



***Pennsylvania Transition to Home  
Year One Progress Report  
October 2002***

# **Pennsylvania Transition to Home Progress Report**

## **Introduction**

The Pennsylvania Nursing Home Transition Grant 2000, a collaborative effort of the Pennsylvania Intra-Governmental Council on Long-term Care, has been operating since July 2001 through a federal Centers for Medicare and Medicaid Services (CMS) grant. Now known as Pennsylvania Transition to Home, or PATH, the demonstration project involves consumers, the Pennsylvania Departments of Aging, Public Welfare and Health, community-based service providers, nursing home associations, advocates, and other interested stakeholders.

The overarching goal of the PATH project is to learn about perceived or real barriers that nursing home residents face when considering alternatives to living in a nursing home, and is expected to strengthen the Commonwealth's overall efforts to expand and improve home and community-based options for both older Pennsylvanian's and Pennsylvanians with disabilities. Specifically, the PATH project will assist and support 95 people to transition from a nursing home into their own home in the community in the four counties targeted in the project proposal: Dauphin, Cumberland, Lehigh and Schuylkill. Recognizing that there are already existing transitioning programs for younger people with disabilities through Department Public Welfare Office of Social Programs, it was proposed that the grant funding would be used to target 80 older Pennsylvanians, and 15 people under age 60.

## **Program Description**

### ***2000 Federal Grant***

In September 2000, the Commonwealth of Pennsylvania Office of Medical Assistance Programs (OMAP) was notified of a \$500,000 one-year grant award from the federal Center for Medicare & Medicaid Services (CMS.) The Deputy Secretary of OMAP identified a state contact, Dale Laninga, Executive Director of the Intra-Governmental Council on Long-term Care in the PA Department of Aging. Charles Tyrrell of the Department of Public Welfare Office of Policy serves as the state contact for DPW. Both state agencies have been involved in the implementation and oversight of the project through the designated state contacts, and both state agencies are closely monitoring the operation and outcomes of the project.

### ***Preliminary Planning***

Initial planning included recruiting and convening an Advisory Committee, developing outreach materials, and contracting with a consultant using discretionary funding made available through the PA Department of Aging. In July 2001, the CMS grant funding became available through a fiscal intermediary, United Disabilities Services, in Lancaster. While CMS funds were not expended prior to July 2001, several outcomes should be noted, as they were critical in the initial project start-up.

- Established Advisory Committee, which met for the first time in April 2001. The Committee has held monthly meetings until June of 2002, and continues to meet on a bi-

monthly basis. The committee, facilitated by Dale Laninga, has provided ongoing feedback and recommendations to the project, and is a valuable resource to project staff.

- Contracted with consultant Jennifer Burnett to serve as Project Director.
- Developed project name and logo, to be used in all public relations materials.
- Created and printed project brochure for use in outreach and community education.
- Established an Identification Subcommittee, to explore a variety of opportunities to identify residents appropriate for transition, including using MDS indicators. This Committee met once prior to July 2001.
- Researched and interviewed nursing home transition grant staff in other states.
- Established staffing ratio for project. It was determined that two transition coordinators would be necessary, one covering Dauphin/Cumberland, and one covering Schuylkill/Lehigh. Wrote minimum requirements and job descriptions for transition coordinators.
- Researched and began to develop relationships with waiver providers in four county area.
- Provided information to support the Pennsylvania Project Access grant from HUD.

## ***Operations and management***

### **STAFF**

The project staff includes two Transition Coordinators, and a Project Director. The Transition Coordinators are Amy Townson who works in Dauphin/Cumberland Counties, and Lynne Miles, who works in Lehigh/Schuylkill Counties. Both Amy and Lynne began working with the PATH Project October 1, 2001, as fulltime, 40 hours per week independent contractors. Jennifer Burnett, the Project Director, began working with the project in May 2001, and is an independent contractor working 100 hours a month.

### **OFFICE**

The staff works independently in “mobile offices,” using laptops and cell phones. Supervision is conducted via telephone and email, and PATH staff meetings are held every two weeks at the PDA offices, or in other locations convenient to staff. Both Transition Coordinators have been offered space to work at the Area Agencies on Aging (AAAs) in each of the two counties they work in. Other organizations, including Pennsylvania Health Care Association, have also offered space. However, most of the Transition Coordinators’ time is spent in nursing homes or meeting with community-based providers, and consequently they are not spending much time in the office space provided.

### **DATA MANAGEMENT**

The project data, including confidential client information, community-based service provider information, as well as information on all nursing homes in the 4 counties, is entered into a customized Microsoft Access database. The data is managed through a contract with the Polisher Research Institute, and is updated once a week via secure email synchronization. A password is required in order to download the database. The database is used regularly in supervision, and to prepare reports for the Advisory Committee and CMS. The database program is revised and refined as needed, when additional reports and client information are requested.

### **STAFF DEVELOPMENT AND ORIENTATION**

Project staff orientation occurred during the first month (October 2001), and ongoing training is an integral part of PATH staff development. The initial one-month orientation included an overview

of the Medicaid Waiver programs in Pennsylvania, with an emphasis on learning about the Waivers and other community based services available to people transitioning from nursing homes. Orientation also included a review of state and local community-based programs, and contact with all local agencies by both Transition Coordinators. The Transition Coordinators initially contacted and met with staff at all nursing homes in the regions they are working in. This included administrators, directors of nursing and admissions, as well as social work and discharge planning staff. Staff is encouraged to develop working relationships with both nursing home staff and community service provider staff.

### **PDA IN-KIND SUPPORT**

In addition to project staff, two PDA employees have provided numerous hours of technical assistance as an in-kind resource to the project. Dale Laninga is instrumental in overseeing the PATH operations, attending staff meetings and providing day-to-day supervision of the Project Director. Laurie MacAskill provides administrative support to the project, including assistance with presentations, communication with Advisory Committee, and recording and disseminating meeting notes.

