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Sustaining Nursing Home Transition in Connecticut

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STATE POLICY IN PRACTICE: SUSTAINING NURSING HOME TRANSITION IN CONNECTICUT

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Summary

This *State Policy in Practice* brief describes the process of sustaining Connecticut's nursing home transition program. Connecticut focused on bringing key stakeholders (including consumers) together and building evaluation into their efforts to make the case for obtaining state funding for the transition program. This brief is intended to help state policy and program leaders, advocates, and providers learn from their peers and colleagues across the states. Similar briefs feature other states, such as Washington,[1] New Jersey,[2] Indiana[3] and Minnesota,[4] and a summary of 10 states that are working to sustain their programs.[5] Also available is a "toolbox" of information on nursing home transition.[6] These documents can be found at www.cshp.rutgers.org and www.hcbs.org.

Major Points

- Involving key state policy and budget decision makers during the project design and implementation process built awareness and interest in the program, its outcomes and sustainability.

- Data collection, evaluation and a cost effectiveness analysis from an external evaluator were essential to obtaining support and state appropriations to sustain the program after the grant period.

- The average daily savings per person after transition was $95.90 per day.

- The availability of affordable and accessible housing was a key need for those transitioning. Program staff worked with the state to secure housing vouchers and funds for home modifications. Housing vouchers decreased the time it took to transition by almost three months (79 days), on average.

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[1] Gillespie & Mollica (2005).
[2] Reinhard & Petlick (2005).
[3] Reinhard & Farnham (2006, February).
[4] Auerbach & Reinhard (2005).
[5] Reinhard & Farnham (2006, January).
[6] Reinhard & Gillespie (2005).

- The program created a "common sense fund" for transition related expenses that participants could access when no other funds were available.

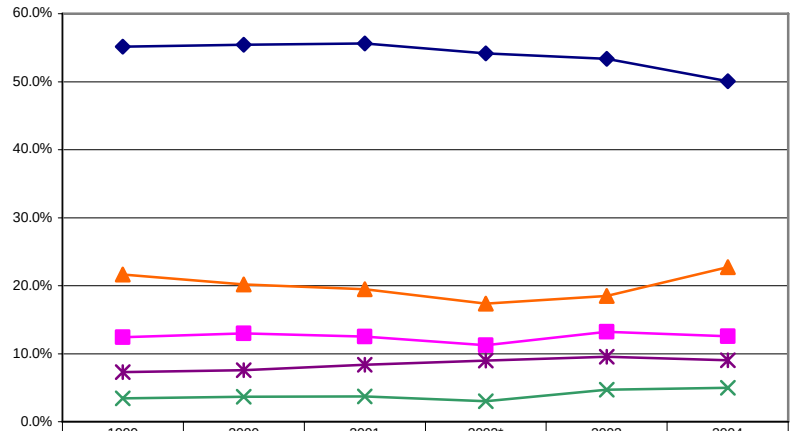
Background

Long-Term Care Spending

In 2003, Connecticut ranked second in long-term care spending per capita (behind New York).[7] In 2004, Connecticut spent about two billion, or about half its Medicaid budget, on long term care services. The percentage of the long term care budget going to nursing facilities has declined from around 55 percent in 1999 to 50 percent in 2004. During this same period, Aged and Disabled Home and Community-Based Services (HCBS) waivers grew from 3.4 percent in 1999 to 5 percent in 2004 (nearly 50 percent), while Home Health grew from 7.3 percent of the budget in 1999 to 9 percent in 2004.[8] See Figure 1 below for an illustration. In 2004, 21.8 percent of long term care spending for the aged and disabled went toward community services.[9]

Figure 1: Composition of LTC Budget, 1999-2004

Source: Burwell et al. (2005)



	1999	2000	2001	2002*	2003	2004
Nursing Home Svc	55.2%	55.4%	55.6%	54.2%	53.4%	50.0%
ICF-MR Total	12.4%	13.0%	12.5%	11.3%	13.2%	12.5%
HCBS Wv-MR/DD	21.7%	20.2%	19.5%	17.4%	18.5%	22.7%
HCBS Wv-A/D	3.4%	3.7%	3.7%	3.0%	4.7%	5.0%
Home Health	7.3%	7.6%	8.4%	9.0%	9.6%	9.0%

