

Introduction



The following ten portraits illustrate remarkable examples of human determination and transformation in the lives of people with severe disabilities. These are the stories of people who, in spite of their limitations, have become artists, workers, gospel promoters, entrepreneurs, and community members in ways that have never been imagined until now. These are the stories of members of a quiet revolution who heal the world through their courage to break through the stereotypes and limitations that would otherwise confine them.

Each person has gradually moved away from extreme forms of devaluation, segregation, and low expectations to define their lives anew as contributing members in community life. William, Bernard, and Nina survived more than 20 years each in the now notorious Willowbrook State School. The young people in transition from school have emerged from segregated special education programs that predicted dim adult alternatives.

At some point in their journey, each person was touched by a vision for a different life, and they built a circle of allies to help them work toward the dream. Each person also benefits from new individualized services that enable them to live in their own homes with support, and to work and contribute to community life in their own unique way.

These people with disabilities and/or their parents, advocates, or allies are dynamic and experienced teachers. They are available to speak and consult with others about the art of capacity thinking, and the value of individualized, inclusive lifestyles and supports. Contact information is available for each person.

These ten profiles are only a glimpse of what is happening throughout America as people with disabilities become liberated from old ways of thinking and consequent segregation. My dream is that every person with a disability, their family members, and the people who support them will be touched by the imaginative possibilities demonstrated by these ten people in a way that will inspire new possibilities for all.

Dr. Beth Mount

William Britt



William and some of his work

William is a sixty nine year old accomplished self taught artist. He currently lives on his own in Stony Point, New York in a house with an art studio. He grew up and lived at the Willowbrook State Hospital in Staten Island for thirty four years. As a young boy he was angry and frustrated and was given paints by a doctor at the hospital to express himself. William found solace in painting and has been a prolific artist since that time. He left Willowbrook in 1974 and moved into a group home in Westchester where he continued to further develop his skills as a still life and landscape painter. William has exhibited his painting in galleries and museums and he is also featured in numerous private collections including Nancy Reagan, Mario Como, George Pataki, Prince Charles and the Emperor of Japan. William is also the recipient of numerous awards including the Kennedy Center Award for Outstanding Artistic Achievement.

In his own words, "God gave me the gift of painting when I was young. I like making pictures of nature and landscapes. Autumn is my favorite season to paint. Oil paint is better than acrylic because it doesn't dry too fast. My goal is to sell my paintings and to own my own home."

Selected Exhibition History:

- 2004 The 12th Annual Outsider Art Fair, New York City
- 2003 Pure Vision Arts Exhibition, Credit Suisse First Boston, New York City
- 2003 Art View, Carnegie Institute, Washington, D.C.
- 1985 The Gallery, Westchester Community College
- 1984 National Gallery for the Arts, Washington D.C., New York State Representative
- 1983 "Me and My Imagination," Rockefeller Center, New York
- 1976 New York State Regional "Very Special Arts Festival"

The Joseph P. Kennedy Jr.
Foundation
International Award in Mental
Retardation for Art

William Britt

Fancy a distressed solitude, beyond the grasp of human reason. So far separate the sounds are like the noisome clattering of unwelcome guests, and affection an inexplicable mirage.

Fancy that William Britt lived in such a desolation from the age of five. The magic of puberty and the malestrom of adolescence arrived and departed, leaving him locked behind a door that had no key.

A miracle happened. Divine imagination and human concern reached into that barren otherness and claimed Britt as Special. As Artist. He drew on paper, on wooden boards and finally painted on canvas.

The triumph of William Britt is our triumph. He is telling us our individual stories; Despite the ignorance which imprisons us, and the loneliness of our lives, each of us can be reached and liberated by Divine Imagination and Human concern.

Greetings to the Special Artist who allows us all to be special at his side.



A piece of William's artwork

The art of William Britt is represented by Pure Visions Art Studio in Chelsea, New York. Contact Pam Rogers or Margaret Bodel to learn more about his art, and the work of many other visionary artists. Pure Vision Studio: 212-366-4263



By Maya Angelou
Washington D.C
November 17, 1986

Ken Berg



Ken Berg continues to surprise everyone with his growing capacity to be fully included in community life. His life story and his transition from high school to adult life is an inspiration to all who meet him. He has continually defied the odds, stereotypes and limitations stacked against him.

