



Our Stories

Celebrating

Four Decades of Living
in the Community

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Over the past forty years there has been a tremendous change in how people with developmental disabilities are cared for in Massachusetts and throughout the country. In the first half of the 20th century, parents of children with developmental disabilities were encouraged to place them in institutions early on. The thinking was that these children required too much special care for families to deal with, the public schools weren't equipped to educate them, and that institutions were the best place for them. Families who decided not to place their children in institutions had to fend for themselves. The network of services that could support families to care for their special needs children at home had not yet been developed. The only alternative to the state institutions, a small number of private programs, were only within the reach of the very rich.

The institutions for the mentally retarded, called State Schools in Massachusetts, were created in the 19th century as part of a reform movement. Prior to that, the state assumed no responsibility for caring for people with intellectual disabilities and they, along with "all rogues, vagabonds, and idle persons," were relegated to almshouses. In 1751 a hospital in Philadelphia created a separate section for people with mental retardation and people with mental illness. By 1756 they were putting these people on display for a small fee.

While the State Schools were initially hailed as an improvement, funding didn't keep pace with need, and over time the institutions became overcrowded, conditions deteriorated, and quality of care fell.

In the 1960s the principles of the Civil Rights movement began to be applied to other disadvantaged groups whose rights were being denied. In 1963 President Kennedy tried to reverse the flow of people into public institutions. He called for a reduction "over a number of years and by hundreds of thousands" of the people confined to residential institutions. He asked that methods be found "to retain in and return to the community the mentally ill and mentally retarded, and thereto restore and revitalize their lives through better health programs and strengthened educational and rehabilitation services."

At the same time, parent groups were established to improve the lives of their children with intellectual disabilities. In 1972 Benjamin Ricci, President of the Belchertown Friends Board and the father of Robert Ricci, a resident of the Belchertown State School, filed a class action suit against the

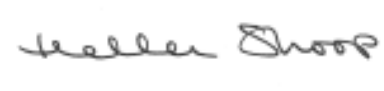
Commonwealth of Massachusetts for the sub-standard care provided at Belchertown and four other State Schools in Massachusetts. This suit resulted in a consent decree that required the Commonwealth to greatly improve conditions in the institutions. Rather than rebuild the institutions to provide top quality care for the thousands of residents who were living there at the time, the Commonwealth used the consent decree as an opportunity to invest resources in building a model system for care in the community. Though the state followed through in upgrading care in the institutions, they steadily moved residents out into community programs, reducing the population in the State Schools over time.

MAB was an early participant in the de-institutionalization movement. In 1973 MAB worked with the Commonwealth to design a residential Life Learning Program to prepare people who were both blind and intellectually disabled for life in the community. The program was housed at Sunlight House in Scituate, which MAB had used as a short term vacation house for people who were blind, including blind residents of the State Schools. The first longterm residents of Sunlight House were eight men who had lived their entire lives in institutions and lacked even the most basic personal skills. They could not count, brush their teeth, or even recall their own last names. The severe social retardation that life-long institutionalization had forced upon them had discouraged them from ever trying to take care of themselves. At Sunlight House, these men were assigned responsibilities, instructed in daily living skills, and given job training. Within eighteen months, they all held reasonably demanding jobs, and with the help of a volunteer, arranged a trip to Washington D.C., which included having lunch with their congressman.

Now almost forty years later MAB serves more than a hundred adults who are developmentally disabled or brain injured, in residential, vocational, and day habilitation programs in Greater Boston. It seems most fitting to celebrate this move to community living through the life stories of some of the people we serve. Their stories dramatically illustrate the great change that they have born witness to in our society.



Barbara Salisbury
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Heller Shoop
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As the father of three healthy,



Steve with his nephews Alex, Ben and Danny.
Photo courtesy of Gary Blumenthal.

active and mischievous young boys, I often ask myself how my mother ever survived having five children. Life for my mom, Blanche Blumenthal, was much tougher. Widowed in mid-life with five kids under 18, including my younger brother Steve, who had autism, she had to face schools, social service systems and a community ill prepared to welcome her or my family into the fabric of our hometown.

During this time – the mid-1960s – school systems throughout the nation felt no shame in closing their doors to people with disabilities. My mom, with no other options, had to make a profoundly painful decision and put my brother in a state institution for people with mental retardation.

