

Out of Institution & You're Home

Success Stories
1969 – 1999

Speaking For Ourselves
Plymouth Meeting, PA
www.speaking.org

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Dedication

We dedicate these Stories to the people who died in institutions and the 2,100 people still living in State institutions waiting to be free and live in the community.

We offer a special memory to Patti Summers (1955-2000) for her dedication and belief in people living independently in the community.

Acknowledgement

We thank all the people who shared their stories with us and the public so that others may be freed.

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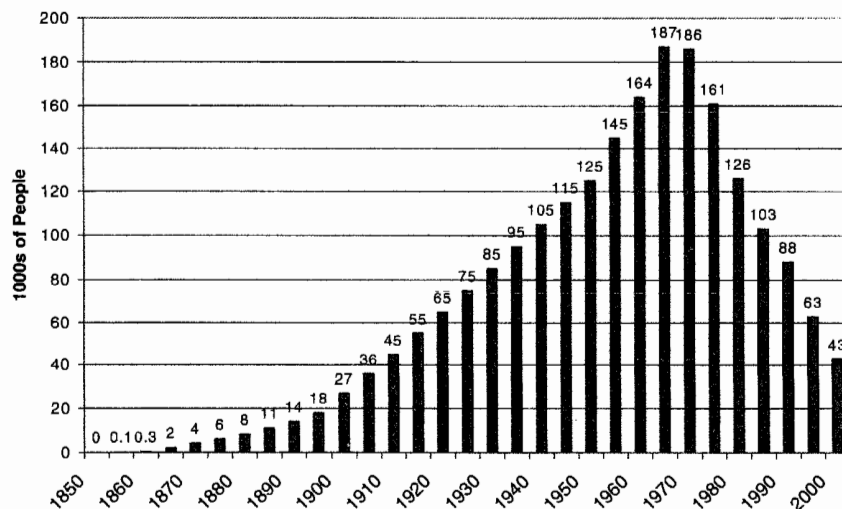
Introduction

By James W. Conroy, Ph.D.

This brief book captures the essence of one of the most important social movements of the last 50 years: getting people with mental retardation and other developmental disabilities out of institutions. I find it strange that so few citizens know about this dramatic achievement in America. Perhaps it is a function of the media, so willing to publish bad news, and so reluctant to publish good news. My 30 years of research in this field leads me to conclude that this “deinstitutionalization” of people with mental retardation and developmental disabilities is the most successful social program of my generation.

This graph shows how many American citizens lived in public institutions since 1850.

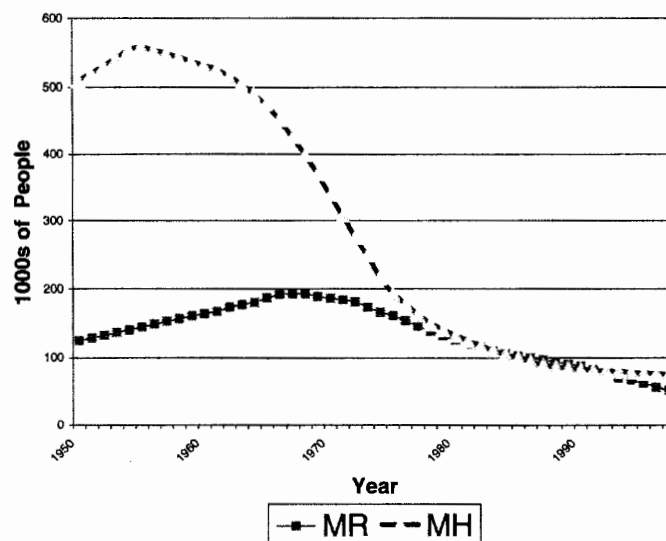
**Number of People With Mental Retardation and
Other Developmental Disabilities In Public Institutions, 1850-2000**



The United States reached its peak of institutionalization in 1969, at nearly 190,000 people. Since then, more than 100,000 people have moved out, and have gone into family-like homes in regular neighborhoods. Many more thousands never “needed” to go into such places, because options became available in the community.

Although the graph makes it look as though deinstitutionalization happened quickly, the contrast to deinstitutionalization of people with mental illness is remarkable.

Deinstitutionalization Compared: Mental Health Versus Mental Retardation



The idea of placing people into segregated, isolated, large scale settings was brought from Germany to America by Samuel Gridley Howe in 1850. As a result of Howe’s advocacy, several institutions were built in the following decade. However, by 1866, just 16 years

later, Howe said this in a speech at the cornerstone ceremony of an institution for people with visual impairments in New York state:

All great establishments in the nature of boarding schools, where the sexes must be separated; where there must be boarding in common, and sleeping in congregate dormitories; where there must be routine, and formality, and restraint, and repression of individuality; where the charms and refining influences of the true family relation cannot be had, ... **all such institutions are unnatural, undesirable, and very liable to abuse. We should have as few of them as is possible, and those few should be kept as small as possible.**

Research has repeatedly shown, over the last 30 years, that people with the most significant disabilities tend to benefit the most from the change from institution to community. This may at first seem strange, but thinking about it, who would we expect to benefit the most from individual, personal attention? Of course, it is those with the most intense needs for support.