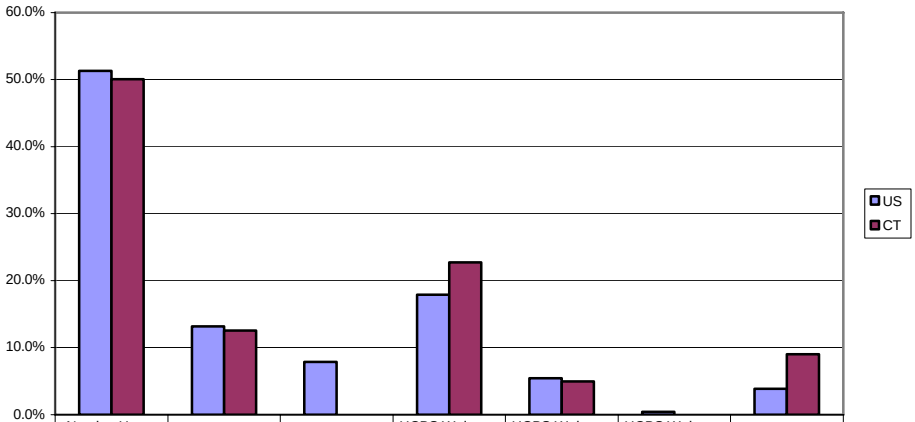
**Note: Figures for HCBS waivers are understated for 2002*

Compared to other states, Connecticut spends a little less of its long term care budget on institutional services such as nursing facilities and intermediate care facilities for the mentally retarded (ICF-MR). Conversely, it spends a little more on community based services such as

[7] Gibson et al. (2004).
[8] Burwell et al. (2005).
[9] Ibid.

HCBS waivers and home health (Connecticut does not cover Personal Care services under the Medicaid state plan).[10] See Figure 2 below for an illustration.

Figure 2: Composition of LTC Spending, FFY 2004
Source: Burwell et al. (2005)



	Nursing Home Services	ICF-MR Total	Personal Care	HCBS Waivers-MR/DD	HCBS Waivers-A/D	HCBS Waivers-Other	Home Health
US	51.3%	13.2%	7.9%	17.9%	5.5%	0.5%	3.9%
CT	50.0%	12.5%	0.0%	22.7%	5.0%	0.0%	9.0%

Long-Term Care—Population and Policy

Population

Connecticut had about 3.5 million residents in 2004 (the 29th most populous state). Almost 14 percent of Connecticut residents were over age 65 in 2004—the 12th highest rate in the country. [11] Among its civilian noninstitutionalized population, it has the lowest or second lowest rate of disability in the country—about one-third of the elderly population, less than ten percent of the adult population, and less than five percent of youth report a disability.[12] Connecticut's nursing facility population peaked in 2001 at nearly 28,000 and has since declined by 16 percent to about 23,000 in 2004.[13] Two-thirds of the nursing facility population's costs in 2004 were paid by Medicaid, 14.5 percent by Medicare and 19 percent from other sources (mostly private-pay).[14] In 2001, over 42,000 consumers were served in the community—almost 27,000 by home health and almost 16,000 under the HCBS waiver.[15] Connecticut's Long-Term Care Planning Committee has set a goal to increase the percentage of clients served in the community from about 48 percent in 2003 to 75 percent by 2025 (the percentage of residents with a disability is expected to increase by about 20 percent in that time period).[16]

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[10] Ibid.
[11] Statistical Abstract of the U.S. (2006), Tables 18 & 21.
[12] American Community Survey (2004), Tables R1801, R1802, R1803. Age categories are 65 and above for elderly, 21 to 64 for adult and 5 to 20 for youth.
[13] Harrington et al. (2005). In 2004, Connecticut ranked number 21 for size of nursing home population (Ibid.).
[14] Ibid.
[15] Kitchener et al. (2005).
[16] Connecticut Long-Term Care Planning Committee (2004), p.G33. The percentage of clients served in the community is based on the monthly average of Medicaid LTC clients in SFY 2003: 19,095 in the community and 20,654 in institutions.

