

# Messages of Hope and Possibilities

March 2009



Imagine being told where you can live. Imagine that you couldn't leave the grounds...that you were forced to live there...told when and what you can eat...when you sleep and when you wake...who shares your room, what you watch on TV and when you watch it...where you go and when you can go there. How would that make you feel?

Well, in fact, many people with developmental disabilities in large state institutions feel isolated. Every aspect of their lives is controlled and supervised.

The following pages present descriptions of experiences within the walls of Illinois institutions for people with developmental disabilities. Presented in their own words and unfiltered, these are stories of our fellow citizens with developmental disabilities and their families...stories filled with courage, determination, hope and possibilities in pursuit of their freedom.



## DAVID'S MESSAGE: DREAMS

I'm David. I'm in my 60's. I lived with my mom for a long time. I helped her get her groceries and helped her with her walker. We had some problems and she had me arrested. After jail, I went to the institution. They checked my head but they couldn't find nothing wrong. It was clear. I never saw my mom again and she died. When I left, they were supposed to send me my stuff but I never saw it...my cowboy boots and stuff. I don't take any meds now. I used to sit all day. Now I'm busy. I have my own furniture and my collection. I collect horses. I can be by myself when I want to. I go on trips. I've been to the State Fair. I had lunch with an

**"One time I hadn't seen my family in so long, they came to see me, I didn't know who they was."**

~ spoken by a woman with a developmental disability in Illinois who lived in an institution

Amish family. I saw the old time trains. I've stayed at a hotel. I go to the YMCA and recently had my first pair of tennis shoes. I like to plant flowers. I do Meals on Wheels. Every week I take food to people who can't leave their homes.

They like to see me. I like to help. I want to go to a Dude Ranch and to the Kentucky Derby. That's what I dream of. I think it will happen. No more institutions for me.



**These stories were told by self-advocates and their family members to advocacy organizations such as Macon Resources, Inc. and other stakeholders. They represent their experiences and hopes for the future.**

~ Illinois Council on Developmental Disabilities



**ROBERT'S MESSAGE:  
FEELING GREAT**

I was six years old when they put me in an institution. I went there

because there was no place to go. I didn't like being in the institution.

I never went anywhere. People beat me up. They gave me bad food that made me sick. There was no work and no workshop and no spending money. I was going nowhere. No TV. No radio.

Living in the community is better. It makes me feel great to live in the community and be able to do the things I want and go places. This is better.

**SANDRA'S MESSAGE:  
HAPPINESS**

I was 14 years old. I had a nervous breakdown. My nerves fell apart, and I went to the institution for ten years. My family wasn't getting along.

I worked in the laundry. I folded laundry. I wiped tables off for the other people. I helped the old people. They didn't pay me nothing. They made me work with no pay and I didn't like that. No vacations or nothing.

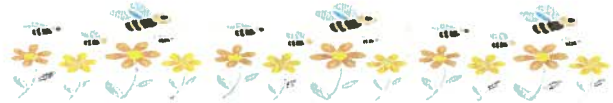
They gave you shots and different kinds of pills. They locked you up and wouldn't let you have a key. You couldn't go out. 24 hours a day staff. No privacy. Too many people. They cut your hair short. I don't know why they want to cut your hair so much. Some people pull your hair.

I got out and lived with three other women. Now I have my own apartment. Staff don't crowd me or boss me now. I'm still on medicine. I go out to eat, to movies, to bingo. I still get help with my nerves. I like the community. Institutions are no good for nobody. If you go through that, you know. I experienced it all. I've been through a lot. I'm happy now.



**"How would you feel if you lived with a bunch of strangers and never got to make a choice?"**

~ self-advocate in Illinois



**SHARON'S MESSAGE: VOICES BEING HEARD**

My name is Sharon and I am a person with a developmental disability who lives in her own apartment. I like living in my own apartment, and I also think that institutions are NOT the best places for people with disabilities to live in. In my apartment, I have more freedom than I would if I lived in an institution. I can come and go as I please, which I would not be able to do if I lived in an institution. I do not have a roommate, even though I did before, and I'm sure that if I lived in a place like Howe, I would have had several roommates and would not have had my own room. I can watch TV by myself in my own apartment and do whatever I want whenever I please. This has not always been my history.