Now, in 1999, we have eight states that have completely renounced public institutions as an option in their support systems for people with developmental disabilities. These eight states (New Hampshire, New Mexico, Vermont, West Virginia, Rhode Island, Maine, Alaska and Hawaii) have shown the rest of America that it is both possible and desirable to do away with these large congregate care settings, perhaps gradually and carefully, but certainly as soon as is humanly possible.

The Stories



Larry Angstadt

*"I dreamed many things.
I have a CHOICE!"*

I lived in an institution for 17 years in Hamburg. There were many other people with disabilities living there. In 1989 I moved to a home of my own to live with two other men. At first I was afraid because I didn't know the people, the place or what life would be like. I was also excited about the newness.

I dreamed many things. I have a CHOICE! I can see my mother and friends on weekends or when they come to my home I show them my own room and my own TV.

I can go shopping, go to the movies or sports events. I can help cook dinner which I like—being part of life! I go to workshop everyday where I see friends make crafts, go shopping or on picnics. My nephew visited me at the workshop because he was close. Staff care a lot about me and I have learned to say how I feel. I have learned to trust that I will be heard. My life in the community is like everyone else's with a little help from my friends.

My dream is to learn to have a job with regular pay, to make friends who will appreciate me despite my different abilities as I appreciate them despite their different abilities (ie. tall, short, skinny, plump) he he!



Ron Brown

*"They told me I would not
make it in the outside."*

I was thirteen when I moved to Polk. They told me I would not make it in the outside. I have been out of Polk for 20 years now. I testified at the hearings to close Polk. It was very hard for me to go back there to testify. Now I can do whatever I want.

I have interviewed staff for my group home. I am an officer in the On Our Own group. I ride around my city on my own. I travel to Florida. I visit with my family. I want to see all institutions close.



Luann Carter

*“Out of Institution
and you’re home.”*

Out of Institution and you’re home. I came to Elwyn near the middle of the year in 1960 and I left in 1976. Then I started to live in a group home. Then living Community Arrangements before I got in Supported Living Program which is my new life which I am more willing to share to my friends and others who might be interested.

For being a role model I deeply feel that this can be a great learning experience such as: to have a safe place to call your own, being free by going anywhere you want, to be near by places, to make your health arrangements, public transportation, getting a job, and having your own checking account. There is a very important thing I have learned as well in the year of 1994, to be careful by crossing the highway.



Rudy Cranarich

*"If you get a chance to get out,
take it and don't look back!"*

I am 67 years old and my name is Rudy Cranarich. I was placed in a state institution (Polk) when I was 7 years old. My roommate John and I have been best friends ever since. We are inseparable. We are both the same age but John has no known family life like I do. Whenever my family visited me, they visited John too and brought him presents for the holidays just like they brought me.

I have four brothers (one dead) and a sister. We were all born in Cambria County. In 1988, my brother helped me get out of Polk and into a group home here in Cambria County. I wouldn't go without my buddy John however, so my brother helped him get out too.

John and I will always live together. We're like brothers. We share our group home with another fellow. John and I are both in wheelchairs but we can manage our chairs independently around the house. Our housemate can walk with some assistance.

With help from staff, we do many things together in the community. We especially enjoy going shopping and to McDonalds for hot apple pie. This summer we plan to go on a vacation fishing trip with our staff.

What would I say to those people who are still in an institution?

“Don’t be afraid of moving out into the community. I know that I was afraid at first. But, I took a chance. Now I find that I have more freedom in everything. Group Homes are a good place to live in and there are many caring, loving staff people who will help you.

I wouldn’t go back for anything. If you get the chance to get out—take it and don’t look back!



Mark Felix

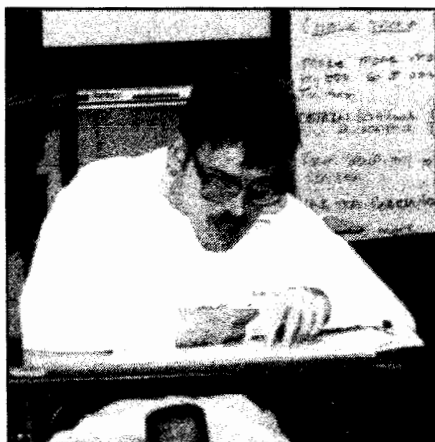
*"I work in a workshop
but want a regular job."*

I used to live at Pennhurst, but now I live in a community living arrangement in Norristown.

