

The Quality Initiative

What People Have to Say About their Quality of Life

Introduction

In 2009, the NYS Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD), in partnership with eighteen (18) organizations involved in providing services and supports by, with, and for people with disabilities, formed the Quality Coalition. Coalition members worked together to learn more about the diverse lives of people with disabilities to help government agencies and community based organizations ensure that services, supports and standards promote a good quality of life.

With CQCAPD in the lead, the group conducted focus groups with individuals with disabilities and their families to discuss what constitutes a good quality of life, the challenges that are faced in attempting to have a good quality of life, and what still needs to change. People with disabilities and their families were also invited to describe their quality of life in more detail by sending their individual life stories to CQCAPD.

Excerpts from 31 of these stories follow. While writers gave permission for their stories to be shared, pseudonyms have been used and personal identifying information has been removed. Some individuals' stories were recorded by a third party and are written accordingly.

The report about what people with disabilities said about their quality of life can be found on the CQCAPD website at www.cqcapd.state.ny.us.

CQCAPD and the Quality Coalition members are grateful to the individuals who shared their lives through their words to increase knowledge and understanding about what is important to people with disabilities.

The Stories

Lisa - age 19

"Having seizures has a big affect on my life. I spend a lot of time in the doctors' offices and hospitals. My seizures stop me from doing what normal people do. My cousins go tubing in the summer, but I cannot do that because it causes seizures to come on. I really love to play sports, but I have to be careful of being over heated. My seizures affect my ability to think. Seizures hold me back from my school work. Sometimes I have seizures that affect my hands and make it hard to write. Although I have many challenges, I still want to have a job. This is hard though because most employers are afraid to have someone around who may have a seizure. Even people who are supposed to help are sometimes afraid. I have been sent home from summer camp for disabled kids five times because I had seizures there. On the bright side I joined a Special Olympics program. I play basketball and volleyball. The staff there are not afraid of my seizures...I think a lot of people out there need to learn more about seizures so that they are not so afraid of me. Sometimes it keeps me from doing what I want to do and this makes me really sad...."

Marge - age 46

"Getting to live where you want" and "having control over your own life" are two of the biggest factors contributing to a positive quality of life.

Some of the challenges to having a good quality of life include businesses saying that they are accessible, yet they are not truly accessible for individuals with disabilities. This limited mobility detracts from her ability to have a good quality of life as it limits the experiences available to her. Also she has difficulty locating full-

service gas stations in her area which means she must alter her trips to drive by one of the few full-service stations.

Leonard - age 54

Leonard describes his quality of life as "excellent" thanks to the support of his family and friends. He believes that close relationships are the best support system an individual with disabilities can have. A close friend of Leonard's comes to his residence each day and provides transportation to and from work. In addition to transportation services, his friend prepares dinner for Leonard twice a week.

Some challenges to having a good quality of life are related to transportation. While Leonard has a stable transportation system in place, others without the same supports from family/friends may find it difficult to travel rural areas. Leonard cites the limited operating hours and coverage area of "Dial-a-Bus" service as problematic for anyone without additional supports. The "Dial-a-Bus" service works great during business hours within the city limits, but service to outlying towns is very limited. This lack of mobility may hinder individuals' ability to live the kind of life they desire.

Additionally, Leonard believes that a lack of handicap accessible housing is an issue. While there are multiple places/complexes that offer handicap accessible living quarters, many of them have age requirements, often benefitting people who are elderly, but excluding younger individuals. The fact that individuals with disabilities may be denied accessible housing because they fall short of age restrictions may inhibit good quality of life.

Finally, Leonard voiced some concern over the availability of personal care services. While not in need of them now, he is unsure what to expect from care services he may require in the future. This uncertainty may be a factor in decreased quality of life for individuals with disabilities.

Leonard suggested that having reliable care and transportation is

necessary to a good quality of life. Immobility and lack of accessible living options are issues that detract from individuals having a high quality of life.

Carrie - age 49

Carrie describes her quality of life as "OK. Not great, but OK." Her quality of life has improved since she moved from an institutional setting (where she spent much of her young life) to owning her own home with her husband. Carrie's quality of life is improved by her ability to own an accessible automobile driven by her husband, along with the availability of transportation services like STAR (Special Transit Available by Request). Additionally, Carrie cites the support of family and friends as being integral in having a high quality of life.

Some of the challenges faced in attaining a good quality of life for Carrie included the process of purchasing an accessible home. Carrie found that the process of buying a home was complicated by realtors showing her husband and her homes with multiple flights of stairs and very few accessible houses. Carrie said, "a lot of the houses they showed us had like 20 stairs; there was no way we could get into it."