It is impossible to fully describe the grief this decision brought her and our family. Traveling 300 miles round trip, once a month for years, did little to ease the pain. Our pain turned to torment when we learned that during these and future decades, many of these institutions provided little more than “three hots and a cot” in locked and isolated wards, and were often cited as repositories of abuse and neglect.

In the late 70s, Steve was given an opportunity to return to our home community to live in a county operated program that offered a sheltered workshop and a rigid group home that had difficulty dealing with Steve’s behavioral challenges. That placement lasted only three years, and Steve found himself back in another institutional placement for another 15 years. Finally in 1995, one week before our mom passed away at age 83, a wonderful community program, Community Living Opportunities of Overland Park, Kansas, developed an individualized employment and residential program tailored to his individualized needs.

Thus for the last 17 years, Steve’s life has been fulfilling and active in his local community working and playing alongside both people with and without disabilities. His success has been mirrored by thousands of others aided by strengthened community programs that develop individualized service and support plans. He and his roommate of several years now live with a wonderful family in a shared living program that they both love. They are supported by a wonderful family that includes a mom, dad and two adorable young kids. Steve loves his home life and his busy day activities that include work, exercise and numerous community outings.

The irony of my family’s life is that my mom spent years trying to get Steve back home. She succeeded in that quest, but sadly only saw one week of his successful life back home in our hometown. Each summer, Steve, accompanied by a direct support professional or a family member, visits us in Massachusetts for a family vacation. I often think of how happy my mom would have been seeing Steve living a fulfilling life in his own home in the community. Hopefully she knows.

A handwritten signature in black ink that reads "Gary H. Blumenthal".

Gary Blumenthal
President and CEO
Association of Developmental Disability Providers

Bob

My father was an alcoholic and always came home drunk. He picked on me because I was the youngest; couldn't pick on my brothers because they would break his neck. He'd take a chain and try to choke me with it. I was born blind and had seizures where my right hand would shake and everything would be spinning around and I couldn't speak. Somebody suggested to my mother that they put me in Monson State to see if they could cure me. I was twelve.

Monson State was murder. Oh Christ! They were going on like mad men over there. Yelling, screaming, and hitting each other. They had me working all the time. I had two wards that I had to take care of, 12 patients in one and 14 in the other. I had to bathe them, shave them, even had to dress a couple of them. Some would want to go out, so I would take them out, and bring them back. About half the time I couldn't take them out because I was the only attendant on the ward.

I had to work day and night with no help. One time the superintendent came in and said, "where's the rest of them, the paid help?" We took a walk to the attendant's rooms. I had a key that opened every door. We went down the basement, I opened the door and there they all were, dead drunk, sleeping it off. Then he says, "You got any more?" I said "yeah, one more floor." So we went up on the last floor. Same thing: sleeping. That's around when I started getting ready to leave Monson State. My social worker said to me, "do you want to leave Monson State and go to a group home?" "Well," I said to him, "I'd rather get out than stay."

I met Theresa at Monson State. She was my girlfriend all these years. I took that girl everywhere. Even places she didn't want to go, she went anyway. I took her to KFC out in Brighton, Newton, took her to one there, Country Buffet at the Watertown Mall. Theresa dying was a real heartbreaker. She died just about where you're sitting, in that chair. We were gonna get married, but she said she couldn't on account of her seizures. She'd black out now, and then fifteen minutes later she'd have another. I did everything I could for her.

Somebody suggested to my mother that they put me in Monson State to see if they could cure me. I was twelve.

I've had the same friends for almost forty years. Curtis and Albert were at Sunlight House with me in Scituate. Richard and Donny were at 190 Ivy Street. Donny's real smart, that and then some. He goes to work without a cane. And Richard has a big record collection. Saw half of them and said, "what the heck do you have here?" I love country music.

The big man upstairs isn't ready for me yet. If I had to live my life all over again I don't think I'd change any of it; leave it the way it is.

Based on an interview with Bob, MAB resident since 1974, who lives in Dedham.



Reggie

When I was born they left me in the incubator too long, so I didn't have much sight, just light perception. My father didn't like me very much. He drank a lot and would get violent. One night he got drunk and dropped a cigarette in the bed and my baby sister died in the fire. I had problems with my kidneys and wet the bed. My mother would make me take all my clothes off and then she'd use a belt on me. She used the belt a lot. When I was four they put me in Fernald because they didn't have any other place to put me. I didn't have any choice.

