

ORAL HISTORY AND PHOTO PROJECT:



A CELEBRATION IN TRIBUTE TO THE STARS



THIS PROJECT WAS FUNDED BY:
THE PENNSYLVANIA DEPARTMENT OF AGING AND
THE OFFICE OF LONG-TERM LIVING

W *elcome from the Secretary of Aging*

It is with heartfelt thanks that I welcome each of you here today. Your stories of courage, perseverance and strength are to be shared with the Commonwealth.

Each of you is a shining example of choice: the choice to stay and thrive in your homes and neighborhoods, rather than institutions. Shining examples, too, of empowerment and independence and dignity, integration in the life of your families and communities. You represent all the values that energize our work at the Department of Aging and the Office of Long-Term Living . . . and you make us proud.

Every day, our agencies work to create and expand choice, offering real, tangible long-term living alternatives to seniors and adults with disabilities here in Pennsylvania. The Oral History and Photo Project documents our progress and the difference we're making in the quality of life for you and your fellow citizens who participate in our community-based programs.

The people whose stories are told come from all walks of life and every region of the state. You range from young, busy adults to some of our oldest and wisest senior citizens. And the Oral History project portrays participants in a wide variety of our

programs: Medicaid Waivers, personal assistant services and attendant care, adult day centers, senior community centers and mealsites, family caregiver support, domiciliary care and assisted living residences.

Life sometimes presents situations over which we have no control. But how wonderful that barriers can be overcome and lives enhanced by these programs. Your personal experiences and the life stories you've contributed to the Oral History Project will encourage and show the way to generations of fellow Pennsylvanians as they strive to live and prosper independently. Your stories of independence and determination inspire other seniors and other adults with disabilities, as if to say, "I did this . . . you can, too,"

We published this book with pride, honor and respect for the individuals who took the time to tell their stories and encourage others. I hope you will share these with a loved one, a neighbor or friend, helping them to appreciate your challenges and triumphs.

Again, thank you and welcome!

John Michael Hall
Secretary of Aging



**John
Michael
Hall**



Essie Anderson

Mrs. Anderson, age 81, lives with her daughter Audrey in suburban Lititz. Audrey has converted a back room off the kitchen into her mother's bedroom.

Essie lived by herself in a senior citizen apartment building until 2007, when she had a stroke.

"I miss Baltimore. After my stroke, I was in the hospital and my daughter kept coming back and forth to visit. At the time, I didn't know it, but she talked me into moving to a hospital in Lancaster."

"I spent one year in the hospital. After that I moved to Maple Fair Nursing Home. I was improving so the doctors approved a transfer to my daughter's house."

"Here I get better attention. I don't have to sit in a chair all day, mope, and look at the wall or out the window. My nurse's aide, they call them caregivers now, comes in the morning and at night to assist my daughter."

"Every day a van comes to pick me up at 8 in the morning and I go downtown to the Albright Center. I have coffee, chit chat and devotions with other people. There are so many activities and people from outside come in as entertainment."

"People from there invite me to their homes and I invite them here."

"I go to meet the therapist and she works with me for three hours. I'm learning to walk and turn over. I can walk sometimes so I'm getting better."

"There's no romance in my life. I think I'm through with that. Although my daughter teases me that if there are men who catch my eye, even a handsome movie star that means romance isn't over."

"I have really been blessed by my daughter, son-in-law and grandkids and this little dog, Ozzie. When I was middle-aged, I never dreamed I'd have all this. I count my blessings," Essie adds.

Both Pam and Mike are wheelchair riders and are employed at the Center for Independent Living (CIL) in Central Pennsylvania. Pam is Director of the Living Well Program and Mike is the Comptroller. We met them at their accessible home where they live with their 11-year-old daughter Kristen. Pam, age 39, has spina bifida and Mike, who is 41, has a form of muscular dystrophy.



“I’ve done accounting in all my jobs, even when I was Executive Director of Pennsylvania Center for Independent Living (PCIL),” notes Mike. “I like how it all comes together. There is order and you can evaluate. The gifts and skills of accounting allow me to help make independent living a reality. I understand how the fiscal and program parts of a CIL come together to make the overall vision of civil rights for people with disabilities a reality,” Mike explains.

Pam’s career managing the Living Well program focuses on wellness through helping people choose healthy goals and realize them. “Our Director, Theo Braddy, came up with the Living Well program based on his experience living in institutions. He sustained a spinal cord injury at age 15 and his family put him in a nursing home. He thought about designing a program to help others. Living Well helps you look at all the things you need and what you want to do but thought you could not because of your disability. For me, living well is being home with my family and participating in my church community,” Pam says.

“So many people think they have to live a certain way because they are

limited by their disability. We had to fight to keep my mom out of a nursing home. My sister questioned us because the doctors and medical social workers think institutionalization is the only answer. Mike and I were able to talk my sister through it.”

For us, as people with disabilities living in the community, there is hope.” Mike and Pam have realized their own dreams of building an ideal home and family life. “What defines Pam and me is our home. We worked hard, saved our money, and had this accessible house built,” states Mike.

“If we were going to invest in our home, we didn’t want it to have any areas that caused us hardship. We had to constantly push our builder. We changed plans, we customized, and the builders balked. At one point he got a little disgusted,” says Mike. He said, “What are you building – the Taj Mahal?””

Their home is an exceptional reflection of all their planning and effort. The bedroom has a lift on a ceiling track so Mike can get easily from bedroom to bath and toilet. There is no place in the yard, home, or basement that is not easily accessed by either party.

Pam and Mike Auer



Theo Braddy

Theo Braddy is a handsome, well-spoken man with a commanding presence. He is the Executive Director of the Center for Independent Living of Central Pennsylvania, located in Camp Hill. He sustained a spinal cord injury playing football in high school. Mr. Braddy could not return to school and so completed his GED. He then went on to receive a bachelor's degree from Edinboro University and a master's in social work from Temple University. He is married to Rowena Braddy and has two children.

We interviewed Theo at his church, Dayspring Ministries. He views church and community as an essential part of his life. The interview took place in Mr. Braddy's office at the church. He serves as a minister and handles administration for the pastor. He is also President of Arms Around Communities, a non-profit faith based service ministry that is part of Dayspring.

"Part of Arms Around Communities is a marriage enrichment program and

new men's ministry. We also have a men's breakfast four times a year where we serve 300 men and have a nationally known speaker. We also have a program for single mothers and mentoring for young men 8-18 years of age."

We spoke about his work in the Pennsylvania independent living movement. "Everyone wants to live well. Society tells seniors and people with disabilities that you need to be institutionalized. Our goal is to give every individual in the community the services and supports they need. The majority of us want to be successful doing those things that everyone else can participate in. Here at my church, for example, there are no physical or attitudinal barriers to prevent me from full participation."

Theo reflects, "My mother put me in a nursing home for one year. Since then, I always wanted to do something to help people navigate that maze. It's what led me into the work that I do. It is people who are hurt who hurt other people. Once people help you then you are obligated to help others."

Theo Braddy receives attendant care through the Act 150 waiver. "I've been using attendant care for years. Pennsylvania has a wonderful array of programs. We have our problems but on the whole, it's a good system."

Mrs. Brown 86, has lived in a brownstone for 35 years. Occasionally the neighbors hollered over to say hello. There was an awareness that humans had sat in these places for 200 plus years, staying cool during the heat of summer, greeting one another, and checking to make sure elders were not in need.

“My mother lived here until she passed away at 87,” notes Mrs. Brown. “This is my home. I have a house and front porch to sit on. I go where I please when I please. My days are my own to live.”

“If I wake up in the morning and think today I’d like to go to Wal-Mart, I can get in my car and go to Wal-Mart. I can go to ShopRite. Or if I want to, I can stay home and sit on my front porch all day and say hello to my neighbors.”

“There have been many changes in the neighborhood. I know my neighbors and we speak to one another. If one of them is going to the store, they stop and ask if I want anything.”

“I just got my PACE card. I use the PACE program for medications. I can’t afford my acid reflux and high blood pressure medication. And then there is my Arthur (arthritis).” Mrs. Brown sounds as though she’s made friends with her arthritis, realizing he will probably stay around.

After talking for a time, Carletha revealed the care she takes to protect herself from exploitation. “I called the aging people about you. They didn’t know anything about this and told me



not to open the door when you came.” We explained that the Philadelphia staff were most likely not aware of this project since it was out of Harrisburg and reminded her that she had signed a permission slip and arranged the interview over the phone. Yet in her view, that could have been part of a scam too. She must have made a snap assessment that we meant her no harm since she remained outside and sent me into her house for a chair shortly after we arrived.

“I live with my cat, Buttons, and don’t go visiting very much. Two houses over the kids are very sweet. I used to be friends with their mother before she passed. They say they don’t have a mother anymore so they call me Mother. The battery on my car went dead and my neighbor, Andre, went and got it fixed. I asked what I owed him.” He said, “Mrs. Brown, you don’t owe me a thing.” “I can ask my neighbor Abby to rub my back or call a kid and send him to the store. I can’t complain. There is lots of life in this neighborhood. It’s a nice place to live. There’s no trouble.”

Carletha Brown



Mary Carter

Mary Carter and Doris Piovanetti spend many of their days at the White Rose Senior Center where we met them. They're close friends and wanted to be photographed and interviewed together, although both were comfortable being featured in the Office of Long-Term Living materials individually. We arrived in the morning and were scheduled to have lunch with them. However our time was cut short because a friend who also came to the senior center had passed away and both women wanted to attend the funeral, scheduled to take place early that afternoon.

Mary Carter is a 70-year-old African American woman who's been volunteering at the senior center for eight years. "I like being busy and involved. I like helping people and staying active because it keeps you young. Don't I look young?" asks Mrs. Carter. "And I have lots of friends here because of the senior center."

"I drive everyday. I've owned my own home since 1989 and raised six kids in that house – five of them are still living. Two live in York, two live in North Carolina and one lives in D.C.," she says. "I see my kids every day. I've had high blood pressure since I was 38 and have fallen twice so my kids check on me. I put four kids through college before I retired."