One factor Carrie suggested may lead to diminished quality of life for individuals with disabilities is certain rules and regulations put in place by health insurance companies. Recently, Carrie was told she would have to leave the hospital because her insurance would not cover a continued stay, so she left and returned a few hours later when, because she had left and returned, the insurance company would cover the remainder of her stay.

In all, Carrie finds her quality of life to be good, but the difficult process of locating accessible housing and having reliable transportation can be issues that impact her quality of life. The person writing this for Carrie wrote that Carrie's biggest grievance seemed to be with regulations imposed by insurance companies that limit her ability to receive the care she needs. The availability/ease of locating accessible housing, transportation, and medical care are

issues that tend to result in a perceived good quality of life.

Tom - age 34

Tom, a man in his 30's, lives in an attractive apartment located in a large and well-kept townhouse development. He takes care of his home, doing cooking and cleaning chores and decorates it with his extensive collection of miniature lighthouses that he has purchased in his travels. Several days a week he receives some limited help with his residential needs from direct care staff. During the week he takes a public bus to his job at a supermarket where he has worked for over ten years. He is active in a local self-advocacy group in which he was elected President. He has also been a valuable part of the Self-Advocacy Association of NYS and he has made numerous presentations to community groups, including college students taking the human services major curriculum.

This independent life was not always the case. Back in 1999, Tom was living in a group home with three other individuals. The house was in an isolated rural area and he was frustrated with this living situation and his lack of personal freedom. He advocated for himself and managed to leave and move to his present apartment. Tom enjoys the fact that he can now make his own schedule, do the things he wants, including independent out-of-state travels to visit family and friends. When asked what he would say if he was asked to move back to his prior group-home living situation, he quickly replied "Absolutely no!!"

Samantha - age 22

"My name is Samantha. I am 22 years old and I have cerebral palsy. I use a power wheelchair. I recently graduated from college with an Associates Degree in Liberal Arts. Currently, I am volunteering at an AmeriCorps project through the Self-Advocacy Association of New York State. Eventually, I want to get my bachelors degree.

I currently live with my family. Eventually I would like to live either on my own or with some friends. I would definitely need supports to

help me reach this goal. Other than not living with my parents, one of the goals of living on my own is to meet people and make further connections in the community. Right now I definitely feel that I am too dependent on my parents for personal care. I would really like more independence going out in the community. I have support staff to help me with that for a couple of hours each week, but I need much more. In the ideal world, I feel that in order to live on my own, I would first need to be almost completely independent of my parents' care so that when I move out it will be a natural transition.

I have been fortunate to be able to participate in several activities that really play a major role in my life. One activity that really is more of a family activity is downhill skiing. My family members have always been big skiers. In fact, when I was little my Dad would take me down the ski slope between his knees. When I got older, we found an adaptive ski program. I also do therapeutic horseback riding. I feel that I have a great deal of independence when I'm on the horse. It also helps me relax. For the past couple of years, I have been playing power wheelchair soccer, I really love it because I can be the most independent playing this sport. I also like it because it gives me an opportunity to be a part of a team, something that I had not had a lot of experience with in the past."

Emily - age 34

"I love my life. The quality is great. My husband and I have a house and a van. We have excellent staff. We get to participate in the community. These activities make our quality of life...the freedom to choose, the ability to commit to the responsibility. We own a home; it comes with the responsibility to take care of it. Financial demands are also a challenge if you have to keep up with items like the house and a van. Mostly the growth we are committed to will need supports like staff and financial support that can be used to help with large home repairs, etc. Quality of life depends on what you want it to be. If you make an effort, supported by family and friends, you can have the kind of life anyone can do it. We have had all kinds of challenges that help us grow. OPwDD has helped with many modifications and making our home a place that welcomes all.

Quality of life is always changing and that makes life good."

Joe - age 39

"I feel extremely blessed to be in the position I am in. What makes me feel I have a good quality of life are the opportunities that I have been given- going to Albany, being able to speak my mind when it comes to my life, trying to make other people's lives better, and just being me. The obstacles are attitudes in society, saying you can't do this you can't do that, passing judgment on someone like me. The most important thing to me is to be able to love, to share my hopes, my dreams, my faults, to be able to make mistakes, and to be able to learn from them. Wheelchair access, transportation, good staff, making money, being productive and feeling like I am important and ultimately the ability to get married and share my life with someone are important to my quality of life."

Jason - age 31

"When I was a child I lived on a very busy street, so it wasn't very safe for young children to play in. There were no other children with visual impairments in the neighborhood. I eventually went to school locally, graduated with a local high school diploma despite bullies and my difficulty with having to have someone read homework and tests to me all the time and difficulty with math.