State-funded HCBS program

In addition to the Medicaid programs mentioned in the section above, Connecticut also uses general revenues to support the Connecticut Home Care Program for Elders which is available to individuals age 65 and older with at least one critical need with respect to activities of daily living (ADLs) or instrumental activities of daily living (IADLs). The state-funded plan has no income limit, and its asset limits are much higher than those for Medicaid. Depending on their income, program participants may have to contribute toward the cost of their services.[17] In state fiscal year 2002, the program spent about $23 million and served 4,591 participants.[18] According to a report comparing the state funded plans in 48 states, Connecticut spent more per participant in 2002 than the other 26 programs for which cost and participant data were available—close to $7,000 compared with an average of about $1,500 for the other states.[19]

Recent long-term care activity

Connecticut established a moratorium on the construction of new nursing facility beds in 1991, which is currently extended until 2007.[20] In 1998, Connecticut passed legislation authorizing the Long-Term Care Planning Committee and the Long-Term Care Advisory Council. The committee is composed of several state agencies that have a role in long-term care, and its purpose is to exchange information, coordinate policy and create a state plan periodically (thus far in 1999, 2001 and 2004). The advisory council, which provides recommendations to the committee, is composed of representatives from various groups with an interest in long-term care policy.[21]

In 2000, the Long-Term Care Planning Committee and the Connecticut Department of Social Services established the Community Options Task Force, made up of representatives from the elderly community as well as adults of all ages with disabilities and relatives of disabled individuals. Under the leadership of the Department of Social Services, all representatives to the Community Options Task Force were appointed by the Commissioner of the Department. This group authored the state's Olmstead Plan, released in 2002. The action steps contained in the plan—transitions from institutions, housing, supports and community connections—were to be overseen by the Long-Term Care Planning Committee.[22] A separate coalition of advocates called the Connecticut Olmstead Coalition organized itself early in 2000 in response to the Olmstead Decision. The Coalition was a grassroots organization representing over 100 organizations. It was administered by the Connecticut Association of Centers for Independent Living and funded by the Council on Developmental Disabilities. The Coalition was represented

[17] See http://www.ct.gov/dss/cwp/view.asp?a=2353&q=305170, visited March 2, 2006.
[18] SFY 2002 was July 2001 through June 2002. By comparison, the Medicaid funded home care program served 10,348 people in this same period. Connecticut Long-Term Care Planning Committee (2004), p.G-3.
[19] Summer & Ihara (2004); Appendix 2, Table 4. The CT Long-Term Care Planning Committee (2004) lists a higher number served than the Summer and Ihara report, but does not specify if it is an unduplicated count, and does not calculate a number for per-person expenditures. Using their numbers, the amount per person served would be about $5,000, which would put CT in third place behind CA ($5,400) and MN ($5,300).
[20] Connecticut Long-Term Care Planning Committee (2004).
[21] Ibid.
[22] Wilson-Coker (2002).

on the Community Options Task Force but was dissatisfied with the final plan, releasing its own plan, which also influenced the planning committee.[23]

There have been changes over time in the committee and advisory council. In 2000, the advisory council's membership was expanded from nine to 19 members, adding several new associations. In 2001, the committee's mission was broadened beyond the elderly to persons of any age in need of long-term care and members were added accordingly. In 2002, the advisory council's membership was expanded again, mostly to include consumers and caregivers, and now contains 27 members.[24]

Connecticut received a Nursing Facility Transition grant for $800,000 in 2001 from the Centers for Medicare & Medicaid Services (CMS), the first of five "Systems Change for Community Living" grants the state has received.[25] The Nursing Facility Transition project, called "My Community Choices," transitioned 101 people between 2002 and 2005, when the grant ended.[26]

Program Practices

Program Structure

The My Community Choices program has five full time transition coordinators, located in the five Independent Living Centers (ILCs) across the state. The locally-based support provided by the ILCs, and the team approach they take to working with consumer, were seen as key to program success. The coordinators are responsible for contacting nursing homes, identifying and working with consumers and facilitating relocation. One project coordinator is located at the Connecticut Association of Centers for Independent Living and is responsible for providing technical assistance to the transition coordinators, and handling requests for home modification and state rental assistance requests. A program manager oversees the program and is located at the Department of Social Services.