"Now I like to travel – travel, travel, travel," states Mrs. Carter. I've been to Jamaica, Barbados, Haiti, St. Thomas, and Las Vegas. I love to gamble and play the slots and bingo. But I only play penny slots because my limit is \$25," she says.

Doris Piovanetti was a volunteer at the center for one year before she became part of the staff. She works there five days a week. Half her time is spent doing kitchen work and the other half translating, helping with medications and making appointments. "I'm a 62-year-old Jill of all trades," she says. "I came to the center with a group of Spanish-speaking people who don't know English so it helps that I can translate for them."

"I have a Section 8, two-floor apartment and a caregiver who lives there. He's been a friend for years. He takes me to the doctor and makes

sure I take my medication. I have a mental disability. I've been diagnosed with depression and anxiety and some of the doctors say I'm bi-polar but I don't know. I do know the important thing is staying busy," states Mrs. Piovanetti.

"Your caregiver can be your son or your friend. It's better to be in your own home than in a nursing home. Before I came to White Rose Senior Center, I was more depressed. My kids live in New York and I only see them on Mother's Day and Christmas. Now, through the center we go on trips to the casino and to auctions. I have friends and a good life today."



Doris Piovanetti



Jesse Charles

Jesse Charles, age 47, lives outside of Lancaster in farm country where his family has lived for generations. At age 20 he sustained a spinal cord injury when he fell out of a tree while was trying to cut off a limb. Charles lives with his wife and 15-year-old son on the top of a ridge in a home he designed to be fully accessible.

Jesse lives an active, vital life. He worked for years in a bank mortgage department until he was laid off in the housing market crash. Six months later he was hired to do orders and sales for steel roofing and siding.

“I enjoy office work. I like paying attention to detail and talking with people on the phone. Outside of work, I have many interests. I think I’m the only quad that does wing shooting. Growing up on a farm, I always had my eye on hunting. I shot groundhogs, rabbits and ringed pheasants. I’d skin them and we’d eat them. After my injury, it was always a dream to hunt birds on the wing again. My cousins made a number of gun mounts for me so I can shoot from my wheelchair. I also shoot deer from my van.”

“When I’m hunting, it can be freezing outside and I won’t care or notice it,” Jesse explains. I use a Binelli 12-gauge shotgun for Canada geese.

“I’m on the Act 150 program and get 38 hours a week of attendant care. You need to know how to manage your disability or it will end up managing you. You can get in a situation where you get sick or get pressure sores.”

“I have lots of friends who are quads. All of them use attendants except the Amish,” notes Jesse.

Charles is also an avid birdwatcher. During the winter months, he spends many off-hours watching birds. “It’s why I built this house on a ridge,” he says. Jesse drives an accessible van, lives in a house he designed positioned where he wanted it on land occupied by his family for generations. It is clear that he knows how to manage living with a disability.



Monserrate “Monse” Cintron

Monse, as she likes to be called, is a 62-year old Hispanic woman with striking looks. She is a quiet person who attends White Rose Senior Center most days.

Mrs. Cintron arrived from Ponce, Puerto Rico, in 1990. She came to Pennsylvania because her son lived her. He moved away and she remained. Monse lives alone in her apartment.

Monse looks forward to coming to White Rose Senior Center every weekday. “I enjoy the many activities offered at the center, talking with the other Spanish speaking people and making new members feel welcome.”

“I also like visiting with my family. I have five sons, two daughters, 24 grandchildren and two great-

grandchildren. One of my sons lives in Florida and one daughter lives in California. All of my other children live in York and I see them daily. We talk, cook, eat and sometimes we go out to dinner.”

When Monse lived in Ponce, Puerto Rico, she did not work outside of the home. She was busy raising her family. When she moved to Pennsylvania she worked at Maple Donuts and at Shadowfax Corporation packing items.

The interpreter from White Rose Senior Center, José Rodriguez, asked Monse what she most likes doing and she replied, “Dancing at the Latin dance clubs in Baltimore, Maryland, going to parks and casinos and playing bingo with her friends every weekend.”

Mrs. Culp is an 84-year-old bursting with vitality. She has a tracheotomy because of a bout with cancer three years ago and has low vision. She speaks without any aid or device in order to exercise her lips. When Mrs. Culp can't make herself understood, she writes the words.

Although surgery followed the diagnosis of cancer, she refused radiation treatment. Her medical team was surprised when all tests confirmed there was no cancer in her system. Mrs. Culp, however, was not surprised.

"I knew before I refused treatment that the cancer would be taken from me and I would live. I knew it in my heart." Indeed, something is very right about Martha Culp.

We interviewed Mrs. Culp with her daughter, Gerry, at the Living Independence For Elderly (LIFE) program. Mrs. Culp lives with her granddaughter and great-grandson. The house is fairly small so she sleeps in a large recliner in the living room. The recliner makes it is easier to breathe. She doesn't use personal assistance services.

"I take care of myself," Martha says. Gerry backs up her mother. "Sometimes when I'm down she takes care of me, too."

"I come to the LIFE program for fun. I'm here four days a week. Just being here with all the people – it's wonderful," notes Martha. "We cook, we bake cookies and pretzels. I can't do much myself because I can't see. But I like to watch. I like the people."

"There are three things that happen here all the time and they are



Martha Culp

important to me: concern, respect and love."

Yet one might suspect that Martha Culp experiences love, respect and concern because people are mirroring what she gives them.

Mrs. Culp has a twin sister whom she visits whenever she can. They are a close-knit family. In addition to her daughter and sister, Martha's family includes four grandchildren, six great-grandchildren, and two great-great grandchildren.

"We're together every holiday. I think families should be close to one another. I've never had to live in a nursing home. There should be more places like this and more support so people can come here in the day and live at home."

"I look forward to living for at least 10 more years. I feel so good every single day. I thank God for my life. For people who worry or are unhappy, I say don't be so foolish. There is so much to live for. There is the world and everything in it. You are loved."



Penni Dallas

Penni Dallas lives with her husband Michael in a large yellow home with a wide, welcoming porch on the corner of the block. Michael and Penny are Civil War reenactment fans and their home reflects that passion.

Penni, who is disabled herself, could be considered the mother of home- and-community based services in Pennsylvania. It was through advocacy for her son, Michael Jr., born with Aperts syndrome in 1985, which led to the Michael Dallas Waiver in 1987.

“Michael was born 10 weeks premature and weighed two pounds. He had to have a trach and a G-tube because his stomach and esophagus were not connected,” explains Penni.

At the time, Penni worked in a tool and die shop. Her husband was a mechanic with Ford, where he’s worked for 30 years. “We were getting a few \$60,000 medical bills at a time. My husband’s health insurance tried to get my employer’s insurance plan to pick up some of the cost of Michael’s care. Shortly after that, I was laid off. However, we did not qualify for any assistance because our income was \$200 over the limit,” Penni says.

Penni wanted to bring Michael, Jr. home from the hospital, but at the time supports were not in place to allow for in-home services. But she was a determined parent.

She networked with a Pennsylvania group called Sick Kids – Involved Parents. She wrote all her elected representatives and asked to meet with them. A delegation went to Washington, D.C.

“We met with Senator Heinz and Representative Tom Ridge. Senator Specter sent an aide. We discussed federal funding for a waiver that would benefit 50 children by funding in-home private duty nurses. It was passed and the family was ready to go on the waiver in 1987. But then Michael died. He was 2-years-old when he died,” states Penni.

Penni has Crohn’s disease, which was exacerbated by the stress of her son’s

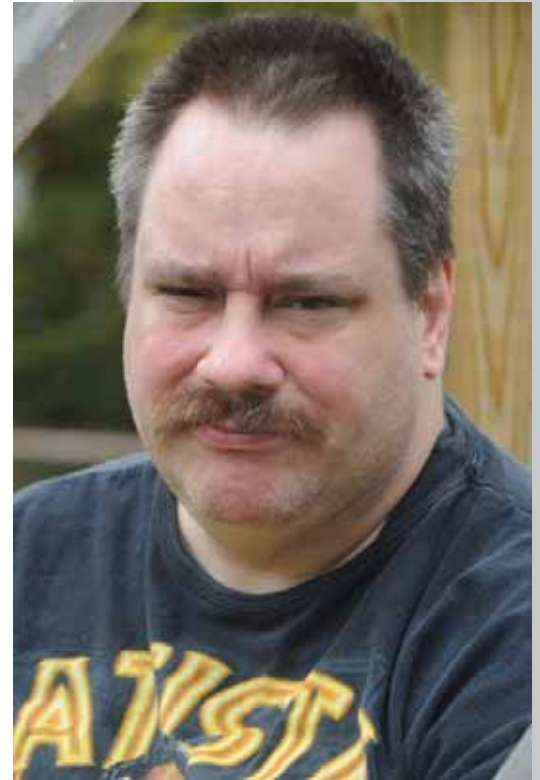
death. Seven years ago she was diagnosed with a continuous arterial venous malformation and had brain surgery. She now takes anti-seizure medications. We asked Penni what keeps her going in the face of life’s most challenging trials: the death of a child and her own disability.

“The waiver we fought for was named the Michael Dallas Waiver. In the beginning, after Michael’s death, that gave me great comfort because I thought Michael’s legacy would continue. His life and our fighting for the waiver were not in vain. People need care and support in the community to have a quality of life. We were part of those programs getting started in Pennsylvania.”

Penni and her husband have worthwhile activities that enhance life. For many years, they’ve been part of a group that participates in Civil War reenactments. The Friday after we spoke, she was giving a lecture in Erie on fashion of the Civil War era.

“Four or five years ago I started playing the dulcimer at reenactment events. Three of us ladies play for the groups. I’ll play this Friday in Erie.”

Before we left the Dallas home, Penni played “Down in the Valley” and “You are My Sunshine” on the dulcimer. Here is a woman who has two disabilities and has endured great suffering and grief after the death of her son. Yet Penni does more than endure life’s trials, she uses art and history to bring positive moments to others.



William ‘Bill’ DeLuca

Bill DeLuca is a person with mental illness who uses Pennsylvania services to purchase medication. He lives alone in a Berwick apartment. However his family lives in the area and they visit frequently.