Ken is a twenty two year old young man, works fulltime at the Adriance Farm in Queens, New York, where he is responsible for the gathering, washing, drying and packaging of eggs produced by the farm hens. In addition to this morning job, Ken assists with many other jobs that are required on a farm throughout the week. Why does this ordinary job seem so extraordinary?



This small part-time volunteer job grew over time into his current full-time employment at the farm. The old images of Ken as a deaf-blind, self-abusive, profoundly cognitively and medically impaired boy have turned into powerful experiences of Ken as a farmer, a worker, and a happy, fulfilled, handsome young man. The tears, fears and nightmares of his parents have paled in comparison to their sense of pride, accomplishment and optimism.

Clara Berg is an international speaker and parent advocate inspiring people world wide to create real worlds for people with severe disabilities, particularly those who are deaf and blind. Ken and his support worker, Ame Mejia, often travel with Clara, and in doing so, help bring Ken's vision to life.

Ken on the farm, taken from the newspaper article on the following pages

Spencer Browne



Spencer's mom, Vaulda Kendall Browne, is an inspiring speaker who talks frankly about inclusion, autism, racism, and risk-taking by sharing her journey with Spencer. Vaulda is a dynamic key-note speaker and is also writing a book for other parents. Contact Vaulda Kendall Browne at: 718-385 -4577

Hi there, I am writing to you from Brooklyn, New York. I am twenty six years old, 6' 3" tall... a really cool guy and reasonably good looking (laugh.)

I live in Brooklyn, New York, still at home with my Mom. She is from South America and my Dad is from West Africa... don't ask me how they managed to get together!

I have a job in the shoe department at K-Mart. Occasionally, I work part time helping my sister with her catering business. I enjoy all kinds of music including jazz, R&B, reggae and latin. Some of my favorite artists are Carl Anderson and Art Porter. I love sports and am quite good at bowling, table tennis and shooting hoops. I also love to dance. Playing Nintendo is one of my past times. Actually, I am a genius at Nintendo! People are still trying to figure out how I got so good!

To those who thought it could never be done, hey! I get around my community quite well, thank you: shopping, going to the barber, the Chinese restaurant, the laundromat and the cleaners. I can also cook a lot of my own food.

My best friend is my little sister, Connie. I call her Boo. She and my mom are my biggest advocates, my loudest voices. They listen to me and believe in me. My other sister, Candace, are cool too, I just don't see as much of her because she lives a really busy New York City lifestyle. Candace is a dancer and an actress.

As a man living with autism, I am most times in my own world. I'm okay there but everyone else seems to want me to join theirs. You might be wondering if I write this by myself... no! My Mom and my sister help speak for me, they wrote this out and helped me type it.

The people who see me as a whole man, not as someone with a disability, are my true friends. These friends can see beyond the label and really get to know and understand me from a capacity view. Those who cannot do that for me are really not welcome in my world.

Cristina Rodriguez



Cristina Rodriguez speaks passionately about her life, her work and her dreams but she would rather send one of her parents, Ramon or Lucia Rodriguez to tell her story, particularly to Spanish-speaking families. Ramon or Lucia Rodriguez can be reached at: 718-329-1938

My name is Cristina Rodriguez. I am twenty one years old.

Until I graduated I was a student and I was in the Pathfinders transition project. I worked Monday through Friday during school at The Jewish Home for the Aging. There I worked in the Guild Care Department helping the residents with their breakfast and lunch. I helped set up tables, and put their food plates on their table. After they've finished eating their meals, I helped by clearing up the tables.

The Spanish-speaking residents seek me out when they need my help. They speak to me in Spanish. I feel very good whenever I am able to help them.

On Saturdays, I also volunteered at the Scheiver Nursing Home in Riversale. There, I helped keep the tables clean in the coffee shop. I took food from the cafeteria counter to the tables for the residents. I also enjoyed talking to them. More about me...

I like music. My parents tell me that I discovered the singer Jewel. I heard and liked her songs before anyone had heard about her. I have all of her CDs including the last one. But the one I like the most is her first CD called "Pieces of You."