## **Community Education and Outreach**

### ***Initial Community Meetings***

One of the keys to the PATH project success is its ability to work with nursing home staff, and to work with the many agencies and programs that provide service and support to people in the community. During the first three months of the project, a series of meetings with representatives from local nursing homes in the four-county PATH area, as well as local community service providers were held. In the first round of meetings, Dale Laninga and Jennifer Burnett met in each county with a group of community service providers in each county, including both AAA staff and those Waiver providers who provide services to people under-sixty. The purpose of these initial meetings was to introduce the project and discuss how we could best work within the home and community based system that is set up in each county. One of these meetings was held at a Center for Independent Living (CIL), and three others were held in a county office building, with a total of 78 people attending these meetings.

Following this series of meetings, a second set of meetings was set up, with AAA Directors and other staff assisting in local logistics, and hosting the meetings. Participants in the second set of meetings included a broader network of community-based service providers, staff from housing authorities, transportation providers, hospitals, and nursing homes. The purpose of these meetings was to introduce the project to a larger group of community stakeholders in each county. Two of these meetings were held in a public housing authority building, one was held in the county nursing home, and one was held in a church. These meetings ranged in size from 20 individuals in Cumberland County, to over 75 in Schuylkill County. In total, 140 people attended these meetings.

### ***Formal Presentations about the Project***

The PATH staff has been invited to speak to a number of groups, describing the Project and informing participants about the availability of community-based services and how people can move into the community. These presentations have yielded new referrals, as well as clarifying the role of PATH.

Formal presentations about PATH made to:

- Schuylkill County Ombudsman Residents Council meeting
- Area Agency on Aging staff meetings in all four counties
- Brain Injury Association of PA
- Schuylkill County Office of Senior Services County HCBS luncheon
- Cumberland County Quarterly NH/Hospital administration meeting
- Pottsville Hospital Warne Clinic CHAT program
- Intra-governmental Council on Long-term Care Quarterly meetings
- DPW External Stakeholders meetings
- Dauphin County MH/MR staff meeting
- DPW CSPPPD contractors meetings
- PA Statewide Independent Living Council quarterly meetings
- DPW staff representing OMAP, OMHSAS, Bureau of LTC, Policy, and OSP
- Balancing Fellows project and other nationally recognized forums

### ***Individual Contacts with Nursing Homes***

The staff orientation included, and continues to include, individual contacts by the Transition Coordinators with both nursing home staff and home and community based service providers. During the first 2 months working with PATH, the Transition Coordinators contacted and visited 59 of the 60 nursing homes in the 4 counties. The 60<sup>th</sup> facility was reluctant to meet with PATH, and a meeting was finally scheduled and held following intervention by the nursing home association representative who sits on the Advisory Committee. See nursing facility chart for more details on nursing homes in the four counties (*Appendix A.*) These visits provided an opportunity to introduce the Project, and learn about logistics of visiting and working within each nursing home. During the initial visits, the Transition Coordinators met with staff that each facility identified as most appropriate. Many of these meetings were with several NH staff members.

**Initial Visits to nursing homes**

NH Staff	# met with
Administrators	34
Social workers	67
Directors of Nursing	22
Admissions	6
Activities	6

Follow up contact with each nursing home visited involved a letter sent by the Transition Coordinators three months later. The letter went to each person at the initial meeting. In addition to thanking the nursing home staff, Transition Coordinators sent materials including the PATH brochure, their business card, the current PATH newsletter, and a letter encouraging them to call if they have a referral. This method of outreach and education to the individual nursing homes was discussed at length at two Advisory Committee meetings, and the result of that feedback was that several Advisory Committee members sent out letters to nursing homes reinforcing the PATH Project role. These included a letter from PA Health Care Association, PA Association of Non-Profit Homes for the Aging, and the PA Department of Health.

The outreach efforts to nursing homes have yielded several significant results:

1. The Transition Coordinators have developed a positive working relationship with the social workers responsible for discharge planning.
2. The Transition Coordinators understand and adhere to the individual nursing home visitation policies, and other policies related to discharge.
3. Referrals by nursing home staff have been our most frequent source of consumer identification.

### ***Consumer Identification***

The NH Transition grant proposal to CMS suggested that the Project would target 95 people currently living in nursing homes, estimating that 15 would be people under 60, and the remainder would be people 60 and over. However, PATH has not excluded any referral due to age, and nearly half of the referrals to date have been younger people with disabilities. During initial meetings of the Advisory Committee, the issue of consumer identification and criteria for participating were discussed. It was agreed that while the project would primarily serve Medicaid-eligible participants, it would include non-Medicaid consumers. The main criteria that would initiate a Transition Coordinator intake was a desire and a willingness to proceed and follow through with what is involved in moving into the community. An additional factor agreed to was that the consumer should not be in the nursing home in a short-term stay situation, because consumers in short term stay would receive discharge planning from the nursing home social workers, as required by law.

### **REFERRALS**

PATH has been responding to referrals for 11 months, and the Transition Coordinators are working actively in 29 nursing homes, with the bulk of referrals coming from nursing home personnel in these facilities.

**Referral Sources**

<b>Who makes referrals?</b>	<b># received</b>
Nursing facility staff	64
Center for Independent Living Staff	6
Self-referral	5
Area Agency on Aging	4
Ombudsman	3
Public Housing Authority	2
Friend	3
Family	1
County Adult Services	1
PA Protection & Advocacy	1
<b>TOTAL</b>	<b>90</b>

### **MINIMUM DATA SET INDICATORS**

PATH staff worked with DPW and PDA data analysts to develop a program using Minimum Data Set (MDS), a data process that is required by all nursing homes. The intent was to identify individuals who are in nursing homes that could move back into the community. There were several meetings to discuss the project, and these meetings included PATH Project Director, DPW

and PDA project liaisons, DPW and PDA data analysts, and Registered Nurse Assessment Coordinators (RNAC) identified by the Advisory committee nursing home association representatives. The following characteristics were selected for the analysis.