“I work four days a week for the RR Donnelly Queen Smart Cleaning Service. Until 1994, I was Assistant Manager at ShopRite. It was a good job but it was too much stress for me. Now I get \$1,327 a month from SSDI. **Once in a while I regret not having money, but I’d rather have mental health,**” explains Mr. DeLuca.

“The drugs make it so I don’t feel anything. I feel separate from life. I hope to find a way to not take as many or get off of them, but I can’t do that until I know the symptoms would be fewer,” Bill states.

“I’m pretty close to my dad. I’m 40 and I have a brother who is 39.

I grew up in Newark, New Jersey, and miss the activity. Oh and the great Italian food. Well, with the meds food doesn’t taste as good anyway and they are part of the cause of my weight gain. You wouldn’t believe I ran track in high school.”

“Years ago I started collecting beer cans. Some are quite valuable. Before pull tabs were invented, there were flat top cans and the really valuable cans are the cone tops from the 1930s and ’40s. I’ve found a couple on EBAY worth \$2 and \$3,000.”

“Other than collecting and working, there’s not much to do here. But I’ve made some really good friends at work and we go out together. Even though the pills make me distant, I’m glad to live in my own place and feel positive about the future. I’m getting in better physical shape and working on lowering my meds too,” Bill smiles.



Teresa DeMauro

Teresa DeMauro does not speak a great deal. And although she has dementia due to arteriosclerosis, she still knows all of her family members and is able to answer some questions about her current and former life. She is small, with short gray hair, and sometimes her eyes focus on you with concentration and a smile blooms.

The morning we were coming to interview her, a caregiver misspoke by saying the project was to help people stay out of nursing homes. Ms. DeMauro. “NO! Don’t let them put me in a nursing home,” she cried. Teresa receives support through Services My Way. She has used those services for five years.

“Mostly I just sit down all day. I enjoy my family.” At 90, she’s earned that right. Ms. DeMauro lives in the home of her daughter who’s been a caregiver for several family members. She’s also a care manager for the commonwealth.

On the day we arrived, Teresa’s granddaughter was there with her

two young children, which accounted for four generations in an average, middle-class home. This is a model often lost in our society: that of the extended family. From the youngest family member to the oldest was a gap of 87 years. The house was full and bustling with relatives. It’s a lifestyle Teresa DeMauro has always known.

“My mother died when I was 14. Since my father had to work long hours, I raised my own sisters and brothers. Then I had four children of my own.”

“Sometimes I watch talk shows, but I don’t like the stories or much on TV. Mostly I’m just so grateful to spend every day sitting and being with my family.”

Teresa is only able to remain with her family because of the Aging Waiver program.

Shona and Mike Eakin both have disabilities and are wheelchair riders. Mike, 48, has muscular dystrophy and uses a vent, while Shona, 40, has cerebral palsy. Both are committed disability rights advocates.

They live in an accessible home in Erie, PA, with their two children: Elizabeth, age 5 and Brandon, age 6. Shona is the Executive Director of Voices for Independence, one of the Centers for Independent Living (CIL) in Erie. Both Shona and Mike use the supports offered through Pennsylvania's Department of Aging and the Office of Long-Term Living to enable them to live the lives they choose. Shona receives 39.5 hours a week in Personal Care Assistance (PCA) services under the State Act 150 program. Mike receives 18 hours a day in PCA services as well as home access technology support under the Omnibus Budget Reconciliation Act.

Shona's goals were "always to have a home, career, and family. Attendant care is the tool that enables me to live independently and with it I can be anything I want to be. Without it, I would have to make desperate choices."

In 1991 as an advocate and peer counselor at the CIL in Washington, PA. She had no PCA services. Kathleen Kleinman, Director of that CIL and Shona's boss, is a leader in ADAPT, the national disability rights group that engages in non-violent direct action.

"In order to get to work by 8:30 a.m., I had to get up each day at 3:30 a.m. Doing my morning routine with no assistance took me five hours," says Shona. One night after an advocacy action meeting, we all stayed late at work having pizza. I looked at my watch and it was 10 p.m. I told



everyone I had to leave right away to be on time for work the next day. Kathleen questioned me, realizing right away what the problem was. She ordered me to apply for attendant care the next day and made it clear that I wouldn't have a job if I didn't. At the time, the wait was two years to get into the program," notes Shona.

"Later, when we were advocating for expanding PCA services and shorter waiting lists, we met with the Governor. Kathleen Kleinman told me I had to go to the meeting to tell my story. Until that experience, it never occurred to me how important our stories are.

"While I was on the waiting list, I had to pay out-of-pocket for PCA services. My whole salary went to pay for them."

Mike Eakin has used PCAs since 1990 and as the years go by he has lost more function. "I could work outside the home with a trach and using a ventilator but economically there are insurance and housing disincentives. The kids are in daycare but I do the meal preparation, bills, shopping and other home related tasks," says Mike.

Mike described an average day. "Shona gets up, dressed, then she and the kids leave by 8 a.m. Then I get up

Shona and Mike Eakin

and start my routine. That takes a few hours since I use a vent 12 hours a day. Then I have lunch or go grocery shopping. I spend quite a bit of time online. Also, I have to supervise the meal preparation," Mike adds.

"On a typical Saturday, we're out of the house and take the kids to Chic-Fil-A. Then we go grocery shopping, take the kids bungee jumping and then usually have some things we have to buy at WalMart," notes Mike.

Shona and Mike were a part of the demonstrations and activism that brought attention to the need for extensive community-based services in Pennsylvania. "I used to think that demonstrations and activism led directly to the programs and services available now. I know now that a great deal of administrative and bureaucratic change had to occur. But I believe the direct action was a catalyst," Shona claims. "I worry that people with disabilities will become too complacent because there are good services now.



Donna Faus and David Grubber

Donna Faus and David Grubber live and work in a small town west of Williamsport. Donna is a 50-year-old power wheelchair rider who has spinal muscular atrophy, one of the 40 neuromuscular diseases lumped into the muscular dystrophy category. David is her aide and significant other. They've been together 11 years. David is a veteran. They reunited when he returned and over time have grown closer. Clearly they share many interests and are best friends as well as partners.

Dave started working as Donna's substitute aide. Then it evolved into part-time. "Then she got stuck and I became her full-time Personal Care Assistant (PCA). Do you know what that means? For five years, I have never had a day off. Do you know what else? I have never regretted it," smiles David.

"I worry about the expanding role that home health agencies are playing in the provision of PCA services," noted Donna. "They are killing the consumer control model in many states because of the home health agencies. We could not move to many states because David could not be my attendant," she explains.

Donna is on the Medical Assistance Waiver and currently receives services through Community Resources for Independence. She's allotted 66.5 hours per week.

Both Donna and David have Native American blood. Donna is part Cherokee, David part Narragansett. Both are artists who craft a variety of media. Donna fashions greeting cards and jewelry, while David works in ceramics, wood, and makes dream catchers.

"Four to five years ago I found out I was part Cherokee," explains Donna. "I ended up going to a powwow and loving it. I thought it would be awesome to camp with these people, and a few hours later they invited us. That started us on the Red Road."

"A few years later, I volunteered to help with an archeological dig for Native American artifacts on Canfield Island near Riverside Park. I was pulled to the southeast corner of the island so I left the dig and went there. I had a spiritual experience and later took Dave back there."

"Dave said this would be an awesome place for a powwow. We were a little overwhelmed. It was a huge undertaking. Now it's in its seventh year with more than 25 vendors and 3,000 to 4,000 people attending."

Donna and Dave began by asking businesses and people in Williamsport for donations. and ended up with their likenesses on a mammoth mural downtown.

"One day we went to the Bullfrog Brewery. We were telling people about the first powwow and asking for donations. That day Michael Pilate the mural artist was there. He was asking about Native American history in this area. The mural depicts the entire history of Williamsport and covers the walls of three buildings." Donna explains.

"As long as there is breath in this body, Donna won't be in a home," says Dave. "People like Donna and others – they are part of the community and give and contribute to the community."



We met Leah Fink and her Personal Care Assistant, Brenda Knight, at her home in Phoenixville. When Leah began using a wheelchair, she had an accessible apartment built in the basement of her home. There is a separate entrance and a screened-in porch.

“I have neuropathy, fibroneuralgia, and a rare copper deficiency that caused lesions to grow on my spinal cord. That’s why I can’t walk,” explains Ms. Fink. “It came on slowly beginning last February. I came home in July after being in a hospital, rehab and then a nursing home.”

Leah uses the home health agency services of United Cerebral Palsy to provide her 48 hours per week of personal assistance services through the Independence Waiver program.

“I have five children, and my boyfriend lives here too.”

“John is 20. He attends Temple, is a volunteer fireman and a lifeguard. He wants to join the FBI or the police. There’s Briana, 17, who just graduated high school. Joseph, 17, is in high school and also a volunteer firefighter. Christopher, 15, attends Milton Hershey boarding school. My 10-year-old, Johnny Benditt, is in public school, but I want to send him to Milton Hershey. It’s an excellent prep school.”

“The hardest thing I ever did was send my oldest son to Milton Hershey. He was homesick and it broke my heart not to have him at home. But now he thinks it is the best thing I did for him.”

Leah Fink



JoAnn Forkin

JoAnn Forkin is a woman who has amazing strength but is not content with her living situation. For eight years she has lived in Eastern Comfort Assisted Living IV and two other similar facilities.

JoAnn's story underscores the importance of sufficient waiver programs and affordable, accessible housing. The work of staff in the Dept. Of Aging, Office of Long-Term Living, and her Area Agency on Aging helps JoAnn and others like her to live lives they choose in the community.

She is a wheelchair rider with multiple sclerosis, spinal stenosis, significant arthritis, and health issues not improved by the stress of her environment.

JoAnn, now 63, graduated from Columbia University with a Bachelor of Arts in early childhood education. She taught kindergarten in the Bronx and then in New Jersey for eight years. She was married for 29 years until her husband passed away 15 years ago. She had four daughters; two are living in Easton, Pa.