We need to close the institutions and we need more freedom in the State of Pennsylvania without taxes. We need more children without welfare. For spending money to raise taxes again.

We need more jobs. I work in a workshop but want a regular job. Wall Street closed because they lost money. Without jobs we need more money. We are short on the Stock Market in the United States of America.

People need to understand we need more education for everyone to achieve the American Dream.



Rob Gorman

*"I am happy that we can
make our own decisions."*

I got out of Pennhurst Institution. I am very happy living in my home in Collegeville. I want to go to a different workshop: Helping Hands. I am learning to brush my teeth by myself. I am happy that we can make our own decisions. I am very happy living in a group home.



Meg Greenwood

"Then I moved to a half way house in Philadelphia."

I was in Elwyn Institution for six and a half years from 1970 – 1977. Then I moved to a half way house in Philadelphia. The next home was in a group home. The new home I am living in is in Collegeville. I am very happy. I have been dating Rick for twelve years.



Carole Iannuzzi

"I feel everyone on earth has a right to live where they want to live."

My husband, Jerome Iannuzzi said, tomorrow is my wedding anniversary. We've been married four years. You people don't know what it's like to be in an institution. When I was three years old, I was taken from my family. My family didn't have a choice. They didn't have the money. I grew up in Elwyn for 23 years and in plain words, they ain't no damn good.

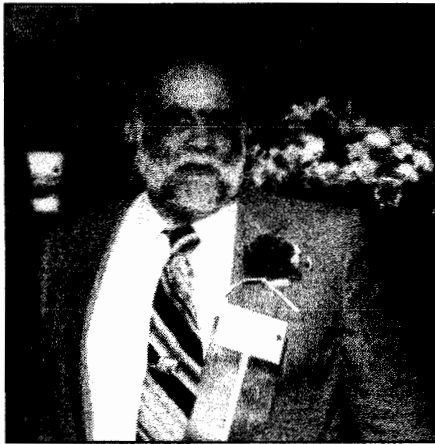
I feel that everybody on earth has a right to live where they want to live, not in an institution. I feel every time people mention the word retarded, I get very angry because I hate that word. They should use the word disabled. I had to fight to get a ride here tonight but when I believe in something, I do it. I wrote a story about my life and it's difficult to read.

I feel all institutions should be closed for good. I wish that families and government officials could be in an institution to see how it is for themselves. Maybe someone could come out and talk with me because I lived in three of them and I can tell them how it was. They were no fun to be in. When I was two years old, my doctor examined me and did not expect me to live. I kept going back and forth to doctors. My parents did without many things because of the medical bills. I walked into the table and they found out I had a tumor on my

brain and my parents had to pull me away. I had water on the brain and a tumor pressing against my nerves. They had to take it out using needles. I thought I was going insane. I went under a bull and my parents were looking for me and I was in the feeding trough. The bull wouldn't let anyone get near me.

They put me in an institution. My grandfather wanted me but my Mom said no. When I went to the institution they told my parents they would teach me reading, writing and arithmetic but they did not teach me anything. When they left me alone in a classroom and a couple of boys got a hold of me and raped me. When my Mom left, the other kids beat me up. When you have an accident they would make you kneel on the floor and put your hands out and put the dirty panties over your face. Every time my Mom would come to see me she could see marks. When she would say something, I would get beat up and put in the locked side room. Every five minutes I was in the side room. My parents couldn't visit me. This happened to me before I got married.

I could tell you about three institutions I lived in; Elwyn, Pennhurst, and Woodhaven. I really feel that I was left out in the cold, because people called me names and labeled me retarded. I wish people would refer to us as disabled. I hope you will understand what I am saying and apply it in policy. I've had a very difficult life. I think that people who receive services like Medicaid, Medical Assistance, SSI, and Social Security should stay on it.



Jerome Iannuzzi

"You have to try to do it."

"What am I doing in this place?" the bewildered boy of 13 asked himself. "What am I doing in this place?" asked the bitter man of 29, still penned up in the institution he called prison: Pennhurst State School and Hospital in Spring City, Pennsylvania.

Now, 19 years later, I am an independent and successful man, a member of the Developmental Disabilities Council of Pennsylvania, on the Board of Directors of the organization, Speaking For Ourselves, public speaker, experienced traveler, and perhaps most important, a proud man.

When I was 13, my parents decided their lives would be better if I was cared for in an institution. Although an aunt and uncle wanted to adopt me, the judge said no, and I was committed to Pennhurst. Today, I wish families and the government could be institutionalized and see how it feels for themselves.

And so the years trickled slowly by, until 1969, when Pennhurst became crowded beyond its capacity and the decision was made to release the "brightest patients". I credit my freedom to hospital psychologist, Dr. James Hersh, who helped me get out with the proviso of "good conduct".

