

# ILRU NetWork

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## ILRU/IL Net step up Olmstead support, activities

### ■ Information and training will help CILs “strike while the iron’s hot”

...by Richard Petty, IL Net Director

This month my article shares the page with a story about John Marshall, a terminally ill man who refuses to spend his remaining days in a nursing home. Through his own determination and with assistance from a Michigan center for independent living, he won't have to. He moved into his own apartment last summer. He intends to stay in the community “no matter what.”

Marshall's story is but one of hundreds that can be told to describe how some CILs are stepping up to the responsibility of helping people get out of nursing homes and institutions to live in the community. It's a timely topic, especially in light of the explosion of funding opportunities and initiatives related to implementing the 1999 *Olmstead* decision. There has never been a greater opportunity for CILs to influence and participate in bringing about significant change and improvement to community-based services.

The IL Net wants to support CILs and other advocates who are taking advantage of these opportunities, beginning with this issue of *ILRU NetWork*. In these pages we feature a variety of ideas, perspectives and experiences gathered from CILs that have been actively involved in community transition—some of them from well before *Olmstead*. We asked them for practical information and ideas—and did they deliver! We think every reader will find at least one idea that will be useful in helping more people with disabilities exercise their fundamental right to choose to live in the community.

In addition, we've included summary information about the federal Health Care Financing Administration's (HCFA) new budget. There's approximately \$70 million

for states to use to strengthen and expand community-based services. Grant funds are available to CILs—or are dependent on independent living and other advocates' involvement in states' applications—in each of the three initiatives. (See p. 9 for the summary.)

As always, we'll post this newsletter on our website ([www.ilru.org](http://www.ilru.org)) and will add updated information as it becomes available. If there's something you'd like to tell us about or think we should add, let us know!

In the meantime, we're really excited about a brand new project to strengthen the IL community's presence in state efforts to implement *Olmstead*. Using grant funds from the federal Departments of Education, Health and Human Services (HHS) and Labor, ILRU and the Brain Injury Association, Inc., have joined forces to train a core group of cross-disability leaders to help states get their *Olmstead* acts together.

Continued on page 8

### **MICHIGAN MAN DETERMINED TO LIVE —AND DIE—ON HIS OWN TERMS**

“I am not going to die in a nursing home.” John Marshall is certain about that—even as a devastating illness casts a shadow of uncertainty over his future. He doesn't know how much longer he can hold out against the aggressive cancer that has ravaged his body for more than three years.

He can't control the disease or its physical effects on him, but Marshall is determined to be in charge of how—and where—he spends whatever time is left. And, he says convincingly, it will not be spent in a nursing home.

Marshall's conviction to live in his own place on his own terms stems from his personal experience as a nursing home resident. In three years he lived in three such facilities, all part of a chain of nursing homes operated by a large corporation. Going into a nursing home seemed like the logical thing to do at the time, he recalls. “I didn't know there were other options.”

A career machinist, Marshall was starting a new job with a North Carolina lumberyard when he got sick. Unable to work and getting sicker by the day, he headed for his family in Michigan. He was diagnosed with diabetes and terminal cancer and required more care, he says, than his family was prepared to give. He went from the hospital to a nursing home near Detroit. A few months later he transferred to a rural facility “a couple of hours” away from the city to be closer to younger relatives.

Marshall was miserable in the nursing home. In his late 40s at the time, he was the youngest resident and, by his own account, the most assertive. Though gravely ill, he was more mobile than many and frequently “made the rounds” in his power wheelchair, making friends with a few other residents.



John Marshall

Continued on page 3

# Transition means teamwork for Michigan CILs

“Passion. Persistence. Patience.”

The three “P’s,” according to Ellen Weaver, are the basic elements in the formula for success in helping people get out of nursing homes. Weaver is the transition project coordinator for the Michigan Association of Centers for Independent Living (MACIL). She serves as the point person for all 12 Michigan CILs working together on a statewide nursing home transition project.

The project got its start in 1999 with funds from a HCFA one-year planning grant. Weaver says the individual centers were already “doing their own things” around community transition. The grant

provided funds to hire a coordinator to pull together those individual efforts to create one focused, collective effort. “It took a lot of meetings and team building,” Weaver recalls, but it had an almost immediate payoff.

In a year primarily devoted to planning, MACIL’s transition project still helped 12 people get out of nursing homes. Beyond that, having a cohesive network already in place made MACIL an attractive target for a big contract from the Michigan Dept. of Community Health.

As the federal grant period ended at the beginning of 2000, the state funds—intended to increase independent living

and community-based services—kicked in. In its first year with the state contract, the transition project helped 52 people get out of nursing homes and prevented another 153 from having to go in. Weaver credits the success to the strength and diversity of the CIL network.

“We have transition ‘gurus’ in each of the centers,” she says, “who have a lot of different skills and backgrounds.” We draw on those individual strengths and experiences in different combinations, she adds, depending on a consumer’s specific needs. And when a person’s situation requires expertise the team doesn’t have,

Continued on page 3

## The Michigan Method

MACIL’s “transition gurus” find it useful to follow a step-by-step process to make sure all the bases are covered as they help each consumer find his or her place in the community. This chart is a simplified view of the process as outlined in the 30-page “how to” manual the Michigan team put together.

RoAnne Chaney, operations director for the Michigan Disability Rights Coalition, works closely with Ellen Weaver and the statewide network of CILs. She stresses that the time and effort required to move from one step of the process to the next is highly variable, depending on each individual consumer.