I love to travel almost anywhere. I went to a conference in Albany by train. I like trains and city buses. I know about city bus routes. I learned how to travel to many places in the Bronx by bus. I also take the bus from my home in the Bronx to my job in Manhattan.

When I graduated I began working at the Gap clothing store in Manhattan and now I work at Daffy's clothing store on thirty fourth street.

Josh Wolf



Hi, I'm Josh. I live at home with my parents and my sister on the Upper West Side of Manhattan. I am a friendly, funny, outgoing and enthusiastic person! I love sports, dancing, geography and the weather channel.

I graduated from high school a year ago.

I have been in a job training program for the part year to improve my skills as a mail room clerk. I have already been a mail room clerk at my summer camp, and at a local college. I like the mail room, it is fun. I get to look up all the places where the mail comes from, and all the places that it is going.

I love geography. I love to look up places in the Atlas. I am a big fan of the weather channel and I like to find the places discussed on the weather channel.

The mail room job is perfect for me because I learn more about geography. I move around all day and I sort and put things in order, which I love.

After graduation I became employed in a mail room that serves the Goldman Saks Office Complex in lower Manhattan. A person in my Synagogue wrote a recommendation to help me get a job. He remembers my enthusiasm during my Bar Mitzvah.

Yes, you heard me. To the surprise of many people, I completed the requirements for and participated in my Bar Mitzvah at my Synagogue. I memorized many of the songs, prayers, and Hebrew and I sailed through the service! I was so excited because I did so well. It was the first time I ever spoke in front of a lot of people, and everyone was so happy. People said such wonderful things to me. People never cheer during services, but everyone was cheering that day! It was one of the best days of my life!

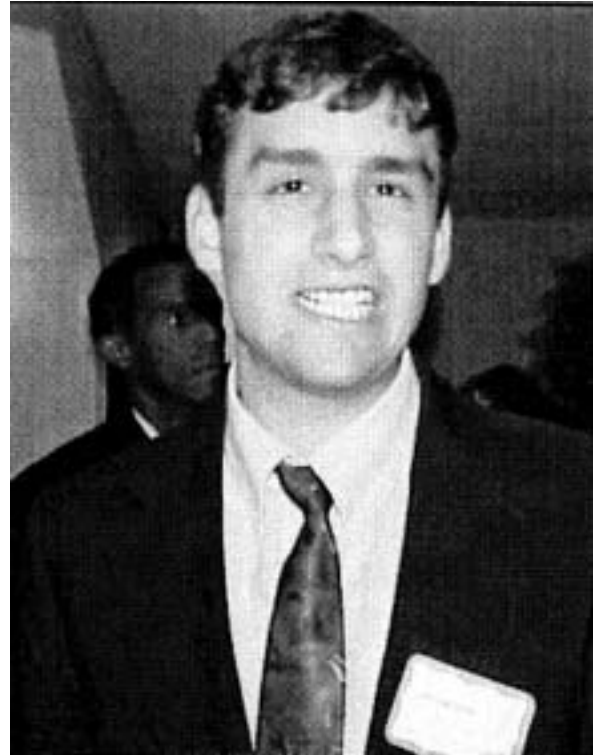
I also have earned the 6th belt required of a Tae Kwan Do master. I am a member of a Tae Kwan Do School on the Upper West Side. The whole place works together to help me earn my belts. I was amazed that I broke the board to earn my last belt. I was shocked, I couldn't believe it! Everyone cheered. It is a great feeling to belong to this group and be invited to all the great parties too.

I also love to travel, to take long trips with my parents, and also I use the subway, city buses, and regional railroads on my own.

I am a very enthusiastic person!!! Sometimes people don't even understand me because I am so eager and so excited. Fortunately, the people closest to me understand and appreciate me.

When I think about the future, I would like to have a nice apartment, to make more money, to have a girlfriend and a cool car.

Michael and Roberta Wolf are Josh's dynamic parents who challenge others to "defy deficiency thinking" by staying focused on capacities. They consult with other parents to support them to see past obvious deficiencies to focus on a dream. Josh is too busy working on Wall Street to consult, so contact Michael and Roberta Wolf at: 212-874-6151



Bernard Carabello



My Hero: The Story of Bernard Carabello is Inspiring
by Malachy McCourt

There are people on earth who have not met Bernard Carabello and I pity them. The millions, if not billions, of people who have lived their lives and died and those who are now heading towards the grave, as we all are, and have never set eyes on this magnificent man, or been in his presence, must feel some loss in their lives.