I began my interest in music when I was taken to Boston for multiple eye operations. My eyes hurt so much that the only way I could relax was to listen to music. When I wanted an escape from the reality of my world, which was a cross between the blind world and the sighted world- both of which were unfriendly sometimes- I liked to either watch TV, listen to music, or sometimes just lay down in my room and daydream about how life would be different for me if I weren't blind, or how I wished things were different if I didn't live on a busy street.

I attended a local recreation program from the time I was a child for people with disabilities and eventually out grew the program as I got older. This program got me out of the house and away from my

younger siblings, so I was happy for that. Then one summer my mom put all of us on the bus and my younger siblings followed me to summer camp- that was the last year I ever went to summer camp. I really liked my space from my siblings- we saw enough of each other at home.

Today I live in a group home that opened up about 4 years ago. In a way I chose to go there just to see the truths and myths about group homes for myself. When I was a child my mother used to threaten me saying if I didn't behave she would put me in a group home and they would do this and that, and I wouldn't be allowed to do this and that. When I was really young, it was an institution they would threaten me with. When I moved in a group home, I was happy to get away from my family for a while and see them when I wanted to see them. I have five other housemates who all have disabilities, which in one sense is sometimes easier than dealing with people who are non-disabled all the time.

I met my girlfriend about 10 months ago. We weren't even at day program yet-we met in the van on the way to day program! I thought I was only supposed to be her peer mentor and help her get adjusted to program. Well, God had other ideas. Ever since that day we both fell in love, we both got out of other bad relationships and we have been happy together ever since. In fact, she has been the reason for me pushing to further my independence and get out of the group home, get a job, go to school, get my Ph.D in music, and start a music career. My dream is to take a day job doing music therapy at a special school for children with developmental disabilities where I went for preschool, when I am not on tour performing. I also would like to settle down with my girlfriend and get married someday and start a family of my own.

Waking up knowing that I do something different every day, having time with friends, being able to get out of the house, say to go out to dinner with my girlfriend, all the things I do with self advocacy, having challenging and stimulating educational experiences in the arts- writing and music and acting, and being productive and busy; all of these things make my life worth living."

Ray - age unknown

"I have connected to other people in the community by being a self advocate and being involved in my church.... I am a person with Cerebral Palsy and that has some challenges in itself, but I do not let them slow me down. I live life to my fullest potential..... My church actually helped me get involved in bringing in a new facility and asked me what I needed to get around in the church...I live in a group home with two other individuals. ...I have a great team that helps me do what I want to do, but even though sometimes there are difficulties they always seem to bend over backward for me...My goal is to move into my own apartment so I will become more independent. ...because of my aquatic and physical therapies I am now able to turn light switches off, get in and out of my van by myself, take covers off my joystick, and take my hat off by myself."

Gregg - age 41

"I would like everyone to know that we are all the same. Just because we have a disability doesn't mean that we are that different from you. We want the same things as you do.

I grew up with my mom, dad and sister. I started off going to public school. I was in special education and separate from people without disabilities. The school wanted me to go to a program where they separate people with disabilities even more so than where I was already at. My parents took me out and put me in a private school. The private school helped me learn how to discipline myself. They also allowed me to learn at my own pace and did not make me learn certain criteria in order to graduate. In the private school, I took class with everyone else. They had high expectations of me and I worked hard to meet those expectations.

I have been to all different places. I have been to California for the Self-Advocacy national conference. While I was there, the New York State board of directors for self-advocacy helped the people in California learn how to lead their own conferences and learn more about self-advocacy. I visited Washington D.C., my brother in North Carolina, and I have been to Albany many times for different self-

advocacy related events.

When I worked at a sheltered workshop, the staff would move me from one job to another because they didn't know what to do with me. They also would criticize me and tell me that I would never get a job in the community because I had poor attendance. I didn't go often because I didn't like the way they treated me and other people.

I enjoy working with Joe in [not-for-profit service provider] the training department. He respects my opinions and values my position. I also like working on developing opportunities for people with disabilities. The staff that I work with respects me and I enjoy coming to work.

I benefit [my employer] because I help the staff develop their skills and offer a different perspective to their training. I also help [my employer] because I am a b advocate and I help people learn about self-advocacy and the opportunities that are out there for them.

In a couple years, I would like to own my own house, be speaking publicly about self-determination and self-advocacy, and own my own car. With the support of my self-determination plan and consolidated support services, I can pay for people to help me with my dreams. This plan is going to help me reach the goals and dreams that I have for my life, and that most people have for theirs.

I have told you my story because I want you to know that although I have a disability I am just like you. I have had ups and downs in my life, I have positives and negatives about me and I have my own goals and dreams that I am getting support with reaching."