However, with no preparation for living on the outside, scared and

friendless, I bumped around from pillar to post, with support only from my aunt and uncle, who reassured me that I was not handicapped and only needed to learn how to get about and take care of my needs. I lived in a succession of boarding homes, and worked for a time as a housekeeper in a hospital, while helping the undertaker on the side, and then in a 7-Eleven as a stock boy until the hours and available transportation back to my home clashed.

Then two things happened which turned my life around. I moved into my own apartment in West Chester under a community living arrangement run by Kelsch Associates, in which I had minimal supervision and twice-weekly caseworker visits. And six years ago I joined Speaking For Ourselves, a group that teaches us to stand up for our rights, do things for ourselves, and go out and speak for ourselves. I was one of its directors.

I decided that the only way things were going to get better was to do something for myself. Now I never depend on my caseworkers to do anything. I do it on my own and she tells me that if everyone were like me, her job would be very easy. I found further encouragement from the Council. First as a member of its Adult Services Committee for the past two years, and then as a full Council member appointed by the Governor of Pennsylvania.

Although I was extremely nervous the first time I tried it, I became a speaker, and took part in conferences in such places as Temple University in Philadelphia; Princeton, New Jersey; Stanford, Connecticut; and Toronto, Canada. In the process, I became something of an expert on travel, whether by bus, train or car, and on choice of routes and where to stay.

The only way to learn is to do it yourself. I also became a travel

guide for others of heart. You have to try to do it, is my motto.

I also took part in a Coatesville based radio program to talk about Pennhurst. All the institutions should be closed. The more I talk about them the angrier I get. Until the last one is closed down there will be nothing but problems. I feel strongly that government officials should go to talk to people and to check living conditions for themselves.

Helping others is an important part of my life. I enjoy bowling but mainly because you can meet all sorts of different people and talk — just sit down and talk and help each other out. I also enjoy baseball, football, boxing, and wrestling.

And, unlike the old days, I'm proud of myself because I can do things. But, I have a goal of taking on more responsibility to show people that I can do the job, and to show other people with disabilities that they can learn too.



Carl Kieseewetter

"I'm working toward my yellow stripe in karate class."

Hi! I'm Carl Kieseewetter and this is my success story. I was placed in Cresson State School when I was about 9 years old because of family problems. I had the opportunity of going home for regular family visits but I was unhappy about returning to the Center each time. My father managed to calm me down, but I always wanted to return to live with my family at home.

I was placed in the Cottage Program for the last year of my residency at the school and it was much better. I enjoyed many privileges that most of the others in the dorms didn't have and I learned a lot in that program. But still I wasn't very happy. Finally, in 1973, my father got me out of there and brought me back home to live with my family.

I completed my schooling and graduated from my high school's special education classes in 1982. I had begun some vocational job training during my school years. I've held several jobs since then, ranging from janitorial work through food services. This includes a job at a car wash, where I worked for a number of years until my knees and ankles began to give me problems and I had to quit.

But the real successful part of my story began when I finally got

to move into my own apartment in 1995. With a little help from my family and supportive services, I am living independently. I've held a part time job as a janitor in the building I live in for a year and a half and I work at Burger King. I'm a community volunteer and I serve as an usher every Sunday at my neighborhood church. I'm active in Special Olympics and in bowling. I'm working toward my first yellow stripe in my karate class. I really love my life and my new found independence in my own apartment.



John Lech

*"The whole family has adopted
me too."*

My name is John Lech. I'm 67 years old. In June 1988 I was transferred from Polk to a community group home in Cambria County. I have no known living relatives but thanks to a family member of my roommate, I was able to leave the institution when my friend Rudy did. We had been roommates since we were both 7 years old. His family shared holidays and visits with me for all those years and after Rudy's parents died, his brother wanted to move him back to Cambria County where most of them still lived. Rudy didn't want to go without me and I didn't want to see him go. We had become very supportive of each other and we were like brothers. So Rudy's brother got me out too and we moved to the same group home together.

Now, Rudy goes home to visit his family twice each month and some holidays and I've "adopted" a family of my own. It's the family of one of my prior staff people. The whole family has adopted me too. I visit them twice every month and on holidays. I have brothers, sisters, aunts, uncles, cousins, and a mom (dad passed away a few years ago). I spend one weekend each summer with my new family and when I visit, many of them come to Mom's to see me. Mom spoils me rotten but I really love the attention.

This summer Rudy and I and our housemate will be going on a

fishing trip with our staff. I'm very happy to be living in a group home. You should see all the boxes of stuff that I've collected over the past ten years from my family members. I'm very proud of my own room and possessions that I've acquired and I have the pictures to prove that—hundreds of them!!!