Grant staff set up a communication and information-generating infrastructure to ensure that staff remained informed and involved. While the locally-based support of the ILCs was identified as important, it was also important to provide information and support to the remotely sited transition coordinators as well as ensuring that their expertise flowed in the other direction to the steering committee and project director.

Steering committee

The project director formed a steering committee to guide the program. Bylaws required that committee co-chairs had to include one person with a disability and one person from a state agency. The 25 member committee included representatives from the Medicaid home and

[23] Wilson-Coker (2002); Connecticut Association of Centers for Independent Living, Inc. & Connecticut Department of Social Services (2005). See http://www.ctolmstead.org/index.html visited March 2, 2006.
[24] Connecticut Long-Term Care Planning Committee (2004).
[25] Connecticut Long-Term Care Planning Committee (2004); CMS (2005).
[26] Lambert & Ford (2005); Connecticut Association of Centers for Independent Living, Inc. & Connecticut Department of Social Services. (2005).

community based services waiver program and state agencies responsible for policy and budget decisions. Selecting the right people was critical, as the quote below indicates:

> *[Participants] "were individuals with the global or specific knowledge needed, who could speak for the entities they represented or had direct access to the decision-makers, and who were committed to outcomes consistent with the grant's goals."*[27]

Program staff attributed their success sustaining the program to the involvement of key staff throughout the project. The steering committee met monthly to discuss strategies to implement the program and to review progress and results.

> *"The steering committee has been valuable because individuals, consumers, organizations and agencies act not merely as advisors, but with both ownership of and responsibility for the outcomes of all activities. Collaboration … was furthered by the committee's decision to work by consensus"* [28]

The steering committee continues its work despite the grant being finished:

> *"A testimony to the effectiveness of the Steering Committee is that most members continued on it, even after the federally funded component of the grant was completed. Several members continued on the committee after they retired."*[29]

Common Sense Fund

In order to transition, consumers may face a variety of expenses for which they have difficulty acquiring funds, either because their needs do not fit into existing programs or because of barriers in accessing funds due to complicated applications or lengthy waiting periods. To be able to fund these expenses quickly and with a minimum of red tape, the program developed what staff termed a "Common Sense Fund" for transitionees to access when other options were found lacking. The use of these funds was generally limited to $500 per individual, but could be increased to $1000 without committee approval. A "Common Sense Workgroup" separate from the steering committee oversaw the management of the funds. Applications were done with a short form filled out by the transition coordinator and the consumer, and disbursements were generally made within 24 hours of application. The best practices guide notes that disbursements from the fund "not only helped bridge the gaps but also generated data on where the gaps exist as a tool for system change."[30] Among other things, the funds paid for security deposits, furniture, utility deposits and community-appropriate clothing. Private donations have helped to sustain these funds beyond the grant.

Housing

Recognizing early on the importance of housing to transition efforts, grant personnel partnered with a local housing authority and made two attempts to reserve vouchers for consumers transitioning from institutions. These initial attempts were unsuccessful--however,

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[27] Connecticut Association of Centers for Independent Living, Inc. & Connecticut Department of Social Services (2005), p.11.
[28] Ibid., p.9.
[29] Ibid., p.14.
[30] Ibid., p.23.

they then approached the state housing agency to modify its housing plan to create a set-aside for consumers leaving nursing facilities. The policy change reserved 50 vouchers per year for program participants. The vouchers became available in 2003.[31] Evaluation data showed that the availability of the vouchers decreased transition time by an average of 79 days.[32] Although federal funds for the voucher program were cut, the state continued to fund the vouchers with general revenues.[33]

In 2003, grant staff, together with the Connecticut Department of Economic and Community Development and the Corporation for Independent Living, applied for $300,000 in state bond funds for housing modifications for transitionees. The proposal was not accepted, but they reapplied in 2004 and were approved for $500,000. The funds can be used for owner occupied or rental units.[34]

Evaluation

Evaluation was a critical component of grant activity:

> *"Evaluation and monitoring of the grant's activities at each step … was identified as a critical need from the grant's inception…. Evaluation was built into all aspects of the grant work, which followed the following process: Develop, pilot, evaluate, revise, implement and evaluate again."*[35]

Project staff recognized the need to evaluate the project. The project director worked with the University of Connecticut Health Center, Center on Aging to develop a data base to track transitions and collect data to evaluate the effort. After the first year, the University volunteered to be the evaluator at no charge because the data was of value to their research. The evaluation was designed to understand how consumer characteristics affected the transition process and to allow coordinators to understand the amount of assistance and time it takes to help people make successful transitions.