My mother put me in Lincoln State School as a young adult, which was later called Lincoln Developmental Center, because she did not think I would be able to make it on my own in the community. I lived at Lincoln most of my adult life. I hated life at Lincoln. I was just put in there, and I didn't want to be there! The staff told us when it was time to take a shower, when it was time to go to the cafeteria, when it was time to go to bed. At times I felt like I had time to myself, but mostly not. There was nothing much to do during the day. Now that I get disability services in the community, I am so busy and glad that when I come home, I'm tired. At Lincoln, there were girls' dorms and boys' dorms and I definitely feel like I have more privacy now. I left Lincoln Developmental Center when it closed down, and I am much happier getting services in the community than I was getting services at Lincoln. I don't know where I would be if Lincoln hadn't closed.

You can say what you want to say about "the handicapped", but we have rights and opinions and our voices need to be heard.



**"I lived in an institution. I like community better. I don't have to worry about getting locked up in a dark room."**

~ self-advocate in Illinois



**LARRY'S MESSAGE: PRIDE**

My brother Larry moved into Shapiro Developmental Center when he was 18 years old. Our Mom died when Larry was 13. He didn't understand the death and it was hard on all of us. He finally had to go to the institution, where he stayed for 22 years. In Shapiro, he had lots of outbursts; there were lots of fights going on. They changed his room a lot due to roommate difficulties. Since he has been in the community for a year and a half, he has had only one outburst.

I didn't know what to expect of him moving from a larger state facility to a small home. It was a smooth transition. He visited the home and he liked it, so then he stayed overnight and he liked that. He visited the workshop and then went to the home again for dinner. He did really well.

Larry has gone through so much. We had an explosive environment as children. There was abuse and neglect. To see him turn out the way he has is a blessing.

Larry has always been afraid of women. Since he moved to the community, he has a girlfriend from his "workshop job". They go on dates and he pays. We went on a double-date with him and his girlfriend. He is very happy. His meds have been changed and he takes less than he did in the institution. He lives close to us now and he has more home visits, which we all like. Most important, Larry is happy.

I would like to tell other families to 'try it. You will see a change in your person'. You will never know the outcome if you don't try it. I loved Shapiro but it's an institution. The group home is more like home. There are less people and more one to one attention. You can smell the food being prepared. The food is better. It is home. He will ask us now: "Are you proud of me?" And we are proud of him. Families should try it.

Jacqueline (Larry's sister)

**"I never broke a law, but I was sent away and locked up."**

~ self-advocate in Illinois

**FRANK'S MESSAGE: RESPECT**

My son was at Howe for about a year and a half, which was entirely too long. My son's appearance was neat and clean when I brought him to Howe on his first day. He was happy, excited, and expecting new experiences. None of these things happened.

On my first visit, he was unshaven, wearing mismatched clothes and looking very unhappy. The women staff people working in the cottages were dressed very risqué, the clients living in these cottages were all male. The clients were in a room sitting in a circle doing nothing.

Very soon I found my son's clothing missing—personal items missing—underwear, t-shirts, socks, coats—I mean everything. My son stopped speaking, became very quiet and not interested in anything. Incidentally, I saw staff wearing my sons clothing at times. Ironically, a staff person had on a shirt of my son's at a staffing. My son and I both looked in awe. When I broached a supervisor about this, she did nothing. Howe should have been closed the day it opened.

Our adults with developmental disabilities deserve the best to them that can be given. They deserve respect, a chance to develop their potential, get out in the community, enjoy sports and to socialize with everyone. Since my son has been at South Star Services, he has come back alive. He talks, he laughs, he enjoys people, loves all staff at work and at his CILA. He goes bowling, out to eat, parties at home and work. Best of all, Special Olympics. He does chores and his clothes are intact. He loves being clean and looks forward to each new day.

I know things at Howe went on that I'll never know about. However, the things I do know about is what every parent and agency should know. South Star is the best! Our staff is the greatest, most knowledgeable, compassionate, understanding people I know. I am so grateful to my son's community services and so is my son.