Rita - age 46

"I work at a restaurant. I just got a new boss who is not understanding of people with disabilities at all. I work part time without a job coach. That is not my choice....I went to college and have a BS degree. Finding jobs and job developers and coaches who

are used to working with college-educated people [is difficult]...this is so frustrating for people with disabilities...Just like the rest of the world as a high school senior, I wanted to follow my parent's dreams to go to college and use my degree in teaching and teach....I wanted to...get a degree [and a good job and benefits]. Just because I had disabilities people seem not to want to help me achieve the dream. To others the dream is not worth pursuing. To this day, why do state agencies still question one's desires; people with disabilities want what others want, they want paid vacation and decent pay for a days work for their skills."

Anita - age 52

"I am 52 and have been ill most of my life... [I have been diagnosed] with bipolar disorder, OCD, schizoaffective disorder, and paranoid schizophrenia, all of which I consider myself recovered from. I now run my own art business...art is my passion, my love and my healer....I attribute my wellness to medication, therapy, supportive family, friends, my psychiatrist, creative activities, [my partner] and my own will to get well. I have a b faith in a higher power who wants me to be healthy and happy.....I love my life! Everyday is an adventure! All is excellent! Couldn't be happier!"

Dave - age 41

Dave volunteers with various community organizations. He likes where he lives and feels like he makes choices in his life. He feels like he is able to participate in activities that he enjoys, yet he does not feel connected to other people and organizations in his community.

Jill - age 53

"I have three children born to me in 1979, 1984, and 1992. My first emotional maladjustment to life manifested itself in 1981. Although my son was less than two years old, I was also raising my husband's three sons (ages 14, 13, and 8) from his first marriage. In spite of my parenting responsibilities I felt unfulfilled. I was also still reeling from the Guyana Tragedy of 1980 in which 900 people

committed suicide in a religious community. I had known some of the people who died. I had stopped using drugs and alcohol. Alcohol and marijuana usage as well as other street drugs had, for so many years, subdued any desire I had to achieve anything meaningful in my life. I understand now that I was self-medicating. Once I stopped using these drugs and alcohol, the pressures in my life began to build until I felt compelled to seek the help of a psychiatrist. He began to medicate me. In spite of the counseling and the medication he provided me with, which was quite good, I stopped seeking his help when I entered college in California in 1982.

By 1987, when my second child was almost three years old, I began to experience emotional turmoil once again. I was no longer married; my husband and I having gone through a long and bitter divorce. Although I had physical custody of my two sons, I was forbidden to see my step-sons whom I loved as if they were my own children. And, although I had the distinction of having graduated from my baccalaureate program Summa Cum Laude, I struggled through Graduate School finding myself on academic probation most of the time. Once again, I sought counseling. My therapist put me, once again, on medication. The medication helped.

Later that year I got into an argument with my ex-husband in front of what had been our home. I was clad only in my underwear as we argued on the front lawn. Because I tried to physically restrain him, I was arrested and taken to jail. This episode so destroyed my self-concept and diminished my self-esteem that I was hospitalized after a severe paranoid attack where I remained for eight days. Before my hospitalization my intellectual skills had dissipated significantly. I could no longer study. My doctor put me on a combination of medication which made it possible for me to return to graduate school and to graduate by December of 1989 with a 3.32 grade point average.

By 1992 I had given birth to my daughter. I returned to my job as well as to graduate school for a Ph. D. in Education when my daughter was six weeks old. Being a single-parent (my daughter's father and I never married and we were not together when she was

born.), working two jobs as an educator, and pursuing a doctoral program as well as a social life proved to be too stressful for me. A reoccurring pattern of behavior, when I am not mentally healthy, began to manifest itself in my life. This pattern of behavior would eventually end up with me being homeless, off-and-on, for ten years. I stopped paying my rent and utilities. I bought exotic foods and expensive clothes instead of providing for the necessities of my life. I quit my jobs (both), dropped out of my doctoral program, and drove cross-country to New York with my children feeling myself to be the victim of racial abuse in October 1993. I was also trying to fulfill my lifelong dream of becoming a famous writer.

By May of 1994 I had forfeited physical custody of my three children to my mother and ex-husband. The children returned to California where they were raised, while I remained in New York homeless and hoping to become recognized for my writing skills. In spite of securing housing in two different board and cares – one on the East Coast and the other one on the West Coast – between 1996 and 1999, until late August of 2004 I was homeless. I lived in shelters; I lived in hospitals (one NYC hospital for six months); and I lived in subway cars and out on the streets in cardboard boxes. Finally, in October of 2003 after a three week hospitalization, I sought asylum in at a drop-in center. I slept on chairs almost every night for ten months until I was accepted by Common Ground for Housing. Thanks to the humanitarian efforts of my care worker and my psychiatrist I entered my own apartment with my own key in August 2004.

