formerly *Together*

Disability Issues

Vol. 19, No. 3

a publication of the Information Center

Anywhere Street, USA: The Perversity of PAS Non-Policy Making

by Stephen P. Gulley, MSW

Prologue:

Jeff Gunderson's voice is choked with worry. He is about to reenter the place he calls "the concentration camp". It is a nursing home, one of two where Gunderson, who has cerebral palsy, was sent from the time he was eighteen until he turned twenty-seven. "I always said if I had to come back here, I'd rather be six feet under," Gunderson says nervously as his attendant tugs him from the car parked outside the nursing home and lifts him into his wheelchair.

Nine years have passed since he has lived here. He has returned to this brown-brick building of his nightmares because he wants to visit his former roommate, another man with cerebral palsy who he says is anxious to get out too. Gunderson wound up at this nursing home, where he says he was abused and forgotten, after his mother and father divorced. His mother could not lift her large son out of bed and care for him. To hire an attendant to come into the Gunderson home was not covered by private or public insurance and was prohibitively expensive for the woman who worked on a canning factory assembly line.

But Medicaid would pay for all the costs of a nursing home. So Gunderson's mother, like many other parents of severely disabled sons and daughters, had little choice: she put her teenage son in a nursing home. (As adapted from Shapiro, J. *No pity*. New York: Times Books, 1994. P. 237.)

As the story above demonstrates, personal assistance policies hold the promise of community integration, autonomy, and choice for people with severe disabilities. Yet these same policies hold the power to limit such people's choices, forcing them into situations bound by isolation, confinement, and even abuse. This story further demonstrates that such policies do not exist in a medical services vacuum, but are instead interwoven with social class, family resources, and ultimately, the fabric of our political-economy.

It has been over twenty years since a fledgling group of college students with severe disabilities on the campus of U.C. Berkeley first demanded and secured Personal Assistance Services (PAS) which were self-directed, portable, and appropriate to their needs as young adults living independently in their community.

Today, the independent living movement has spread across the country and with the passage of the ADA (Americans with Disabilities Act) and various reforms to educational, work, and trans-

continued on page 10

Massachusetts is Ahead of the Game

By Ray Glazier

Here in Massachusetts, we are lucky to have a MassHealth (Medicaid) PCA Program that is an optional benefit for all Medicaid-eligible citizens of the Commonwealth.

Persons who are ineligible because they are working can "buy into" MassHealth coverage through the CommonHealth program by paying a monthly premium based on a sliding scale according to their income and family size.

All persons with permanent or chronic disabilities who need, but don't have paid PCA services should contact their regional Center for Independent Living. (See the list in our last issue or request our Independent Living Fact Sheet.) You will need a letter from your doctor documenting the need; your personal care agency, usually your regional CIL, will do a personal care

continued on page 9

INSIDE

Summer 1999

From the Center

Ray Glazier, Ph.D.

Our last issue presented an overview of the Independent Living movement. This issue focuses in on a key component of independent living, Personal Assistance Services (PAS). In different contexts the definitions and the terminology vary, but here in Massachusetts we speak of PCA (personal care assistance) services, while the federal Health Care Financing Administration, which administers the Medicaid and Medicare programs, calls it “attendant care services.” Whatever the name, the game’s the same -- getting the help we need to live as independently as possible in our communities, taking from them what we need, and giving back what we can.

The contributors to this issue present converging viewpoints on the need for a national PAS policy and program, as well as give you the nitty-gritty of how our model Massachusetts PCA Program works and even tips on hiring PCAs. We look forward to hearing from our readers their reactions to this topical collage, as well as to the concept of themes for each issue. If you have a viewpoint to share, on PAS policy, the MassHealth PCA Program, or another disability-related topic, the Information Center wants to hear from you!

Ray Glazier, Ph.D., guest editor of this issue, is a long-time wheelchair user and PAS consumer; his recent doctoral dissertation for Brandeis University, Preference for Consumer Directed Personal Assistance Services *(1999), is available from University Microfilms, Ann Arbor, MI. Ray was a founding trustee of the Information Center and manages the Abt Associates Center for the Advancement of Rehabilitation and Disability Services in Cambridge, Mass.*

Editor's Note - J. Archer O'Reilly III

The previous issue on Independent Living and this issue, which is heavily devoted to the subject of Personal Care, were produced because the subjects are important and the information was uniquely available to the Center. However, they do not represent a change in the format and content of *Disability Issues* for the future. We will return to a collection of more broadly ranging subjects with the next issue of the newsletter. I hope these two issues will be a valued and useful resource for our readers.

The Information Center expresses our profound appreciation to Bruce Marquis, who has recently resigned as Treasurer, for his years of hard work for, and dedication to, the Information Center. Without his invaluable assistance we would not be publishing *Disability Issues* at this time.