Medicaid and budget offices were asked what data elements would be needed to judge the cost effectiveness of the program. The state agreed to provide data on costs for each consumer transitioned before and after the transition. A timetable was prepared for completing the cost effectiveness study based on the state's budget process. The grant period ended in September 2005. Sustaining the effort required funding for fiscal year 2005 and the budget requests needed to be prepared in October 2004. Information about the cost of services provided to consumers who moved, their length of stay in the community and the nursing home costs that were avoided convinced the Governor's policy and budget staff to seek state appropriations to maintain the program.

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[31] Ibid.
[32] Gruman et al (2005).
[33] Lambert & Ford (2005).
[34] Connecticut Association of Centers for Independent Living, Inc. & Connecticut Department of Social Services (2005).
[35] Ibid., p.15

Miscellaneous Outreach and Communication Efforts

Throughout the grant, program staff continually sought to communicate with important stakeholders and bring them into the process where appropriate. In the start up phase of the project, the transition coordinators worked to create a Transition Guide to serve as a reference for consumers.[36] Connecticut has a pre-admission screening program to divert people from nursing facility admission, but had not developed resources to help nursing home residents who wanted to transition.[37] In the Fall of 2002, grant staff conducted a survey of nursing facility administrators to explore their attitudes to consumer transitions and to see if they needed further information on programs or services in the community. An administrator on the steering committee helped staff to target their message to this group—specifically, the administrator pointed out that nursing facility staff were not opposed to the idea of consumers transitioning, but simply lacked information.

Throughout the project, grant staff utilized a variety of methods to reach both consumers and facility staff, learning that effectiveness meant presenting information repeatedly and in a variety of ways.[38] Grant staff presented their work to the Connecticut Long-Term Planning Committee. In the Summer of 2003, grant staff had a series of meetings with mental health advocates and organizations serving the mentally ill, which expanded the contacts available to transition coordinators. In November of 2004, the grant cosponsored a statewide conference for social workers and transition coordinators presented a full-day session. Fewer facility social workers attended than they would have liked, however.

Program Results

State Funds Obtained to Sustain the Program

The cost effectiveness analysis done in the evaluation found that the project saved nearly $2.8 million in Medicaid nursing home expenditures. Per person and per day, the savings was almost $96 for those who transitioned. The results were so compelling that the project became an initiative of the Governor and funding was requested in the Governor's budget request to the legislature.

The Fiscal Year 2005 budget included $267,000 in state general revenues to fund the five transition coordinators and the program coordinator. Additional funds were approved for 200 home and community based services waiver slots (in the PCA waiver) and additional slots in the assisted living pilot program to meet the service needs of consumers moving to the community.[39]

Additional resources for housing

As discussed in more detail above, grant staff worked with the state to secure fifty Section 8 vouchers per year reserved for consumers leaving institutions. The state allocated state general revenues to continue the vouchers when federal funding was cut. Grant staff and the

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[36] See Connecticut Department of Social Services & CT Association of Centers for Independent Living (CACIL), Inc. (2004) http://www.hcbs.org/files/44/2181/CTTransitionGuide.pdf—distributed earlier than that date as a photocopied paper (see http://www.hcbs.org/files/29/1431/transitionguideCT.12.2002.DOC).

[37] Connecticut Association of Centers for Independent Living (2004).

[38] Connecticut Association of Centers for Independent Living, Inc. & Connecticut Department of Social Services (2005); see also Gruman and Pettigrew (2004).

[39] Gruman et al. (2005); Connecticut General Assembly, Office of Fiscal Analysis. (2004).