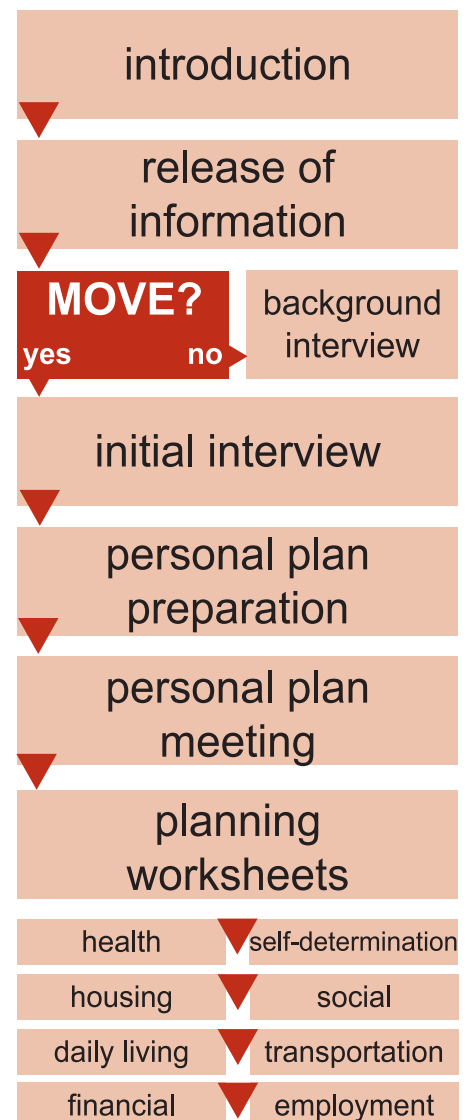
“There’s a direct correlation,” Chaney says, “between the amount of time they’ve been in the home and how much assistance they require to get out. People who have been in an institution a long time are disempowered and generally need a lot of support before and after they get out.”

On a couple of occasions, she recalls, the issue wasn’t so much empowerment as it was equipment—the consumers didn’t have access to telephones. A reminder, she says, that you can’t always just give somebody a phone book and expect them to work out their own transition.

Chaney is putting together a report based on information collected from team members’ ongoing contact with the former nursing home residents. Stressing that the numbers aren’t final yet, she shared what she has collected so far as evidence that people are likely to experience improved health and well-being when they move into the community. For example, of 46 discussions reported:

- 15 people reported better contact and relationships with their spouse and/or family;
- 16 reported steadily improving health and better ongoing care and follow-up services (many report taking fewer medications—especially anti-anxiety and sleeping pills);
- At least 10 say they have an increased level and ability to participate in social activities (two say they need more participation in social or vocational activities);
- At least 10 people have identified goals of either volunteering or seeking part-time or self-employment;
- At least 17 are observed as having an improved attitude;
- Two people are reported to have improved appearance and better hygiene (both commented on how nice it is to be able to shower and wash their hair on a more regular basis).

To contact RoAnne Chaney, send e-mail to [roanne@sprynet.com](mailto:roanne@sprynet.com) or call 517-333-2477.



# “I am not going to die in a nursing home.”

John Marshall, Michigan

## Marshall ... continued from page 1

As he became familiar with the day-to-day workings of the nursing home, Marshall says he became more and more concerned about the way residents were treated. He asked questions and complained when he felt residents were abused or neglected. He complained to the city ombudsman in nearby Kalamazoo. His challenges made him unpopular with the staff, he says, citing a couple of occasions when he was physically abused.

When his closest friend in the home died shortly after breaking her hip, Marshall says he became “very motivated to get out.” He called on family members to help him locate another place to live. They found an apartment in a nearby government-subsidized complex. But there was a lot more to moving than finding the space. Marshall needed

medical care, some specialized equipment and other assistance to live on his own. Figuring it all out was a daunting task.

Enter Mona Khaled, staff member at Kalamazoo’s Disability Resource Center. The nursing home social worker, anxious to help Marshall get out, remembered Khaled and her presentation about how the center for independent living could help people move into the community.

Khaled says, “They were trying to get corporate approval to make the down payment on an apartment in order to get John out of there. They described him as difficult. I never found him to be difficult—just very unhappy.”

Taking advantage of the state’s community-based Medicaid waiver program, Khaled helped Marshall pull together the equipment, services and supports he needed to move out. The process was tricky at times, Khaled recalls, because Marshall is relatively young and “falls in the gap” between programs that serve certain age groups. Beyond that he had credit problems that made it difficult for him to qualify for some forms of financial assistance.

Nonetheless, Khaled’s expertise in making the system work and what Marshall calls her “spunky and caring nature” paid off. Last August, Marshall moved into the apartment, where he lives today. “Being here is a million times better than being in one of those places,” Marshall says.

Even so, he wants to move again “real soon.” Marshall’s rural apartment is a good distance from the doctors’ offices and hospitals he visits routinely. Transportation is often difficult to arrange—a problem that can quickly escalate to a crisis when he has a medical emergency.

Marshall is one of nine people Khaled has helped move out of nursing homes before she changed jobs at the CIL, and he’s not the first to run into the transportation problem. Khaled stresses the importance of taking a hard look at transportation as part of the process of helping people relocate, especially in rural areas.

Though he is frustrated by the transportation difficulties, Marshall is firm in his commitment to live independently. “The nursing home bruised my ego and my outlook on life in general pretty bad,” he says. “But I’m not a quitter. I’ve got nothing else to live for other than trying to make things as good as I can for myself.”