Having my own apartment, working in a profession while not that of a writer is one which I was trained for, continuing to pursue my goal of writing, remaining on medication, remaining in therapy, and utilizing the talents of the staff in my building has literally meant the difference between life and death for me. I sometimes see other people I was homeless with who are still out on the streets. They look so used. In spite of a brief period of time in which I was married and homeless with my homeless partner dying in 2002, I also, like them was always struggling and scrambling to find housing. Delusional and psychotic off of my medication I was frequently unhappy. Like the people I sometimes see, who were,

during that period of time in my life, like my family, I needed housing and the help of competent professionals as well as the humanity which social services can provide to survive. My life would be perfect now if my former homeless friend's needs were being met as are my own."

Gary - age 32

"I am living a good quality of life. I have an apartment and am very independent. I am eager to work and am self motivated and willing to learn. I am very frustrated in getting a job. We need jobs carved out for the disabled. Workshops should develop more jobs and job coaches. NYC should develop more back office jobs as well as more retail training programs. It is very hard for agencies to find jobs for the disabled. The mayor should expand the network with a lot of office jobs for the disabled."

Arthur - age 79

"Today, and for the last 17 years, I have lived a happy life and with financial security for 14 years of retirement, albeit without my wife of 47 years who passed away 7 years ago. I consider myself free of the debilitating episodes brought on by schizophrenia incurred at the not uncommon age of 18.

I was raised, not unlike most of the guys in our gang back in the 30's and the war years of the early 40's. There were three of us in one room with bunk beds, good clothes for school, lots of food on the table and we had a welfare girl who occupied the third bedroom. What she did, I'm not sure but she always seemed to be around. At some point during the latter years of high school my Dad and his Mother really grew the family business and soon we were living in a sumptuous large old house with 21 rooms, 10 functioning fireplaces on 21 acres on the Great South Bay.

I went to college in New Jersey without any knowledge of college life as no one in my family had attended college. It was in the summer of the second year of college at age 18 that I suffered a severe "nervous breakdown" subsequently diagnosed as manic

depressive and/or schizophrenic. I spent 6 months in a private psychiatric hospital where only insulin and electro shock was available; tranquilizers had not been developed as yet.

For the next 62 years I was subject to psychotic episodes that would come on for no reason that I could fathom. I still take a mild medication when I feel it is needed. I did finish college, begin working in our family business which I disliked intensely and finally at age 35 landed a position in public education as a business manager leading to a 30 year very satisfying career. It was difficult, however, in that on one occasion I suffered an "episode" which became grounds for my release. I managed to re-enter public education and because of a trusting wonderful superintendent, who took a chance on me I completed my career.

I have always supported or been a part of my community organizations and the many community residents who are a part of them. I helped found an educational foundation for our local school district, have been a member of Rotary International working to raise funds to assist various community projects, I volunteer to drive indigent and otherwise cancer patients to their treatment centers, and, of course, I am continuing as a panel member for Surrogate Decision Making.

I am living with a lady in a beautiful big house on Great South Bay and we go to my condominium in Florida for the winter. Having achieved the ripe old age of 79, I do have heart disease, arthritis in the hip and back but I am dealing with it. We are world travelers, attend ballet and theatre in New York City and we have a wonderful circle of close friends with whom we travel and socialize. I have two very successful children who somehow understood the challenges of mental illness with which I wrestled most of my life.

For the last 5 years I have attended college level workshops in order to develop and improve my writing skills in order to write my memoir to demonstrate that those of us stricken by mental illness of this kind can survive and lead productive, rewarding lives. I am not aware of anyone who can state with any degree of accuracy that schizophrenia can be cured but my personal experience is a helpful

sign."

Rosemarie - age 20

"Have you ever imagined what life would be like without friends or neighbors to make you feel welcome? I live that life every day. Neighbors tell me to go home when I knock on their door just to see their dog. Kids my age play hockey and football in the street while I sit on my front porch watching because they won't play with me. I love to swim and am really good at it but I can't even get a chance to try out for the swim team at school. If I ever want to participate in school activities outside of school hours there has to be a qualified faculty member or staff to chaperone or I can't attend the function. My best friend is my dog Shadow who I spend most of my free time with. Why is it so hard to ask me to join you when you're bike riding? I have a large tricycle that I use to get around the neighborhood but then I'm told to get away from a car or watch where I'm going. Why can't people wave and say hello, how are you today, would you like a glass of juice and visit for a while?

I'm lucky in that I can participate in a baseball challenger league and compete in the Special Olympics in basketball, swimming, track, and volleyball. I am very grateful to the people who organize these functions and provide me with opportunities to socialize. I also have a great mom who takes me out to hear music and dance. We even go out to dinner quite a bit and I order my own food and talk to the pretty waitresses. I get to pick the restaurants to eat at.