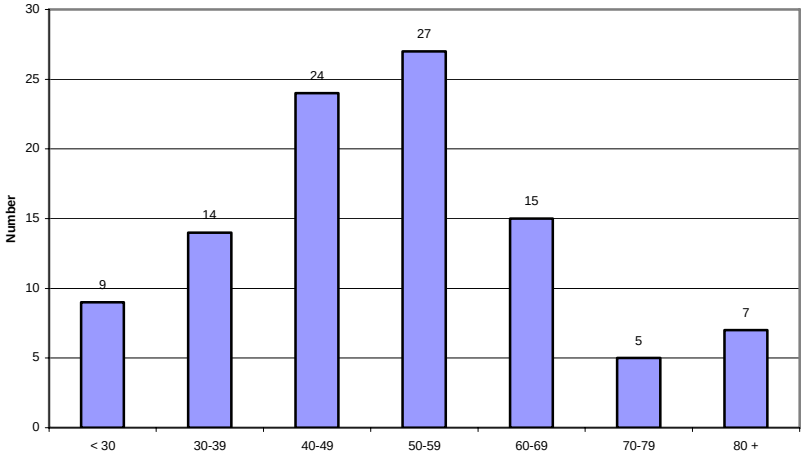
state also worked together to secure $500,000 for housing modifications for those consumers transitioning to rental or owner occupied housing that needed accessibility modifications. Funds for modifications and rent subsidies are submitted by transition coordinators to the program coordinator.

Evaluating the Transition Experience

Who transitioned?

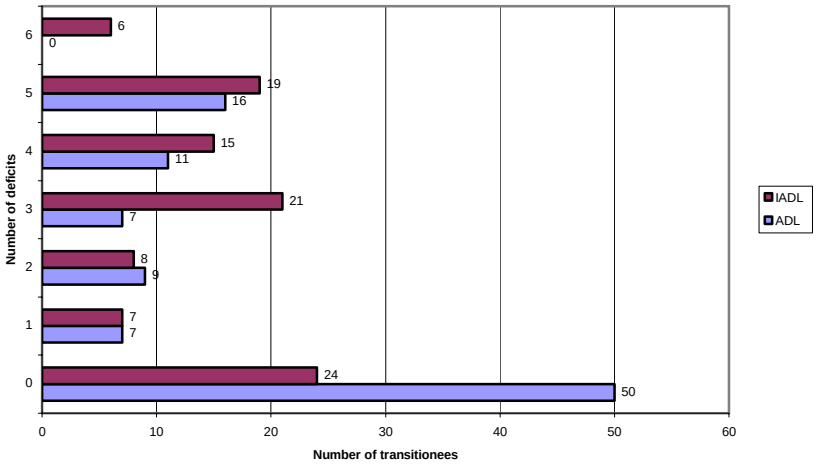
Of the 101 transitionees, 53 were male. The majority (68) were white, with 21 African-Americans, nine identifying as Hispanic, one American Indian and one other. Ages ranged from less than 30 to more than 80. See Figure 3 below for an illustration.

Figure 3: Age Categories of Transitionees
Source: Gruman (2005)



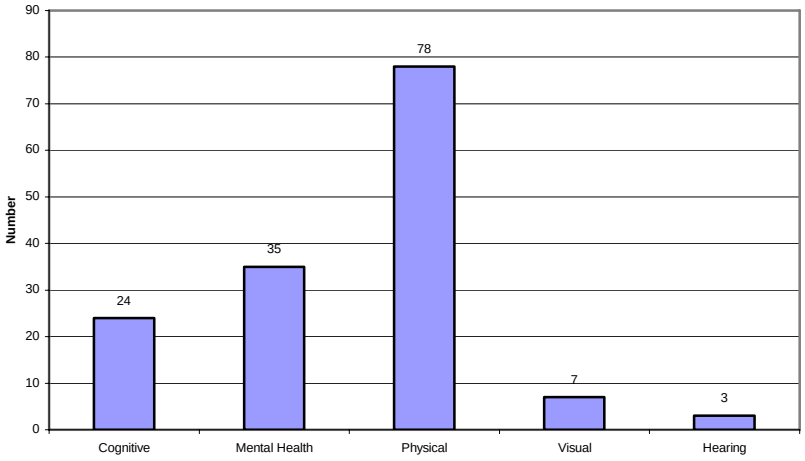
Half of transitionees had no ADL limitations and 24 percent had no IADL deficits. See Figure 4 below for an illustration of ADL and IADL levels.