Grace (Frank's mother)



**"In the institution the staff treated me like I was nothing but a big series of behavior problems. I try not to remember the institutions."**

~ self-advocate in Illinois



**DANNY'S MESSAGE: FEELING SAFE**

My life? It's been rough. I could write a book. In school the kids took my money and called me names. My mom abused me so I went to Adolf Meyer. It was okay. I was safe from her. There were lots of people there and some people heard voices. It was okay, I knew they couldn't help it. They treated me good. One time my uncle dared me to steal a bike out of a garage. He dared me so I did it. The police pulled up and I went to jail. He didn't go to jail. Then they sent me to the institution down south. It was bad. I was in a small room, tied to a bed. This guy burnt my shoulder with a cigarette. I told another staff on him and they laughed. They were mean to me down there. Why do they do that? It's cruel. I was scared to talk about it but now I can. I thank God I'm out of there.

Now? I feel safe. People don't hurt me. I feel safe in my apartment. No one can get in my building. I trust people here. I keep my apartment clean. I even fold my dirty laundry. Food tastes good here. I go out to eat. We go places. Seen snakes and a turtle. I saw Abraham Lincoln. I'm not scared of the swim pool no more. We went to a museum and learned how Black people were treated bad. It made me sad. It's sad when people beat up other people. I can relate to people being hurt. I passed out letters to the Governor. I'm proud of that. I feel good about my life now. I'm happy. People like me.



**STEFAN'S MESSAGE: LIVING IN MY OWN PLACE**

A long time ago I was living with my Mom and she said she couldn't get along with me cause I ran away from school so she put me in Adolf Meyer. After a home visit with family, they would check you for bruises and if you had one, you couldn't go home the next time. They used to put us in a little room. It was sound proof and just the four walls and you couldn't look out at anything. You stayed in there all day. They said I stole something and they didn't let me go home that weekend. I was there a few years. While there, I started coming to classes at Macon Resources during the day. When it closed I got out.

I've been living on my own a long time. At Adolf Meyer you had to do what you were told. You had to go to bed at a certain time. You had to room with other people. It's better than staying outside. You had a roof over your head. I really like living in my own place. It's fun. You can go places. You don't have to worry about somebody telling you what to do. You keep your own keys. You take the bus places. You go to bed when you want to. You eat when you want to. We have rules, but we have freedom too. It's different in the community because you have freedom and you can do stuff.



**"My staffings in the institution were all about what I did wrong and they said I wasn't trying hard enough. I said I tried my best but they didn't believe me. In the community they believe me, support me and respect me."**

~ self-advocate in Illinois



**GWYNNE'S MESSAGE: FAMILY**

My sister Gwynne was born December 3, 1952, in Joliet, IL. Our mother was afflicted with German measles during the pregnancy. Gwynne was slow to develop. Born 1947, my memory of those years is indistinct, but a diagnosis of Gwynne's condition came slowly. Meningitis and other possible afflictions were explored. Truthfully, doctors offered little help, prescribing tranquilizer drugs, usually Thorazine.



Both parents worked, commuting to Chicago, and our grandparents were active in Gwynne's care. She did not enter conventional school or preschool, but attended Trinity School in Joliet for a time, a day school for children with special needs. She was happy there.

In 1962, our parents divorced. Our mother was awarded custody of us both. She and I moved to Chicago when I started high school, while Gwynne remained with grandparents in Lockport, Illinois. In time, the grandparents felt unable to care for Gwynne, who was relocated to a state-affiliated residential facility in Dixon, Illinois.

Gwynne remained at Dixon for a period of months. It was a filthy, inhuman, foul-smelling place. Gwynne resided with much older, aggressive, hostile women, who taught her to curse, and forced her to defend herself. Each time family members came to visit, Gwynne thought that they were coming to take her home. After a nice day visiting public parks, McDonald's, and shopping malls, Gwynne would become hysterical when asked to get out of the car and return to her residence. I have never heard such despair from a human voice in the 45 years since passed. After a few months, our father went to visit Gwynne at Dixon in 1963, and took her home to his residence in Lockport. Gwynne lived there until his death in 2000. She was cared for, and she had grandparents next door, assisting with her care, until their deaths in 1990, but she did not attend a school or workshop, and her interaction with the community was infrequent, visiting malls and fast-food chains. The situation was imperfect, but generally, stable.