Disability Issues [**ISSN 1063-9373**] is a publication of the Information Center for Individuals with Disabilities, Inc., a nonprofit agency that provides information, referral, and problem-solving assistance on disability issues. The publication and distribution of ***Disability Issues*** is made possible only through the financial support of many individuals and organizations. Mention of a product or service in this newsletter does not constitute endorsement.

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Editor: J. Archer O’Reilly III

Support Group News

The Boston Area Ataxia Support Group has changed its name to *New England Support Group of the National Ataxia Foundation* and is now affiliated with the Massachusetts General Hospital Ataxia Unit. Dr. Jeremy D. Schmahmann, Director of the unit, is medical advisor to the group.

Ataxia means lack of muscular coordination and is due to a number of related neurological disorders, causing slow, progressive deterioration of nerve cells. Ataxia first appears with symptoms of stumbling or ‘drunken’ walk, loss of balance, and hand incoordination. In many cases it is an inherited condition.

Symptoms progress over a period of years and eventually the patient may need to use a wheelchair fulltime.

There is no known cure or treatment. Ataxia is difficult to diagnose and is commonly misdiagnosed as Multiple Sclerosis or Parkinson’s Disease.

The support group’s main function is to help persons with ataxia and their families to cope with the associated problems. It offers the opportunity to talk with others and share experiences, feelings, and suggestions to grapple effectively with a chronic condition like ataxia.

For information about the group and meeting schedules, please call Martin Martignetti at (781) 862-1979 or Ben Cantor at (617) 484-7733.

To find out more about ataxia you may contact the National Ataxia Foundation at (612) 553-0167 or visit their web site at **www.ataxia.org.**

The PCA Wars: Battles Won and Battles Still to Fight

by Bill Henning

A combination of quiet advocacy and in-the-face activism has produced major changes in the Massachusetts personal care attendant (PCA) program, changes which in the long-term should improve and stabilize the program.

Perhaps the most profound change commenced on February 1, when for the first time ever, pay for PCAs went into a standard payroll format. When a PCA receives a paycheck now, it includes the deductions all wage employees face, such as Social Security and income tax.

"The PCA program had to meet the requirements of state and federal payroll laws," said Pam Burkley of the Cape Organization for Rights of the Disabled (CORD). "PCA users such as myself have possibly been liable for years for unemployment insurance and workers' compensation and we didn't know it, though a few folks ran into serious troubles, which prompted many of the changes that now provide protection for us and our PCAs."

The changes came as a result of advocacy from the Statewide Personal Assistance (PAS) Coalition, which is comprised of over 20 advocacy and provider groups across Massachusetts. Coalition members initiated efforts with the Division of Medical Assistance (DMA) to make changes as the specter loomed of the IRS and state labor offices imposing penalties on people with disabilities using PCAs without insurance or tax withholding. A three-person team comprised of Lorraine Greiff of the Massachusetts Office on Disability, Linda Long of the Governor's Commission on Disability, and Paul Spooner of the Statewide Independent Living Council represented the disability community in talks with DMA, interacting extensively with the Coalition throughout a two-year process.

"One big result was the protection of consumer control — the right of a person to hire, fire, and direct their PCA — and other gains were the addition of Social Security and unemployment benefit for PCAs," Burkley said.

Advocates acknowledge that implementation of the new system has hardly been glitch-free, but troubles are being worked out by DMA and the four fiscal intermediary agencies now involved with PCA payroll.

A major plus for the program came after 200 activists stormed the office of Governor Paul Cellucci during a day-long protest on March 3rd to demand better PCA pay. A token raise had been implemented in effect in February, but a better rate was needed in order to attract people to the job. Negotiations between the state and activists, led by Charlie Carr of the Northeast Independent Living Program in Lawrence, produced an hourly rate of $9.50, which represents a 21% overall pay increase for PCAs since January.

"The raise will help stabilize the PCA workforce," Burkley said, while emphasizing that the rate still needs to be raised further. PCA users in the urban areas of eastern Massachusetts have had an especially difficult time hiring attendants, putting their independence and freedom in jeopardy.

Burkley said DMA promised to review PCA pay in early 2000. "We'll be out in force again on this," she said, "as well as being sure that DMA follows up on its pledge to provide health insurance coverage for PCAs.

The battle goes ever on."

* * * * *

For more information on PCA issues in Massachusetts or on ADAPT or MiCASSA, contact the Cape Organization for Rights of the Disabled (CORD) at 1-800-541-0282 (Voice/TTY) or **cordwin@capecod.net.**

Bill Henning is director of CORD and is an active member of both the Statewide PAS Coalition and ADAPT.

The ABCs of hiring PCAs

By Karen Breisky

Imagine for a moment you have a long-term disability and an ardent desire to live independently. Let's say you use a wheelchair (as I do), and you need help getting in and out of the shower or fixing dinner or doing a load of wash.

Unless you have a family member able to volunteer 20 or more hours a week, your answer probably is a PCA or personal care attendant.

Unless you're well-fixed financially, you probably have to apply to the state for help in paying for such assistance.