"I am the only one here with a physical disability. The others have mental health problems. In March 2008, I became a Pennsylvania's Empowered Expert Resident (PEER) counselor and then got ombudsman training to do something in this environment that is useful and helpful. For years here, there were no activities. I have found a volunteer to come once a week for a crafts activity, started a game night, and a weekly Bible study through my church," says Mrs. Forkin.

"It's hard to help people here. I'm not a psychologist. I found one program for people with mental health issues. It's called POWER. I called and called the person who gave a presentation about it and finally she got someone out here. Now several residents are enrolled."

"I know what it is like to be depressed. When I lost my baby in a miscarriage, I went through a bad depression. I didn't want to get out of bed. I went to pieces."

Mrs. Forkin brightens when describing her work with the PEER program. "I'm the only counselor in this county, but now we have two more in training. We make people aware of their rights and give orientation to new residents. Recently I went to an ombudsman's enrichment training. I really liked that. It was nice."

JoAnn is on a waiting list for a Section 8 housing voucher. She wants to move to an apartment building in Emmaus, where she has two friends. Meanwhile Mrs. Forkin keeps working for improvement in her own life and the lives of those around her. "I think everybody should try to do all that they can. I will keep on trying to do as much as I can," she promises.

George Foster, age 97, was born in 1912 to a far different world from the one most of us know.

Mr. Foster, who is quite frail and has fallen more than once in recent years, lives with his grandson Reggie and is cared for by two great-granddaughters.

Foster was born in Vermont and spent much of his life as a “cow man,” working with cattle herds and raising champion bulls and cows.

“Never had my own farm. I always worked for rich people. They could spend \$8,000 to \$15,000 on a cow or bull. I rode with cattle clear across the country on trains. It took six days from the east to west coast.”

“When I was about 40, I went to work for Cornie Gerringer. He owned the Reddington Hotel in Wilkes-Barre. He came to Massachusetts to hire me. He said he was getting an importation from Guernsey. The cows that come from the Isle of Guernsey off Great Britain, they give the richest milk. Gerringer eventually wanted to turn the operation over to his son but he wanted me to come along and train his son.”

“I worked there for about a year-and-a-half. I think that was the last importation of Guernseys. Holsteins have taken over. They give 3 percent milk while Guernseys give 5 percent. Women decided they wanted to be thin so everyone wanted Holsteins.”



George Foster

“I raised my kids on Guernsey milk. Jersey cows have come back because of cheese. I had the reserve champion Jersey. She was second best in the country. We sold that cow for \$25,000.”

“After I left Gerringer, I was hired for a farm in Connecticut. Everything has changed now. Now you milk 500 head. We used to milk 50-60 head.”

These days Mr. Foster is glad to be at his grandson’s home. Though he doesn’t qualify for the Aging Waiver, the caseworker has said they want someone with him 24 hours a day. The state does fund an aide to come in three times per week and bathe him, as well as a weekly visit from a nurse.

“The state has been good to me,” says Mr. Foster. “I would not kick about Pennsylvania.” Indeed, the entire family is pleased with services from the Office of Long-Term Living and the Area Agency on Aging.



Bob and Kathy Fuhrman

The Fuhrmans' lives are packed with interests and activities. They live with their dog in a lovely, well-kept house in York that is full of antiques and Americana. "Antique shopping used to be our weekend hobby," says Bob.

Bob, age 67, has multiple sclerosis. He's been a wheelchair rider for nine years. Before retiring, Bob worked for a large corporation as a production and logistics manager. Both he and Kathy, were born in the Lancaster/York area and both have a passion that has supplanted even antiques: volunteering. "I love the way people light up when they realize what benefits they qualify for," says Bob.

Kathy has a degenerative spinal disease. In addition to her own volunteer work, she's been a caregiver for parents, friends, and grandchildren.

Bob volunteers through the APPRISE program by counseling seniors on Medicare Part D, supplemental insurance programs and other benefits. He also offers training on topics such as "Getting Ready to Retire." Both Bob and Kathy display significant knowledge and savvy in benefits counseling.

"The state gives us a lot of training and then tests and certifies us on an annual basis," explains Bob. He spoke about the fullness of his life. "I forget that I have a disability. It is not a major priority. I do everything I want to do from this chair. The only thing I can't do anymore is teach karate."

"Our granddaughter wrote that Bob is like a doctor. He carves, builds things, counsels people, and he does it all from a wheelchair," adds Kathy. Indeed some of Bob's exquisitely carved birds are displayed throughout their home.

"I also like helping people and always have. I was a second-grade teacher where the people I helped were all shorter than I. Bob handles the full range of benefits but I specialize in Medicare, Part D. Each person you see is different. **The nice part of volunteer counseling is when you save someone a lot of money and see the look on their face,"** continues Kathy. **"You might see someone who can hardly pay their mortgage or rent and they qualify for a buy-back and prescription drug benefits. People are not aware of what is available. That extra \$500 they receive can mean the world to them."**

Bob spoke about a recent training for caseworkers at a nursing home. "At the nursing home, they conduct full intakes for Medicaid and welfare. It was hard to see so many younger disabled people there. I think when you are capable of living in the community, that is the best place you can be."

Ms. Gardiner is a larger-than-life presence in body and spirit. Her first name and perhaps part of her charisma derives from the Arabian part of her heritage. She is tall, large, and beautiful in her purple suit and gray hair. Her gaze holds an unusual combination of penetration and kindness.

Ms. Gardiner is 81 and has lived in Philadelphia all her life. She is close to her four children, three of whom live in the same city. There are 10 grandchildren and 16 great-grandchildren.

“I work two days a week in the health department, mainly training staff. The mental health system nationwide is under transformation. Because we have mental illness has nothing to do with stupidity. Slowly society’s image of us is changing and I have been part of fighting for that.”

“I’ve worked in the mental health consumer movement for 20 years. Here I work to train staff and others in the politics of changing from the medical model to a people model,” Hikmah explains.

“I’m black, a female, and mentally ill. In my youth, I fought everything. Now I know how to pick my fights.”

“I got all excited about the President’s new insurance plan. Being an older person, I’m concerned about older people. With Medicare, you pay 50 percent of the cost to see a therapist; I pay 20 percent of the cost if I break my leg. It is unconscionable.”

“Your life is fuller living in the community. Yes, I have ‘dammit-

to-hell’ days where I don’t want to get up. But on my average non-work day, I visit drop-in centers and go talk to seniors. I belong to a handicraft club.”

“While I have several physical ailments, arthritis is the worst. That’s why I use a wheelchair. But I try not to use it too much because I don’t want to lose function. I wrap up in a blanket to stay warm. I can’t stand to get cold.”

“It is important to respect people who are older.”

“People first applies to more than mental health. The transformation to ‘people first’ language means see me as a human being first, as an individual. Then see my mental illness. That can refer to age and race and disabilities too.”

“I know St. Peter is coming after me but I ain’t waiting for him. You gotta come and get me, Sugar.”



Hikmah Gardiner



Kyle Glozier

Kyle Glozier is a 24-year-old student with cerebral palsy (CP) who attends California University. We visited with Kyle after his political thought class, where Professor Hein lectured on the Gilded Age. Kyle's a senior with a double major in criminal justice and political science.

We spoke about disability and the college curriculum. "Cal U has no disability politics," says Kyle. There is one line in a syllabus that mentions the Americans with Disabilities Act (ADA). But no classes where there's discussion or study of this mass movement that led to laws impacting 56 million American with disabilities."

Kyle has a national reputation among people involved with disability rights. He's been attending ADAPT civil disobedience actions since he was 9, gave a speech at the 1992 Democratic convention and gave Clint Eastwood the brush off at a congressional hearing for supporting limitations to ADA.

"Stars – I don't care about stars," Kyle says of his run-in with Eastwood. "The real stars are the ones in the trenches taking direct action for social and political change."

Glozier used to aspire to be the first U.S. president with CP. Senator Tom Harkin gave him a campaign contribution. "I've changed my career plans," notes Kyle. "I'm applying for a summer intern position in the Advocacy Department of the Rochester Center for Independent Living."

Kyle is on the OBRA Waiver and receives 79.5 hours of services per week. He lives off campus in subsidized accessible housing for seniors and people with disabilities.

We asked Kyle what he would say to a newly disabled person who was deciding whether to live independently. "Of course it is personal choice. But the work that we've done has enabled people like me to have attendants and live at home."

We began to discuss Kyle's fears about leaving the security of university and home and going out into the work world and the time that his communication device broke down.

"Everyone has fears, of course. And mine are sometimes stronger because I need to organize so many services to live an independent life. But I'll manage," he affirms.



Mr. Gonzales volunteers at a senior center helping people with their taxes. He's tall and has a subtle, delightful sense of humor. The day we saw him, Luis wore a leather vest and a work shirt. Though the outfit was casual, he looked perfectly turned out – quality clothes and not one thing out of place.

Luis has been a volunteer for years in different settings. In 2001, he retired as Campus Registrar at Penn State Beaver. Then a dear friend drafted him to sponsor several junior high school students. In 2002 he started assisting seniors with taxes. The day we interviewed him, he was a bit frustrated with seniors who had no paperwork for stock sales or Social Security. "If she can't show what she bought the stock for, she'll pay taxes on the full amount of sale," he explains.

Mr. Gonzalez talks about the importance of giving back through volunteering and notes that staying active and interested keeps one younger. "I have a member of my family who at 60 is old. He shuffles around. I'm 71 and not old. Many retirees have to work. My wife Patricia and I

are blessed to be able to volunteer. I help with taxes three days a week and we both help delivering Meals on Wheels. Many older people need the friendliness of visitors. Meals on Wheels provides that and nutrition."

Other interests include playing saxophone in two summer community bands, and a local jazz band. "I'm thankful the directors *tolerate* my playing. Then there's the trip to Egypt he and his wife took in January 2010.

Mr. Gonzalez sits at a table with three people who need help with taxes. He has a subtle way of launching a joke; it can fly right by you. "As a kid, we used to sit in a park and tell each other jokes and practice our timing," he explains.