He spent twenty years of his life at Willowbrook State School, being treated as if he couldn't understand life, love and human affection. He was abused in many ways, and punished for infractions of stupid rules, but he never lost his sense of hope that one day it would all change. And change it did.

He doesn't walk too well, he needs help with his food and sometimes his words are not too clear, but there is no nobler man walking this earth. His message and his passion are clear- there is no rest for him and he will not let us rest as long as there is one suffering disabled citizen left in any institution here or anywhere else.

I will always remember the time Bernard Carabello celebrated his 50th birthday. On a cold, snowy night in January, 200 of his closest friends gathered together to laugh and cry as one person after another spoke of the acts of kindness, inspiration, and irritation Bernard has bestowed on them by being a true friend.

Bernard is a craftsman in the art of relationship building. He repeatedly brings people together to join in a purpose that is bigger than his own. He respects and recognizes the contributions of each person whether they provide him with personal support or benefit the civil rights of all people. He is genuinely compassionate and irreverently intolerant of disrespect. He is generous beyond measure with his time, resources, and concern for others.

I find it hard to believe that he spent most of his childhood isolated and abandoned to a hostile and haunting institution. During the 20 years he spent at Willowbrook State School he spent all of every Sunday sitting by the window hoping that someone would come to visit him, which rarely happened. As he was freed from isolation he gave and received from others without ceasing. He lives with an insider's view of the healing power of relationships and the way that interdependence and cooperation can change the world.
(Story by Dr. Beth Mount)

Bernard Carabello is considered to be "The Father of the Self-Advocacy Movement." He is a compelling key-note speaker and consultant who challenges us all to build new options so that no person has to experience the devastating consequences of living in a Willowbrook type environment. Contact Bernard Carabello at: 212-787-0161

Scott Fowler



Scott Fowler is a young man with severe disabilities who is an advocate, educator, and entrepreneur. He began his education in a highly segregated setting- long before he and his family became familiar with the concept of Inclusion. Scott and his mother worked with the members of the Committee on Special Education, the high school administration, teachers and support staff to create an opportunity for him to attend the local high school.

During his first year of high school, Scott was invited to participate in the Person Centered Planning project led by Dr. Beth Mount. This was the beginning of his Circle of Support, a group of ever changing friends and supporters, who have helped Scott achieve his goals.

During the last ten years, Scott has worked as a docent, a pool gate attendant, a stockboy, a greeter and a ticket taker; he has been both a volunteer and a paid employee. By the time he transitioned from high school, he had two part-time jobs which he kept for over five years.

In 2002, due to a slow economy and resulting cutbacks, Scott was laid off and cut back to one day as a ticket taker. He then began to explore the possibility of self employment which would capitalize on his energy and enthusiasm. Again with the assistance of members of his circle, especially his job developer Carol Carnevall-Gearing, and Dr. Beth Mount, he created Scott Avery Fowler Enterprises; he now sells books and artwork that are meant to inspire people who are involved in person centered

Scott and has done numerous presentation on the topics of:

- * Transition * Supported Employment
- * Self Determination * Person-Centered Planning
- * Circles of Support

Scott presented at the TASH Conference in Chicago in 1999 and again in 2003 where he managed a vendor booth. He is a speaker at workshops and conferences sponsored by the New York State Office of Mental Retardation and Developmental Disabilities, Westchester ARC and the Westchester Institute of Human Development. He participates in the Consumer Directed Personal Assistance training project sponsored by the NYS Developmental Disabilities Planning Council and has been an advocate for services and supports for people with disabilities to become more active in their communities.

His most recent undertaking involves moving into his own apartment and dealing with all the issues that come with living independently.

Scott Fowler is available to teach others about running a small business and living in his own home with 24 hour support. His mom, Jackie Fowler, is also available to consult with others about person-centered transition planning for people like Scott who need 24 hour support. Contact Scott Fowler at: 914-804-3003. Contact Jackie Fowler at: 914-962-2177

Nina Galen



Nina's Transformation

Nina lives in her own apartment shared only with a roommate. She is a neighbor and getting to know her neighborhood. She is supported by Job Path, an agency that provides individualized supports so that she can live in her own apartment and be a member of her community. She and her mom, Diana McCourt, also have the support of a circle of friends and family. Five of the members are friends of Diana's that had not been involved with Nina before until Diana invited them in.. The group meets regularly to learn more about Nina.