Donna Lonesky

*"Some of our friends say we are
like the three musketeers;
one for all and all for one."*

I'm 53 years of age and my name is Donna Lonesky. I am very happy in my life now; I have come a wondrous long way and this is my story. When I was four years old my family placed me Polk State school. I lived in that place for almost 30 years. I met my friend Marsha at that institution. But in 1977, my friend Marsha and I were transferred to the C. Howard Marcy Center in Pittsburgh, Pennsylvania.

We were placed in a program at the center for "intensive rehabilitation" that was designed to teach us how to live in a group home in the community. We were transferred to a group home in Altoona, PA after one year.

We've lived together in several different group homes for a number of years. But about 17 years ago, we moved into the home we are currently living in. This is where we met Herma who became our housemate. The three of us hit it off right from the start. We've been together ever since.

Some of our friends say we are like the three musketeers, "one for all and all for one". Our agency, The Skills Group, is helping us to complete the paper work and all the red tape needed to be done in order for us to become *owners* of the group home we have been living in for the last 17 years. Isn't that great?

I have family that lives in and around the Blair County community and now I am about to become co-owner of the home that I have come to love and to share with my two housemates.

When I was asked if I ever felt like I wanted to return to the place where I lived most of the first thirty years of my life, I was quick to reply, "OH NO! NO WAY!" I love my life and my group home family and staff. I'm very happy.



Marsha Mansell

*"Then we will become Proud
Home Owners together."*

My name is Marsha Mansell. I am 56 years of age. I was born in Windber, Pennsylvania, the daughter of a coal miner. When I was 3 years of age, I was placed in Polk State School. I lived there until 1977 when I was transferred to the C. Howard Marcy State Center located in Pittsburgh, PA. I was a participant in an intensive rehabilitation program at the center. This was a group home type setting designed to prepare the participants for moving out into the community to live. One year later, in 1978, I was referred to Catholic Charities Group Homes Program and I moved into my first real group home in Blair County.

I've lived in several different group homes operated by various agency providers over the past 24 years. But for the last 17 of those years, I've resided with the same two housemates and staff. I have family who keeps in contact with me but they all reside in the state of Virginia. My housemates and long time staff members have become my closest family members to me.

My housemates and I all have jobs in a workshop in Altoona. The Skills Group (the agency that operates the workshop and our group home) has a great Quality Assurance Program (Q.A.P.) and they are helping to make it possible for my housemates and I to purchase the

home we've been living in for the last 17 years. It will be wonderful when all the problems and paperwork have been completed. Then we will become "Proud Home Owners" together. I am very happy and excited about this opportunity and look forward to the day when my dreams of owning our own home finally does come true.



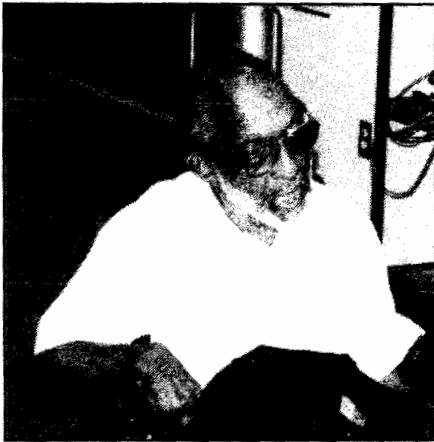
Richard Nilan

"I like to talk about politics and running for office."

When I was a young teenager I was taken to Polk Center by my parents. I took up the clarinet. I was in a Catholic choir. I had a girlfriend in Polk. Her name was Diane. I took her down to the canteen. I got pushed into the wall there. That's when I went to the Barber Center. I lived with my parents. Dr. Barber helped me get out of Polk. When I was at the Barber Center, I worked and made money.

Now I want to move back to Erie. I want to live in a bigger place. I want more money. I want to talk about my rights. People (staff) should not steal from me. I want to be able to have a beer. I want to be back and enjoying the Erie Zoo parade. I want to be in my new group home in Erie instead of Lake City.

I take guitar lessons. I'm an usher in a church. I go horseback riding. I take my girlfriend out to dinner. I like to talk about politics and running for office. I am a member of On Our Own and Faith and Light.



Lester Noch

"I'm 60 years old. I want to be treated like a man."

I'm glad to be out of Pennhurst. My life was better after I got out of Pennhurst. I don't think anybody should stay in an institution. I had a dream many years ago before I got out of Pennhurst. I wanted to get out. I didn't like the way I was getting treated there. If it wasn't for my experience in person centered planning and my friends, I don't know what I would do. They came up with a good idea with person centered planning. I have a job. I have a house. I have a van. I went to Puerto Rico with one of my friends. I used to hire my staff. I changed agencies. Some things are better; some things are worse—I don't hire my staff anymore.

I'm in the choir now. I have a robe and sing with the choir. I used to only sing solos when I wanted to.

I was involved in Speaking for Ourselves for a long time. I have not been able to get to meetings for a while. I'm 60 years old. I want to be treated like a man.