He goes over the tax form with Mrs. Stewart. She has picked up on his humor. "Don't touch my money or I'll smack you," she jokes. At the end of the session, he hands her some papers. "Destroy these forms," Luis tells her. "I don't want to put your name in the garbage."

Luis Gonzales



Jay Harner

Jay Harner is a 31-year-old man living with C-5 quadriplegia. He excelled at high school baseball and was headed to Shippensburg University on a baseball scholarship. He was on vacation at Bethany Beach, Delaware, wave caught him, slammed him head first into the sand, and broke his neck.

Jay spent four months in a in-patient rehabilitation program that consisted of physical, occupational and recreational therapies At Kernan Rehab in Baltimore, Maryland. He then six months in a outpatient

program at Gibson Rehab in Williamsport, PA.

Jay lives with his parents, but is trying to move out onto his own and be more independent with his own life.

“I get 47 hours per week in Personal Care Assistance services through the Community Resources for Independence Waiver,” says Jay.

“Depending on the day, it can take me between two to three hours to get up in the morning. By the time my routine is done and I’m in my chair, the morning can be almost over. Once I am up and in my chair, I’m pretty much independent. I am able to do most things own my own but might need some assistance with getting it started, such as having someone pour me a drink”

Jay attended Penn College and received an Associate Degree in

general studies. He wants very much to work, but there are disincentives and limitations.

“I’ve paid for all the education that I can afford right now. Vocational Rehab has not assisted me very much, so I have been doing most of it on my own. I’m on Supplemental Security Income since I was so young when I broke my neck that I didn’t have the work history to get Social Security Disability Income. For me to work, I have to make enough that I can afford to lose my benefits. I want to work but I don’t want to work to just pay for my daily routine. I want to work and make a life for myself while contributing and being useful at the same time.”

We told Jay of other Pennsylvanians with significant disabilities that are attending four-year colleges, with the Office of Vocational Rehabilitation picking up the full tab.

“I want to live a life a be productive and by doing so have a sense of self worth.. I’m just looking for a financial package that will make life less restrictive. It doesn’t have to be easy but doable.”

A 54-year-old wheelchair rider with a disability known as Spina bifida, Cassie James is Director of Policy at Liberty Resources, Philadelphia's Center for Independent Living. Since the 1990s she's been known throughout the country for her intensity and integrity. Working with Disabled in Action, Liberty Resources, and ADAPT, Cassie was part of the pre-1990 struggle for accessible public transit and has freed numbers of people from nursing homes. In early years, her advocacy was as fiery as her flaming red hair. If you are not totally committed to disability rights, to the full societal inclusion of people with disabilities, you'd best avoid Cassie James.

Eleven years ago, she married Alan Holdsworth. They have a 10-year-old-daughter, Danielle.

"I was a bad teenager and ended up institutionalized in Bayberry State Hospital where they sent people with psychiatric disabilities as well as incorrigible kids. It was horrible and the drugs made me psychotic. I can't remember a lot of the specifics because of the drugs. All I remember is knowing I had to get out of there. It wouldn't work to say I was wild but not crazy. So I started telling them that, yes, I heard voices but I wasn't listening to them anymore. Finally my mother came and got me."

"I got the Independent Living Program at Widener to pay my tuition to Philadelphia Community College. I started to take the train downtown from Fox Chase. It was not accessible. I'd get out of my chair and climb the stairs and pull my chair with me. Then I was told I couldn't do that."

"It became a huge battle. At first no one would help. Then Steve Gold and

other advocates got involved with this little redhead."

"I didn't really want to be an advocate but I had to sue and fight SEPTA," she explains.

"I graduated from community college and started at Hahnemann University. But I got very ill, left school and began using a power chair. I met Tim Cook, ADAPT's first lawyer, and several of us started Disabled in Action."

"I always thought I deserved what everyone else had."

"We realized we needed to develop advocates in Pennsylvania so Nancy Salandra and I started the Community Advocacy Program.

Cassie met her husband, Alan, through ADAPT actions. From England, he is the well known disability rights troubadour whose stage name is Johnny Crescendo. She and Alan moved to England in 1999 but returned in 2003.

"Most people we hang out with need attendant care. I'm on the Act 150 program. I make co-payments and could not have my house or family without it. I have a great attendant named Charmine Davis who works 40 hours a week. She's also a mom so she gets along well with Danielle. I used to be pretty wild but now I love being a Mom. I love being with my daughter."

Act 150 is paid for out of state funds so I worry that it will be threatened by budget cuts. "This state has not been hit hard yet but I think we are going to see some cuts.

"We should be developing our own models. We're the best and most expert at what people with disabilities can do and how services need to be



Cassie James Holdsworth

structured." I love Ed Roberts dream and he did not want us to do it everyone else's way because that has always lead us to dependency and often to institutions. Many disabled people achieve much more then anyone ever told them they would. Ed started an IL movement that went around the world and he was on a ventilator. He and Wade Blanks are the people I try to be like. They are the people who have lead the way for our freedom! Wade Blanks was the co-founder of ADAPT an activist group that has fought for ending the institutional bias. They have been taking people out of nursing homes for more then 30 years. My mentors are Babs Johnson, Bob Kafka, and Stephanie Thomas without their support I would never be who I have become an activist and a Policy Director.



Jennifer Howell

Jennifer Howell is a young wheelchair user who is passionate about her work. She is the Transition Coordinator for United Disability Services (UDS). Her program is funded through a grant from the Pennsylvania Developmental Disabilities Council (DDC).

“The program supports young adults with disabilities in their transition to adulthood. We help find housing, but the program does much more. I say we help people live beyond the label.”

We’re all people with support needs, and if we joined together we would have the voice to show legislators how important community services are. You can’t just focus on housing, attendant care, employment, or transportation,” notes Jennifer.

“What are a person’s unfunded supports? Their friends, family, and faith community are not funding-dependent. I call the entire picture of a person’s support system their circles of supports.”

Jennifer further explains her philosophy and how she uses it in her work. “When someone comes to me, I focus on who they are. I ask them when and where do they want to meet, what do they want to discuss and what do they want to do. I look at their strengths and their passions and see how they can build on these things.”

“The first thing I do is use UDS. We have strong connections to all the state waiver programs. I’m familiar with the supports and services available. If the person wanted to use a waiver through UDS, I’d ask the intake coordinator to come to a circle meeting. If others need to be involved, I’d invite them and facilitate the discussion. I would connect the young person with housing resources in the area. We might invite a realtor or someone from Habitat for Humanity. A circle of support includes family members, friends and support professionals.”

“People don’t realize that people with labels and people who need supports deserve our own homes and our own lives. We don’t deserve to be locked away in some institution that appears to be safe but is not. People need relationships and helping them form relationships in the community is the proven way to keep people safe,” Jennifer states. “It does not work perfectly all the time but I know the resources to help it work. We need to go back to the drawing board if something is not working.”



Chong Wan Kim

Chong Kim is an 89-year-old immigrant from Korea. We met in her apartment in a large senior facility. She speaks Korean and her care manager serves as translator. Some of the translation of Mrs. Kim’s words is literal.

She has personal care assistance services for 3 hours twice a week and her meals are delivered.

“Here I live by my own rules. I read the Bible, watch television, and sometimes walk around my neighborhood. Through church, I have socialization with other people. I attend Senior College where we exercise and learn basic English.”

“Around 15 people from my church live here and we have activities and socialize. My church is the Korean United Church of Philadelphia.”

“I was born in Kaesong, North Korea. After the Korean War, we had to move to Seoul in South Korea.. I have lived in the United States for the past for 30 years. In the

beginning, as a new immigrant, I missed Korea. But you adjust with years. My children, grandchildren and great-grandchildren are in the states.”

“My family visits me often. The two daughters try to visit weekly. One daughter tries to visit often. Her husband is a pastor. All my grandchildren are nice. The oldest one picks me up and takes me to dinner.”

“Since they were born and raised here, it is hard to tell them about Korean culture, but I encourage them to visit Korea. All my grandchildren are married to Americans. I want them to keep their own culture but it is really difficult. Most important, I’m happy for them because they have a good life.”

“I am going to tell you that all people my age should live in the community.”



Wayne Koch

Wayne Koch is a vibrant, colorful character and not just because of his long red hair and painted fingernails. “I painted the nails of one hand the first time on a dare and then discovered it is a great way to stand out. “When I was 35, I rolled my van down a big hill and sustained a spinal cord injury.” A thoughtful individual with a commitment to the societal inclusion of people with disabilities, Wayne has served on the Governor’s Advisory Committee on Disability and been involved with various advocacy groups over the years.

Mr. Koch worked as an auto CAD designer/drawer until 2005 when he formed his own company and began

consulting. He primarily does drawings for barrier-free designs. He has a plethora of interests, including collecting glass and the art of beer.

Wayne Koch has the heart and flair of an artist. “I wish I could weld and not hurt myself. I’d do a large sculpture for my front lawn.” Wayne took us to the Keystone Art Gallery and Cultural Center where he is well known. The center is owned by George Mummert, a renowned bronze sculptor with pieces at Yale and the Smithsonian.

“When Wayne first came here, I already knew who he was from reading news articles about him and his advocacy work. He didn’t know that I knew of him,” explains George.

Mummert welcomed Wayne’s presence because he wanted the art center to be accessible and also with community participation. When we visited, the current show was Perspectives on Preservation with pieces by Lancaster poets and artists.

Wayne buys his granddaughter a piece of art each year rather than “some electronic game or gadget that she will be bored with in a month. She

may not understand it now, but those gifts will hold and increase in value,” he notes.

Koch is on the Aging Waiver and receives 13 hours of services per day. He lives in his own home and still spends part of his time serving as an advocate with the Governor’s Advisory Committee working on home-modification issues. We spoke about the Supreme Court’s Olmstead decision that people with disabilities have the right to choose to live in the least restrictive environment.

“People want to be part of something. In your own home, you can get out and meet people, be a part of the life of your community,” states Wayne. “Boredom keeps me going. I cannot just sit. I’ve got to be active, involved, doing something.

