

easier.

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by ILRU Exchange

People who receive long-term care services in nursing homes have more options to live independently in the community than ever before. Still, making the decision to move—and lining up necessary community-based services and supports—can be complicated and confusing.

This article highlights some philosophies and practical steps that can help launch a successful transition from a nursing home to the community. Beyond that, we feature a series of *Transition Checklists* developed by the Michigan Association of Centers for Independent Living (MACIL) with useful tips and information to make planning the transition

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GOING HOME: TAKING CHARGE OF YOUR TRANSITION SERVICES

There is a national movement among people with disabilities, of all ages, who receive long-term care, to get out of nursing homes. To make it

you are working with a service coordinator or attempting to take steps on your own, we hope you will find this information useful

CONSUMER-DIRECTED PHILOSOPHY

Many people with disabilities who

possible for people to do this, there is a developing effort toward community living options and funding. Spiraling health care costs and the numbers of people who are getting older make this necessary. At the same time, more people are realizing that they have a right to live where they choose. One of the biggest barriers to such choices has been the way that funding and services are set up. It has been very difficult and sometimes impossible in many communities to remain in, or move to, your own home or apartment with the support services you need to live safely and comfortably. The changing trend of community living, however, is opening up more possibilities every day.

If you are considering moving out of a nursing home or other facility, you may face considerable challenges. You may be working with a service coordinator or case manager who is not familiar with community resources. Or you and your family may be left to your own devices to sort out what to do. If you are one of the fortunate individuals who is assigned a coordinator who is experienced and knowledgeable in transition services, you may still feel confused and overwhelmed by all the barriers and choices that face you. This article is intended to serve as a guide and check list as you begin to think about what will be involved in moving back into the community. Whether

receive long-term care services, or their family members, believe they no longer have the right to be in charge of their own life after they enter a nursing home. This happens because the institution takes over making choices about not only the person's care but also about their very life. The majority of people in nursing homes go there believing they have no other choice. Their health or their physical or mental limitations may

require more attention than the individual or family members can handle on their own. If this has happened to you or someone you love, it does not mean that you give up the right to stay in charge of your life or support your loved one in doing so. If you would prefer to return to your own home or apartment, or if you are a family member who would like to support that option for your loved one, remember that you have the right to ask questions, make decisions and pursue goals of your own choosing.

FINDING AN ADVOCATE

Whenever possible, it is very helpful to have an advocate working on your behalf. This is someone who will show you where to find resources, help you break down barriers, and give you all the information you need to make the decisions that are right for you. One person whose job it is to assist you in this process is the nursing home ombudsman. Inquire about this person at your facility. Another source of advocates in many communities is the local center for independent living. There are also a number of other community-based programs that will support your efforts to live more independently. If you are unable to obtain contact information through the nursing home ombudsman, you may call or write ILRU to help you track down a local organization to assist you. Our contact information may be found on the back cover.

An effective advocate should know

such things as how to find or create accessible housing, how to pay for in-home personal assistance services, where to find personal assistants, how to support family members who are caregivers, how Medicaid and Medicare work, and how to get the equipment you need to be as independent as possible.

LOCAL CAPACITY TO SUPPORT YOUR INDEPENDENT LIVING CHOICES

Because every community is different, you and your advocate will need to do research about what is going to work for you. It is advisable to set up a plan so that everyone knows what is going to happen and when it should happen. By taking this approach, you will reduce the number of things that might go wrong, and you will also make sure that you are always in charge of what's happening to your life. On the following pages you will find a check list of activities that need to be done. This check list has been adapted from "Going Home: Nursing Home Transition Services in Michigan, 1998-2002," with permission from Michigan Association of Centers for Independent Living (MACIL).*

MACIL gives this guideline for using the check list:

All activities should be regarded as responsibilities of the person moving. Support should be provided as needed, by family, the center for independent living (or other advocate), and other sources. Not all activities need to be done. The person moving should decide.

All activities should be considered and reconsidered later, if initially declined. Check off activities as completed or declined, add activities as needed.

MORE SATISFACTION WITH INTEGRATED LIVING

Numerous studies around the country are showing that people with even very significant disabilities are able to live safely and comfortably in their own home or apartment, with the right supports. And many people report being happier and healthier when they have their independence and own home environment. We hope that if you decide to make the transition from a nursing home to integrated community living that you will find a great deal of satisfaction in making that move. We also hope this guide and check list will assist in making your transition as smooth as possible. If you would like assistance in locating an advocate in your area, please contact Sharon Finney or Darrell Jones at (713) 520-0232 (voice) or sfinney@ilru.org.

Transition Check List*		
Two-Three Months Prior to the Move		
Issues		Task
Planning Issues		1) Determine scope of planning 2) Decide planning method 3) Initiate plan 4) Identify possible barriers, e.g., outstanding bills, substance abuse problems, etc.
Health		1) Create list of supplies and medical equipment needs 2) Complete OT evaluation and order equipment and/or seek funding
		1) Review type of housing, location

Transition Check List*		
Two-Three Months Prior to the Move		
Issues		Task
Housing		and other preferences 2) Locate housing 3) Get on waiting lists 4) List needs (furniture, supplies, etc.) 5) Begin looking for resources
Transportation		1) Apply for public transportation ID 2) Explore options for transportation training 3) Use public transportation
Daily Living		1) Determine which tasks will require assistance 2) Determine if training and therapies are needed for maximum independence
Personal Finance		1) Get Social Security Administration report to determine income post-discharge 2) Assess other income 3) Identify personal debts 4) Develop personal budget
Social Recreation		1) Begin community activities. Seek to build community relationships (e.g., places of worship, clubs, friends, etc.) 2) Consider center for independent living peer support
Employment		Think about as a possible planning issue