- Occupational Therapy Days
- Short-term memory
- Age
- Payment Source
- Expressed a desire to Return to Community
- Has a support person for discharge

Project staff researched and worked with the Office of Medical Assistance Programs to submit an application to CMS for a Data Use Agreement, which was approved. The data program developed allowed the analysts to produce a list of individuals in the four counties, including consumer name and facility. The Transition Coordinators organized the initial report into smaller lists grouped by facility. They then targeted five nursing homes each, and presented the list for a given facility to the social worker, inquiring as to the consumers' current status. The initial data run was based on older data and did not yield the best results for identification. Currently, staff is exploring the possibility of obtaining more recent data, up to six months may prove more useful.

#### **SHORT-TERM TO LONG-TERM STAYS**

At least three PATH consumers have been identified as individuals who went into the nursing home as a short-term stay in which Medicare reimburses the facility, but because of individual circumstances ended up staying more permanently, past the allowable Medicare reimbursed amount of time, with Medicaid supporting them indefinitely. PATH is exploring the possibility of generating a list of people who are in this situation as a means for identifying potential consumers. Both Transition Coordinators feel that this would be an excellent method for identifying people who could successfully transition.

#### **PUBLIC RELATIONS CAMPAIGN**

A public relations campaign is being developed to reach out to potential participants in the program and their family directly, and not rely on nursing home staff and HCBS service providers for referrals. The campaign, managed through a subcontract with the PA Statewide Independent Living Council, will include an updated and more accurate brochure, a poster, and brief articles to be inserted in newsletters, church bulletins, etc. In addition other products will be added once it is determined that additional materials are needed for outreach.

#### **BEST PRACTICES FOR OUTREACH**

In general, both Transition Coordinators report that the best method of outreach is in-person contact on a regular basis. This involves frequent visits to nursing homes, dropping in on consumers and staff, follow up by telephone and e-mail. While the PR materials provide information to hand out, regular visits to nursing homes and home and community-based services agencies are necessary to keep the concept of transitioning in the forefront of the minds of social workers, residents and families. Both Transition Coordinators also report that large group presentations in the community are excellent methods for getting the word out about the project. These types of presentations generate new referrals, but also work towards the community better understanding the role of home and community based services and the availability of nursing home transitioning. Finally, word of mouth has begun to generate referrals, as well as increase the

incidence of Information & Referral calls to Transition Coordinators. Both Transition Coordinators report that in the past two months, they have spent an increasing amount of time answering Information & Referral inquiries as compared to the initial start of the project.

**Project Access:** This is a HUD Housing Voucher program, which Pennsylvania successfully applied for and was awarded in mid-2001. The initial start-up of the program was delayed in part because there is no statewide housing coordination entity to administer HUD Housing Vouchers in Pennsylvania. The HUD Project Access regulations cite the nursing home transition projects and encouraged states with nursing home transition projects to participate in Project Access. In Pennsylvania, a great deal of PATH staff time and effort has gone into the development and implementation of the Access 2000 vouchers. The program, administered by the Dauphin County Housing Authority, provides fifty Housing Vouchers to Pennsylvanians with disabilities under age 62, who live in nursing homes and wish to move into the community. A procedural agreement, as required by HUD, was established among the PATH county housing authorities, and other parties involved in the Project Access coalition. While this Voucher Program is meant to be a companion resource to the nursing home transition grant, in Pennsylvania there were problems from the initial stages--see *Barriers section for details*. At the time of this Progress report, many of the administrative details had been worked out and the program is up and running, with a Housing Options training provided in early October 2002. The intent of the training, which PATH staff participated in as presenters, was to expand outreach efforts and availability of Access Vouchers to programs that serve the younger population of people with disabilities who live in nursing homes.

### ***Descriptive Statistics—PATH Consumers***

*In an effort to illustrate the progress of the PATH Project to date, a statistical analysis of the program was run on PATH consumers. The statistics in this report reflect those in the database as of October 23, 2002. For purposes of the report, two main groups will be focused on: Those consumers who have successfully transitioned with support of PATH, and those who were unable to transition.*

### **GENERAL INFORMATION**

In the eleven months since the Transition Coordinators began receiving referrals and working with consumers, there have been 90 referrals made to the PATH project. **Table 1** lists general information about the consumers PATH has been working with since November 2001.

**Table 1**

<b>Description</b>	<b>Total Number</b>
<b>Total referrals</b>	90
• Information & Referral Only	4
• 60 and over	39
• Under 60	47
<b>Total transitioned</b>	25
• 60 and over	12
• Under 60	13
<b>Unable to transition</b>	26
• 60 and over	16
• Under 60	10

**BASIC CHARACTERISTICS—TRANSITIONED CONSUMERS**

**Table 2** contains information about the characteristics of consumers who have transitioned with support from the PATH Project.

**Table 2**

Description	%
<b>All</b>	N=25
<b>Percent female</b>	52% (N=13)
<b>Age</b>	
• Percent age 60 and over	48% (N=12)
• Mean age=61.0 years	
<b>Family Involvement</b>	
• Percent with family member involvement	56% (N=14)
<b>Medicaid Status in Nursing Home</b>	
• Percent Medicaid Eligible	72% (N=18)
<b>Time in Nursing Home</b>	
• Mean length of stay in NH=18 months	
<b>Type of Disability**</b>	
• Mobility	76% (N=19)
• Cognitive	8% (N=2)
• Sensory	4% (N=1)
• Mental health	4% (N=1)
• None	12% (N=3)
<i>**Note that a consumer can have more than one type of disability</i>	

**TRANSITION SERVICES UTILIZED—TRANSITIONED CONSUMERS**

The primary transition service is that provided by the Transition Coordinator, and it includes counseling, support, information, advocacy, knowledge and expertise. The two Transition Coordinators utilized an average of 25 hours on all PATH consumers who have successfully transitioned. For consumers 60 and over, the Transition Coordinators worked an average of 17 hours, and for consumers under 60, the average amount of hours spent was 32. The average length of stay in a nursing, before transitioning, was 545 days for all PATH consumers. For those sixty and over, the average length of stay was 310 days, and for those under sixty, the average length of stay was 762 days. Transition funds are available to PATH consumers for costs related to transitioning. The funds are used for security deposits, rent to hold apartment while services are set up, furniture, other household appliances, durable medical equipment, home modifications, and other items necessary for successful transitioning. See **Table 3** for details.