“It’s important that civil rights laws concerning least restrictive environment be enforced. It saves taxpayers money and people who think they can’t contribute to society find out they can. If you give people the opportunity to live outside of an institution, they can give something back – in community service. Then you meet all kinds of people and then if you need something, there is usually someone from your network who might know the answer or have what you need.”

Ms. Kreutzer, who is 69, transitioned from a nursing home and works with the Pennsylvania Association of Area Agencies as well as the Community Living Advisory Committee. Because of her experience, she is committed to helping Pennsylvanians learn their options so they can avoid or transition out of nursing homes. She states that there is not much in the way of solid information for people around the Emmaus area.

Sandra lived in nursing homes after a stroke. Now she uses a wheelchair and gets Personal Care Assistance (PCA) services 35 hours a week through the Aging Waiver.

“I’m so glad for my personal care assistant. Things work well between us. The state has something called hour boxes where everything is supposed to be done at a certain time on a certain day. That is causing problems for us but we work around it.”

When her stroke occurred in 2002, she was living in Oregon. Her children had her moved to a hospital and then nursing homes in the Allentown area.

“I’ve seen photos of me in the hospital in Oregon and boy, do I look angry. I have a little memory of that time. I remember deciding that nothing is going to get me down,” says Ms. Kreutzer. “I have vivid memories of conversations with my sons, but my son said I couldn’t talk.”

“The first home they found for me was in Coopersburg. First of all, because I was in a wheelchair, they thought it affected my mind. By that



time I had comprehension and some memory back.”

“I worked my way up to President of the Resident’s Council. All nursing homes are supposed to have them,” she recalls. “I started a Red Hat Club.”

“I was given a number of a Center for Independent Living (CIL). I called a few times and a woman and man from there came to visit. Both had disabilities but were not wheelchair users. We went out to lunch and they gave me more numbers for staff at the CIL. A person came who was a wheelchair user and brought me here to see this building.”

“That was November 2004. I was still in that nursing home but now I had something important: hope.”

“Nothing happened and then still nothing happened. Finally someone from the nursing home evaluation committee asked if there was anything they could do for me...” “I said get me out of here”. Within a week and a half I had this apartment,” smiles Ms. Kreutzer. “The other thing that is

Sandra Kreutzer

very important for people to know is that they have to ask for help. And keep asking for it. I tell people who have trouble asking for help to remember three things to say: I’m sorry. I love you. Help me.”

Sandra Kreutzer enjoys her life. She loves trying different foods and is a music aficionado. Prior to her stroke, she sang and played the violin. Now she loves listening to music. She also uses her computer for work and leisure activities. Clearly, she is one active citizen.

“I got a second chance. I could have died or been unable to think or communicate. Now I’m on five committees,” concludes Ms. Kreutzer.



Judith Lieberman

Judith Lieberman is a 90-year-old bundle of energy and life. She is small with gray hair and eyes that miss nothing. She is well turned out in a gold dress. And she has a pet peeve. “People in this building complain about everything, but they are not willing to do anything about it.”

At age 90, Ms. Lieberman is still an activist. She’s in the state’s LIFE program. She is chair of the Lehigh County TRIAD program and on the Area Agencies Advisory Board on Aging. She is also a cancer survivor who volunteers at medical facilities.

Judith Lieberman has lived in her current apartment for eight years. She was living in Allentown and got stuck in her bathtub. Her children said she needed a safer place to live and found the senior housing building. Judith has four children.

“I’ll be 90 this year and don’t need a personal care assistant.” Ms. Lieberman is animated, almost crowing about her age and independence.

“I moved from Virginia to Allentown seven years ago. I educate elderly people about what’s available to them. Now I’m starting Project Lifesaver, which can be used to track people with dementia so they don’t get lost. They used it in Fairfax County, Virginia, for people who wonder because neurologic disorders.”

“I had a full career before retirement. I graduated from a teachers college I always wanted to be a doctor but I had three brothers and there was no money to send me to school. Teachers College was free,” Judith explains.

“But there was always something about the medical field that I liked. After I married, I followed my husband all over. We were living in Maine when the evacuees from D-day came there. I volunteered in medical facilities and they were in very bad shape. Local citizens, mainly wives, arranged for them to get fruit and milk.”

“I like being an activist. I’m a stomach cancer survivor. First I got involved with the Cancer Society. Then and there, I decided I would fight for myself and people like me. They gave me a Woman of the Year Award. The audience was quite surprised when I said I was doing all this work for myself and everybody like me. But that’s what it is about. That’s what motivates people to create change and make the world better.”



Dolores Liddle

We visited Dolores Liddle after her Bible study at the Bellmoude where she lives. She's a wheelchair user and not shy about airing her opinions. During the study, the group began discussing health care reform. Ms. Liddle thought state and federal spending priorities were out of whack. "It costs more to send a person to prison than sending a child to Yale," she said to the largely conservative members of her group.

The Bellmoude is a large low-income building for seniors and a few younger people with disabilities. Ms. Liddle moved there after several years in a nursing home.

"I was in 11 different institutions. I'm so glad to have my life back and my independence. I can get up when I want, eat when I want, visit with friends and do the Bible study. It's a world of difference," says Dolores Liddle.

"I wrote to Governor Rendell and he referred me to the Department of Aging. The letter I wrote was simple. I said 'I need help.' If there is help available to me, I need to know. I wish I would have known before I had to sell my house. But I did get help. They evaluated me and I have eight hours of help per day, four in the morning and four in the evening."

Ms. Liddle likes to stay active. **"A person can get around pretty well in a wheelchair. You can do what you want. I like nature and flowers and I can get out to see them. I have a full life."**



Jon McFarland

Jon McFarland is a 48-year-old man with spina bifida and a cognitive impairment. He's been attending the Life Enrichment day program at a Lancaster church for 16 years. He lives with his mother. We had a short interview with Jon because a class was about to begin and he wanted to attend.

“I have an attendant that comes in the morning and at night and my mom does everything else,” Jon explains. He is on the OBRA Waiver.

“I like sports, talking to people and reading the newspaper. I like going places. Here at the adult enrichment, I take two classes a day, four days a week. Every other Wednesday we go into the community to places like the

shopping mall or restaurants. Then once a month we have an outing to someplace like the Baltimore aquarium or to visit the Capitol in Harrisburg.”

We asked Jon his opinion about where he would prefer to live and receive the services he needs. **“It’s a lot better to live at home than in a nursing home because the surroundings are better and you can do stuff on your own. Some of the participants here at adult enrichment even live on their own.”**

Mr. Merkins is a 37-year-old man with C-4 complete spinal cord injury who lives Philadelphia. Inglis Foundation has a housing complex of apartments for wheelchair riders. John Merkins likes living at the complex.

“I speak to high schools and different places to try and let young people know they’re not immortal. That what happened to me could happen to them.”

When he was 16, John was diagnosed with bone cancer, which spread to his lungs. In December of 1996, he had gone through chemo and all other recommended treatment and been pronounced cured of the cancer.

“In March of 1997, I was out with two buddies. We’d all been drinking and wanted to go to a club. I usually didn’t drink, but I think I had decided to let go and celebrate. I was cured of cancer. It seemed like I had been handed life on a platter. I was not going to drive because I was drunk and so were my two buddies. Another friend came in and he said he’d just gotten off work. We asked if he was all right to drive and he looked at us like we were crazy for asking.”

“About two blocks away he started going 85-90 mph and turned down a narrow side street. We screamed at him to slow down, to stop. The driver started laughing. His brakes locked and the car flipped and slammed into a tree. The roof of the car wrapped around the tree. My body and the tree were pretty much one.”

“The driver ran and left us for dead. My buddy got out and went for help. They got me out with a Jaws of Life.”

“When I woke up, I saw my poor mother and dad looking like they had



John Merkins, Jr.

seen a ghost. I thought, first the cancer and now this. What have I done to my parents?”

“I was 24-years-old when the accident happened. If I had not been drinking, I would have known not to get in that car.”

“I ended up moving into the Inglis House and young guys would come to my room and talk with me. They got me up and around. Finally I got an understanding that I had my mind. It made me realize that I had a life.”

“When I moved into my own place, I wanted to give back to the community. I work a seasonal job with the Phillies in guest services at the ballpark. We have a designated driver program. I also give talks about the dangers of drinking. I also serve as a consumer advocate on the Governor’s Advisory Committee for People with Disabilities. I am one of two Pennsylvania state representatives on the National Participant Network. Because I am so grateful to the Inglis Foundation I serve on their on their Consumer Advisory Committee.” Clearly John’s willingness to share of himself has benefited countless other people.

“Eleven years ago I moved out of the nursing home and into the suburbs –

in a semi-rural area. Transportation was a problem there in a rural area.”

When I moved back to the Inglis Foundation apartment complex in the city I was able to get anywhere. I should have been on the Independent Waiver from the beginning because there is so much more in supports. It pays for home modifications. I can call Inglis for anything and they will help me.

“I try to be as self-sufficient as I can. When I don’t have an aide, I like to be alone. I shop for food. I control my environment with voice activation. If I don’t need someone, I feel more independent. I take a regular bus to and from work along with everyone else. Para-transit makes me feel like I’m taking the short bus.”

“I am still John. I have a mind and can do things. People are so ignorant. They look at me strange. I’m just like you except I can’t walk.” “I realize I can still walk tall just in a different pair of shoes”



Peg Pryse

Peg Pryse is a lovely woman who radiates genuine Southern charm, hospitality, and calm strength. Those traits are bundled into a 5'2" package, accented with stunning white hair and a smile that puts one instantly at ease. She is impeccably dressed in attire that radiates quality. At age 89, she conveys a positive, can-do attitude that makes one want to remain in her presence. Mrs. Pryse holds the position of ombudsman and stays active by doing peer counseling for fellow residents of St. Paul's Villas, an upscale assisted-living facility. On the door of her room hangs a sign noting that a Pennsylvania Empowered Expert Resident (PEER) lives here.

Nine years ago, Peg and her husband lived in their Atlanta home. She woke up one morning and said to her husband, "Henry, we must be having a terrible storm."