Transition Check List*		
One Month Prior to the Move		
Issues		Task

Transition Check List*		
One Month Prior to the Move		
Issues		Task
Planning Issues		1) Review Plan 2) Create to-do lists for yourself and your advocate 3) Start contact person/phone list
Health		1) Set up community doctor appointment one to three days post discharge 2) Determine source and procedure for obtaining medical supplies. Find out how soon order can be placed.
Housing		1) Solicit donations for needed household items and furniture 2) Start securing or arranging for others to secure items 3) Complete change of address with post office
Transportation		1) Make arrangements for transportation from nursing home to your home 2) Check on status of ID card
Daily Living		1) Determine hours of assistance required. Select care providers. 2) Contact your state's oversight agency and schedule evaluation for home help services 3) If there are any unmet equipment needs, seek funding
Personal Finance		1) Resolve personal debts 2) Determine money that will be required for the move and enlist help of advocate to seek community resources
Social Recreation		1) Continue community activities. 2) Expand to other places.
Employment		None

Transition Check List*		
One Week Prior to the Move		
Issues		Task
Planning Issues		1) Review plan and update to-do list 2) Review move schedule 3) Develop emergency contact list, copy to key people
Health		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
Housing		1) Set up utilities and phone service 2) Notify SSA, Medicaid worker, bank, etc. of address change 3) Move belongings, if possible 4) Review and prioritize what is still needed
Transportation		None
Daily Living		1) Determine personal assistant (PA) schedule. Make list of PA tasks. 2) Finalize arrangements with state PA oversight agency and providers 3) Food stamp application
Personal Finance		1) Notify SSA and other agencies of address change 2) Review budget 3) Set up bank account near community home
Social Recreation		1) Continue activities, peer support
Employment		None

Transition Check List*		
One–Two Days Prior to the Move		
Issues		Task
Planning Issues		1) Make shopping list for food and personal items. Determine who will do the shopping 2) Review move schedule and update to–do list
Health		1) Confirm delivery of supplies, etc. 2) Select pharmacy 3) Obtain and fill prescriptions
Housing		1) Confirm utility and phone hook–ups 2) Buy phone, if needed. Ensure phone service is working.
Transportation		1) Confirm discharge transportation
Daily Living		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)
Personal Finance		1) Set up automatic deposit for SSI/SSDI checks (800) 772–1213 (voice)
Social Recreation		None
Employment		None

Transition Check List*		
Day of the Move		
Issues		Task

Transition Check List*		
Day of the Move		
Issues		Task
Planning Issues		1) Meet at facility to review discharge instructions 2) Update to-do list
Health		1) Obtain discharge instructions 2) Obtain from facility medications and supplies 3) Review emergency contact list and procedures
Housing		1) Set up home. Involve as many support people as possible
Transportation		None
Daily Living		1) Review emergency procedures and back up plan
Personal Finance		1) If possible, have some cash available for unforeseen expenses
Social Recreation		1) Meet neighbors and community support persons, as desired
Employment		None

Transition Check List*		
First Week After the Move		
Issues		Task
Planning Issues		1) Review plan and outcomes 2) Revise plans as appropriate
Health		1) Make appointments for medical follow-up care (dental, optical, etc.)
Housing		1) Resolve any housing problems with landlord

Transition Check List*		
First Week After the Move		
Issues		Task
Transportation		1) Follow-up with transportation training. If not available, make other arrangements, e.g., peer trainer.
Daily Living		1) Brainstorm problem solving situations
Personal Finance		1) Review and adjust budget
Social Recreation		1) Continue community relationships and activities
Employment		None

Transition Check List*		
First Month After the Move		
Issues		Task
Planning Issues		1) Review and revise plan 2) Confirm duties with other providers 3) Determine follow-up schedule (e.g., two visits/month)
Health		1) Review and problem-solve any health issues
Housing		1) Follow-up to ensure rent and utilities payments
Transportation		1) Follow-up on transportation issues
Daily Living		1) Review caregiver needs; plan for changes as appropriate
Personal Finance		1) Pay first month's bills 2) Review and adjust budget as needed (e.g., monthly for three to six months)
Social Recreation		1) Continue and expand community relationships

Transition Check List*		
First Month After the Move		
Issues		Task
Employment		1) Investigate work and volunteer options 2) Contact Vocational Rehabilitation

*Adapted with permission from "Going Home: Nursing Home Transition Services in Michigan, 1998-2002," published by the Michigan Association of Centers for Independent Living (MACIL).

COMMUNITY LIVING TECHNICAL ASSISTANCE EXCHANGE AT ILRU

On September 28, 2001, the Centers for Medicare and Medicaid Services (CMS) awarded two grants for the implementation of the National Technical Assistance Exchange for Community Living, one to Independent Living Research Utilization (ILRU), a program of The Institute for Rehabilitation and Research, the other to the Center for State Health Policy (CSHP) at Rutgers University. The goal of the grants is to provide, in collaboration, a program of technical assistance for grantees implementing programs under the CMS National Community Living Initiative. The views expressed in this publication do not necessarily represent the position of the funder.

The Community Living Technical Assistance Exchange at ILRU directs its support toward systemic changes to enable children and adults of any age who have a disability or long-term illness to live as fully integrated as possible in the community, to exercise meaningful choices about any and all aspects of their lives, and to obtain quality services consistent with their preferences.

FOR MORE INFORMATION

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