I also get to go to respite that helps both my mom and me. I get to go have fun and be with some friends and my mom gets to take a break and relax a little. She always tells me she did laundry and cleaned but she also gets to see some of her friends and not worry about me.

Thanks to my school staff I get to go to work at a furniture-refinishing factory. I really like it and hope there will be some way to get me a job there when I graduate. I will need someone to drive me and help me at work but I concentrate and do a good job when I'm there.

When I was diagnosed with cerebral palsy after I had a stroke, the doctors told my mom I might never walk or talk. I proved them wrong and can do very well at both but it took a long time. I started talking using a computer touch screen that the school bought for me to use at school and home. I used a stander, wheelchair, braces, walker, and a lot of other equipment to finally get to walk on my own. I have a limp but I manage pretty well. My biggest problem is I can't use my left arm and hand very well and I can't read yet.

School finally listened to me when I told them I want to learn to read and I'm working with a reading teacher to try to learn to read so I can get places if my mom can't drive me.

My quality of life would improve if people could just be educated to understand how we use our abilities for strength and just want to be accepted in society like everyone else. I hope as I transition from school to work those resources such as transportation, job coaches, and financing will be available for a bright future. I'm a little worried right now because of all the state cuts and I'm not sure where I would live if I didn't have my mom. Knowing there will be money to support our quality of life and independence would be a very helpful to my future."

Stanley - age 54

"I was a wild out of control child that had to be home schooled till the fifth grade. The school system at the time said I was retarded so my mother was my first teacher through fourth grade. My mother would get so upset and frustrated with me; she had little patience and she would beat me. This was the only thing I would respond to. I was good for a beating two or three times a day. This abuse started at around five and continued in some manner till I was fifteen. In the early years the abuse was physical, verbal and emotional. As I became older the abuse was mainly verbal and emotional. I went to school for the first time in fifth grade and I had a great time driving the teachers up a wall. You see there was nothing wrong with me except I did not want to pay attention, I wanted to play.

At five years old my mother started to give me shots of liquor, always three or four to help me go to sleep; it worked so well she started giving me shots in the morning when I first woke up. At twelve my brother, six years older, turned me on to the drug world. Now I was drinking and doing drugs. This behavior went on through graduation. The day after graduation, I was in the Navy. I served 28 months before they sent me home. At home I went to work at a lumber company. I was there twenty years before they let me go. That is when I got my job at a college as a lab manager. I was there for 12 years before I lost my job due to my psychiatric problems.

I have never recovered from those problems and today I attend an adult day care program for people with psychiatric problems. At fourteen I met my wife to be and we married at twenty. I have two great kids that are doing well in their own right. My quality of life today could be better but I am satisfied with what I have and the way my life is going."

Mary Lou - age 41

"I have suffered since the beginning of 2001 with a back problem. I take 4 types of pills, have exercises to do in the shower and three times a day on the floor, and I use a Tens unit twice a day. This is the disability issue that I cope with. It even brought on clinical depression for I always worked my butt off and I always thought I'd work until I could retire. I want to share my story to help others. I love to help people and hope I can always help until the day I die."

Marcel - age 26

"I am connected to my community in many ways. I am now working through the AmeriCorps program. I also do many other things in my community such as attending the disco, movies and karaoke through a community skills program. I also do occasional speaking engagements for the disability service provider. I am also involved in an adult choir once a week. We are performing in a holiday concert this December. I am a member of a gym where I work out frequently and have occasional personal training sessions. I get to

do all of these things because I have STAR Paratransit services through CDTA.

Right now I am living at home with my Dad. I get to make a lot of choices for myself with regard to what I do for enjoyment, what I want to eat, and how I spend my evenings. In the future I plan to live independently in a supervised apartment.

My family plays a very important role in my life. My father and my sister and now my brother-in-law are at almost every service coordination meeting I have and they support me in the decisions I make about my life.

My overall health is very good. My disability is not noticeable until you get to know me. I am working on different systems to help me remember things, such as having appointments written on a calendar. I had nine brain surgeries when I was younger due to hydrocephalus. It affects my short-term memory and I have fine and gross motor skill impairments. The biggest thing that affects my life is my disability, but with support I am working with to get by with my challenges. My disability helps me to look at things in a different perspective."

Pam - age 22

Pam has some major challenges in her life, with difficulties with her family, drug use and being raped. Now she is living a good quality of life. Her significant other plays a huge role in her life. She hopes to go to college for nursing.