To contact Mona Khaled at Kalamazoo’s Disability Resource Center, call 616-345-1516 (ext. 33) or send e-mail to [staff@drccil.org](mailto:staff@drccil.org).

## Passion, patience ... continued from page 2

she says they bring in other CIL staff members, professionals from related fields and anyone else that can help.

For instance, Weaver says it’s “real important” to have a medical professional in the mix. She quickly adds she’s not promoting a “medical model” for long-term care. Rather, she says, having someone who knows the issues and the lingo “puts us on even ground with the nursing home doctors” when they have concerns about a consumer’s medical needs.

That’s just one of many revelations Weaver and the project team have encountered in what she describes as an ongoing learning experience. In the course of getting that experience, team members have identified a definite process—distinct steps—that help them help a consumer make an informed choice about living in the community, as well as assuring a smooth transition for those who do choose to move.

They’ve collected what they’ve learned in a detailed manual that outlines the steps

and provides interview questions to draw out consumers’ desires, concerns and needs. The manual includes eight “planning worksheets,” checklists covering all the details related to finding housing, arranging health care, handling finances and more. Team members use the manual to make sure they cover all the bases. And, she says, MACIL is happy to share it with CILs that would find it useful for their own transition efforts. (See boxed information for ordering details.)

The manual makes the job easier, Weaver says, but community transition can be a long, complicated and frustrating process. While some consumers have been able to move in as little as a month, she adds, most take longer—some as long as a year.

And that takes us back to the three “P’s.” The words appear in bold, all caps in a memo Weaver wrote to the MACIL Board last year, in which she described the “characteristics of the ‘super-duper’ transition guru.” In addition to the “P”

## To get the manual:

**ELLEN WEAVER**  
**PROJECT MANAGER**  
**MACIL**  
**(517) 333-4253**  
**MACILELLEN@MATCH.ORG**

words, Weaver included these “guru” attributes: “knowledge of resources, understanding of how a nursing home functions, organized, detail oriented, reliable, able to build trusting relationships, good grasp on care needs, knowledge of medical issues ... resourceful and creative.”

And she had one last idea for HCFA to consider. “Cloning, where available, would be nice!”

For more information, contact Ellen Weaver at 517-333-4253 or send e-mail to [macilellen@match.org](mailto:macilellen@match.org).

# Community-based living a new core service?

For Mike Auberger, director of Denver's Atlantis Community, it's a simple matter of priorities. Helping people move out of nursing homes and other institutions should be a CIL's priority—and that should be clearly spelled out in the law that defines independent living. Community-based living, Auberger believes, should be a fifth core independent living service under Title VII of the Rehabilitation Act.

It's a logical step, he says, for an activity that's already a "moral mandate" for CILs. Some centers feel they have a responsibility, he says, and will do community transition with or without a change in the law. But it will take adding it as a core service, he contends, for CILs that "need a reason" to get involved.

In the late 1990s, the Rehabilitation Services Administration (RSA) added "community-based living" to the performance measures CILs submit annually via the "704 Report." Specifically, centers are asked to report how many people they helped relocate from nursing homes or other institutions, as well as how many were able to avoid those facilities as a result of IL services. *(In 1998, the first year the numbers appear in the Government Performance Results Act (GPRA) Report, CILs reported 800 people left nursing homes/institutions and 8,000 were able to remain in the community. Preliminary totals from the 1999 "704 Report" indicate at least 1,207 people left nursing homes/institutions and 10,400 were able to remain in the community. —Ed.)*

Though getting the questions in the performance report could be considered a step in the right direction, Auberger feels it's not a big enough step. "With *Olmstead* out there, it really makes sense to do something now," he says. "If centers don't do this, who do you think will? Nonprofits? Home health agencies? It seems to me CILs need to be on the cutting edge of designing and creating models around the independent living philosophy."

While he is impatient with small steps, Auberger says he knows getting community-based living added as a core service won't happen overnight. In the meantime, he thinks the existing core services should be "weighted" in accordance with the amount of time, energy and effort they take. Currently, he points out, there are no incentives for CILs to "do" nursing home transitions—and no rewards for those that are doing them.

"Your CIL might spend a thousand hours and a lot of dollars helping somebody move out of a nursing home, but there's no place to report that—it doesn't count toward your numbers," he says. "In the meantime, the CIL next door does 15,000 information and referrals, and their numbers look great. If numbers are going to be so important, then we should attach them to the things that are a priority. Not that I&R isn't helpful, but does it take the same amount of effort or change a person's life to the degree that getting out of a nursing home does?"

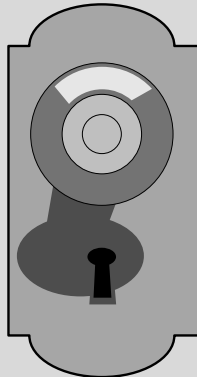
Atlantis, Auberger says, has been involved in community transition for years and currently supports an average of two nursing-home-to-community moves each month. No transition is especially easy, he says, but it helps that Atlantis provides

direct services in several critical areas—personal assistance services, transitional housing and durable medical equipment, to name a few.

In fact, Auberger is a strong advocate of the "CIL as service provider" concept. Does he think a CIL that doesn't provide services can be successful in helping people move to the community? "Sure! It just means you've got to work harder, to build your own provider networks for housing, personal assistance and other services consumers need to make the transition," he says. "Obviously, you have more control over quality and availability if you provide the service yourself. But choosing not to provide services is no excuse for letting people sit in nursing homes."