**Table 3**

Items for which Transition Funds Utilized	% consumers
Security deposits for housing	28% (N=7)
First month's rent	12% (N=3)
Additional rent	7% (N=1)
First month's consumables	20% (N=5)
Household goods - appliances, furniture, and kitchen items	12% (N=3)
Assistive & Durable Medical Equipment	24% (N=6)
Equipment—other	8% (N=2)
Home Modification	8% (N=2)
Occupational Therapy Evaluation	8% (N=2)
Moving Expenses	4% (N=1)
No funds needed	32% (N=8)

**TRANSITION FUND UTILIZED**

While **Table 3** provides information on the practical use of transition funding, **Table 4** shows the average cost of the transition depending on consumer type. The figures in Table 4 reflect the actual cost to the Transitional Fund. It does not reflect the staff time or cost related to TC Hours. More details about each transitioned consumer can be found in **Table 6**.

**Table 4**

Consumer Type	Average Cost
All	\$490 (N=25)
• Over age 60	\$591 (N=12)
• Under age 60	\$397 (N=13)
• Owns home	\$684 (N=11)
• Does not own home	\$338 (N=14)
• Owns home and is over age 60	\$570 (N=7)
• Owns home and is under age 60	\$883 (N=4)
• Does not own home and is over age 60	\$620 (N=5)
• Does not own home and is under age 60	\$182 (N=9)

**COMMUNITY SERVICES NEEDED—TRANSITIONED CONSUMERS**

The PATH Project is exclusively a nursing home transition project. The project is designed to use already existing community based services, with the exception of the activities and services related to *transitioning*. PATH consumers who have successfully transitioned are receiving DPW Office of Social Programs Waiver services, PDA Waiver services, informal support, PDA Care Management services or other means of service and support in the community. Of the 18 consumers who were Medicaid eligible in the nursing home, a total of 10 (40%) use MA HCBS. **Table 5** shows the community services being used by PATH consumers.

**Table 5**

<b>Community Services/Programs Needed*</b>	<b>% of Consumers</b>
Attendant Care Waiver	8% (N=2)
Independence Waiver	12% (N=3)
OBRA Waiver	8% (N=2)
PDA Waiver	12% (N=3)
Para Transit	8% (N=2)
Ambulance Transport	4% (N=1)
Shared Ride	30% (N=7)
Public transit	24% (N=6)
Community MH	4% (N=1)
Human Service Development Fund	4% (N=1)
VNA	4% (N=1)
Home Health Care	12% (N=3)
Caregiver's Support	4% (N=1)
Meals on Wheels	8% (N=2)
Rental Assistance	20% (N=5)
Subsidized Housing	24% (N=6)
Job training	4% (N=1)
DPW Cash Assistance	4% (N=1)
Case management (Only service)	12% (N=3)
None	12% (N=3)

- *Services are not mutually exclusive*

**TABLE 6. CONSUMERS TRANSITIONED IN PATH PROGRAM (10-23-02)**

Age	Reason for Entering Nursing Home	Type of Disability	Days person stayed in NF	Uses MA HCBS?	Community Services Needed	TC Hours
32	Rehab needs following a hospitalization for disk surgery	Mobility	1156	Yes	Attendant Care Waiver, Shared Ride	49
34	Had a stroke one year ago and ended up in a nursing home	Cognitive	645	No	Public Transit, rental assistance	35
39	An ulcer on the back became infected	Mobility	933	Yes	Attendant Care Waiver, Shared Ride	17
40	Fell and ended up in hospital. Sent to nursing home from there.	Mobility	196	Yes	Shared Ride, Independence Waiver, subsidized housing	4
41	The disruption of VNA medication help led to a hospitalization and placement in a nursing facility	Mobility, Sensory, MH	441	Yes	Public Transit, Independence Waiver, Community MH, rental assistance	62
43	A psychiatrist ordered an inpatient hospital stay following the death of a boyfriend. Subsequently discharged to a nursing home	Mobility	386	Yes	Shared Ride, rental assistance, Independence Waiver	62
47	Noncompliance with medication schedule led to decline and hospitalization	Mobility	413	Yes	OBRA Waiver, Shared Ride, rental assistance	91
49	Admitted from hospital with an infection in wound from back surgery	Mobility	135	No	DPW Cash Assistance, subsidized housing	15
52	Informal support in community was no longer available	Mobility	4775	Yes	OBRA Waiver, Para Transit	5
52	Rehab needs following inpatient CVA	Mobility, MH	112	No	Public Transit, home health	14
56	Hospitalization and subsequent nursing home placement	Mobility	543	No	Human Service Development Fund needed but not obtained due to waiting list/consumer's decision	8
57	Rehab needs following a hospitalization for surgery on left foot and leg after a fall	Mobility	117	No	Para Transit	20
59	Rehab needs following a hospitalization for respiratory failure (COPD)	Mobility	59	No	None	8
60	Rehab needs following inpatient surgery	Sensory	326	No	Case management, Public transit, job training assistance, rental assistance	19
64	Regaining ADL skills	Mobility	226	Yes	PDA Waiver, United Way (Meals on Wheels), Shared Ride, subsidized housing.	35
64	Ulcer on foot led to hospitalization and subsequent nursing home placement	Mobility	933	Yes	PDA Waiver, United Way (Meals on Wheels), Ambulance Transport 3x week	21
68	Generalized weakness, pneumonia, respiratory difficulty, rehab from hospital	Mobility	181	No	None	7
68	Rehab needs following inpatient CVA	Mobility	228	No	Home Health Care	8