When I went to Fernald, the children were in ward 21 and the little babies were in ward 22. To the left of ward 22 was a nursery with little, tiny babies. My family would visit on holidays, once or twice a year. We'd sit out in the lobby. I didn't say too much to them; I was very upset.

I had lots of jobs at Fernald. Every day I had to make 24 beds, six in each row. On Wednesday mornings I had to strip all the beds, put a sheet in the middle of the floor, throw all the sheets inside, and tie that sheet up. After that I'd have to put all new sheets on the beds. If I didn't do what I was supposed to do, Ms. Gusten would tell me, "If you don't have all those beds made by the time I get back, you're going in isolation." So I had to make the beds; I had to.

I got along with the day nurses. I used to be Ms. Burke's favorite because I would tell her what's going on from the eleven to seven shift. I had to take care of the patients that were more disturbed; the ones that would chew their fingernails off. I had to put socks on their hands. I never got bitten by them because I knew when they were going to bite me, and I would put a pillow in front of me, like this: you center the pillow, so when they bite, they bite the pillow.

When I was in my teens I left Fernald and went to the Protestant Guild. They had to teach me a lot: money skills, how to cross the street, how to turn your body so you don't fall off the curb, how to learn the inside of a building so you could find the room you were staying in.

When I was at Fernald, me and my friend David used to watch the freight trains a lot. We would know when a freight train would come to the Shell heating plant at night. At the time it was a B&M railroad, 'till it changed to Conrail. There's a lot of history about the trains. You'd ask questions and learn a lot of things, like how things were shipped, how supplies were put in, what kind of cars they had. I started learning the bus routes when I was at the Protestant Guild. I learned the schedules so if somebody needed to take a bus somewhere, I could tell them. There are 179 bus routes and I know the schedules for half of them, but I love trains the best. I go with the Mystic Valley Railway Society on train trips every year. Two summers ago my roommate Gordon and I took a sleeper car to Montana for a train convention.

Me and Gordon share an apartment in Brookline. Philip is my case manager—he watches out for me.

Based on an interview with Reggie, a MAB resident since 1974, who lives in Brookline.

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Ruthie

When my sister Ruthie was born in 1933 they had to give her a transfusion, and the procedure caused a seizure. They did an X-ray and saw a huge black spot on the top of her brain. The doctor told my mother that the baby wouldn't live to be a year old and that the best thing to do was to place her in an institution. When Ruthie was five months old my mother took her to the Fernald State School, kissed her goodbye, and never went back.

For years my mother thought Ruthie had died. Fifty-five years later a friend of my mother's contacted her and told her that Ruthie was still alive and was living in a home for the blind outside of Boston. My mother was stunned. We couldn't believe it. None of us ever knew about Ruthie. After learning that Ruthie was alive my mother took a trip to Massachusetts. She found out where Ruthie was, but she couldn't bring herself to go see her. It was too painful to her that she had abandoned this baby.

Five years later I asked her if she wanted me to go with her to Massachusetts to see Ruthie. She kind of jumped at the idea. We didn't know what to expect. We didn't know how she'd feel about meeting us.

We were there for a week. She loved going shopping, so the first place we took her was to the mall. We were going down the aisles and, oh my God, it was so much fun. Ruthie could only see a little bit, but she loved the color red. She picked out a red sweater and a red blouse. When we went to the counter and checked out, she'd stop everyone we met and say, "I got this." She'd open the bag and pull the sweater out to show them. She was so happy; it was amazing. She had perfectly picked it, you know?

When I first met Ruthie I didn't know what to expect when we took her out. I thought, "Oh my God what are people going to think? I'm not going to be embarrassed she's my sister. I'm going to take her anywhere I want and people can just get over it."

Ruthie died a year ago March. During the last thirteen years of her life we became real sisters. We talked on the phone, baked cookies together and went to the beach. We picnicked in the Redwood Groves and went to a hot air balloon festival. She loved going bowling, and especially liked the pink bowling shoes. She always had a big smile for everyone she met.

She couldn't read or spell, but she knew so much about people, how to make them feel comfortable; how to make them happy. She loved magazines. She'd draw with markers on each page. "I like that," she'd say. So exuberant. She had a boyfriend and went to dances at church. "Did you go with your boyfriend?" I'd ask her on the phone. "Yeah," she'd say. "Did your feet hurt?" And she'd always say, "Don't worry about that."