"It's 9 a.m. and the sun isn't shining."
"What's the matter with you?" he replied.

"I told Henry it was dark. He took me to a specialist who said, 'You are blind and there is nothing I can do for you.'

"We called my son-in-law, who was the chaplain here at that time. He told us to come to St. Paul's. We sold everything and flew to Cleveland and moved in here. I've never regretted it," says Peg. Her husband died in his sleep two years ago.

"There're some things a person simply cannot live without, but sight is not one of them. The day I lost my vision, I knew that if it was gone for good, I was not going to let it destroy me. And I have not."
Mrs. Pryse speaks in strong, clear

tones. **"I can do just about anything I want if I put my mind to it."**

"I have no complaints about living here. If I need someone or want something, I just push this button." St. Paul's Villas is well staffed.

"I stay busy and I want to be busy," notes Peg. "There are meetings, group discussions about issues here. For example, we are trained to help residents get along without demanding so much attention from the staff. PEER counseling has been wonderful for me. Residents tell me what their problems are and I help them solve them."

Besides her PEER activities, Mrs. Pryse spends time reading books on tape. After she moved to St. Paul's, her son-in-law took a position in Ohio so she rarely sees her daughter. Yet she accepts lack of contact with family in stride and often uses herself as an example when orienting new residents who fear losing contact with their children. "I tell them I never see my daughter and her husband either, but that doesn't stop me. There are so many activities. Why just about anything you want to do, the staff will help you do it."

We met Ron Rambo at Square One Coffee in downtown Lancaster. This progressive hang-out is Ron's favorite. "I come here every day. I like to sit outside when the weather is nice, but there is an entrance in back with a ramp that I can use in the winter." We met Ron with his three Personal Care Assistants: Lou, Brandon, and David. Lou has been with Ron for 20 years and says he's still learning. Brandon has worked for Ron for more than two years and David has been with him for six months.

Ron, 48, has cerebral palsy and speaks with a CP accent. He does not use an augmentative communication device. During our discussion, aides at times have to translate.

He's been on the Independence Waiver for five years. He has a Section 8 rental voucher and had been on the waiting list for five years. "I am in the process of finding my own home through the Section 8 Homeownership Program," explains Ron. "I've had to fight for everything I've gotten. It is really hard to find low-income housing – let alone low-income accessible housing. Many landlords won't accept Section 8 vouchers."

"I use a manual chair because I couldn't get a power chair to work well with head sensors. I'm active. I love living downtown and going to the local farmer's markets. We also go camping a couple times a year and a manual chair is easier to get around in crowds and in the woods," explains



Ron. "At home I use an IMac with an adaptive keyboard and Intellikeys. E-mail and instant message are my favorite ways to communicate."

Ron has dreams and plans for his future. He's been consulting with United Disability Services to explore his housing options. He wants to buy or build a home that could be made entirely wheelchair accessible and outfitted with a ceiling track system. In addition to providing a suitable living space, Ron hopes his property could include a raised bed garden built to wheel chair height and possibly a small gallery space for artists with disabilities to display their work.

"One thing I will miss when I move is my landlady. I was lucky to find a good landlady who's a social worker. She gave me a chance to show I would be a good tenant. It is important that people with disabilities be given the choice to live where they want. I like to go out when I want to. I like to run my own life. I have good friends and like living close to all the things I want to do."

Ron Rambo



Helen Rosiek

Helen Rosiek is 86-years-old and has had low vision all of her life. She is fiercely independent and fought receiving services from the state. She credits Cheryl Poling, a caseworker for the S.W. Area Agency on Aging, for convincing her to go on the Aging Waiver. Her aide comes for three hours per day to assist with bathing, dressing, driving and other activities of daily living.

The day we spoke with Mrs. Rosiek, her daughter-in-law Debbie Cermak, was present along with Cheryl Poling, her case manager.

“I was living in this apartment and was prescribed the wrong medication, which produced the effects of an overdose. I went to the hospital. Cheryl had been talking to me about

the waiver. I knew my vision was getting worse and needed help, but my neighbors had been helping. After the hospital I was still confused so I went into a nursing home for a month. It felt awful in that institution. I cried all the time,” recalls Mrs. Rosiek.

“My daughter-in-law called Cheryl late on a Friday afternoon and told her I was falling apart. Cheryl made arrangements for me to come back home and have the services of an aide. It took her about two hours. I’m used to the security of this building. I’ve lived here 21 years. Here, you are in charge of your own life.

“I love my life. I’m content and happy right here in this chair. I don’t like to be around people. I love being by myself and I’m not lonely. I listen to TV and CDs.”

Life has been far from a cakewalk for Helen Rosiek. “My mother didn’t like me. And because of being legally blind, other kids called me names. My first husband was an alcoholic. I raised six boys and sometimes I had to beg for food,” explains Mrs. Rosiek. “We lived everywhere. In Baltimore, I worked for Social Security. There was a test for the job that 300 people took but only 26 of us passed. Then when I was 50, I remarried. Walter was a wonderful man.”

“It’s wonderful that the Area Agency on Aging has someone like Cheryl”. “This program saved us. I thought I’d have to stay in that institution but Cheryl opened all the doors for us.” Cheryl Poling has since received a promotion, but her supervisor has allowed her to remain as Helen Rosiek’s case manager.

“I would not trade my life now for anything. There is structure. I know my buzzer will ring every day. I’m beautiful on the inside if not the outside. In fact, I’m all dressed up today. Maybe I’ll go out and look for a boyfriend,” jokes Mrs. Rosiek.

Mrs. Rosiek passed away on August 6, 2010. She will be sadly missed.

“She was so happy to share her story. She told of how she loved her life and that without the assistance from Southwestern PA Area Agency on Aging she knew it would not be possible for her to continue to live alone and enjoy all the freedoms of being one of our states many valuable senior citizens.”

“We also went to visit many of mother’s friends who were not as fortunate and had to be placed in nursing homes. After each visit she would comment that she wished each one of them could love their lives as much as she did.”

“In life she made so many valuable contributions to the lives of her family and so many others. She truly was a blessing and an inspiration to all of us who knew her and loved her. She taught me that age did not matter nor did wealth it was the ability to love your life no matter what your circumstances. Your program allowed her to continue to love her life even though blindness claimed her eyes and age caused her to become frail. It is with a grateful heart I thank you for the many programs that permitted her to love her life to the very end.”

Loving submitted by her daughter-in-law, Mrs. Debra Cermak.

This 32-year-old with short brown hair has several tattoos that cover well-muscled forearms. Mr. Snyder sustained a C5-6 spinal cord injury in a diving accident in 2005. He lives in Kaen, however we met at Harmsville South institution in Pittsburgh. Joe and his team were using the gym for their last quad rugby practice before traveling to upcoming playoffs. Wheelchair rugby is sort of like playing bumper cars but with less protection.

Joe says, “I love rugby. I get to travel and I’ve made great friends. I’ve actually learned a lot more from my team members about living with a spinal cord injury than I learned in rehab.”

He was working in Myrtle Beach, South Carolina, as a lumber grader determiner when his injury occurred. Because Joe was from Pennsylvania and had family in Kaen, he was flown home, then went through a short, three-month rehabilitation at HealthSouth.

“When they sent me home from HealthSouth it was with no equipment. They told me I could do everything from bed. Because of cuts in insurance, there is no more quality rehabilitation. You have to find out yourself what’s available to help you do what you want to do,” explains Joe.

“You can keep active. In your first year after injury, you either find the heart and strength to continue or you give up,” he adds.



Joe Snyder

“Having Personal Care Assistance (PCA) services from the state allows me to live an active life. It means everything. Without that, I’d be in bed 24/7. I’m still figuring out what I want to do next. I’d like to go back to school and am looking at what the Office of Vocational Rehabilitation can provide. But I’m worried about school loans. Some guys on the team took out loans, got their degrees and now they can’t find a job.”

Joe is on the Community Resources for Independence (CRI) Waiver program and his mother provides his PCA services. “I am her boss, though,” clarifies Joe. He receives 45 hours of service per week and uses his PCA mostly for his bowel routine, cooking, and laundry.

Physical activity is important to Joe. “If you’re inactive, you have more bowel and bladder problems. Many people with SCI don’t take care of themselves so they develop bedsores, I don’t ever want to go to a nursing home. Now or when I’m old,” insists Joe.



Pat Strenk

We walked into the Souderville Mennonite Church and there in the lobby sat a woman with curly grey hair, two dogs, and a 'Lovey The Clown' sign that tells a snippet of Pat Strenk's story.

Pat had a brain injury and had to learn to walk, talk, drive and live again. With her two rescue therapy dogs, Mya and Zebbie, she helps others through the Acquired Brain Injury Network of Pennsylvania." (The Network is a group Pat helped found in Pennsylvania and she serves on its board of directors.)

In 1990, Pat was driving home after church. At an intersection, a car t-boned the driver's side of her car. "There was no traffic light at that intersection then. Now there is. Every time I see it I think, that's my traffic light."

Mrs. Strenk was in a coma for three weeks. One of her earliest memories

was probably at around six weeks post. Her husband and sister were in the hospital room. "They looked familiar so I felt safe. I didn't know who they were."

"My sister said, 'Robbie's okay.' I questioned who Robbie was. She kept saying he was okay but I wanted to know who he was. He was my son, then 2-and-a-half. He was in the backseat of the car. It took me a few years to tell my sister that I was really asking who Robbie was."

"Lovey the Clown started after I rescued Mya," says Pat. Her dog, Mya, is a medium-size Border Collie/Red Husky mix who is a sweet dog, and strawberry blonde. "She lived with a family that fell in love with a puppy, and bought it spur of the moment while on vacation. She was kept in a crate all day while he went to work. The wife never let her out during the day to train or socialize with. Later I found Zebbie, who is a Shih Tzu. I was at a baby shower in Maryland and he was yapping and yapping behind a garage. I asked if I could see him. He was filthy with matted fur."

"I began working with a pet therapy group. We were in a Halloween parade as clowns and I used to be a seamstress, so I made a clown costume to wear."