In order to survive the process of hiring the right applicant, you're going to need a large dose of patience and a sense of humor. I

continued on page 4

Hiring PCAs

continued from page 3

recently had to run classified ads over a three-week period in a major daily and 21 weeklies in the Boston area to find two PCAs willing to work part-time in my home, evenings and weekends.

Because the need for PCAs rarely is communicated in our newspapers, many are not aware of what can transpire when a person with a disability advertises for help. Here are some of the things that have happened to me.

Applicant A: A persistent woman called, seeking to persuade me that I should hire her 17-year-old son. I told her that a teenage boy is not what I had in mind. “But he needs a job!” she insisted.

Applicant B: Over the phone, “Hilda” seemed perfect —- she lived nearby, was available evenings and weekends, and said she had done personal assistance work. But when I mentioned cooking and light housekeeping, she backed away. “I do enough of that stuff at home,” she said. What she wanted, she said, was another job like her last one, where she sat at the bedside of a person on a respirator and read magazines.

Applicant C: In the course of an interview with “Lisa” on a hot summer day, I learned that she had two small children who were waiting in her car. I asked who would care for the children if I gave her the job. She seemed puzzled by the question. “They’re fine in the car,” she said.

Applicant D: “Fun” was the operative word with “Ms. Laidback”—age 22, sports car enthusiast, a daytime nanny who looked forward to a relaxing evening as a PCA at my place. She arrived at suppertime on her first evening with coffee cake and proceeded to make a pot of java while consulting the TV Guide. Asked to vacuum the feathers and seed on the floor beneath the birdcage, she responded, “OK, as soon as this program’s over.” Before long, she moved on to something less demanding.

Applicant E: An extraordinary applicant! A medical doctor from an Asian country who yearned to be doing something productive and useful while her husband completed his fellowship at a nearby university. But our government declined to give her either a Social Security number or a work visa.

Applicant F: I wound up for a while with a morning PCA from Indonesia and an evening PCA from Morocco. Competition ensued over the matter of housekeeping. One day, Indonesia inspected the bathtub and asked of Morocco, “She calls this clean?!” Morocco responded that evening, “OK, I’ll do the kitchen and she can do the bathroom,” averting an international incident.

Applicant G: “What’s your condition?” this suspicious applicant asked over the phone. I told her I had a neurological problem, but she appeared to feel I was being evasive, so she got to the point. “Do you have a deformity?” And then, as if to help me understand: “Because I really don’t want to work with someone who has a deformity.” I thanked her for calling, and felt sorry for the poor soul who hired this woman as a PCA.

Sad to say, all too many Americans consider PCA work beneath them and look down their noses at those who take such jobs. One of my back-up PCAs confided that she tells her friends and family she works with me as a “counselor” or “teacher” for fear she’d lose their respect if she acknowledged doing PCA work. Another tells her friends that she comes to my house merely “to visit.”

PCA work pays little, and much of the work is menial, so the search for caring, competent, reliable people is arduous. But the search must go on. So, from my experiences, I’ve created a list of suggestions to help others in the process of interviewing, hiring and retaining good PCAs.

· Trust your initial instincts. Character flaws have a way of showing themselves, however subtly.

❖ Check more than one reference, preferably work-related.

❖ Insist on a two- to three-week trial period during which either party may back out without a stated reason.

❖ If the applicant fails to answer questions directly, or if you sense a serious personality clash, beware.

❖ Before you hire, make sure the applicant meets any other PCAs you have, so the applicant can be shown how the job should be done. You will also see whether the two are likely to get along and communicate well.

❖ Invite your cat or dog to sit in on the interview. If your cat hides in the closet, or if your dog growls, move on to the next candidate. Pets know.

Karen Breisky teaches English as a Second Language in Cambridge, Mass. (E-mail: **kbreisky@erols.com**). *This article is reprinted, with her permission, from* The Disability Messenger, *published by the President’s Committee on Employment of People with Disabilities.*

A National PAS Program Should Be Our Goal

By Ray Glazier, with contributions by Bob Kafka and Bill Henning

MiCASSA, the Medicaid Community Attendant Services and Supports Act of 1999, goes a long way toward framing the national PAS policy that Mr. Gulley notes is lacking [*see article on page one*]. It is arguably the most far-reaching disability legislation pending in Congress. It would provide persons with disabilities across the nation pretty much the same access to PCA services that we have here in Massachusetts.

Read the full text of MiCASSA, as well as news about it, on the website of Americans Disabled for Attendant Programs Today (ADAPT), the disability advocacy organization: **www.adapt.org**. Essentially it mandates that all states **must** provide attendant services and supports as a Medicaid benefit. Most working persons who are not Medicaid-eligible could also access attendant services through MiCASSA's co-payment provisions, and, absent MiCASSA, through the provision of the Work Incentives and Improvement Act (WIIA) that would allow working persons to "buy into" Medicaid coverage. (*WIIA recently passed the Senate, but has not yet been acted on by the House.*) The latter arrangement is one for which our Massachusetts CommonHealth program is a prototype.