Based on an interview with Ruthie's sister, Karleen, and in memory of Ruthie herself, a MAB resident for 35 years.

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Donny

Donny was born perfect. When he was two they noticed his eyes were the color of pansies, purplish. Something was wrong, but he could still see. His older brother died in a fire. His parents had gone through a lot, and didn't want to risk Donny having surgery. It was the 30s, and they didn't have the medical advances they have now, so they decided to wait until Donny was five. The surgery failed, and left Donny totally blind, deaf, and mentally challenged.

The following year they put Donny in Wrentham. His mother wanted to keep him home but he needed too much care. His brother was eight and the doctor thought he'd be neglected if she had to care for them both. She had a break-down when she had to put him in Wrentham. It was tough.

There were people there who were wackos. They'd hit you, spit on you, push you. It was a real scary place. I went twice to visit Donny at Wrentham and had nightmares after both times. There would be a little old man with a beard sitting in one of those walkers that you put kids in to shuffle around in. Picture it if you can. It was awful.

There was nothing going on at Wrentham, no programming. It wasn't until they were training Donny to leave Wrentham thirty years later that they taught him to use a washing machine and iron, to cook and sew and do Christmas shopping.

Donny runs the show. He worked in the kitchen at Boston College for years. BC was very good to him.

Donny would be just as smart as his brothers if he could have heard better. We bought him a bookcase and it came in pieces. He put it all together by himself with a screwdriver. Last Christmas he wanted some headphones and, of course, I didn't know how to hook them up. He took them out of the box, stuck them behind the TV and said, "Janet, color..." He knew there was supposed to be colors on the end to match up. He's a very smart man.

Donny runs the show. He worked in the kitchen at Boston College for years. BC was very good to him. He'd wear a BC sweatshirt and make sandwiches. I'd call him and ask what he did that day and he'd say, "1,000 sandwiches, one lettuce, one tomato, one cheese, one lettuce one tomato, one cheese." He had a girlfriend there, Ruthie Bradshaw. She was sharp as a tack, but Grandma didn't like him to have a girlfriend. Grandma said, "Donny, what did you buy Ruthie for Christmas?" He said "hairbrush," and then he leaned over to me and said "coat, size 9." I'll never forget that; he knew Grandma didn't want it and he knew I could care less.

I call Donny every night. My children call him. At Christmas he's the one who gets the most presents. My husband died five years ago and I know that Donny still misses him. They used to rough house and my husband would take him out in the boat. My son takes him on the boat now, and Donny sits on the wave runner. They put the chair in and he has his feet in the water. He is king for the day.

Based on an interview with Donny's sister-in-law, Janet. Donny, 75, lives in Hyde Park.





Paula

My mother was a Rockette. She knew people in show business and traveled around performing. That's how she met my father. He was a top car salesman. They were always entertaining. Frankie Fontaine, Crazy Gugenheimer from "The Jackie Gleason Show," came over and sang and played piano during one of their parties. We had a big house and a pool.

It was the summer of the 1967 World's Fair, and we lived in Montreal just north of Expo '67. Paula was six years old at the time. My parents were having a party and the dog got loose and ran off. Paula was chasing the dog, trying to catch her. She ran across a street, a big two lane highway, and a car hit her. It wouldn't have been that bad, but the driver had a dog in the back seat who was barking at our dog; the driver was trying to restrain her dog and she hit Paula again, in the head.

Paula was in a coma for eight or nine months. The doctor was concerned that not enough oxygen was getting to her brain and that even if she came out of the coma she'd just be a vegetable. They tried an experimental procedure where they put a tube in that went from the carotid artery in her neck to a little valve up in her brain, pumping oxygen. A month later she regained consciousness.

Paula came home in a wheelchair and there weren't any ramps in our house. My brother and I carried her up and down the stairs. In the winter, and winters are about nine months long in Montreal, I would put her on a sled and pull her down the driveway to the school bus. At the time they were big on integrating handicapped people into the schoolroom, but Paula hated it. She said, "They just put me in the gym

She loves MAB's music class, and talks about going on the road with her guitar, singing "Lucy in the Sky with Diamonds."

and leave me there." They didn't understand that her eyes didn't work well. The muscles were all spastic. She never learned to read.