Brigette Scaramozzino

*"I can make it now—
I already have."*

My name is Brigette Scaramozzino and I will be 42 years of age on my next birthday. When I was an infant the doctors diagnosed me with cerebral palsy, a seizure disorder and mental retardation. I can remember bits and pieces of my growing up years. I have been in the hospital a lot since I was little. I had five surgeries as a kid. The doctors told my parents I wasn't going to live more than 11 years old. They were very wrong. Back in the 1960's I had a twin sister die within 24 hours. I am living proof that I am able to do things—just watch me!

I was the oldest member of a family of four children. I lived in Ebensburg for eight years, then my family moved to Altoona. My parents had to wait for one year because I wasn't ready for school. My dad used to take me to see the Carmelite Nuns at the Church, he asked them how can I help my child. They said just give her a lot of love and understanding. That has been done. Since I was small I was 4 pounds when I was born.

I was in Shriner's Hospital when I was about 13 so I could correct some muscles that were stiff. So I went and saw a specialist named Dr. Sand Zane and he was excellent. Because I didn't feel normal it

was hard for me to get used to things and I would cry a lot as a teenager. I was in counseling for eight years, that helped me a lot. My friends kept me on my toes.

I can still hear Dennis say—“You’re pretty, Brigitte”, and we looked at each other and my face got really red. I used to get upset all the time because I was depressed. I gave my friend a hug and it wasn’t easy for anyone. I do a lot of creative writing and I send it as gifts for my friends.

I watched my brothers and sisters grow up and leave home, some to college and some to marriage, but all of them out on their own. I had to be dependent on my family for everything. I felt cheated because I couldn’t do the same thing as my siblings. That is, up until the year of 1995 and that is the year that, with the help of my mother and other family members, “I stepped up and stepped out.” Now with some supportive services and a little help from my family, I live independently in my own apartment. I feel more comfortable, confident, and fulfilled. I’m learning the skills I need to make it on my own. I can make it now—I already have.



Jean Searle

"This story is about a very important person, this little girl is me."

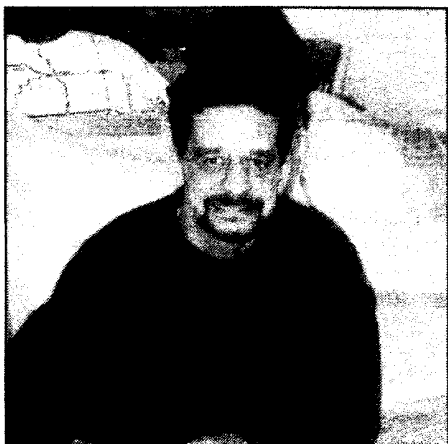
Once upon a time there was a little girl who used to live in an institution with a whole bunch of different people with disabilities. The little girl was so scared to be up there. She didn't know anybody up there. She was a strange little girl in a different place. She had no idea where she was going or who her roommate was going to be—or if she was even going to have one. She was in a place called Allied Services from 1972 to 1984.

This scared little girl wanted to come back home for the holidays, but was not allowed to come down to Philadelphia. The staff had to have to have two months notice before she could even come down home to visit her family and friends. She was not allowed to call her family until she had a note from her supervisor or caseworker. She was only allowed to use the pay telephone for a very short time. Living in an institution was like living in jail. This scared little girl only had one person to talk with and that was her roommate. Until one day, the little girl had company. They asked her if she would like to leave the institution and live in the community.

The reason I am writing this is because our people like me are being put into places where they do not belong. I think ALL institutions are death traps for people with disabilities. I think that all

institutions should close their doors for good instead of leaving them open. I know some friends of mine who used to live, and even some who still live in institutions today and they are no different than me. I wish people with disabilities would have a place to live in their own communities instead of pushing them off into a dead zone. This story is about a very important person, this little girl is me.

I left the institution about thirteen years ago. Now I live in my own apartment and work three part-time jobs. I go to music concerts and I go shopping. I do a lot of traveling. Last year I went to Houston, Texas and to Las Vegas. I could not have done these things if I still lived in an institution. No one should live in an institution.



Frank Sergi

"I've worked so hard to get there."

I was so happy to get out of Woodhaven Center. I lived there a long time. I think it was 6 or 7 years. I lived with a lot of other people and there were arguments and fights. Now I live with three other men who I get along with pretty well. We live in a two story house in Plymouth Meeting. Before I came to Woodhaven I had a job in the community. I always thought about doing that again. I've worked so hard to get there. I work at a local restaurant. I take public transportation by myself. It makes me feel better about myself, plus I make money. My life is going in the right direction.

Note: On July 15, 2000, Frank moved to Palm City, Florida to live with his grandfather and parents.