The circle has helped to make Nina's life in her new apartment and in the city full of activity in a welcoming community. Nina was registered at Bed and Bath and Pottery Barn for her big housewarming party. She goes shopping at local stores for clothes, she goes out to lunch, and she gets lots exercise from walking and going to Riverbank State Park . She has had several small parties in her apartment for friends and family who have been attracted to the vision and drawn into Nina's life to participate. Even her father has become reengaged in Nina's life after an absence of 40 years.

At age 42, Nina's ordinary life doing ordinary things is extraordinary when compared to her former life isolated from community as a resident of Willowbrook State School and several large group homes who failed to understand her. Nina's ISP labeled her with profound mental retardation with Residual Autism, Nina gets around on her own but has no speech.

Nina suffered abuse, general neglect and extreme frustration. As a young girl she spent her days mostly rocking from side to side, foot to foot abusing herself by biting her arm and hands resulting in huge welts. As she grew older she developed much more dramatic behaviors, running out of the day program building to the street, eating the intercom wire after she tore it off the wall, biting herself so badly that she had to wear a helmet to protect herself during especially bad self attacks. She was also put on psychotropic drugs.

Nina's mom Diana, is a student of possibilities and followed her vision of a better life for Nina as she learned that Nina's behaviors were her way of saying, "I am bored out of my skull. I am a prisoner of the group. No one listens. Now I have some ideas at least about what I I want one-on-one with a helper/friend. That's how I flourish. I am tired of practicing for life. I want to live my life."

Since her participation in her one-on-one day program and move to her new apartment shared with one roommate, Nina has completely stopped her self-abusive behavior. Nina looks relaxed and happy.



Diana McCourt, Nina Galen's mom, is a powerful advocate for change. She was involved as a parent organizer and advocate of the closure of the Willowbrook state school and remains involved in promoting individualized day and living options for people who need 24 hour support. Contact Diana McCourt at: 212-662-9746

Tony Phillips



Believe in Your Dream By Tony Phillips

As a child.....

I love music for as long as I can remember. At age 14, I begged my mother to buy me a transistor radio. I grew up in a church that valued Gospel music. At age 18, I saved up all my money and bought a nice big JVC stereo that went with me everywhere. I would spend hours in my room recording music off the radio.

As a young adult.....

My early interest in music focused on rock and roll. At age 36, I was called by God to put my musical interest into Gospel.

In 1991, I led my first Gospel program at the UCP center. From that point forward, I began to live my dream of organizing and promoting Gospel programs in the community. In 1991, I was still going to a traditional day program, so I did everything related to Gospel music in my spare time.

For the last four years, I've organized and conducted at least one program a year. Even when I worked in a mail room, I realized I could use the money I earned there to pay for promotion expenses such as decorations and refreshments.

The future.....

My dream now is to promote many more Gospel programs throughout the community, particularly in places where people can't get out, like in hospitals. I would like to record more music, maybe sell the music as well as promote. Anything is possible as long as I have assistance.

What I really need is an administrative assistant to help me organize programs. I even know someone who I think will help. If Self-Determination can get going, then I can hire my own help. They (the funders) tell me I have to write another plan to get my vision going. I've written two plans already, so my image for the future says:

**THIS IS IT, MAKE IT HAPPEN!
I DID MY PART, YOU DO YOURS!
THE GAME IS OVER, I HAVE ENOUGH TO DO, LETS MAKE IT HAPPEN!**

About the artwork that describes my dream.....

I want an image that almost looks like a gospel singer, but also looks like a holy person. I see a big sun in the sky with rays shining down on the man. He has a cross around his neck and a Bible in his hand. His other hand is a fist of power, like the "in your face" power people have in the National Action Network. The man has sandals on his feet, because like Moses, God says to take off your shoes when you are walking on holy ground. He is walking on holy ground and the ground is nice and filled with flowers, but it also has rocks on it, because the journey is a rough one. This is an image of me holding onto my dream, and leading others on the path of Self-Determination. (The image discussed here and depicted above was envisioned by Tony and made into a quilt by Beth Mount. The image now appears on Tony's promotional cards.)