After our father's death, Gwynne joined our mother in Chicago, who began plans anew for Gwynne's well-being. We were referred to a Chicago pediatric dentist, Dr. Mary Hayes, who restored Gwynne's smile, and we were also referred to a talented and committed physician, Dr. Kristi Kirschner, at Rehabilitation Institute of Chicago, where Dr. Kirschner and her associates specialize in treatment of women's issues and disability-related afflictions. These sudden and significant changes in Gwynne's life were, initially, problematic. Each time she went outside, Gwynne feared needles or invasive medical procedures. At one point early on, in Dr. Kirschner's office, Gwynne was so afraid of a blood test that she attacked a nurse physically, from a perceived need for self-defense. Also, for a time, Gwynne's menu of medication included Risperdal, a strong drug used to treat mood swings, and one which has very undesirable and dangerous side effects. Over time, however, assisted by Dr. Kirschner and other physicians, Gwynne has come to understand that medical procedures are necessary and beneficial. She discontinued the Risperdal in July of 2008, and now has no trouble with blood tests, flu shots, or needles.

Since 2002, Gwynne has attended a day workshop at Anixter Center in Chicago, where she interacts with peers and counselors, goes on field trips to museums and places of interest to local residents and tourists, and receives ongoing care from counselors committed to helping her better understand and enjoy life. One day per week, she works and receives a very small paycheck, usually stuffing envelopes for mail-order firms, filling bags with toys to be distributed to children attending Disney movies, that sort of thing. Anixter has become her family, so to speak. Her program at Anixter will shortly be increased from 4 days per week to 5. Unfortunately, approximately 15 months ago, her vision declined sharply from glaucoma and other complications. Cataract surgery failed to yield benefits.

In summary, Gwynne, despite many undesirable events in her past, is now probably happier than she's been since childhood, as a result of capable treatment by a variety of professional people and the assistance of committed counselors and community support agencies. Our mother passed away in August after a long illness. Gwynne has resided with me, her elder brother and court-appointed legal guardian since May of 2008. Soon, a residential plan for her long-term care in the event of my absence, disability, or death must be embraced, and this project is underway. The challenge, of course, is to find a place for Gwynne to live where good care is available 24/7, and where the well-documented horrors of substandard care, and neglect, are never to be found.

Greg (Gwynne's brother)



### TIM'S MESSAGE: QUALITY OF LIFE

I hope that families of those individuals who live in institutions will seriously consider community placement for their loved ones as my family did for our brother Tim.

My brother Tim is 56 years old. He enjoys listening to music. He also likes helping in the kitchen and helping with the laundry. Family holiday traditions are especially important to Tim. He looks forward to weekend visits to our home.

Tim is developmentally disabled and testing indicates that he is in the severe-profound range of mental retardation. He is autistic, non-verbal, and has incidents of self abuse. Tim was also a resident of two different state operated facilities for about 28 years.

In 1991 when my family learned that the developmentally disabled unit at the state operated facility where Tim resided was closing we were very concerned. It was recommended that Tim be in a group home. We weren't sure that Tim's needs could be met in a community placement; however, after several months of consultation and visits, Tim moved into a group home in Pekin and began a day program in nearby Morton. It was not an easy transition for Tim but after several months Tim, his new peers, and staff members became more comfortable with each other. Tim has been in that same community placement for almost 17 years now. Although Tim still has some challenging behaviors, our family believes there are definite advantages for Tim living in a community placement as opposed to a state operated facility.

These are some of the advantages:

- His group home is more family-like and a quieter and calmer place.
- There are some higher functioning residents in the home who model appropriate behavior for Tim.
- Tim has had fewer incidents of self-abuse.
- Tim has more opportunities to get out into the community.
- Tim is more willing to participate in his day program. He is now earning a small paycheck for crushing cans and folding linens.

For these reasons, I believe that Tim's move to a community placement has improved the quality of his life. I hope that others will have that same opportunity.