I still have the outfit and I've learned about compassionate clowning. These are clowns that go to hospitals and other therapy programs in costume and share compassion with others. I may give that a try one day. I volunteer with Grandview Hospice doing Pet Therapy and am on the Board with the Acquired Brain Injury Network of PA, "Pat explains.

Recovery from BI still continues. I'm 53 now and was 34 at the time of the accident."

"When I was injured, they did not have things like the Commcare

Waiver in place. I received help from OVR. Doctors had suggested four or five therapies for me such as activities of daily living (ADLs), cognitive and physical. My insurance would only cover one, but my husband found a community re-entry program that covered a piece of all these therapies." Insurance coverage was soon exhausted for hospital and rehab.

"I can't do what I used to do, but have found new things that I can do. I found that seeing the smiles on other faces brings joy right back to me.

"When I take Zebbie to hospice visits, it is not just the patients who respond, but other patients, nurses and staff who are positively affected, too. These people don't know I have a brain injury. They think I'm just like anybody else."

"I can live in my home because I have family. Institutions are like prisons. Like the conditions these dogs were in when I rescued them. Mya was in a little crate all day which she outgrew. It's just like people that are warehouse." Pat is referring to the recent dedication of the Pennhurst Historical Marker where she was present.

"These are things available today to help people stay in their homes that weren't available to me. I don't understand all the services, but I know they're out there. The doctors should tell people what options are available to them. Patients with BI aren't given hope and they need to be informed of that. They can improve. They can have a life."

"I hope this work you're doing, this interview, can reach out to others with brain injuries to understand that they're not stuck where they are. They can move on."

Ed Viadock lives in a large, secure, subsidized apartment building with his tortoise shell cat, who is tuned to Ed's every move. His 35 years in the mining industry left him with COPD, and he has advanced diabetes. While he can walk around his small apartment, he uses a power wheelchair for longer journeys.

He receives six hours a day of services through the Department of Aging Waiver Program. "Aging finds and hires my girls (Personal Care Assistants) for me. There are four: Michelle, Michelle 2, Chrissie, and Ashley. All of them are very good. "They come in the morning and help me. They shop, cook for me and clean up. I don't need them at night. I'm still independent."

Mr. Viadock also served 49 years as a volunteer fireman with Excelsior Duryea Hall Ladder 963.

He is a large, stocky man and it's not hard to imagine Ed's strength as a fireman or operator of heavy equipment in the strip mines.

I notice he often uses a plural pronoun and finally ask who he means when he says "we."

"That's Pennsylvania coal mining country talk. We have a certain way of speaking that's almost its own language. One guy was at a bar in Paris and the barkeep told him he bet he was from coal country in Pennsylvania," says Mr. Viadock. "He could identify that coal mining talk."



Ed Viadock

"I've strip mined from Pennsylvania to Alaska, worked in Alaska when it was 65 below and that is a little chilly," Ed says. "I've run a drag line and all kinds of heavy equipment. If you name it, I've run it."

I notice that Ed's walls are adorned with pictures of wolves and sled dogs. He spends much of his day working at his computer. He is a veritable library on the history of mining, with an emphasis on Pennsylvania.

"I know most all of the amazing history of mining around these parts. I'd like to write a book about it for children. They should know what children went through then and how much easier life is for them now," Ed says. **"These girls (PCAs) that come help me are learning the computer. They all love to learn. I've taught them to cook, too,"** explains Ed. **"Hey they even appreciate my collection of music from the 60s, 70s, and 80s."**

After listening to even a slice of Ed's encyclopedic knowledge, one hopes he completes that book.



Gary and Donna Wood

Gary and Donna Wood were an industrious couple working to improve their home and surroundings and create their dream of life in retirement when their world went topsy-turvy. In 2006, Mr. Wood got a light scratch on his leg while working one weekend on that retirement dream home in the woods. The scratch, which seemed so minor it needed no attention, became infected with staphylococcus (staph) bacteria and he nearly died. Mr. Wood was left a wheelchair user with paraplegia.

Donna Wood is now his full-time caregiver, supporting the family from the profits of a hair salon in her home.

While the story of Gary and Donna is more dramatic than many where one member of the couple acquires a disability, it's reflective of struggles that occur when the nondisabled spouse has to assume all caretaking and financial support.

Gary has difficulty speaking and asked Donna to answer interview questions. "You tell it better," he said, eyes locked on his wife.

"It was just a blood blister," explains Donna. "Then he was in intensive care for six weeks.

"We have a place in the mountains. Our goal was to sell our house and build a place there. Gary came home complaining of pain and our doctor said it was from a previous injury," Donna begins Gary's story. "When I got home from work, he was in agony and Gary is one of those people that never goes to a doctor unless he's half dead. Somehow I got him to the top of the hill and he started having seizures. When we got to the hospital, they said it was a four-hour wait. I said he wouldn't live for four hours.

"They put him on life support as the staph ate his spine away and formed huge abscesses. Six months later he had a colostomy, a super pubic

catheter and could not walk. He's had physical therapy but there is so much nerve damage there is not much that can be done.

"After six months, we ran out of insurance.

"I wanted Gary at home so I turned the living room into his bedroom. We made the porch accessible so he can come out here when it's warm and go down to my shop when I'm working. I used our retirement money to make the home accessible for him.

"Now we have to plan everything. I have had one day off since Gary got sick. You have to anticipate everything."

Gary enters the conversation. **"I am so afraid of Donna getting sick or something happening to her. If she goes into a hospital, I'd have to go to a nursing home,"** he notes. **Clearly that prospect looms large and terrifying.**

Donna explains that there may be some bright spots in the future. "We gave the land to our daughter and her husband. Our son-in-law is building Gary's cabin. It's all wheelchair accessible and there are windows on every wall."

Brian Woods, 52, has led one of the most difficult lives many of us could imagine – yet there is not one iota of him, no ounce of his soul or heart that says, “poor me.” Instead of a victim, one meets an upbeat man who lives in his own apartment in a building filled with friends. Brian Woods has been an artist since he was 10 but “it never got off the ground until I was 13.” He sculpts miniatures from modeling clay.

Mr. Woods was born with spina bifida, and a stroke in 2009 left him with some brain injury. He uses a personal care assistant four hours a day, six days a week through an OLTJ waiver program.

“My family did not believe I could live on my own. They put me down like salt and pepper having a fight,” explains Brian.

From age 5-10, Brian was in a rehab facility to teach him to walk. His doctor told his parents that he would receive services and rehabilitation there. “My parents finally came for me when I was 10.” He began using art as his means of keeping a centered and positive outlook.

Brian kept telling his family that he could not live there with “all the fighting.” One day his mother opened the door and threw his wheelchair onto the front lawn. When I went out to get it, she told me never to come back – that I was no longer part of them and locked the door.”

Brian was homeless. He slept under garages, sometimes near hospitals. One day a nurse who had treated him before brought him inside Allegheny Hospital. He was ill with pneumonia and was treated. Hospital staff had no idea where to house him after release so he continued to live on the streets. He slept in an alley in a cardboard box and was attacked a few times.



Brian Woods

He was in downtown Pittsburgh around the corner from Three Rivers Stadium when a teenager in a group asked him for the time. He started to look at his watch and they all attacked him, beat him, stabbed him, and left him for dead. All six are now imprisoned, serving life without the possibility of parole.

Many people would have given up if they experienced what Brian endured. Yet he fought his way back from an abusive childhood, homelessness, the attacks, and maintains a positive life outlook as he continues to create his artistic miniatures.

“If you don’t have an upbeat attitude,” explains Brian, “you don’t have much of a life. Now I have so many friends in this building. When I had the stroke they heard about it, sent cards and visited me while I relearned how to read and write. It was wonderful to see how many people cared.”

Brian was married for several years and adopted his wife’s children. Brian is now in a long term relationship with a very caring partner named Katie Mozeyko.

“I go forward. I don’t let things get me down. Now I enjoy playing bingo and other games and having dinner with friends.”

“Art has been my life. I’ve written poetry and am now writing stories that I hope will be published.”

We spoke about what makes his independent life possible. He had rave reviews for his care provider, Christian Hills. “Without her help and the waiver program, I could not do any of this,” he says. Brian has personal care assistant services four hours per day except Saturdays.

“Often parents and the society tried to take self esteem away from people with disabilities. We should have the supports to live like everyone else – like a human being. We bleed. We breathe. We are like everyone else.”

The stroke in October 2009 left him with no feeling in his hands. “I was lucky. I can still write and sculpt. As long as I have art, I have life. Thank God I am living. I have a high quality of life,” Brian concludes.

Acknowledgments

Tom
Olin

Janine
Bertram
Kemp

Sarah
Galbraith

We would like to thank several individuals for their extraordinary work on this project. Their sensitivity and compassion created an environment of trust, enabling our stars to openly share their very personal stories. Without this openness, the stories that unfolded would not have been as inspiring or engaging. It is their strength, courage and love of life portrayed in these oral histories that will serve to encourage others to find in themselves the confidence to explore alternatives to live their lives with dignity, independence in accordance with their values.

Photographer, Tom Olin and writer, Janine Bertram Kemp, have disabilities, themselves, and have been working with other people with disabilities since 1985. Tom is the only photojournalist to have documented, in photos, the history of the disability rights movement since 1985. His deep understanding of our participants is reflected in his photographs. Both Tom and Janine are well known in the national disability movement. Tom's photos have been displayed at the Smithsonian, at the United Nations

and are in many books and papers on disability and in many Centers for Independent Living around the country.

Janine has been an advocacy leader for people with disabilities for many years. Using her knowledge, passion and sensitivity, her work has resulted in accomplishments that have benefited individuals as well as the disability movement as a whole.

Sarah Galbraith, Meeting Well LLC, coordinated the project. Like Tom and Janine she also has a disability and has been working with others with disabilities in Pennsylvania since 1992. She plans conferences and coordinates logistics for projects such as this one.

On behalf of the Pennsylvania Department of Aging and Office of Long-Term Living our sincere thanks and gratitude to these amazing professionals for the undertaking of the Oral History and Photo Project: A celebration in Tribute to the Stars.