My father left. He just couldn't deal with it, and after he left we had no income. My mother started hanging out with a biker group, selling psychedelic drugs to feed us. Things were tough, so she decided to move back home to Boston where she had family. My mother, my brother and I moved, but Paula stayed in a hospital in Quebec for three years, with no family, before my mother, fighting with immigration and social security, could figure out how to bring her to the U.S. to live with us. My mother was devastated that she had to leave Paula behind. She went from having a nice house, nice clothes, fame and parties, to being on welfare and living in the projects in Somerville.

When Paula finally came here they placed her in a nursing home. I remember walking into the mess hall and Paula was sitting with her head on the table shoveling food into her mouth. We were horrified. Then there was some type of scandal and my mother got her out of there. She went to Crotched Mountain for several years, and when she graduated my mother moved to a first floor apartment so Paula could come home. Before she died, my mother made sure Paula was settled at MAB.

Paula's got a lot of my mother in her. She's a little fashionista, loves to shop and talk about being a fashion model. Paula's been strumming the guitar and singing since she was little. She loves MAB's music class, and talks about going on the road with her guitar, singing "Lucy in the Sky with Diamonds." She goes on vacation up to Hampton Beach, and loves going to bars. My mother was determined that Paula could do normal things like everybody else. Paula's a survivor, very, very much a survivor.

Based on an interview with Paula and her sister, Laura. Paula, 49, lives in Hyde Park.

Judy

There's an old wives' tale that if the husband fooled around while the wife was pregnant, you'd have a retarded child. So when Judy was born my father felt very, very guilty. He was an excellent provider and a good father, but because he had a tremendous guilt complex, he spoiled Judy rotten.

Judy wasn't learning to take care of herself at all, and when she was 11 or 12 they convinced my father to put her in Fernald. They convinced him that she'd have a better life there, but Fernald was kind of depressing. There was a lot of screaming, a lot of people out of control, and a lot of people trying to control them. Sometimes it was hard to tell who was doing the controlling and who was being controlled. It was a big facility.

When Judy was at Fernald we'd all go see her every Sunday. We were a family of ten children and we'd all get in the car and go visit Judy. We'd have a big Sunday dinner and take her out for ice cream. It was mandatory, part of the family routine.

After a few years they informed my father that Judy had progressed as far as she could and they were going to put her to work in the laundry. My father looked at them and said, "If she's going to do anybody's laundry, it's going to be mine, at home." And he took her out.

After dad died, Judy came to live with me. I was in the bar business at the time, managing clubs. She would come with me during the day and she just loved it; sitting there and talking to all these people. People would have long conversations with her and never realize that she was retarded.

I felt it would be better for her if she had something more structured than living with me. In the club business, I'd be coming home at three in the morning. Judy had to wake up at seven to go to her day program at eight o'clock. One of the neighbors would come out and find Judy sitting on the porch waiting for her ride at 3:30 a.m. She couldn't tell time. A lot of things weren't quite right.

My sister Joanie, may she rest in peace, loved Judy and was very, very helpful in taking care of her. One time she called me up and said, "I'm going on vacation to Aruba and I'm taking Judy." And I said, "Why would you take Judy to Aruba with you?" And she said, "Because I want someone to come with me, but I don't want them to tell me what to do. Judy will go anywhere I want to go, and she's a lot of fun to be with." So they went to Aruba and had a great time, went out gambling every night.

I came to a conclusion a long time ago: we're all retarded in one way or another. There are certain things that I just can't do, but I excel in others. I have a terrible problem with people's names. Judy, on the other hand, can remember anybody's name from nine million years ago.

At the old institutions, they didn't have any rights. The thing that's great about MAB is that they respect Judy's rights as a human being. They speak to her like she's a person, and she keeps developing. Part of the day is spent trying to improve her social skills and her ability to be out in public and things like that, which is tremendous.

I just want her to be happy.

Based on an interview with Judy's brother, Jack. Judy, a MAB resident for 25 years, lives in Hyde Park.

Brian

By age two, Brian had had five surgeries on his eyes, which left him totally blind in one eye and with light perception in the other. They diagnosed him as being moderately retarded, so right from the beginning the doctors were telling my parents to institutionalize him. My mother would cry for weeks on end. My dad was just stubborn Irish. "That's not going to happen. Not my boy; not my son. We will keep him home."