At this time ADAPT is seeking a Congressional lead sponsor for the revised legislation. It was first introduced in June of 1997 by House Speaker Newt Gingrich and championed by him, but he has resigned from Congress. In Massachusetts, Congressmen Bill Delahunt and Barney Frank have signed on as co-sponsors, but more co-sponsors are needed.

"We urge people to contact their Congresspersons to ask them to support MiCASSA," said Pam Burkley, also a member of ADAPT.

One caution I (*R.G.*) must voice about MiCASSA is that attendant services are to be provided "under an agency-provider model and other models." In other words, the default service delivery mode is the home health

continued on page 6

Act Calls for Care Choice

By Bob Kafka, ADAPT

Imagine you have a stroke, your child has a car wreck or your newborn has physical and/or mental disabilities. What do you do? Where do you go? What kinds of services are available?

Accessing community-based services for the growing number of people with disabilities, older Americans and their families is one of the most critical issues facing this country.

The current public system of support services was designed more than 30 years ago based on a medical model of service that held that people with disabilities, regardless of their age, should receive services in nursing homes or some other congregate institution.

This system is primarily funded by Medicaid through Title XIX of the Social Security Act. It has institutional services as an entitlement and community-based programs as the alternative. Though everyone involved dislikes the program — families, people with disabilities, providers and government bureaucrats — it has been a difficult program to change.

Last Congressional session Speaker Newt Gingrich and Minority Leader Dick Gephardt introduced HR 2020, The Medicaid Community Attendant Services Act, MiCASA. MiCASA was Congress' attempt to take a beginning step in reforming the institutionally biased Medicaid system by allowing individuals the choice to use their entitlements for community-based services. Though it got 75 cosponsors and a hearing in the Commerce Committee's Health and Environment Subcommittee, the bill bogged down in the politics of the 105th Congress.

Advocates for people with disabilities and elderly people have worked together to get a second version of the bill introduced in the 106th Congress. The new version will be called The Medicaid Community Attendant Services and Supports Act of 1999, or MiCASSA.

MiCASSA has been restructured to include a Purpose section that makes the philosophical foundation of community services much stronger. The Service section remains essentially the same, but the addition of the words "and Supports" to Attendant Services makes it clearer that MiCASSA serves people of *all* disabilities and ages. Those individuals eligible for institu-

continued on page 6

Our Goal

continued from page 5

agency, not the consumer-as-employer model we have in the Massachusetts PCA Program, even though the Act's statement of purpose has consumer empowerment language. A few twists and tweaks in amendments could turn MiCASSA into a boon for the home health agency industry and send the program's costs out of sight. Researchers at the World Institute on Disability (WID) in Oakland, CA found that agency provided attendant care was orders of magnitude more costly than the consumer-as-employer model.

(See a list of WID's many PAS-related publications at **www.wid.org**.)

Care Choice

continued from page 5

tional services will be able to choose to have those dollars used for community services, as in the old MiCASA.

The new bill will also have a "Real Choice Systems Change" section giving states financial incentives to move from the current institutionally biased system to one that offers community-based services as a priority. In addition, there will be an optional Medicaid "buy-in" section that will allow people of higher income (ineligible for Medicaid) to "cost share" and receive services while paying a portion of the costs.

MiCASSA will not be an easy bill to get on the President's desk. The disability and senior communities are planning a grassroots campaign to educate Congress and the general public on the need for reform of the long-term services portion of the Medicaid program. MiCASSA is the key to open the door to reform of the complex long-term care system.

Bob Kafka, from Austin, Texas, is a national organizer for ADAPT, a disability-rights group advocating for community services (E-mail: **adapt@adapt.org**). *This article is reprinted, with his permission, from* The Disability Messenger, *published by the President's Committee on Employment of People with Disabilities.*

Book Shelf

Write Now, a Free Resource

A third revised printing of a guide to maintaining a creative spirit through writing while ill and homebound is available without charge to patient groups, service providers, and individuals. The book, *WRITE NOW: Maintaining a Creative Spirit While Homebound and Ill*, is made possible through a generous grant from the Puffin Foundation Ltd. and via support from the Townsend Press.

The Puffin Foundation supports projects that encourage "a dialogue between art and the lives of ordinary people." The 92-page *WRITE NOW* provides many insights on the benefits of writing when one is ill, limited, or confined for lengthy periods. The guide suggests numerous ideas and exercises to tap a creative spirit, covering everything from lists and letters to poems and fiction. Several people living with long-term health problems share thoughts and writings in the volume. They range from teenager to elderly; from several months to a lifetime of disability; from novice writer to published poet; and from Connecticut to California. *WRITE NOW* offers a welcome dose of help and hope to all.