Tony Phillips teaches others to "Be Determined." He is a fierce self-advocate who challenges others to "live their dream," which he demonstrates through his leadership in the self-advocacy movement, and in his business as a Gospel Promoter. Contact Tony at: 212-964-4011

Bob Smith



He cannot speak, walk or care for himself, but words give voice to his emotions. Bob Smith is a 43-year-old man with cerebral palsy. He was raised in an institution where he was often neglected because he couldn't make his most basic needs known. And from time to time, he was abused. But Bob is a poet who has learned the power of self-expression.

At age 22, Bob moved into a group home sponsored by Westchester ARC. There he found a supportive staff willing to get to know him. One of the agency's speech therapists discovered that Bob had taught himself to read and designed a communications board that enabled him to better interact with those around him. He uses his right thumb to point to letters and words displayed on his wheelchair's lap board. The process is laborious for Bob, whose motions are not fluid, and the "listener" needs time and patience.

A person centered plan was begun with Bob in January of 2001. During the process, his circle discovered that not only could he communicate but that he had written poetry. The facilitator helped the team to brainstorm ways in which Bob's work could be promoted. At first the planning focused on putting the poems together in an appealing format. Gradually the idea of a book emerged. Other uses for the poems, calendars, cards etc. were also discussed. It was decided to concentrate on copyrighting and publishing a selection of the poems.

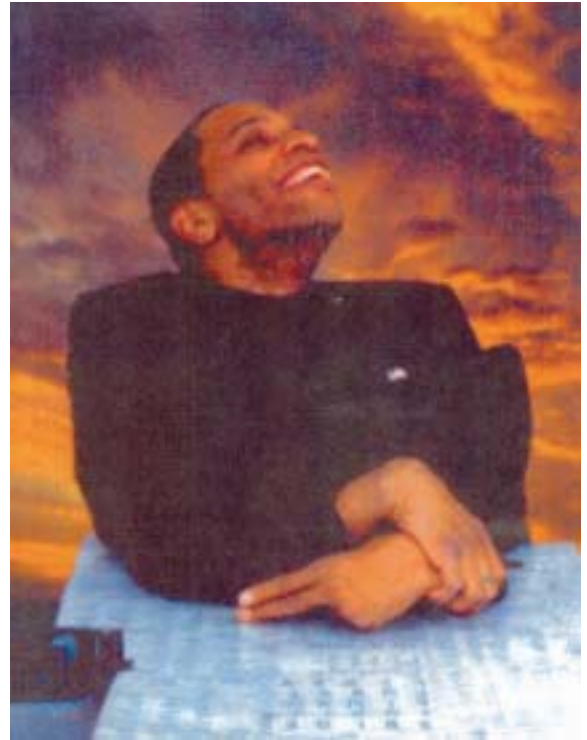
The Westchester ARC staff then collected his work into an anthology, *Reflections of My Life*, with themes spanning institutional life, the experience of having cerebral palsy and the desire to advocate on behalf of others with disabilities. Cards composed of poems and nature photographs were printed. Another product was also created, Bobs poems were superimposed over nature photographs and then matted ready for framing.

Bob's writing ranges across loneliness, despair, dreams and kindness.

With the aid of the agency's Life Planning Center, Bob has now launched a business venture in order to publish his work. Westchester ARC also helped him to obtain a state-of-the-art Dynavox voice synthesizer. Using a wand attached to a headband, Bob points to menus displaying letters, numbers, words and phrases that are translated into digitized "speech." No longer restricted to communicating with individuals who can lean over his lap board, Bob can address large audiences.

"My book is very important to me," says Bob. "I want people to know about me and my work. I want them to understand me better, and I want them to understand cerebral palsy. I am writing for all people with cerebral palsy."

In addition to selling his books, Bob has given poetry readings, and is currently creating material to be used in training professionals about working with people who have disabilities. A short video has been produced about Bob and person centered planning.



Bob Smith is accomplished as both a published poet, a lecturer and teacher of disability issues. Contact Bob Smith via Ralph Szur at: 914-949-9300 ext. 3002