**TABLE 6. CONSUMERS TRANSITIONED IN PATH PROGRAM (10-23-02)**

Age	Reason for Entering Nursing Home	Type of Disability	Days person stayed in NF	Uses MA HCBS?	Community Services Needed	TC Hours
69	Rehab needs following a hospitalization for disk surgery	Mobility and cognitive	533	No	Caregiver's Support	25
74	Girlfriend passed away; son took him in, but this did not work out and family placed him in facility	Frail	457	No	Public Transit, subsidized housing, case management	22
76	Poor circulation in a leg led to amputation and nursing home placement	Mobility	264	No	PDA Waiver, Shared Ride, subsidized housing	7
79	Hospitalization and nursing home admittance	Mobility	102	No	None	6
83	Regaining strength and ADL skills following a hospitalization for pneumonia	Mobility	48	No	Temporary Home Health service	5
88	Noncompliance with medication schedule led to decline and hospitalization	Cognitive	62	No	RN 1X week for monitoring medication	6
92	Had a stroke and was transferred from hospital to nursing home	Mobility	359	No	Public Transit, case management, subsidized housing	25

*Note: This chart contains information about the 25 consumers who have transitioned by 10-23-02. More current statistics available upon request.*

## HOUSING STATUS & ISSUES

The housing status and needs varies greatly among people who can successfully transition from a nursing home to the community. The housing status and needs affects how much time and effort the Transition Coordinator spends to assist in transitioning. It has become clear that the more willing and able the consumer is to work towards the goal of finding appropriate housing, the sooner and more likely they are to transition. Another factor, which contributes to successful transitioning, is the availability of informal supports, and the willingness, on the part of the informal supports, to be involved in the transition and support the consumer once in the community. **Table 7** illustrates the basic housing and informal support situation for consumers in the PATH program who have successfully transitioned.

**Table 7**

Consumer housing and informal support status	% of Consumers
<b>Housing Situation before Transition</b>	
Percent who already had housing	44% (N=11)
<b>Housing Type after Transition</b>	
Apartment	72% (N=18)
House	24% (N=6)
Group housing	4% (N=1)
<b>Need for Accessible Housing</b>	
Percent who needed accessible housing	56% (N=14)
<b>Informal Caregiver Availability</b>	
Percent who live with spouse or other adult	36% (N=9)
Percent who live alone--informal caregiver visits	24% (N=6)
Percent living alone who lack an informal caregiver	40% (N=10)

### *Factors that facilitate transition*

Each consumer who has successfully transitioned in PATH has had to overcome obstacles to transitioning. While each individual has had their own unique experience of transitioning, there are several common factors, which have contributed to their success.

- **Consumer Participation.** Perhaps the biggest factor reported is actually a characteristic of the consumer himself. Consumers who follow through, and advocate for themselves, are willing to do what is necessary to make it possible to move into the community are the ones most likely to succeed. The process, however frustrating and slow, of making all the arrangements necessary to move can be empowering, and those consumers who follow through on the information and guidance of the Transition Coordinator move into the community with greater independence and ease.
- **Existing informal supports.** A supportive family or friends can facilitate the transition, particularly when the consumer is less able to participate as noted above. Initially, a family may be hesitant or object, but that can be overcome by education and information about HCBS, and the family can become an invaluable support. Family and friends tend to help a transition in two areas—emotional support for the consumer to keep going and not give up

hope, and the logistical, hands on aspects of the transition. Once transitioned, strong informal supports can play an important and necessary ongoing role.

- **Existing housing.** If the existing housing is appropriate or easily adaptable for the consumer to move into, existing housing is an excellent resource and will ease transition enormously.
- **Cooperation and good communication among all people involved.** A general cooperative effort from all involved in the transition can expedite the transition process. Conversely, one individual can delay a transition indefinitely. A frequent task of the Transition Coordinator involves facilitating communications among the consumer, family members and other informal supports, and professionals involved in and necessary to move the transition along. Cooperation from the nursing home social worker, for example, can expedite a transition or delay it, making some nursing homes much easier to work within. The same is true for HCBS social workers (care managers, service coordinators, case managers, etc.) Within an agency, there are sometimes disparities between workers: some choose to utilize the latest technology to enhance their ability to communicate (e-mail, voicemail, cell phones, faxing) while others seem to be unable to communicate well, and it may take weeks of phone tag before the issue is addressed.
- **Knowledge and information about how the system works.** When the players have information and access to services, the transition is a smoother process. While it is essential for the consumer to be knowledgeable, it also helps to have well-informed informal supports. An increasing amount of PATH Transition Coordinator time is being spent providing information to the players involved in the transition, as this seems to enhance the process.

#### **BASIC CHARACTERISTICS—CONSUMERS UNABLE TO TRANSITION**

**Table 8** contains information about the characteristics of consumers who the PATH Project initially worked with but ultimately did not transition.