WRITE NOW has been used by people of varied ages and circumstances throughout the United States and abroad. While many have benefited by using it at home, the guide has also been successfully utilized in hospices, assisted-living communities, hospitals, and nursing homes; by support groups and outpatient services; in counseling and occupational, recreational, and art therapies; and more. There is an unusually generous open-duplication policy; organizations, agencies, or individuals are encouraged to made additional copies for others.

To receive a free copy of *WRITE NOW*, send a self-addressed and stamped ($1.21 in postage 6x9 envelope to: S. Dion/ WRITE NOW, 432 Ives Avenue, Carneys Point, NJ 08069. For requests outside the United States, send six international postal coupons or $5.00 in U.S. funds.)

WRITE NOW is also available for use in desktop publishing or personal use on a Macintosh in Microsoft Word 4.0 or 5.1. To receive, send a 3 ½ disk (DD or HD) and a self-addressed return mailer (appropriate size) with correct postage, to the address above.

Independent Living and Mental Retardation

By Jim Ross

The Independent Living movement in Massachusetts began with strong advocates with physical disabilities, especially spinal cord injuries. Over the years, people with other disabilities have come aboard this movement and the core elements of “control” and “access” have deeply informed public policy.

People with developmental disabilities, especially people with mental retardation, have been on the fringes of the I.L. movement. Some independent living centers have been very open to including these folks in their services and supports. Other ILC’s have balked at including them, citing the inability of some people with significant mental retardation to make their own decisions — self determination is a key ingredient.

But fairly recently several things have happened that are bringing more people with mental retardation squarely into the IL movement:

1.) The Massachusetts Department of Mental Retardation (DMR) has a Mission Statement that resonates with key components of the IL movement. Individual service plans (ISP’s) for individuals, contracting with vendors, certification of vendors all have elements that involve consumer choice and control, etc.

2.) A DMR representatives sits on the Statewide Independent Living Council (SILC) and — in at least one region of the state — has initiated collaboration amongst DMR, the SILC Executive Director, local ILC directors, etc.

3.) The regulations allowing surrogates to help people with their personal care assistants (PCA’s) opened the doors to many people labelled “MR” to use PCA’s. This core support brings together people labelled “MR” and the ILC’s which are PCA vendors. Discussions with the Division of Medical Assistance (DMA) to expand eligible activities in the PCA program (such as allowing cueing and prompting) would bring even more individuals with MR into contact with ILC’s.

4.) Both individual desire and public policy are steadily reducing the “housing” of people with “MR” in congregated setting. Larger institutions are slowly being phased out. Group homes over 4 people are increasingly rare. It is more and more common to see people with MR living comfortably in their own apartments. And an increasing number of people labelled “MR” have been supported to buy their own homes. This movement fits nicely with gains made by people long involved in the IL movement.

5.) More and more people with “MR” are working productively in the community. This has increased their confidence to a point where they want more in their lives, including greater control.

6.) The rise of Self-Advocacy efforts has empowered people with “MR” to take control of their lives.

Despite the good “fit”, it is important for ILC’s to recognize that — due to their disability — many people labelled “MR” may be more vulnerable in some ways to influences in the community. They may need more skills training to master the complexity of PCA management. The ILC’s may have to interact more with families and guardians in some cases. The ILC’s may need to collaborate with agencies from other “systems” with which they have previously had little contact.

But these extras are worth it. The Independent Living philosophy and action makes this a better world for all of us.

Jim Ross is Executive Director of Community Partnerships, Inc. in Taunton, Massachusetts and a member of the board of the Information Center.

Massachusetts Funds Access Modifications

The newly established Home Modification for the Disabled Loan Program in Massachusetts will begin operation in September. This program will have $2 million in the first year and is expected to have $1.5 million annually thereafter. The money may be used for loans to low- and moderate- income people with disabilities (including children, adults, and elders) who require access modifications to their homes. Homes may be apartments or houses and modifications may include a wide range of household adaptations such as ramps, wider doorways, floor covering, accessible bathroom and kitchen features, or visual safety devices.

For more information about this program and for an application, contact the Massachusetts Rehabilitation Commission at (617) 204-3637.

Smile, Don't Stare at People with Disfigurements

by Josephine Davidson

Being beautiful or handsome takes center stage in our society.

Beauty is big business; on television and radio and in popular songs, "how-to" books, magazine covers and beauty pageants.

This raises an important question: Are we saying that beauty is what makes a person worthwhile? Is it having that gorgeous smile, those big wide-open eyes, that perfectly formed chin? Apparently these play a big part.

They shouldn't. What about the majority of us who are not born into exquisite beauty or through some accident or illness are faced with living with a disfigurement? How do we react to someone who is different?

Many people play "the stare game."

According to Paul Lohr of Massachusetts, a man with one eye, it is played this way: "People stare at you until their eyes meet yours. They look away quickly, then stare again when they think you are not looking."