To contact Mike Auberger, call (303) 733-9324 or send e-mail to [national@adapt.org](mailto:national@adapt.org).

## GETTIN' IN TO GET 'EM OUT



In order to help people get out of a nursing home, you've got to know who's in and wants out. That can be a challenge, since nursing homes usually aren't known to roll out the welcome wagon to community living advocates, say Stephanie Thomas and Bob Kafka, national organizers for ADAPT. They travel thousands of miles each year to work with community organizations involved in getting people out of nursing homes and institutions.

One of the first things to know, Kafka says, is that Medicaid law gives nursing home residents the right to have any visitor they choose. Beyond that, he says, the law requires long-term care facilities to give a variety of agencies, organizations or individuals, "immediate access" to residents.

For example, he points out that facilities must allow representatives of the protection and advocacy systems for people with developmental disabilities and mental illness to come in and meet with residents. The law also requires facilities to provide "reasonable access to any entity or individual that provides health, social, legal or other services to the resident." In all cases, the law gives residents the right to deny or withdraw their consent to visit with anyone. *(The part of the Social Security law that contains this section is available on SSA website: [http://www.ssa.gov/OP\\_Home/ssact/title19/1919.htm](http://www.ssa.gov/OP_Home/ssact/title19/1919.htm). It's a long document, so if you're in a hurry to find the right section do a word search for "access and visitation." —Ed.)*

With that background, ADAPT offers the following ideas for getting into a nursing home to meet people who might want to get out:

- Go as a visitor to someone you know in there.
- Visit the nursing home as if you might want to move in, or put someone from your family in.
- Volunteer at the nursing home.
- Go as a peer counselor.
- Arrange a visit to help residents register to vote.

For more information, contact Bob Kafka and Stephanie Thomas at Texas ADAPT, 512-442-0252 or e-mail [adapt@adapt.org](mailto:adapt@adapt.org).



Sometimes the biggest barrier confronting a person who wants out of a nursing home or institution isn't availability of housing, isn't lack of personal assistance services, isn't transportation or any of the supports we're used to worrying about. Sometimes, the biggest barrier is attitude—and here's the eye-opening part—it's the attitude that belongs to the CIL folks who say they're on the scene to help people get out of those places.

That's Nancy Salandra's take on why some people who would otherwise be out of nursing homes are still in them—they are confined by someone else's prediction of whether they will succeed in the community. Salandra, is a "consultant/activist/advocate" with Philadelphia's Liberty Resources where she's worked on nursing home transitions for nine years. She says she doesn't mean to minimize the "very real" issues like housing, transportation and PAS, which can be big problems—especially in communities where they're hard to come by. She only wants to point out they are not always the only barriers.

"Everybody does have a right to live out here and we have no right to put our beliefs on them. Sometimes we know far too much about a person's life and that interferes with our judgment," Salandra cautions. You may have to know a lot about a person's habits and lifestyle in order to help them get out, she says, "but their freedom shouldn't depend on your approval."

That may be hard, especially when you know a person became disabled or wound up in a nursing home because of certain habits or lifestyle choices, Salandra says. "It's not like it's going to be erased," she says. They may continue in that lifestyle when they return to the community and it's tempting to predict how things will turn out, she adds. But you really don't have any way of knowing and you may be underestimating their survival skills. "People who live in institutions have to do the most god-awful things to survive, and they will use those skills on the outside," she says.

For CIL workers accustomed to "living the good life" with the support of family and friends, adequate services, jobs, transportation and the like, Salandra says, that kind of survival instinct can be difficult to grasp. The same is true, she adds, for understanding the impact long-term segregation has on a person's ability to make informed choices.

CILs that are the most successful in helping people get out of nursing homes, she says, focus on helping people understand and experience the full range of choices available to them. For Salandra, that means accepting people "where they're at" and—without making judgments about them—doing everything you possibly can to help them learn about and understand their options.

"When you've lived in a nursing home for years, it's hard to make an informed choice unless you've been exposed to some other things. Consumer choice is not consumer choice unless it's informed."

Contact Nancy Salandra at Liberty Resources in Philadelphia at (215) 634-2000, ext. 272.

## TO SCROUNGE

To search about and turn up something needed from whatever source is available.

*Merriam-Webster's Collegiate Dictionary*

A way to get good stuff and make things happen with little or no money.

*Mike Oxford, Executive Director, Topeka Resource Center for Independent Living*

"It's one of those things that got started almost by accident," Mike Oxford says. "Several years ago one of our consumers mentioned his brother worked for a hotel that was getting rid of a bunch of beds and TVs and stuff. Did we want them? We said, 'Sure!' and went over and picked them up." That was the beginning of what Oxford laughingly refers to as the Topeka Resource Center for Independent Living's "Scrounging Effect Program."

Today, the center has "scrounged" enough furniture, equipment and supplies to fill three storage warehouses. Not that anything stays in storage very long. As soon as someone needs it to set up a household in the community, it's loaded up on the center's pickup truck and on its way.

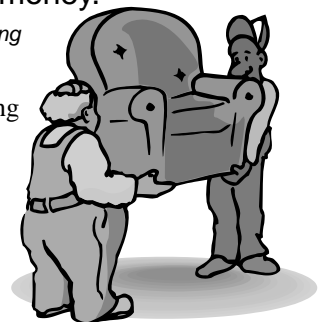
"When you're dealing with folks coming out of institutions, there are

things that everybody needs that there's no real way to fund," Oxford explains. Through scrounging, the CIL is able to provide beds, furniture, appliances, sheets, towels, pots and pans, brooms and mops—most of the basic necessities, he says.

