, etc.)

K. Recreational Activities

If the person wants assistance in planning activities, assist with this task.

L. Peer Support

If interested, have the person meet with a peer counselor who has gone through the transition process.

M. List of contact people

If the consumer does not have an address book, assist them with making a list of contact people (i.e. yourself, doctor, family, friends, attendants) that they can put in an accessible place.

N. Employment and Education

Discuss this with the consumer. Explore possible paid or volunteer opportunities. Make Vocational Rehabilitation Referral.

O. Food

Make sure that the person has enough groceries on hand for at least one week.

IV. Discharge Meeting

Approximately one week prior to discharge, schedule a discharge meeting with all interested parties. This meeting should establish the actual discharge date and provide the opportunity to review the community-based services and supports that have been obtained. Assign responsibilities for obtaining the services and supports that are not yet in place. Also, determine how the person will be getting home on the day of discharge.

V. Day of Discharge

You should meet the consumer at the facility to review the discharge instructions. You should then meet the consumer at his/her home to make sure that they get settled in.

VI. Follow-up

Follow-up after discharge will really depend on the consumer's desires. Sometimes a consumer will want you to meet with them on a weekly basis to assist them in getting adjusted to community living.

Appendix E

Timeline of Activities for Transition

(From IL NET an ILRU/NCIL National Training and Technical Assistance Project
How to Free Our People: Real Life Solutions, A National Conference Participant's
Manual, May 21-23, 2003)

A. Planning Activities

Two to Three Months Prior to the Move

1. Determine scope of planning.
2. Decide PCP [Person Centered Planning] methods.
3. Initiate PCP.
4. Identify possible barriers, e.g. outstanding bills, substance abuse problems, etc.

One Month Prior to the Move

1. Review PCP.
2. Create to-do lists for the consumer and Coordinator.
3. Start contact person/phone list.

One Week Prior to the Move

1. Review PCP & update to-do list.
2. Review move schedule.
3. Develop emergency contact list, copy to key people.

One to Two Days Prior to the Move

1. Make shopping list for food and personal items. Determine who will do the shopping.
2. Review move schedule and update to-do list.

Day of the Move

1. Meet at facility to review discharge instructions with the consumer.
2. Update to-do list.

First Week after the Move

1. Review PCP and outcomes.
2. Revise plans as appropriate

First Month after the Move

1. Review & revise PCP.
2. Confirm duties with other providers.

3. Determine follow-up schedule (e.g. 2 visits/month).

B. Health

Two to Three Months Prior to the Move

1. Create list of supplies and medical equipment needs.
2. Complete OT evaluation and order equipment &/or seek funding.

One Month Prior to the Move

1. Set up community doctor appointment for 1-3 days post discharge.
2. Determine source and procedure for obtaining medical supplies. Find out how soon order can be placed.

One Week Prior to the Move

1. Assure timely delivery of supplies and equipment.
2. If hospital bed is required, set up delivery date.
3. Change address with established doctors and Medicaid/insurance company.

One to Two Days Prior to the Move

1. Confirm delivery of supplies, etc.
2. Select pharmacy.
3. Obtain & fill prescriptions.

Day of the Move

1. Obtain discharge instructions.
2. Obtain from facility medications and supplies.
3. Review emergency contact list & procedures.

First Week after the Move

1. Make appointments for medical follow-up care (dental, optical, etc.).

C. Housing

Two to Three Months Prior to the Move

1. Review type of housing, location and other preferences.
2. Locate housing.
3. Get on waiting lists.
4. List needs (furniture, supplies, etc.).
5. Begin looking for resources.

One Month Prior to the Move

1. Solicit donations for needed household items and furniture.
2. Involve consumer and other support people in securing items.
3. Complete change of address with post office.

One Week Prior to the Move

1. Involve consumer in setting up utilities and phone service.
2. Notify SSA, FIA, Medicaid worker, bank, etc of address change.
3. Move belongings, if possible.
4. Review and prioritize what is still needed.