**Table 8**

<b>Description</b>	<b>%</b>
<b>All</b>	31.3%(N=26)
<b>Age</b>	
• Percent age 60 and over	62% (N=16)
• Mean age=64.4 years	
<b>Family Involvement</b>	
• Percent with family member involvement	60% (N=15)
<b>Medicaid Status</b>	
• Percent Medicaid Eligible	Unknown
<b>Time in Nursing Home</b>	
• Mean length of stay in nursing home=32 months	
<b>Type of Disability*</b>	
• Mobility	65% (N=17)
• Cognitive	27% (N=7)
• Sensory	0% (N=0)
• Mental health	12% (N=3)
• None	8% (N=2)
• Unknown	12% (N=3)
<i>*Note that a consumer can have more than one type of disability</i>	

### TRANSITION SERVICES UTILIZED—CONSUMERS UNABLE TO TRANSITION

It is possible for the Transition Coordinators to utilize transition funds for a consumer who ultimately does not transition. There are currently people in the caseload who have used transition funds, and have received a great deal of support from the Transition Coordinator, but have not yet transitioned. These consumers are in the ongoing database as “open,” and are not included in the “Unable to transition” category. There are, however, 26 people who have been identified as “Unable to transition,” and are currently considered “closed” in the PATH database. The only transition service that was utilized to move towards a transition was Transition Coordinator work hours, as illustrated in Table 9.

**Table 9**

Consumer Type	TC Hours
All	4.9
• Over age 60	5.2
• Under age 60	4.3

### AVERAGE LENGTH OF STAY

One of the factors that is difficult to measure but seems to contribute to the success of the transition is the length of stay in the nursing home. PATH will continue to record this factor, which is demonstrated in **Table 10**.

**Table 10**

Consumer Type	Average Length of Stay in Days
All	946
• Over age 60	1,064
• Under age 60	531

### UNABLE TO TRANSITION—DETAILS ABOUT CONSUMER

Table 11 provides details about each of the 26 consumers who were not able to transition. A narrative description of barriers encountered will follow this section.

**Table 11**  
**Consumers in PATH Program Unable to transition (10-23-02)**

Age	Reason for Entering Nursing Home	Disability	Reason(s) not to Transition	TC Hours	Decision to not Transition
35	A stroke led to hospitalization, subsequent NH placement	Mobility	Consumer changed mind	3.9	Consumer
38	Skilled care needed for psoriasis and depression	MH	Was discharged by nursing home to a homeless shelter	11.6	Social worker
47	Wounds and infections on feet led to hospitalization	Mobility	Consumer died	15.2	Death
55	Unknown	Unknown	Consumer died	1.0	Death
55	Unknown	Unknown	Received needed services before PATH could do initial visit	0.3	Consumer
55	Unknown	Mobility	Consumer died	0.3	Death
58	Unknown	Mobility	Consumer changed mind	0.3	Social worker
58	Unknown	Mobility	Consumer not interested	1.0	Consumer
58	Informal caregivers not available at home after a 30 foot fall at work	Cognitive	Consumer not interested	2.0	Consumer
59	Heart attack in February of 2001 resulted in hospitalization	Mobility	Consumer died	8.1	Death
61	Major CVA resulted in left side hemiparesis	Mobility	Consumer changed mind	20.9	Consumer
61	Right leg amputation due to diabetes, followed by a nervous breakdown and psychiatric hospitalization	Mobility	Consumer changed mind	7.2	Consumer
61	Unknown	Mobility	Consumer not interested	0.8	Consumer
63	Admitted from hospital to nursing home due to unstable mental status and failure to thrive in independent setting	MH and mobility	Consumer changed mind	6.6	Consumer
65	Had a stroke 6 years ago	Mobility	Consumer changed mind	7.4	Consumer
65	Unknown	Frail	Consumer not interested	0.5	Consumer
65	Unknown	Mobility	Consumer not interested	1.2	Consumer
69	CVA, wife was ill and could not care for all of his needs at home	Mobility and cognitive	Consumer unrealistic about status + family objections	3.8	Family
72	Admitted to nursing home from hospital following severe weakness from CHF and swelling behind right knee	Mobility	Consumer died	3.7	Death
75	Mild stroke	Cognitive	Consumer unrealistic about status	3.6	Family
77	Came from hospital after recovering from encephalitis	Cognitive	Severe decline in health	5.1	Consumer
79	Leg amputation (diabetes and poor circulation) led to hospitalization and subsequent rehab needs	Mobility and MH	Services nonexistent]	10.5	Consumer
83	Fell at home, sent to hospital for major knee surgery	Mobility and cognitive	Consumer changed mind	4.7	Consumer
85	General weakness, unstable diabetes	Mobility	Consumer changed mind	3.3	Consumer
86	CVA	Mobility and cognitive	Consumer unrealistic about status and no informal support	0.3	Transition coordinator
90	Failure to thrive at home	Mobility and cognitive	Consumer died	3.4	Death

## ***Barriers to successful transitioning***

An important aspect of the PATH Project is to provide the Commonwealth with practical information about perceived or real barriers that nursing home residents face when considering alternatives to living in a nursing home. Such information will be used to strengthen the Commonwealth's overall efforts to expand and improve home and community-based options for both older Pennsylvanian's and Pennsylvanians with disabilities. The database allows staff to run a report on barriers, which is provided at the Advisory Committee meetings and as requested to other groups. However, the report does not provide specific information, so the Transition Coordinators were asked to review their caseloads and provide details. The following is a qualitative review of the barriers, which have prevented successful transitioning.