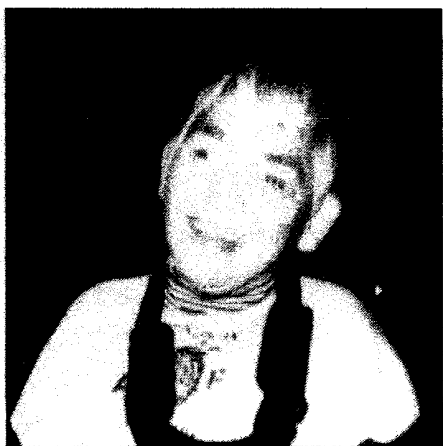
Pauline Smith

*“People who live in institutions
should be able
to live on their own.”*

I lived at Polk for a long time, for about 30 years. Then I moved out of Polk and lived at Coriopolis. I moved to Sycamore Street for two years and then moved to Beechview. All of these places were group homes. I have always had a room mate.

Now I live at Sweetbriar by myself. I will stay there. I am a house keeper there for a long time. I have a good friend; her name is Phyllis. Phyllis helped me to get the job. I like and have many friends at Sweetbriar. Phyllis helps me with my checks and bills. She also takes me shopping. I like going to the movies and I do my own shopping. I like to meet with this group [Speaking For Ourselves]. I do many things on my own.

People who live in institutions should be able to live on their own.



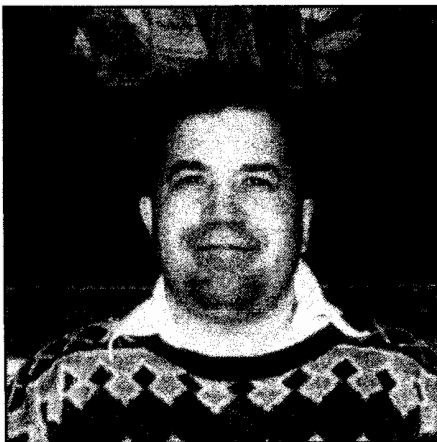
Vivian Smith

"I can make a real good chili."

I am a 53 year old woman and I live in a group home. I am in a wheelchair and have limited use of my arms. I was placed in Polk when I was an infant. But two years ago, my brother got me out of that place and brought me to Blair County to live at this group home. Now, I get the chance to visit with my family members more often. I can have parties and invite my friends to come to dinner or a visit. I love to cook and with a little help from my support staff, I can make a real good chili.

I really like to help people and I enjoy painting pictures and other things. I attend a training facility during the weekdays but there is no "paid work" for me to do just now. I would really like doing that kind of work.

I belong to a support group called Open Doors for the Handicapped and I attend these meetings regularly. I would love to live with my own family but that is not possible just now, so I live with two housemates named John and Doris. Someday maybe I will find a way to have my own place with supportive services and a roommate of my choice. Till then I'm just happy to be out of Polk!



Oscar Vargas

"I would like to see people get on with their life."

My name is Oscar Vargas. I have lived in an institution when I was 12 years old. I did not get the support that I needed. I got out of the institution when I was 21 years old. I got some help at Still Meadow. When I got out of an institution I have been part of Speaking for Ourselves and I have worked in the workshop.

I have been supporting people to get out to do things with their life. People that live in the institution don't have any support that they need. I would like to see people get on with their life. I would like to support others who have disabilities.



Bonnie Whippo

"I have taken many GIANT steps."

My name is Olga Whippo (also known as Bonnie). I live in Altoona, PA. I am 52 years old and this is my story. When I was about 12 years old I began to have a lot of behavior problems while living at home with my family. I was placed in Cresson State School and later on transferred to the Ebensburg Center. I hated the institution and wanted to get out of them. I finally got transferred to a boarding home for people who had behavior problems. It was a farm way out in the country and there were nine of us living there. I was really unhappy with my treatment there. It was worse than the institution.

My case manager helped to get me out of there and into a group home in my home county. I've lived in two group homes since then and there has been a long period of adjustment. With the help of my case manager, support services, and friends I have met along the way, I have taken many GIANT steps and I presently live in my own apartment. I can come and go, eat and sleep, work or play, as I choose—just like everyone else. I have many friends in the building and neighborhood. I don't want to this to change for any reason. I am very happy now.

Closing Remarks

By Justin Dart

I congratulate Debbie Robinson, Mark Friedman and all the members of the Speaking For Ourselves movement.

It is the people of the Speaking For Ourselves, not the astronauts, who are the true pioneers of today. They are not simply moving human beings faster and farther, they are expanding the definition and quality of human being itself.

They have proved that people thought to be physically, mentally and economically hopeless, people warehoused like animals in institutions, could, with simple supports, become productive participants in the mainstream of society.

SUCCESS STORIES detail this beautiful progress, progress that offers solutions for some of the major problems of society.