One to Two Days Prior to the Move

1. Confirm utility and phone hook-ups.
2. Buy phone, if needed. Ensure phone service is working. .

Day of the Move

1. Assist consumer in setting up home. Involve as many support people as possible.

First Week after the Move

1. Work with consumer and landlord to resolve any housing problems.

First Month after the Move

1. Follow-up to ensure rent and utilities payments.

D. Transportation

Two to Three Months Prior to the Move

1. Apply for public transportation ID.
2. Explore options for transportation training.
3. Use public transportation.

One Month Prior to the Move

1. Make arrangements for transportation from NH [nursing home] to home.
2. Check on status of ID card.

One to Two Days Prior to the Move

1. Confirm discharge transportation.

First Week after the Move

1. Follow-up with transportation training. If not available, make other arrangements, e.g., peer trainer.

First Month after the Move

1. Follow-up on transportation issues.

E. Daily Living

Two to Three Months Prior to the Move

1. Determine which tasks will require assistance.
2. Determine if consumer is maximally independent. If not, plan for training & therapies.

One Month Prior to the Move

1. Assist consumer in determining hours of assistance required. Select care providers.
2. Contact FIA and schedule evaluation for Home Help services.
3. If any unmet equipment needs, seek funding from FIA PDS fund.

One Week Prior to the Move

1. Determine PA Schedule. Make list of PA tasks with consumer.
2. Finalize arrangements with FIA and providers.
3. Food stamp application.

One to Two Days Prior to the Move

1. Confirm initial visits and schedule with PAs.
2. Obtain keys for PAs.
3. Obtain food and personal items adequate for several days. (Check food banks.)

Day of the Move

1. Review emergency procedures and back up plans with consumer.

First Week after the Move

1. Assist consumer in problem-solving situations.

First Month after the Move

1. Review caregiver needs; plan for changes as appropriate.

F. Personal Finance

Two to Three Months Prior to the Move

1. Get SSA report to determine income post discharge.
2. Assess other income.
3. Identify personal debts.
4. Develop personal budget.

One Month Prior to the Move

1. Resolve personal debts.
2. Determine money that will be required for the move and seek community resources.

One Week Prior to the Move

1. Notify SSA, MA, MC, FIA of address change.
2. Review budget.
3. Set up bank account near community home.

One to Two Days Prior to the Move

1. Set up automatic deposit for SSI/SSDI checks. (1-800-772-1213).

Day of the Move

1. If possible, have some cash available for unforeseen expenses.

First Week after the Move

1. Review & adjust budget.

First Month after the Move

1. Assist consumer in paying first month's bills.
2. Review & adjust budget as needed (e.g. monthly for 3-6 months).

G. Social/Recreation

Two to Three Months Prior to the Move

1. Begin community activities. Seek to build community relationships (e.g. places of worship, clubs, friends).
2. Consider CIL peer support.

One Month Prior to the Move

1. Continue community activities. Expand to other places.

One Week Prior to the Move

1. Continue activities, peer support.

Day of the Move

1. Assist consumer in meeting neighbors and community support persons.

First Week after the Move

1. Continue to support community relationships and activities.

First Month after the Move

1. Continue and expand community relationships.

H. Employment

Two to Three Months Prior to the Move

1. Introduce as a possible planning issue.

First Month after the Move

1. Investigate work and volunteer options.
2. Make Vocational Rehabilitation referral.

Notes

¹ Encarta® World English Dictionary 2006

² ADA (28 C.F.R. § 35.130(d))

³ ADA (28 C.F.R. pt. 35, App. A, p. 450)

⁴ AIMMM (Advancing Independence Modernizing Medicare and Medicaid). (2003). *AIMM for a Better Tomorrow* (updates). Retrieved from <http://www.aimmm.org/updates.html#nick>.

⁵ Encarta® World English Dictionary 2006

⁶ Perske, R. (1981). *Hope for Families*. Nashville, TN: Abingdon.

⁷ Ibid.

⁸ Arkansas Division of Aging and Adult Services. (2001). *Transition To Freedom: Best Practices Manual* (hcbs.org). Retrieved from HCBS Clearinghouse for the Community Living Exchange Collaborative: http://www.hcbs.org/files/19/files/19/930/AR_Transition_to_Freedom.pdf.

⁹ Ibid.

¹⁰ Connecticut Nursing Facility Transition Project. (2002, December). *Transition Guide:..a booklet for individuals who want to leave a nursing facility and move to the community*. December 2002 (2002). *Connecticut Nursing Facility Transition Project, Connecticut Association of Centers for Independent Living, Inc.*

¹¹ Ibid., pp.14

¹² The Advocacy Center for Persons with Disabilities, I. *Fact Sheet.Keys To My Dream: Opportunities for Persons with Disabilities to Start a Small Business*.

[Http://www.advocacycenter.org/FactSheets/Keys_to_My_Dream.pdf](http://www.advocacycenter.org/FactSheets/Keys_to_My_Dream.pdf).