### **HOUSING**

Lack of affordable, accessible housing is the most prominent barrier encountered by consumers in the PATH Project. There are several distinct factors, which contribute to housing as a barrier:

- Accessible affordable housing is not available, or there are lengthy waiting lists. Community apartments that have accessible units available are rare, and although some landlords will do minor modifications, PATH funding is often the only resource to make the modifications. See next item.
- Funding for home modifications or equipment is not available in Waiver programs until the consumer is actually physically in the community. This is a significant barrier in the Waivers, and also the PDA Family Caregiver Support program. PATH funds have been used to transition consumers in this situation.
- Home modification resources not available: The DCED Access grant has waiting lists or the lottery used to determine who qualifies excluded PATH consumer. The PDA Family Caregiver Support Program had no resources at the time of application, in some PATH counties.
- Consumer's existing housing prevented consumer from successful transition. These homes were very old with small rooms, and built on steep embankment so ramp or lift could not be installed safely. Cost of modifications was prohibitive, and unrealistic given the consumer situation. Solution for this was relocating consumer to a new location.
- For some home modifications, there was no single funding source with enough resources to pay for the total modification. Solution was to piece together different sources of funding to complete the modification.
- Funding for rental assistance is not available to people who are on the Independence Waiver, in the nursing home yet remaining on the Waiver, and have lost their apartment due to length of stay in the nursing home. The PATH Project has become a resource to those people currently in nursing homes, on Independence Waiver, and who need rental assistance. Rental assistance to those who are new to the Waiver or are in OBRA is available only on a limited basis as a loan, and must be paid back to DPW. This presents a significant barrier, which can prevent people from deciding to move into the community. Federal rules prevent the Commonwealth Waivers paying for room and board.
- Project Access vouchers are a resource, but there are several barriers, which make them less useful within the scope of the PATH project. The PATH Project and Project Access have different target populations in terms of age—PATH is primarily targeting people sixty and over, while Project Access requires that the consumer be under 62 and disabled. However, the PATH Transition Coordinators have been the primary source of referrals. In an effort to expand outreach for Project Access, a training was conducted in October 2002

to train OSP providers, CIL staff, AAA staff, and other interested parties on housing options, specifically the Access Voucher program. A second barrier is the fact that there is no statewide entity administering Housing Vouchers, which has made implementation of the Voucher program very difficult in the Commonwealth.

- Lack of available centralized database or clearinghouse providing list of accessible housing. While PATH has been able to build a relationship with some landlords, the housing authorities are not all cooperative with providing lists of accessible apartments, nor are landlords willing to accept Project Access Housing Vouchers.

## SERVICES

Several PATH consumers have run into difficulties because they do not fit into a HCBS Waiver or other community service program, or there is no direct service worker to provide actual HCBS to consumer. The following describes several aspects of service provision, which has caused barriers for PATH consumers:

- **Consumer is too high functioning**, and they are under 60 so do not qualify for Care Management through the Area Agency on Aging. When people under 60 can do their own personal care, they are automatically excluded from the Independence Waiver. If they have a need for assistance with housekeeping, groceries, financial management only, there is no DPW or other Commonwealth program to fulfill this need. While there may be smaller local community programs that could fill this gap, these often have long waiting lists, are not well publicized, and are generally difficult to access.
- **No Waiver funding available for transition needs.** The OSP Waiver programs allow for the consumer who is transitioning to take out a \$1000 loan to pay for transition costs such as first month's rent, utility deposits, furnishings for apartment, and initial food. PATH has worked with OBRA and Independence Waiver consumers to fill this need.
- **No service for specific disability for people under 60.** There are some disabilities, which do not fit neatly into a Waiver program, and for people living in nursing homes this can prevent them from being able to move back into the community. For example, people who do not have a disability currently served by a Commonwealth Waiver program, such as acquired brain injury, or people whose disability is due to an illness or acute factor, such as cancer, are not served by any Waiver of the Commonwealth.
- **Consumers excluded from program due to dual diagnosis.** The Independence and OBRA Waivers, as well as both the Attendant Care waiver and Act 150 programs, are designed for people with physical disabilities. If an individual who wishes to transition has both physical and MH disability, it is very difficult to get services. PATH has been successful in transitioning people in this situation, but it has required bringing both systems together in meetings, with follow up by PATH, to make it work. The primary concern to OSP providers is that the MH system cannot require that a person with MH disability seek treatment, rather it is done on a voluntary basis. Prior to approving services, a Waiver program must be assured that a person can reside in the community without risk of significant harm to the individual. Without a guarantee that necessary mental health services will be provided, a Waiver program may be forced to determine a person ineligible based upon "health and safety."
- **Consumers who have a high level of service needs.** This is especially a problem with older consumers. Several PATH consumers who did not transition were denied services because they would have needed more services than a program can provide, due to the cap on services. Another aspect of this problem are people who have a moderate income, and

who would need to cost share: they may have such a high level of service need that they could not afford to pay the 80% cost sharing that they need to live in the community.

- **Lack of direct care staff.** At least two PATH consumers have not been able to transition due to lack of available direct care worker.
- **Consumer history.** Several PATH consumers were denied services because of their history with a community-based services program. One consumer with a previous history appealed a denial for Independence Waiver, and the result of the hearing is that she qualifies for service. She is now waiting for services. Another was denied services through AAA due to history of alcoholism.
- **Established timelines and process in HCBS system.** The length of time it takes to process requests for Waiver and other HCBS can delay transition. In one PATH consumer situation, the lengthy process resulted in losing housing. The system has many layers and even within one Waiver program, 2-3 agencies must approve a request for services before the request even gets to OSP. In addition to the layers within one program, there is the OPTIONS functional assessment and County Assistance Office financial eligibility approval adding more time and slowing the progress of a transition.

### **CONSUMER FEAR**

There are people who have expressed an interest in transitioning to the community who change their mind due to fear. They may be indecisive, wavering between their desire to move out of the nursing home and their fear of transitioning. This may take months, possibly years to overcome, and thus far some PATH consumers have not overcome this barrier. Peer counseling, adequate information, and support of nursing home and HCBS professional can successfully support the development of consumer confidence. One PATH consumer under 60 is moving towards transition with peer counseling from CIL. Following suggestions of the Advisory Committee, PATH is considering the development of a peer support program using peers who have transitioned with PATH.