Figure 4: Number of ADL & IADL Deficits Among Transitionees
Source: Gruman (2005)



More than three quarters of transitionees (78) had a physical disability. Thirty seven of the transitionees had multiple disabilities. Figure 5 below shows the number in different categories.

Figure 5: Disability Category of Transitionees
Source: Gruman (2005)



The amount of time that transitionees had spent in a nursing facility ranged from less than a year (in three cases) to more than five years (in 17 cases). The average was almost four years. The average daily savings per person after transition was $95.90 per day.

Consumer satisfaction

The satisfaction of transitionees was considered the most important outcome measure.[40] As part of the evaluation process, consumers are surveyed twice per year once they have

[40]Lambert, D. comments at Nursing Home Transition Summit, September 2005.

transitioned from a facility to track their progress over time.[41] The most recent evaluation data includes responses from 55 transitionees. There were minor differences between those who responded to the satisfaction survey and those who did not. Consumers with a cognitive disability were more likely to respond.

Seventy percent of transitioned consumers reported being satisfied or very satisfied overall with their current living situation. Only two were dissatisfied. Fourteen thought their situation could be okay with some changes. Housing inadequacy and perceived privacy were significantly related to a lack of satisfaction.

Even among those who were satisfied overall, transportation and financial resources were a problem—slightly less than half of respondents reported satisfaction with these specific items. Nearly half the consumers were able to participate in recreation or social activities and 45 percent received regular visits from family members and friends. Nearly three quarters had weekly or more frequent contact with others.

Barriers and delays to transition

The evaluation, done by the university, was useful in identifying characteristics of consumers that facilitated or delayed the transition process. Consumers experienced one barrier and two delays, on average. The most common barriers to transition were denial of benefits sought by applicants (nine occurrences), a new or undisclosed medical condition (nine occurrences), loss of housing (seven occurrences) and poor credit history (eight occurrences). The most common delays to moving to the community were lack of housing (25 occurrences) or difficulty locating affordable housing (in 19 cases), the time required to process applications[42] (22 occurrences), a lack of family support (in 18 cases), and absence of discharge planning at the facility (in 15 cases).

Some aspect of housing was identified as the major need of consumers wanting to relocate. Over 56 percent needed housing and 57 percent required rental assistance to afford an apartment. Accessibility – wheelchair access, accessible main entrance, and limited stairs – was required by about a third of the participants. Over 20 percent needed a live in personal attendant and 24 percent required a roll in shower.

The average amount of time it took to transition was 225 days, or about 7.5 months. Project data allows coordinators to predict how long it will take to assist consumers with specific circumstances, conditions and barriers. The data indicate that people who need help with bathing take 46 more days to relocate than someone who do need assistance with bathing. Consumers needing help with toileting take 68 days longer to relocate. Criminal history adds 30 days and poor credit adds 85 days.

A preliminary analysis of 72 consumers was able to quantify the cost of delays. For example, consumers who needed affordable housing required 212 more days to transition at a

[41] Connecticut Association of Centers for Independent Living (2004).
[42] Applications could be for anything transition related—utilities, housing, waiver services, etc. (personal communication with Dawn Lambert on March 10, 2006).

cost of $20,417. The availability of state rental subsidies reduced the delay by 79 days or 37 percent.

Conclusions

Connecticut's experience shows that there are several essential factors to creating and sustaining systems change. Assembling a governing committee with the proper knowledge and authority is important. Setting up an infrastructure so that stakeholders can communicate with one another and learn from one another is another key factor. Gathering and analyzing information to learn outcomes with respect to consumer satisfaction and costs will show what is working and what is not. Having an external evaluator gave legitimacy to the presentations on program outcomes. Consulting with state personnel about the proper way to measure costs and benefits had the same effect. Finally, given information on outcomes, program staff must be flexible and willing to adjust their approach if things do not work at first.

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