JoAnn (Tim's sister)



Tim helping out in his family's kitchen

**"You can come over now because I have a real home and I have a real life."**

~ spoken by a man in Illinois to his family after moving out of an institution

### RENA'S MESSAGE: SPEAKING OUT

Hi. My name is Rena. I'm 46 years old. I was born with Cerebral Palsy. My family couldn't take care of me any more. My mom died so I went to an institution where I didn't get to do that many things.

Then I got the opportunity to move to a group home with six other housemates where I got to do more things. I went to a carnival and got to ride the tilt-a-whirl. That was fun. I got to go to concerts and out to eat with friends and shopping and to the movies. I have my own job at home smashing cans and to earn some money. I love doing that.

I also participate in Illinois Voices. I get to speak out my opinion on things. Sometimes I get paid for that. A lot of people think they have to do things for us and we are people too and we can do a lot of stuff for ourselves and they let us do that in group homes. We are treated like everyone else and I like that. And living in group homes are more like a real home setting than institutions and they can be mean to you. In group homes, people are nicer and listen to you like a human being.

Then I got the choice to move in an apartment with one other girl and that's what I always wanted to have is my own apartment. But I do wish there were more jobs out there for us and hopefully one day there will be.





**MARSDEN'S MESSAGE:  
SIMPLE JOYS**

My brother Marsden moved to an institution when he was four years old. He has lived in three Illinois institutions for nearly 50 years. He got good care in two of the facilities but not the other one. When they told me they were closing the

institution and he needed to move to a community group home, I was not happy! As his sister and legal guardian, I wanted what was best for him and I didn't think he would be happy or successful in a small group home. Marsden is blind and profoundly challenged. He used to roam and walk the long hallways at the institution. Where would he walk in a small group home? He also had some behaviors that I didn't think could be handled in the community. However, we tried it. We spent a lot of time in helping him with the transition. It took some adjustments and there were good people to help him. He had suffered some abuse and he had to get over some bad stuff. I am grateful to the people who took the extra steps to be with him.

People don't think he has any gifts to give, but he does. His great gift is to love unconditionally. He has an innate ability to recognize people by their voices. He has a great sense of humor. He loves to be in the community with one staff. His favorite thing is to listen to tapes at the library. He loves to go to the park and outdoor concerts. Being in a small home has exposed him to interact with people in a different way. Instead of such a large group, he has made real friends and has been more social. He still has behavior problems but they occur less often. It has been a real credit for him to be in a smaller place.

I encourage other parents/families to consider community placement for their loved ones. There is an adjustment period but it can be very successful and worthwhile. I encourage people to give it a fair chance. There are a lot of advantages. It can be the simple things that bring joy. It is fun for me to see him go in a car with just a couple people for something as simple as an ice cream cone. That never existed in the institution.

Carolyn (Marsden's sister)



**GEORGIA'S MESSAGE:  
FREEDOM**



When I was a teenager they put me in the hospital. My parents couldn't take care of me so from there they put me in the institution because there was no place for me to go.

I didn't like living in an institution. I didn't like it at all. They would steal my clothes. Clients would throw chairs and hit me. They don't let you go outside. They make you stay inside. They don't let you wash your clothes or nothing. They don't let you get your own money. They don't let you have coffee either! We had food trays but they were no good. The food was really bad. I didn't like just sitting there. I had a roommate who would holler all the time.

No, I don't like living in an institution. I wish they would close them up. I like living in the community. I can go shopping, out to lunch and out to dinner. I'm happy now. Everyone should be able to live in the community and have freedom.



**JOE'S MESSAGE: BETTER  
LIVING**



I was in Howe in Tinley Park. I didn't like it. They treated me bad.

They took my radio away. The staff didn't make any sense. They were mean. They beat the clients, they beat me too. They called my mother dirty names. I couldn't go anywhere. I didn't like anything about it.

I like living in the community better. They treat me good. I can have a radio and everything. I can do what I want. I like going to workshop and earning money. It is better living in the community. I like going on vacations. I don't want anyone to live in an institution.

**"Those who deny freedom to others,  
deserve it not for themselves.**

~ Abraham Lincoln, April 6, 1859