Debra - age 62

"My quality of life is varied, partly good and partly bad. I was disabled from 1968 to 1976 due to mental illness. Then I became a church organist and have worked full-time at five jobs for 32 years. I have lived alone for that time in my own apartments. I have lived for fifteen years in my present apartment on the first floor, and I retired on April 2, 2008 due to disability of the physical and mental nature.

My health is declining, so I cannot do my clerical job duties anymore. My psychotropic medicines make me dizzy, making it hard to walk, and I use a cane or walker. I have a phobia of walking across open spaces, such as sidewalks, streets, or parking lots. I rely on friends, relatives, and transportation drivers to lend me an arm upon which to hang. This greatly limits my options about where I can go. I can no longer drive a car or go on a vacation. I also am incontinent and diabetic and have double vision. I suffer from OCD, which makes me count words and list tasks and phone providers too much. I have anxiety disorder and bipolar disorder. I am recovering from a contusion of my foot.

I am connected to other people in many ways. I work for a service provider for older people where I call, visit or write my seven clients and report my time. I do volunteer work for the Red Cross collecting data. I write articles mainly on mental health for our local newspaper. I play the piano and tell jokes at all our local nursing homes, assisted living, and adult day care and hospital. I have volunteered with several agencies that serve the disabled. I have won many awards for my work. I won the New York State Senate Woman of the Year award. I wrote two books on mental illness that are used in hospitals, group homes, etc.

My housing requires an air conditioner and space heater to remain comfortable. This winter has been too cold for comfort, and I sit with blankets, hood, and thermal clothes. In winter I close off the bedroom, which is too cold.

My apartment is cluttered, but I like it that way, as I need visual stimulation in order to see what I need to do. My landlord is very good to me because he likes my attitude and because I pay my rent one month ahead. I get support from my counselor, who comes to my house to see me. I see half a dozen medical providers each month, including primary care, podiatrist, dentist, orthopedic surgeon, eye doctor, and nephrologist. I access the crisis service when I have something I am worrying about. I have numerous relatives and friends, and I call them and write 100 letters per month. I do not have a computer. I go out to eat with my friends

and relatives. I do not enjoy movies or sports.”

Mary - age 66

“I am an adult home resident. I am currently doing an apartment search for myself, and I am working as a peer advocate. My reason for coming into the home was homelessness and depression. Until now, those of us who find ourselves in that position get the choice of homeless shelters or adult homes. We are not offered anything else. This is the first barrier to residents who are more vulnerable to coercion and bullying tactics, which are pretty much the norm in the homes. I’ve had some residents tell me that they have been threatened with hospitalization if they tried to move out. It works because residents are kept ignorant of their rights. This makes trying to teach them those rights extremely difficult. For the above reasons, I intend to continue the advocacy I am involved with after I move from the home.”

Matthew - age 23

“When I was a baby I had infantile spasms, also known as West Syndrome. It was not known if I would live and it was not known how my development would turn out. My family helps me in many ways and believes in my ability to learn. I had a lot of sensory issues. Bright lights and loud noises bothered me. I couldn’t sleep and I couldn’t handle being touched. My behavior was a challenge. I had a lot of frustration and could not express myself. For the loud noises I went to auditory integration training. My teeth were very crooked and interfered with my speech. Braces were another challenge. I had a lot of trouble with canker sores and it was painful when the braces were tightened.

I want to do what everyone else does. I wanted to be a Boy Scout and I wanted to do the things other kids did. I became a Boy Scout when I was 11. An aide helped me learn the Boy Scout program and helped me at meetings and on camping trips. My brothers and friends have been positive mentors for me. A passion of mine is downhill skiing. I only had opportunities for this because of my parents. No programs would allow this because of liability, risk, etc.

I volunteer weekly at an animal shelter to visit and care for the cats. I became an Eagle Scout at age 18 and planted over 300 trees for my Eagle Scout project. I met President Bush on Earth Day 2002.

I always wanted to be part of a team when I was in school. I did shot-put and discus for the track team and I ran cross country. Although I was afraid of needles, I overcame my fear to become blood donor. I voted in the 2004 and 2008 presidential elections, and took driver's education and passed my road test.

My parents have helped me through a lot of tough times and believe in my ability to learn and to work. I hope our Governor continues job hiring and the Access Pass for people who have disabilities.

What do I want? The same things you want. I want to have friends, I want to belong and I want to have enough money to live on my own. I don't want to be afraid of people and I don't want to be teased or ridiculed. I want to have friends. I don't want to be stopped from doing things because I have disabilities. Just because I have disabilities doesn't mean I only want to be with other people who have disabilities.

My parents always asked the question: How do we know what Matthew can really do unless we let him try?"

Lucy - age 39

"I live in a beautiful apartment which I got from my supportive housing program. It is one bedroom, big and near transportation and shopping. I am one of the few to have an apartment as nice as mine. It was my choice. I make choices on where I go and how I handle my life. I have freedom!"