America today is the greatest nation ever. We have the principles, the knowledge, the money, the productivity and technology to eliminate poverty and discrimination, to create lives of quality for all

our people - with and without disabilities. But on the threshold of the promised land, we are blocked by primitive concepts and primitive politics.

Americans seek a new vision - a forward vision that includes all unconditionally, that guarantees all real choice, real security and the tools they need to be productive, that loves them for their humanity rather than their fashion model bodies and fashion magazine symbols of prestige.

SUCCESS STORIES suggest that vision: a revolution that empowers all. A revolution to establish a culture that focuses the full force of science and free-enterprise democracy on the customized empowerment of each individual - with or without a disability - to achieve full personal potential to govern self - and all, to create a good life for self and for all.

I urge the reader to investigate and to support the Speaking For Ourselves movement. An investment in Speaking For Ourselves is an investment in the future of all human beings.

They Came Back

They Have Something To Say That The Whole World Needs To Hear.

By Robert Perske

They were born with disabilities. All twenty did time in institutions. They know what it means:

to be stared at on the street
to be laughed at
to be told they didn't belong in their neighborhoods
to be taken from their families
to be stripped of their possessions
to be sent to far away institutions
to follow rules there that were as rigid as rocks
and to be herded like sheep

Now they are back and they carry two messages in their hearts that they want the whole world to hear:

No person with a disability belongs in an institution. In their stories they talk about life in institutions known as Altoona, Cressen, Ebensburg, Elwyn, Polk, Woodhaven, and the infamous Pennhurst that has now been closed. They make it plain that they will fight to keep from going back. They speak with passion about their "brothers and sisters" who still live in Pennsylvania institutions. Last spring there

were 2,915 souls in those places. By fall the count was 2,221. They cheer every time the count gets smaller. But they are not cheering alone. For example, great leaders, like Gunnar Dybwad, the leading disability rights activist in the United States and Europe, cheers with them. He concluded that four decades of work improving the living conditions of persons with disabilities has taught us one major lesson: "There is no such thing as a good institution."

Persons with disabilities must fight for self-determination. Of course, they appreciate counseling and support, but they now refuse to let others make decisions for them and try to chart the course of their lives. They have experienced enough of that kind of smothering. That's why they now call themselves *self-advocates*. They seek to change things for themselves for better or for worse. They believe in the *dignity of risk*.

Actually, 150 persons with disabilities wanted to voice these messages. They posted their stories and their photographs on a "story wall" at a rousing Self-Determination Conference in Valley Forge, Pennsylvania, on June 26, 1999. Then in their own way they picked these twenty stories to represent all of them.

These self-advocates remind us of Indian tribes in the late 1800's whose hearts were broken when they were captured and herded into out-of-the-way reservations. When they talked about their situation, their speech was plain but powerful. Sentences were short and often in less-than-perfect English. Quite often one short understated sentence packed volumes of emotions and experiences.

For example, Luann Carter ended her piece with a single sentence: "There is a very important thing I have learned in 1994 which is to be careful crossing the highway." In 1994, Carter, while walking home from her job at a nursing home, was hit by a truck. Her thigh and leg bones were shattered. During the next years she used true grit (another word for self-determination) to move around in a wheel chair. Then she graduated to a walker and crutches. Now she is a vigorous long-stepping, arm-swinging walker again.

Another example, Carole Iannuzzi dictated her story to a person who transcribed it. She was asked to read it at a governmental hearing, but she felt she couldn't do it. Consequently, Nancy Thaler, the Director of Pennsylvania's Mental Retardation Services, read it for her. After Thaler voiced that story in her calm, soft voice, the eyes of many in the audience were wet.

In 1997, when the state investigated Polk Center, Ron Brown, a former resident, used gumption (still another word for self-determination) to serve as a key witness. He had to work hard to speak, but his questioners were patient because what he said about Polk was right on the mark - just like the words in his story.

Native Americans now receive full hearings when they tell how the United States Government used its "manifest destiny" programs to shove them off their land and put them on reservations. We now listen carefully as survivors of the Holocaust tell how Nazi "superman" programs drove them out of their neighborhoods.

Isn't it time to listen - truly listen to institutionalized persons with disabilities as they describe what happened to them?

We sent them away as if they were ugly ducklings. Now they are back with these strong urges for self-determination in their guts. I think they are developing qualities of character that will enable us to see them as swans - whose presence in a good community will make it more beautiful and better.



Roland Johnson (1945-1994) lived in Pennhurst as a child and young adult. He was a freedom fighter. He led the way in opening the doors and fighting for our brothers and sisters to be able to get out of institutions and live in the community. Without Roland's leadership we wouldn't be where we are today.

We have a Campaign For Freedom Web site www.speaking.org where we have published all these Success Stories. Please send us your Success Story so that we can add it to the Web site. Get your story included. Send us your story now. There are instructions and sample Success Story forms on the Web site.

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