It's like everything I remember them saying he couldn't do, he's doing. He's independent.

"No, Diane, no I don't like it when dad yells." We were in that room for four hours, doing it over and over again, trying different techniques. Periodically, I'd hear my parents eavesdropping and whispering at the door. We had high and low points, but after four hours we walked out and I said, "Brian, do you have something you want to show mom and dad?" And he said, "Yes, mom and dad, I have something I want to show you. I can button my own shirt." And he proceeded to button his own shirt. Mom and dad both sat there and sobbed.

My dad taught Brian to swim. He was afraid of the ocean because he couldn't see it coming. But the lake was okay. My dad would walk backward and Brian would rest his hands on his palms, and step by step we got Brian into the water. He would go out as far as his waist and splash. There are pictures of him head up to the sky laughing because he actually enjoyed being in the water.

Being introduced to MAB was the best thing for Brian, because they have a holistic approach that could deal with all his handicaps. Every other place would just deal with one part of the problem. It's been great to watch this evolution from "he'll never amount to anything," to him having a full time job and friends and a mobility cane to get around with. It's like everything I remember hearing them say that Brian couldn't do, he's doing. He's independent. He lives in his own apartment. He goes to work. He has friends. He does social things. He goes out for a haircut.

Brian's dependence on my mother is diminishing. As he's become involved in MAB social events the dependence has lessened. That would never have happened if he hadn't gotten immersed in his own life. I want him to know that he has family and support, but I also want him to have his own life.

Based on an interview with Brian and his sister, Diane. Brian, 57, lives in Newton.







Willie

We grew up in West Roxbury, four of us kids. Willie was the smartest, and everybody liked him. At Roxbury Latin they called him Wee Willie Walker or W3. He got a full scholarship to Amherst College and was a Greek and Latin scholar. I would call him with my Latin homework and he'd translate it over the phone. He was that smart.

He came home for Thanksgiving vacation his freshman year and was driving around with friends, sitting in the back seat, when they had a fender bender. Willie hit his head. It was 1973 and passengers in the back seat weren't required to wear seat belts. They sent Willie to the hospital and he had a massive cerebral hemorrhage. If my mother hadn't been there with him he would've died. The stroke left him blind, paralyzed on the left side, and without any short term memory.

They brought him home and he stayed there with my mother for thirty years until she died in 2002. He was the center of attention. My mother took him everywhere. She took him to classes at Harvard extension, but without short term memory he couldn't learn anything.

When my mother died, my uncle stayed with Willie in the house until it became too much for him and we put Willie in a nursing home. They kept him clean and fed, and put him to bed, but they left him alone and he didn't have anything to do. There was no one for him to talk with and he began to decline terribly. Mass Rehab sent someone over to talk with him every week, and finally they told us they could place him in a community residence as part of the Rolland consent decree.

When he moved into the house on Summer Street his life improved dramatically. The house manager worked with us to reduce his medication and Willie began to emerge from his shell. He's very funny. The nursing home overmedicated him to make it easy for them.

At MAB Willie has a real life. He loves going to his day program and living with the guys at Summer Street. There's always a lot going on, and it gives him something to talk about. We come over every Saturday and bring lunch for the guys. That's a big treat. Willie loves French toast and fried chicken. He has his favorite TV shows. Lawrence Welk is his favorite, though he admits it's kind of corny. He loves the staff who work with him.

Willie's the kid who went from being number one in his class, tops on the sports field, and the most popular guy socially, to being just so limited and needy. All the things he thrived on were suddenly gone. It can happen to any of us.

Based on an interview with Willie's sisters, Annie and Joanie. Willie, 56, lives in Hyde Park.

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Denise

Denise was born with cerebral palsy. She was a beautiful baby, absolutely beautiful. She was never able to walk or talk, but boy was she expressive. We're from a big Italian family and all the aunts and uncles lived close together in West Roxbury. Denise was always the center of attention, and very loved. My aunt and uncle were old Italians, so they took care of all her needs. Anything she wanted she got. She was never forced to learn to do anything for herself until her dad died and she moved into a group home.

Growing up, Denise lived at home and went to public school. She graduated from Boston English High School at 22, but never really learned how to read and write. She can barely sign her name. How can they have her graduate without her knowing how to read? I understand that they just want to get them through and out of their hair, but it's so unfair. Denise is a smart cookie. Having things done for her didn't help her to move on. She's grown so much since she left home.