"We're not talking about junk," he hastens to add. "We get some real nice things and a pretty big variety. Someone gave us a stair-glider that belonged to a family member that died. We even got a piano once."

Other than the occasional newsletter blurb and mentioning it to folks at meetings, the CIL doesn't do much to advertise the program, Oxford says. Yet the donations come rolling in from hotels, hospitals and individuals. "We're even getting stuff from the state hospitals as

they're closing down," he says, chuckling at the irony of putting institutional furniture into the community.



The hotels and other large companies enjoy the tax write-offs and the fact it doesn't cost them anything to get rid of the furniture, Oxford says, noting that CIL staff picks up the donated items. Beyond the obvious benefit for consumers, he adds, the program is good for the CIL because it builds relationships and strengthens presence in the community.

Continued on page 8

# RWJF grant helps Alpha One pinpoint policy and organizational issues for community transitions

## ■ Skills training, housing and assistive technology are major policy issues

“People with disabilities want to live in the community. They want to be independent. If a CIL is not getting people out of nursing homes—they’re in the wrong business.”

Dennis Fitzgibbons is operations director for Alpha One, Maine’s center for independent living. He says the CIL has been in the business of helping people get out of institutions and into the community since 1979. “It’s always been part of our mission, but in the early years our capacity to do it was very limited,” he says. Back then, he explains, the center relied solely on Title VII dollars to fund all programs and services. Financing the range of services that people usually need to make a successful move into the community could quickly put a strain on the budget.

In 1996, Alpha One’s effort got a big boost from a four-year grant from the Robert Wood Johnson Foundation (RWJF). As a demonstration site under RWJF’s Building Health Systems for People with Chronic Illnesses initiative, part of the CIL’s charge was to identify and help people to get out of nursing homes and institutions. More important, Fitzgibbons says, RWJF asked the center to identify public policies that are barriers to community living and figure out ways to break through them.

The grant period is almost over, and Alpha One will fall short of its goal to help 40 people move out of nursing homes. But Fitzgibbons says the “lessons learned” in helping the 23 who did move out will benefit a lot more in the future.

Perhaps the most surprising discovery about how to make community transition work had less to do with public policy than with Alpha One’s organizational chart. For the first half of the grant period, the whole staff had general responsibility for transition activities. “We were way behind in meeting our objectives,” Fitzgibbons says. “We realized we needed to bring this program up in priority. It was just one more thing on people’s plates.”

The mid-course adjustment included giving one staffer statewide responsibility for coordinating transition activities,

## “Part B” dollars may help fund transition

You know the problem. This person needs something to get—or stay—out of a nursing home, but there’s no way to pay for it. Medicaid doesn’t cover it, the consumer doesn’t have it and the CIL’s cash flow—isn’t.

In Maine, through a collaborative effort between Alpha One, the statewide independent living council, the state rehab agency and others, a person may be eligible for up to \$5,000 to pay for goods or services that will enhance or increase their independence.

Where does the money come from? It’s Title VII, Part B funds that flow from the feds, through the rehab agency (the designated state unit), to Alpha One, which has a contract to administer the program. Dennis Fitzgibbons, the CIL’s operations director, says it’s not a huge pot of money, but it’s enough to make a real difference for some people.

Since the funds are limited, they’re given out in accordance with priorities the rehab agency established, in consultation with the SILC and others, a few years ago:

Priority #1—People in danger of going into a more restrictive environment such as a nursing home or institution.

Priority #2—People who want out of a restrictive environment.

Priorities #3 & #4—Everybody else.

Fitzgibbons says, so far, the funds have not been used to help anyone get out of a nursing home. That’s because there’s such a huge demand from people trying to stay out. That’s likely to change over time, he says, as folks in the first group get more of their needs taken care of.

The amount of Part B funds available for this use will obviously vary from state to state, as will ideas about how they are best put to use, Fitzgibbons acknowledges. For states looking for a new way to deal with an old problem, though, it might at least be worth a look.

assigning a “point person” in each branch office, setting clear, individualized objectives to reflect the new expectations. It works much better, Fitzgibbons says.

“The project team has a monthly conference call about what’s going on, which consumers they’re working with and what kind of progress they’re making. It gives them a chance to brainstorm and to provide support and encouragement to each other. Knowing the monthly conference is coming up makes it easier to stay focused on the project. And they seem to feel good about being part of a focused team effort.”

“That model worked so well,” Fitzgibbons says, “now we’re using it with all our programs.”

The list of practical and policy barriers Alpha One identified during the project is, if anything, too familiar to the independent living community: limited funding for, access to and/or availability of housing, transportation, personal assistance services, assistive technology

and independent living skills training. The RWJF grant afforded the CIL an opportunity to try out tactics to overcome some of those long-standing barriers. Among them:

- Medicaid funding for IL skills training. Long-time nursing home residents often need training—sometimes a lot of it—to learn or renew basic independence skills, Fitzgibbons says. But Medicaid doesn’t pay for skills training and providing it without reimbursement can take a big bite out of a CIL’s budget. Alpha One is working with the state legislature to pass a bill that would allow Medicaid dollars to pay for the training.
- Statewide public housing database. It’s as true in Maine as in most states and communities—accessible and affordable housing is in short supply and hard to find. With a grant from the state public housing authority (PHA), Alpha One is

Continued on page 8

# Williams: CILs must step up to ‘historic’ opportunity

## Independent living advocates need to unify in cross-disability effort

“Many of us have always believed that (independent living) centers and other consumer-directed groups have a vital set of contributions to make. Now is the time to make good.”