According to MengFong Tan, a native of Singapore, who has a port wine stain that covers half of her face, playing "the stare game" is very difficult for her emotionally. Each time she struggles to keep her composure. As a child walking in the park, she heard another child screaming "monster, monster" as she approached. So now when MengFong sees a child she smiles, hoping children realize, because she is friendly, she will not hurt them.

When Martina, my nephew's wife, was 19 years old, her eye was removed because of cancer. One day, she ran to catch a cable car in San Francisco, the one she always took at the same time to her doctor's appointment. "Hey, it's the one-eyed bandit, make room folks" the cable car conductor yelled as she hopped aboard.

"He meant well, but I froze in my seat, not daring to look at anyone," she recalls. "A one-eyed bandit? A one-eyed girl? A one-eyed woman? That's what I am now, I thought, a one-eyed person, and any self confidence I had vanished. Pride in my other accomplishments melted away, I was a one-eyed person, no more, no less."

Fortunately, Martina is back on track, sporting eye patches that match her clothes, taking pride in her abilities as writer, editor, and mother of two wonderful children.

Betsy Wilson of Bellingham (*Washington*) knows all about this. Betsy lost her jaw to cancer 27 years ago and is well aware of "the stare game." She says it was a full 14 years after her initial surgery before she knew anyone really understood how she felt.

What brought about this knowledge? A friend gave her a book written by Christine Piff, an English woman who had given up her palate and an eye to cancer. After reading the book, Betsy felt the Christine had experienced exactly the same emotions.

She read about how Christine Piff started a network in England, entitled "Let's Face It." Betsy, who at the time was living in Massachusetts, knew she must start a branch in the United States. She did, and is still working at it 100 percent of the time right here in Bellingham.

Knowing Betsy has been an inspiration to me. She meets life head-on. I see the pattern in her life: She accepts her problems and works for others. Her faith and deep spirituality are her mainstays. And you know something? She is wonderful fun.

Betsy has compiled and prints a yearly booklet. "Resources for People with Facial Difference." This 56-page booklet is a must for anyone who has disfiguring facial problems, has a family member with the same, or is an educator. The booklet is on their web page (**www.facit.org/letsfaceit**) or Betsy may be contacted at Let's Face It, Box 29972, Bellingham, WA 98228-1972 or by e-mail at letsfaceit @faceit.org.

[**ED:** *For a copy of the resource booklet, send a 9/12 self-addressed envelope and $3.00 postage to the address above. They would also like a short note about yourself.*]

We must educate people not to play "the stare game." Looking back on it, I realize I played it years ago. Now I smile and continue on my way; smiles spell acceptance.

So let's give three cheers for "Let's Face It" and recognize people for the persons they are, not by outward appearances.

Josephine Davidson has used a wheelchair for more than 44 years and is an independent advocate for the disabled, the author of four resource books for teachers and the co-author of a book of lesson plans for teaching about disability.

Massachusetts

continued from page 1

needs assessment; in order to qualify for the PCA Program, you must require at least 10 hours per week of direct assistance with activities of daily living (ADLs) *e.g., meal preparation, dressing, bathing, toileting* and a need for a combined total of 14 hours per week of assistance with ADLs and instrumental activities of daily living (IADLs) *e.g., housekeeping, shopping, laundry.*

Your personal care agency will contact your doctor with the needs assessment results, so he/she can document that need to the Division of Medical Assistance (DMA). MassHealth, the Medicaid program operated by DMA, makes the final decision about your eligibility and how many day hours and, if applicable, night hours will be approved for you. To qualify for CommonHealth coverage if you are not Medicaid-eligible, you must be working at least 40 hours per month (**not** per week) and present two recent, consecutive pay stubs to prove it.

Once you have been determined to be eligible for the MassHealth PCA Program and your number of hours determined, you or your surrogate (someone like a family member acting on your behalf) will need to recruit, hire, train, and schedule your PCAs. As Karen Breisky's story in this issue illustrates, this is not always a piece of cake. The pay is low, currently $9.50/hour, and the work not highly valued by society at large. Workers are hard to find in this booming economic climate. As the employer of record for your PCAs, you have to check their papers and make sure that those you hire are either U.S. citizens or resident aliens with working papers (the famous "green card").

You will be given the choice of Option One (consumer delegates payroll functions to a fiscal intermediary, a company or organization with which DMA has a contract) or Option Two (consumer receives one check from DMA; withholds and pays both employer and employee shares of state, federal, and unemployment taxes; buys workers' compensation insurance; and prepares PCAs' checks).

If you choose Option One (see above), the PCAs' checks come to your home, and you hand them out or mail them to your workers. In Option Two, as your PCAs' employer, you are responsible for scheduling their time so it does not exceed your weekly approved hours, signing their timesheets (*PCA Activity Forms*) and mailing them to the fiscal intermediary promptly.