Anonymous - age 40

"I live in a supported apartment program in one of the boroughs of New York City. The apartments are close to other people in the

program and staff come visit once a month or more if needed. The apartments are usually new or newer apts. The supported apartment program is a good program and needs more single apartments."

Peter - age 45

"I lost my mother when I was 19 and I immediately became homeless. I have slept on friends couches and for sometime I lived with my girlfriend. I spent a lot of time in city shelters and most of the time I was living on the streets or subway system. I turned to alcohol and became depressed, feeling no sense of being. I know that supportive housing will make a great difference in my life. It will give me a new start and a sense of independence and it will save my life. I would appreciate if this letter will be taken to heart."

Michele - age 56

"Until November 2008, I had no "quality of life." I had completely given up on life and was seriously contemplating ending the painful existence that was considered "my life".

I came to one of the boroughs of New York City in April 2007 from Gulfport, MS. I am a Katrina Survivor, and also a domestic violence survivor. I considered Katrina a blessing because it forced me to have to leave the home I loved so much that I stayed and took all types of abuse just to try and keep my home. My ex-husband and I owned a beautiful brick home which was heavily damaged by the storm. I was forced to evacuate my home from September 2005 until May 2006. We purchased our house in July 1994, and for the first time in my life I had a home of my own and had stayed there longer than any other place in my life.

My husband and I were together from May 1991 until February 2007. He retired from the Navy in 1993, and he became more and more abusive. It started out first verbal abuse, which escalated to physical abuse and then sexual abuse, whereby he transferred a STD to me. My husband owned a double-barreled shotgun, and an AK-47 assault rifle which he pulled on me so often while threatening

my life I became immune to his acts of violence. He was a very cruel man.

I had lived in madness for so long I developed chronic hives, agoraphobia, panic attacks, eating and sleeping disorder and anxiety and major depressive disorder. He was killing me even if he didn't pull the trigger.

When I fled to New York I was running for my life. Every agency I went to shut the door in my face. The only assistance I could get was public assistance which only gave me \$215.50 per month toward rent, and \$67.50 bi-weekly in cash assistance. No one could help me with getting a place to live, so I kept moving around and moving around until I lost all hope. I was tired of my existence. I longed for it to end. I contemplated taking enough pills so that I could just go to sleep and not wake up to face another disappointing day. I just wanted it to end.

I was placed in a NYC hospital for three weeks. During my stay at the hospital, I was given a pass to come to a program for individuals who are mentally ill and have chemical abuse problems (MICA programs). I had previously applied for the program but had no hope of getting in.

When I came to the MICA program on my pass from the hospital, it was as if a divine intervention took place. I met with Lucinda. She told me that she had a place for me to live, and as soon as I was released from the program at the hospital to come directly to her. She assigned Roberta as my case manager. Roberta brought me out to see my apartment and told me to come directly to her upon my release from the hospital and get my keys.

That day she handed me the keys to "my" place to live my life changed. I had hope again. Even though I have been diagnosed with PTSD, major depression, spinal stenosis, irregular angina, arthritis in hands, carpal tunnel and tendonitis in my right hand and shoulder, with a place to live of my own, it has made all these conditions easier to live with. I had forgotten how to live, how to relax and how to look forward to the next day. Now, the quality of

my life is much better. Thanks to the MICA program, it helped save my life and my sanity. My prayers were answered and each and every day I am grateful to the people at MICA for helping me get my life back.

Please don't cut this program. I'm not just asking for myself but for all the people who are victims of circumstances beyond their control."

Fred - age 48

"My quality of life is very good. I find all my needs are getting met. I pay for my own heat, electric and telephone out of my disability check. I do my own shopping in a neighborhood where transportation and stores are close-by. The greatest help is the financial assistance for rent. Without that benefit I would be in a shelter. A good quality of life is being comfortable in a neighborhood with no crime. The way to improve my quality of life is to get a job. I am in the supported housing program located in a borough of New York City. I enjoy reading, listening to music and exercise (walks). The program staff keeps in touch on a regular basis."

Male -age 35

"I live with my family. I would prefer my own apartment, but I can't afford it. My family and friends give me emotional, physical, religious, financial, housing and medical support. I attend college part-time and have some friends. I go to college but would prefer substantial work. I had a delay in finishing high school due to illness and its consequences. The medications I take cause side effects. The usual problems are compounded by the presence of illness and lack of work and health insurance. The worst obstacle to a better life is dependence on Medicaid for treatment and medication which prevent taking any job that would cause loss of Medicaid. One feels imprisoned by the system which prevents progress and kills the spirit.