So says Bob Williams, outgoing Deputy Assistant Secretary for Disability, Aging and Long-Term Policy for the Dept. of Health and Human Services (HHS). On Jan. 10, HCFA issued *Olmstead Update No. 5: New Tools for States*, the latest in a series of letters to state Medicaid directors providing information and guidance about how to carry out the Supreme Court’s 1999 *Olmstead* ruling.

The letter from Timothy Westmoreland, outgoing director of the Center for Medicaid and State Operations, highlights changes to the Medicaid rules to “remove barriers that previously prevented States from providing effective health and long-term care coverage to selected groups of individuals.” The letter also outlines three new grant initiatives which will infuse as much as \$70 million into state efforts to beef up community-based services in 2001. (See related story on p. 9)

The day the update was released found Williams—like scores of federal workers—packing up his desk to make way for a new President and administration. Many in the independent living community say he was a driving force in getting significant funding for the grant initiatives, as well as making sure people with disabilities are at the table as states make their plans for grant funds. No doubt, Williams would prefer to stay put and keep working with coworkers and the advocacy community as the grants roll out. He will settle, though, for knowing he’s helped to strengthen the disability community’s place in the process. In each of the three grant initiatives, funds are available to CILs—or are dependent on independent living and other advocates involvement in states’ applications.

“This represents an historic opportunity to get off the dime and really begin to improve the life and future of people with the full range of significant disabilities,” he says. “The critical part of ... these efforts is to get states and the disability community around the same table to roll up their sleeves and develop viable, mutually agreeable ways to expand personal assistance services and supports.”

Equally critical to the success of the initiatives, Williams continues, is the

disability community’s ability to work together in a unified, cross-disability effort. “This is about the community getting beyond the squabbles we have with each other and looking at what it will take to support one another, as well as recognizing states have legitimate costs and concerns.” It is crucial, he says, “if

we are going to get rid of the artificial barriers and silos that keep people from getting the types of services and supports they need to live the lives they want to lead.”

Send e-mail to [bobrw@bellatlantic.net](mailto:bobrw@bellatlantic.net) to contact Bob Williams, private citizen and disability advocate.

## The New President’s “New Freedom”

Where does President George W. Bush stand on *Olmstead* and community living? In his *New Freedom Initiative*, presented

Feb. 1, during a White House ceremony, the President commits to signing an order “supporting swift implementation of the *Olmstead* Decision.” While some advocates had expected the order would be signed that day, at this writing it remains pending. The following is an excerpt from the initiative summary posted on the White House website:

### OVERVIEW

On June 22, 1999, the Supreme Court decided *Olmstead v. L.C.*, ruling that, in appropriate circumstances, the ADA requires the placement of persons with disabilities in a community-integrated setting whenever possible. The Court concluded that “unjustified isolation,” e.g., institutionalization when a doctor deems

community treatment equally beneficial, “is properly regarded as discrimination based on disability.”

**“My New Freedom Initiative will help Americans with disabilities by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of Americans with disabilities to integrate into the workforce, and promoting increased access into daily community life.”**

**George W. Bush  
February 1, 2001**

*Olmstead* has yet to be fully implemented. President Bush believes that community-based care is critically important to promoting maximum independence and to integrating individuals with disabilities into community life.

### SUMMARY OF ACTION

President Bush has committed to sign an order supporting swift implementation of the *Olmstead* decision. The order will support the most integrated community-based settings for individuals with disabilities, in accordance with the *Olmstead* decision. The Administration will

pursue swift implementation in a manner that respects the proper roles of the Federal Government and the several states.

## Learn more about it ...

### New Freedom Initiative (full text)

[www.whitehouse.gov/news/freedominitiative/freedominitiative.html](http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html)

### President Bush’s Introductory Remarks

[www.whitehouse.gov/news/releases/20010201-3.html](http://www.whitehouse.gov/news/releases/20010201-3.html)

### Candidate George W. Bush’s Speech on June 15, 2000, at Alpha One

[www.georgewbush.com](http://www.georgewbush.com) (go to speech archives)

## Alpha One ...continued from page 6

building a statewide database of barrier-free public housing units. With access to current and reliable information, Fitzgibbons says, it should be easier to find out "what's available where" at any given time.

- Funding assistive technology (AT) and home modifications. For more than a decade, Maine residents have been able to get long-term, low interest loans for AT through a \$6.5 million revolving adaptive equipment loan program. It's a good deal, Fitzgibbons says, for people who have enough money to qualify for a loan. For those who don't, the CIL is determined to find other funding sources. One good prospect, he says, is the Title VII, Part B money the Maine rehab agency designates to pay for goods or services that will help a person be more independent. (See related story on page 6.)

Alpha One is working to integrate these and other initiatives with the services the CIL already provides, Fitzgibbons says, to become "the one-stop center" for community transition. To reach that goal, he says the center works "on all fronts," from systems change advocacy to providing services to consumers statewide. "I think this is why centers were created," he says. "People with disabilities want to be in the community. They want to be independent."

To contact Dennis Fitzgibbons send e-mail to [dennis\\_fitzgibbons@alpha-one.org](mailto:dennis_fitzgibbons@alpha-one.org) or call (207) 767-2189.