The Massachusetts DMA has published *A Consumer Handbook about the MassHealth PCA Program* that gives an overview of how the system works. The *Consumer Handbook* covers questions like "Will Mass Health pay my PCAs for overtime?" and "What if one of my PCAs gets injured on the job?"

For general publications regarding PCA recruiting, hiring, and management, you may find useful the set of PAS resource materials published by Independent Living Research Utilization (ILRU) in Houston, Texas. Each of the three publications in the *Independent Living with Attendant Care* (1980) series [*Vol. 1, Guide for the Person with Disabilities* (20 pp.), *Vol. 2, A Message to Parents of Handicapped Youth* (12 pp.), and *Vol. 3, A Guide for the Personal Care Attendant* (24 pp.)] is available for $3.50, or $10.00 for the set, and these can be ordered from ILRU's website: **htpp:/www.ilru.org**. The ILRU website has other interesting independent living publications and links to other disability-related websites as well.

Your Assistance Requested

The fact that you are reading ***Disability Issues*** means that you have an interest in the lives of people with disability and in access to useful and accurate disability information. We do not believe that this newsletter is your only trusted source for this type of information. Therefore, we consider you just the type of expert we need to advise us on other disability resources.

The Information Center would greatly appreciate it if you could take a few minutes and tell us about disability information sources you have found that are uniformly; timely, accurate, useful, and entertaining. These may be newsletters, magazines, telephone information lines, or internet sites.

Please tell us what areas of disability they serve, what geographical area they serve, and how you have found them useful in solving your own life situations.

You, persons with disability, family, friends, and service providers, are the best evaluators of the resources available. Your knowledge and your judgement are very important to the Information Center and to the people we serve.

Send your advice to: Information Center, P.O. Box 750119, Arlington Heights, MA 02175-0119 and mark the envelope "Resources." Thank you!

Anywhere Street, USA

continued from page 1

portation policy, we are beginning to make our point; we belong in society, not on its margins, and certainly not in its nursing homes. However, for all of our progress, life in the community remains an uncertain proposition for many of us, especially for those with the most severe physical, cognitive, sensory, developmental or mental disabilities. Even as we have grown in our awareness of the services we need and the possibilities they bring to our lives, the struggle to find adequate funding and appropriate programs for PAS goes on.

What do we need? At the level of public policy, there is little consensus over which populations require which services, let alone what the scope of PA services actually is, who should provide them, or how they can best be offered. Do we give "consumers" cash and let them buy the services they need on the market? Do we insist upon agency-based home health services to insure that "patients" receive services which are licensed, monitored and regulated? Do we compensate family members for the assistance they provide? And even if we had answers to these questions, how should we pay for these services? The Medicaid program? The Medicare program? Private health insurance?

Why do the answers to these questions elude us, and why have we yet to implement a comprehensive, national PAS policy in an era when so much else has changed? After all, if some individuals need agency-based services while others prefer consumer-directed services, why not simply provide a choice of either model? And, after all, if some individuals prefer to receive assistance from family members, then why not build a policy that allows for this? Providing individualized help with things like dressing or bathing, shopping or cleaning, reading or writing should not be rocket science.

Enter the politics and economics of healthcare in the United States. The approach this country takes to funding and providing PAS is patchwork in design and constrained by its own legacy. Change, when it comes, is incremental in nature, as revisions and patches are made to funding sources and service systems which have long since been patched and revised. And while we have made progress since the early years at UC Berkeley, what we witness now is a great inequity in the availability and the nature of personal assistance services, both from state to state and from person to person.

Most private insurance plans have only limited provisions for home health care, designed for a brief recuperation following injury or illness. And given that 75% of people with severe disabilities live at or below the poverty line, do not work and have significant "pre-existing conditions," access to the private health insurance market is quite limited. Most of us must turn to public sources, in the form of Medicare or Medicaid.

For its part, Medicare will pay for "non-skilled care," but only through Medicare-approved home health and homemaking agencies. Consequently, individuals in the Medicare program have limited choice of workers, which they neither train, supervise nor pay. Further, Medicare only pays for home health services if a skilled need (such as home PT or nursing services) is also present. Moreover, Medicare will discontinue payments should an individual not remain confined to his or her home (except for doctor visits).

Medicaid, on the other hand, has three relevant programs. First, home health is a mandatory Medicaid benefit; all participating states must offer it. However, before services can be provided under this benefit, a skilled need must be present, the individual must be confined to home and only Medicare-certified home health agencies can be utilized. Second, states can opt to offer what Medicaid calls a Personal Care Services (PCS) benefit, as Massachusetts does. This allows the states to provide services with greater latitude, including consumer-directed PAS. However, twenty states currently opt not to offer a PCS program, and for those that do, there are practically no uniform regulations.

Third, Medicaid also offers a "waiver" program to the states. So long as a state can show that it is not spending more on a target population than would otherwise be spent on keeping them in an institutional setting, it is permitted to provide PA services with great flexibility. Yet waiver services can be limited by geographic region (even within a state) and by other terms or limits any particular state sees fit to put in place. And they come and go, needing renewal every few years. All told, waivers are perhaps a patch for a system that is already patched.