### **FAMILY ISSUES**

In some PATH consumer situations, the family objects to the transition and poses a significant barrier to transition. In these situations, the consumer must be involved in informing the family that this is what they want to do. A family meeting usually yields best results, and the consumer must be available and willing to do this. However, family dynamics can be the most difficult barrier to overcome. In other PATH consumer situations, the family is hesitant about a transition. In these situations, the Transition Coordinators or other social worker or community service professional can provide information about services, and heighten families' awareness of what is available to support the consumer in the community. It helps to develop emergency back-up plans to reassure the family, and to explain the consumer's accepted level of risk.

### **INACCURATE INFORMATION**

The consumer is sometimes misinformed about how the system works and can have unrealistic expectations about how long it takes, what they need to do, etc. This can present a barrier, as it heightens consumer frustration and they may give up. The Transition Coordinator can assist by presenting accurate information and support in developing realistic expectations. This barrier can be resolved fairly quickly once identified, as Transition Coordinator can work with the consumers to lay out all tasks needed to progress with the transition. A second source of inaccurate information may be between an agency and the PATH staff. There have been situations where a NH social worker will tell PATH staff and a consumer that they have taken care of something critical to a transition, and it has not been done. As the Transition Coordinators learn who they can

trust and who will follow through, this barrier can be overcome. A third source of misinformation is when a consumer has misrepresented him or herself. When this situation has occurred, it has been very difficult if not impossible to overcome. When the consumer is dishonest about something, such as criminal background, and the Transition Coordinator finds out about it through someone other than the consumer, another layer of barriers is created. The Transition Coordinators have to be proactive with consumers and get them to both be up front and willing to follow through and not give incomplete or false information.

### **NURSING FACILITY SUPPORT**

In situations where the facility does not work cooperatively with PATH, the transition can become very time consuming and difficult to accomplish. The facility will be slow to send in necessary paperwork or other authorizations, or the facility will not do anything at all to support the transition and PATH and other HCBS will become the only active partners with the consumer. Transition Coordinators both report that when this happens, the best solution is to get to know the social workers, discuss the case with them regularly, and remind them if certain things have happened. Also, getting the consumer actively involved in following up with facility staff has been another effective method for resolving lack of facility support.

### **CONSUMER INACTION**

When the consumer is simply unwilling to follow through on things they need to do, this presents a barrier that can prolong the effort to transition. If the consumer fully understands what needs to be done to proceed with a transition, such as filing necessary paperwork or checking out an apartment for accessibility, and the consumer doesn't follow through, this can delay a transition indefinitely. The Transition Coordinator solution to this situation, after reminding and reviewing responsibilities with the consumer, is to write a clear letter explaining exactly what needs to happen in order to proceed with the transition, and if it is not done, they will not transition. Usually, when the consumer sees it in writing, with clear definitions and responsibilities, they take action. This barrier is not able to be resolved unless the consumer takes action.

### ***Case Review Process***

As PATH continues to show progress and demonstrate that nursing home transition should be a critical aspect of any state long-term care system, it has become necessary and practical to develop a case review process, one in which a consumer who may disagree with a PATH decision can have an option to have his situation reviewed. A subcommittee of the Advisory Committee has been working to develop the standards for this process, as well as forms and written material to be disseminated to PATH consumers, explaining the process. The subcommittee's goal is to complete the development of the Case Review Process by the end of 2001, and begin implementing it in January 2003.

### ***Summary***

The PATH Project has received a second one-year no-cost extension from CMS extending the project until September 30, 2003. It became clear that this would be necessary to carry out the goals of the Project, and to successfully transition 95 people. The Project start-up time, including staffing and training, occurred in a very short period of time, and ongoing training and outreach shall continue. With the PATH Project up and running in four counties, the current capacity indicates that the goals and objectives of the demonstration will be fulfilled.

The Project has been and will continue to demonstrate that with support to transition, people can, and do, leave nursing homes and lead independent and fulfilling lives in the

community. The PATH Project has thus far proven to be an asset to people living in a nursing home who may wish to return to the community. It is particularly useful to people who lack informal supports, including friends and family, to assist them in transitioning. The Project continues to illustrate the barriers, and encourage a variety of programs in the Commonwealth to address those barriers. While PATH currently exists in just four counties, the demand for assistance in nursing home transitioning exists across the Commonwealth.

While nursing home transitioning is not currently a service provided by Area Agencies on Aging, a statewide nursing home transition program would enhance the Commonwealth's long-term care system by providing choice and options to people currently living in nursing homes. It would give consumers an option with support to transition from a nursing home, while being fiscally prudent for the Commonwealth. The eighteen PATH Project consumers who were living in a nursing home, with the price of their "bed" paid by Medicaid, were costing the Commonwealth approximately \$612,000 per year, based on an average annual rate of \$34,000. The cost, to the Commonwealth, per year for those same consumers following their transition will be approximately \$153,050 for those who use MA HCBS, based on a Waiver service average of \$15,305 per year. It will be significantly less for the 8 consumers who will not need MA HCBS in the community. Not only is nursing home transitioning a good alternative for people who live in a nursing home, it is a fiscally responsible alternative for the Commonwealth.

## APPENDIX A.

### Nursing Facility Statistics in PATH Counties\*

<i>County</i>	<i>Nursing Facilities</i>				<i>Nursing Facility Beds</i>
<b>Dauphin</b>	<b>Total = 13</b>				<b>Total = 2,106</b>
	Non-Profits	For Profits	County	Accept Medicaid	
	8	4	1	13	
<b>Cumberland</b>	<b>Total = 16</b>				<b>Total = 2,000</b>
	Non-Profits	For Profits	County	Accept Medicaid	
	10	5	1	16	
<b>Schuylkill</b>	<b>Total = 14</b>				<b>Total = 1,671</b>
	Non-Profits	For Profits	County	Accept Medicaid	
	2	11	1	14	
<b>Lehigh</b>	<b>Total = 17</b>				<b>Total = 2,817</b>
	Non-Profits	For Profits	County	Accept Medicaid	
	11	5	1	14	

---

\*Figures obtained from the Pennsylvania Department of Health