## Scrounging ... continued from page 5

Everybody at the CIL is involved in the scrounging program, Oxford says, adding that staff members have developed "excellent garage sale skills" and are almost always able to come up with needed items that aren't in the warehouse. "It's a group effort. Everyone is very committed and proud of being able to do things like this and help people move out of institutions."

In the average year, the Topeka center helps between 20 and 25 consumers move into the community. A lot of the donated furniture and equipment goes toward helping them out, Oxford says, but it's available to anybody. "If somebody needs it and we have it, we give it to them," he says. "We hear from people just moving into town as well as folks who are moving away from their family and out on their own for the first time."

Oxford estimates the value of the current inventory of donated equipment and furniture at about \$50,000. On the

## Training will strengthen Olmstead leadership

### Continued from page 1

The training is for advocates who will be actively involved in working with their states to implement the *Olmstead* decision. The organizations they represent must also make a significant commitment to support their work. We'll have five regional trainings in a six-month period, beginning in Texas at the end of March and wrapping up in Connecticut in October. (See the box for the dates and cities.)

An impressive collection of national experts on *Olmstead*, Medicaid and exemplary home and community services will present the training. You're familiar with many of them, including Mike Auberger, Allan Bergman, Lee Bezanson, Sue Flanagan, Steve Gold, Bob Kafka, Jay Klein, Mike Oxford, Bobby Silverstein, Janna Starr, Cathy Ficker Terrill, Bob Williams, and many others. Advocates from each of the states will also meet together during the training to develop working strategies.

Each state may send eight advocates to the training. Participants must be nominated by disability leaders and must demonstrate that they have the backing of a disability advocacy organization such as a CIL. A limited number of \$250 stipends to cover some travel and lodging costs are available, and will be awarded based on the organization's stated commitment to support the effort beyond the training and the order in which the nominations are received.

In addition to the advocates, we're inviting two officials from each state. We think the training will give them the chance to learn about best approaches and exemplary programs. And their presence will give advocates the opportunity to initiate or strengthen working relationships with them.

For more information about the training and to request nomination packets, contact Sharon Finney, ILRU research assistant. Her e-mail address and phone numbers appear in the box.

### OLMSTEAD TRAINING

Houston, TX  
March 28-30

Atlanta, GA  
June 28-30

Kansas City, MO  
July 18-20

Portland, OR  
August 14-16

Hartford, CT  
October 1-3

#### For more info:

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expense side, there's the cost of leasing storage space (the fire marshal didn't go for the "any spare inch in the office" method), a pickup with a lift gate (moving furniture was taking its toll on the center's passenger van), and occasional payments to a small, local moving company or "a couple of young guys who hang around here" when the job is too big or needed more quickly than center staff can handle.

In light of what it accomplishes, Oxford says, the scrounging program is well worth the comparatively small expense. One of the best things, he adds, is it's something that can happen in any community. It's just a matter of letting folks know you can make good use of the furniture and equipment, he says. "It's not so bad to go talk to a state institution or your community hospital or rehab center. Everybody rotates that stuff out. Otherwise it goes to the dump."

The scrounging program—in spite of its accidental beginning—Oxford says, is a shining example of the kind of "practical

and creative" things centers must do to help more people get into the community. It would be terrible for someone to be stuck in an institution for lack of basic furnishings, he says. "Thanks to scrounging," he adds, "that's one barrier we have an immediate solution for."

Oxford says the main focus of the Scrounging Effect Program will always be helping consumers get set up in the community. But he and his staff are exploring ways to get even more mileage from the program. "We're looking at purchasing or building our own warehouse. It's kind of expensive to rent," he says. "Maybe we could hire people with disabilities to work there and find a way to provide some jobs. Maybe we could have a durable medical equipment repair shop in there."

For more information, call Mike Oxford at the Topeka Resource Center for Independent Living at (785) 233-4572 or send e-mail to [tilrc@tilrc.org](mailto:tilrc@tilrc.org).

# HCFA grants highlight CIL role in transition

The following is an overview of the grant initiatives announced in HCFA's *Olmstead Update #5: New Tools for States*. The full update is available on the agency website: [www.hcfa.gov/medicaid/olmstead/smdltrs.htm](http://www.hcfa.gov/medicaid/olmstead/smdltrs.htm)

## REAL CHOICE SYSTEM CHANGE

**OVERVIEW:** With these grants, HCFA wants to bring about "effective and enduring improvements in customer-responsive long term service systems that support people of all ages who have a disability or chronic illness to: (a) live in the most integrated community setting appropriate to their needs and strengths; (b) exercise meaningful choices about their supports; and (c) have quality services arranged in a manner as consistent as possible with their community living preferences or priorities."

To get grant dollars, states must collaborate with a "Consumer Task Force" to develop the application. The task force will be comprised of "a broad range of people of all ages who have a disability or chronic illness and rely on long-term services and supports..." and representatives of families or children with disabilities and organizations that "promote the interests of people who have a disability or chronic illness" as their primary purpose. Statewide independent living councils appear on a list of example organizations.

Beyond that, states that get more than \$750,000 must conduct two specific initiatives: "(a) improvements in personal assistance services, and (b) improvements in quality assurance or quality improvement systems for home and community-based services."

**FUNDS AVAILABLE:** \$50 million

**APPLICATION DEADLINE:** July 2001. (The grant solicitation is expected in March or April, with funds to be distributed in Sept.)