A few other funding sources bear mention. Many states use Title XX federal block grants, Veteran's Administration funding, Rehabilitation Service Administration dollars and their own self-funded initiatives to

continued on page 11

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continued from page 6

finance PAS. However, the amounts involved are typically small or earmarked for particular populations. A patch to the patch to the patch.

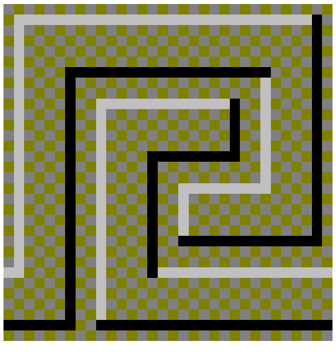
As stated earlier, the struggle for PAS has not yet ended. Advocates are vying for funding streams in a regressive, fiscally-conservative and programmatically-fractured healthcare arena. Programs within this arena, such as Medicare and Medicaid, are constrained by their own policy legacy, which ties coverage to inability to work, restricts services only to those deemed medically required, avoids paying for long-term service needs when possible, and when it does pay, prefers institutional to community-based settings. PAS policies built within these political-economic systems are bound to be perverse with respect to people with severe disabilities who require long term, self-directed, non-medicalized services in order to live and work in the community.

Indeed, the policies are perverse. As it stands now, the federal role in financing and regulating PAS is sorely limited. States are left to pay largely out of their own pocket for these services, competing for patchwork block grants or waivers or relying upon a Medicaid program they must partly finance. Put simply, this nation has a PAS non-policy.

The costs of this perversity are distinctly human. Like most other areas of American life, the only true guarantee that we'll be able to maintain a modicum of control over our lives comes in cold hard cash, something most of us do not have in any quantity. Absent lottery winnings, most of us rely primarily on our families for the physical assistance we require. Most of us do not even receive formal personal assistance services. And while for some of us this is an adequate solution, for others it results in dependence, neglect or even physical abuse.

The current state of PAS policy is such that some fortunate people, in some fortunate locations can hire personal care assistants (PCAs), get out into the community and get on with their lives. On the other hand, the bulk of us run headlong into the legacies of U.S. healthcare policy. When we do, we discover that PA services will not be provided either because we aren't quite poor enough, don't live in the right city, aren't willing to remain confined in our homes or because we are attempting to work. Jeff Gunderson was one of the lucky ones. But we are left to wonder over what has become of his friend at the brown-brick nursing home on Anywhere Street, USA.

Mr. Gulley is a doctoral student at the Heller School for Social Welfare Policy at Brandeis University, where he participates in research on a variety of contemporary healthcare and disability policy issues; he is a wheelchair user.



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Faithworks, Emergency PCA Help Program

Finding help when a PCA can't come on a certain day is always a problem, and the best remedy is to have a list of back-up PCAs, friends, neighbors, or family members who can be called to fill in. The personal care agency through which one gets MassHealth PCA services approval also maintains a phone list of back-up PCA candidates that the consumer can tap into.

However, the recent changes in regulations have pretty much eliminated PCAs without legal work permits (green cards), draining a large part of the PCA labor pool. The fact that all PCA income now has taxes withheld from the employee's paycheck makes it virtually impossible for anyone to work "under the table." This has caused a situation approaching crisis proportions among many PCA users in Massachusetts; by some estimates 50% of the PCA labor pool has disappeared because of these changes.

Enter FaithWorks, a new emergency volunteer PCA program sponsored by Vision New England's Disabilities Ministry. Currently the program is only able to supply volunteers from Boston area churches for evening assignments Tuesday through Thursdays for up to 3 hours with a 10:00 PM end time. PCA consumers may use the service no more than twice a month for true emergencies. As more volunteers are trained, FaithWorks hopes to be able to cover all evenings of the week on a less restricted basis.

It helps to register in advance for the service by calling **(617) 723-1750**. A volunteer coordinator will visit you at home to get a profile of your daily routine and service needs. When that inevitable emergency arises, you can call the number above as late as 4:00 on the day you need help.

FaithWorks will match you up with a volunteer who will come to your home. Men will go to work with men; women to work with women; training sessions will have taught the volunteers how to be PCAs.

FaithWorks seems to have a good grasp of the problem, but the program is just getting started, so patience and understanding on both ends are important. In recruiting volunteers, FaithWorks encourages them to share their faith in Jesus Christ as appropriate, but discourages pressure proselytizing. The whole idea is to spread the message by living examples of Christian service.

The program's brochure, available on telephone request, asks, "Does anyone seem to care?" FaithWorks proclaims, "God cares, and so do we!"

FaithWorks, Vision New England Disabilities Ministries, P.O. Box 873, Boston, MA 02130. E-mail: DisabilitiesConnection@juno.com.