¹³ In *Americans with Disabilities Act of 1990* (2). Retrieved from website file:<http://www.usdoj.gov/crt/ada/pubs/ada.txt>

¹⁴ ADA (42 U.S.C§ 12101 (2)(a)(b))

¹⁵ Ibid

¹⁶ Ibid

References and Resources

1. 261-264. (1996). *Health Insurance Portability and Accountability Act (U.S. Department of Health and Human Services)*, pp. 104-191.
2. Dart, J. (2002). *Toward the Individualized Empowerment for ALL*. [Http://www.worksupport.com/Perspectives/dart.asp](http://www.worksupport.com/Perspectives/dart.asp).
3. Dart, J. (2004). *Revolution of Empowerment*. [Http://www.worksupport.com/Perspectives/dart.asp](http://www.worksupport.com/Perspectives/dart.asp).
4. *Assistive Technology Projects*. Retrieved from <http://www.resna.org/taproject/index.htm>.
5. *Wisconsin Assistive Technology Initiative*. Retrieved from State of Wisconsin: <http://www.wati.org/index.html>.
6. ILRU Community Living Partnership. (2003). *Community Living Briefs (Houston, TX)*, 1(1), 1-7.
7. Independent Living Research Utilization at TIRR, B. I. U. S. U. C. f. P. w. D. (IL Net). (2004). *Participant Workbook (Houston, TX)*, p. 23 *Olmstead and Community: Olmstead for Newbies*.
8. January [Findings and Purposes] (S.933, Trans.). (1990). In *Americans with Disabilities Act of 1990 (2)*.
9. Lyer, P. (2005). *The ABCs of Medical Records: Medical Abbreviations*. Flemington, NJ: Med League Support Services, Inc.
10. Michigan Association of Centers for Independent Living (MDRC). (1998-2002). *Going Home: Nursing Home Transition Services in Michigan*. Retrieved from <http://www.tilrc.org/docs/advocates02.htm>.
11. Michigan Association of Centers for Independent Living (MDRC). (1998-1999). *Planning Tools for Assisting Individuals to Transition from Nursing Homes to Community Living- Michigan*. 1998-1999. Retrieved from HCBS Clearinghouse for the Community Living Exchange Collaborative: <http://www.hcbs.org/files/17/845/MINFTplanning.htm>.
12. Pennsylvania Aging and Disability Resource Center. (2005). *PCA: Community Choice Assessment Instrument*. Retrieved from HCBS Clearinghouse for the Community Living Exchange Collaborative: http://www.hcbs.org/files/60/2962/Pennsylvania_Community_Choice_Assessment_Instrument.pdf.

-
13. Perske, R. (1981). *Hope for Families*. Nashville, TN: Abingdon.
 14. Texas Independent Living Partnership. (2004, November). *Inventory of Community Service and Support Needs*. Retrieved from <http://www.arcil.com/tilpatch/invform.doc>.
 15. Topeka Independent Living Resource Center (2005). Move Out – Freedom Plan. Retrieved from Topeka Independent Living Resource Center. <http://www.tilrc.org/docs/advocates05.htm>.

Microenterprises

1. Abilities Fund- developer and financial institution targeted exclusively to advancing entrepreneurial opportunities for Americans with disabilities. <http://www.abilitiesfund.org/>.
2. BOLD Business Consultants - (Businesspersons Overcoming Limitations from Disabilities) various entrepreneurial resources and services. <http://www.bold-owners.com/>.
3. Disabled Entrepreneur - new online community. <http://www.disabledentrepreneur.com/MPN/index.php>.
4. Example of a successful entrepreneur who has a significant disability: <http://www.thethdegree.com/default.asp>.
5. National Disability Institute - low interest loans for people with disabilities: <http://www.ncbdc.org/default.aspx>.
6. Office of Disability Policy - summary information on self employment for people with disabilities. <http://www.dol.gov/odep/programs/promotin.htm>.
7. PWD - Self Employment - Yahoo Discussion group on issues of self-employment for people with disabilities http://groups.yahoo.com/group/pwd_self-employment/.
8. Self Employment in Rural Areas – research and resources from the Research and Training Center on Rural Rehabilitation Issues. <http://rtc.ruralinstitute.umn.edu/SelEm/RuSelfEm.htm>.
9. Small Business and Self-Employment Service - information and advice on business development for people with disabilities. <http://janweb.icdi.wvu.edu/sbses/>.