**Eligible Applicants:** States or their instrumentalities (such as state universities), U.S. Territories and District of Columbia.

**HCFA CONTACT:** Jean Tuller at [jtuller@hcfa.gov](mailto:jtuller@hcfa.gov)

## NURSING FACILITY TRANSITIONS AND ACCESS HOUSING

**OVERVIEW:** This is a two-prong initiative intended to capitalize on previous transition demonstration grants carried out in a few "pioneering" states. "State program grants" will fund a range of activities "to design, implement, and/or provide outreach for the transition and the ongoing support system" to assist people in their transition to the community. Local public housing authorities, in partnership with agencies responsible for transition programs, will administer the HUD rent vouchers. HCFA anticipates that most applicants will include requests for the program grant and rent vouchers in a single proposal; however, there is flexibility and states can apply for one or the other separately.

In addition to these components, HCFA will distribute as much as \$2.4 million in "partnership grants" to five to seven centers for independent living "to develop outreach, technical assistance, specific aspects of the infrastructure needed to make the nursing facility transition initiatives successful." The grants are intended to create "cross-disability competence" and funds will go to CILs that serve a broad range of age and disability groups and have "effective partnerships" with other consumer directed organizations.

**FUNDS/RESOURCES AVAILABLE:** \$12-15 million dispersed in "state program grants" ranging from \$300,000 to \$1 million. Approximately 400 Section 8 rent vouchers. \$2.4 million dispersed in "partnership grants"—exclusive to CILs—ranging from \$120,000 to \$350,000. \$1.2 - \$2.1 million to establish and evaluate a national technical assistance network—exclusive to states or state entities (such as universities).

**APPLICATION DEADLINE:** Unknown. Announcements expected by Sept. 14 for grant awards effective Sept. 30, 2001.

**ELIGIBLE APPLICANTS:** States or their instrumentalities (such as state universities), U.S. Territories and CILs

**HCFA CONTACT:** Tammi Hessen at [thessen@hcfa.gov](mailto:thessen@hcfa.gov)

## COMMUNITY-BASED ATTENDANT SERVICES WITH INDIVIDUAL CONTROL

**OVERVIEW:** With this round of grants, HCFA wants to build on a number of previous state-level demonstrations that have laid the groundwork to establish the essential elements of self-directed services. The new grants will be geared toward incorporating the concepts of consumer choice, control and responsibility into the day-to-day workings of the service system. Included on the list of "example activities": support brokerage, consumer education and support, provider training and technical assistance, consumer-directed service delivery approaches (i.e., consumer-directed cooperatives, micro-enterprises and similar ventures), simplifying provider qualification procedures, expanding task delegation and creating means to hook up consumers with qualified attendants.

**FUNDS AVAILABLE:** \$5-8 million dispersed in grants ranging from \$150,000 to \$1 million. No state match required, but in-kind match is expected.

**APPLICATION DEADLINE:** Unknown. Announcements expected by Sept. 14 for grant awards effective Sept. 30, 2001.

**ELIGIBLE APPLICANTS:** States or their instrumentalities (such as state universities), U.S. Territories and CILs.

**HCFA CONTACT:** Mary Jean Duckett at [mduckett@hcfa.gov](mailto:mduckett@hcfa.gov)

# NetNotes

■■■ As we go to press, Health and Human Services Secretary Tommy Thompson has just announced that any state that wants one can have a \$50,000 advance on the "Real Choice" grant funds described in our article on p. 9. We've added a link to more information about this announcement on the ILRU NetWork Online page of our website—[www.ilru.org](http://www.ilru.org).

■■■ If you could only have one resource for info about implementing *Olmstead* and getting people out of nursing homes and institutions, it would have to be *Freedom Clearinghouse*. The website—founded by Lucy Gwin, editor of *Mouth*, and Mary Johnson, editor of *Ragged Edge*—is chock full of "stuff to know" and "stuff to do" and is sure to be your most frequently used bookmark for transition "stuff." Check it out at: [www.freedomclearinghouse.org](http://www.freedomclearinghouse.org).

■■■ The U.S. Health and Human Services Dept. has published a reference guide: *Understanding Medicaid Home and Community-Based Services: A Primer*. George Washington University's Center for Health Policy Research developed the manual in collaboration with HHS' Office of Disability, Aging and Long-Term Care Policy. It's available on the web: [www.aspe.hhs.gov/daltcp/reports/primer.htm](http://www.aspe.hhs.gov/daltcp/reports/primer.htm). For more information, contact ASPE Project Officer Gavin Kennedy at [gkennedy@osaspe.dhhs.gov](mailto:gkennedy@osaspe.dhhs.gov).

■■■ The deadline for comments on the TWWIIA regs has passed, but don't pass up the opportunity to check out some good info on the proposed regs and background on Social Security work-related programs. The Rehabilitation Research and Training Center on State Systems and Employment at the Institute on Community Inclusion published two new briefs—both of which are available on the ICI website. If you can't get to the website call 617-355-6506 (V) 617-355-6956 (TTY) or send e-mail to [ici@tch.harvard.edu](mailto:ici@tch.harvard.edu) to request a print copy.

*Tools for Inclusion: The Proposed Ticket to Work Regulations*  
<http://www.childrenshospital.org/ici/publications/text/twwiia.html>

*Policy Brief: Proposed Regulations Implementing the Ticket to Work and Self-Sufficiency Program*  
<http://www.childrenshospital.org/ici/publications/text/pb6text.html>

## ilru NetWork

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