After she graduated she lived at home and went to a day program. She was bored to death but we didn't seem to have the clout to get her into a program that would make her happy. After her mother died she went to live with her aunts; they had ramps built so she could get around. When her dad retired he moved in and took care of her.

We started looking for a group home but nothing seemed to fit, and even if we found something, it didn't mean there'd be an opening. When her dad died, Denise moved into a respite program while we looked for permanent housing. She was there almost a year, but we finally found the MAB house in Roslindale. It's wonderful.

Denise has grown a lot since she's moved to Roslindale. She's much more independent and happy. She loves to set the table and help out. She's always wanted a job. She didn't understand money but she knew that if she could get paid she would feel like she was okay. It was very comforting for her. At MABWorks they gave her a job shredding paper and she's happy as a clam. She loves getting paid. Once or twice a week when she feels like ordering out, she tells them what she wants and they order it. It makes her feel good that she is paying her own way.

Denise is a very social person. Living with other people has motivated her to learn to use her DynaVox speech machine. She's worked hard to learn to use the DynaVox and now can finally communicate. Once a week after work they have a social. They have dances or whatever. On weekends she loves going to the aquarium and baseball games. She's a big Red Sox fan. Every year one of the aids takes her on vacation. Last year she went to Sea World. This year they're planning a trip to visit Sister Rhonda, the head of the respite care program, who's now been transferred to Vancouver. It's so good that she's able to get away and be independent.

She loves having her fingernails polished. Those kinds of things pick her up and make her feel better about everything. Since she's moved to MAB she's lost 100 pounds. She wants to look nice and is really proud of how great she looks. She loves to pull out her old ID card to show people how much she's changed.

Based on an interview with Denise, and her cousin, Ruthie. Denise, 47, lives in Roslindale.

At MABWorks they gave her a job shredding paper and she's happy as a clam. She loves getting paid.



Artie

Artie was born premature, and kept in an incubator for two months. When he came home they told us he was blind in one eye. Later they told us he was completely blind. It was the oxygen in the incubator.

My mother always wanted Artie to be as normal as he could be. He went to Fernald as a day student when he was seven or eight. It was horrible because he was blind and retarded and they put him in a big room with retarded sighted people of all different ages. He'd come home with bites on him. A person without sight can't defend themselves. After six months we took him out. He got into Perkins and was there until the third grade. He learned Braille but they wouldn't keep him because he was too slow.

We have a big family and growing up Artie was with us a lot. When Artie was six or seven I had a girlfriend who knew the captain of the Nantasket Boat. Every Sunday in the summer we'd take Artie on the streetcar to Rowe's Wharf and go on the Nantasket Boat. Artie still talks about those trips.

When Artie turned 18 my parents decided that it would be good for him to live in a group home, because if anything happened to them, what would happen to him? MAB's been a wonderful home for him, a wonderful group of people. I feel so happy bringing him there, so fortunate. You don't have that angst, "Oh, I'm leaving him, and I feel bad that I'm leaving him." In the residence he used to make salad with Inman. He'd set the table. When they went grocery shopping he'd go with them. Helping out made him feel good.

He always loved to work, and was always one of the best workers. One time we went into Boston and they gave him an award. Artie always tried so hard. It didn't matter to him what the job was; he just liked the recognition. He liked that he could do it and have someone say, "you're doing a good job." That made him proud.

Artie loved earning the money too. He'd go to the Cape every summer to my cousins' place and he would treat everybody for ice cream and dinner. For Christmas he would take his money out and buy gifts for the grandkids. That made him feel good; just the idea that he was capable of doing something.

We have Christmas at my daughter's house now and they have a tradition of playing kazoos. He loves that. He's the one who knows how to do it best; he'll play the kazoo to each Christmas carol they pick out. He likes to harmonize. I have a cousin who used to take him to karaoke on the Cape, at a Mexican place. Artie loves to sing. When she comes down, she sings with him, Patty Paige "Old Cape Cod" or the Everly Brothers "Just a Dream," and they harmonize together.

He always comes home on weekends, and enjoys staying in his room, playing his tapes and walking. He has over 400 tapes, bags and bags of them, a lot of '60s music, Beach Boys, Elvis. He has a tape recorder and likes to record people when they come over on the holidays. He just turns the tape recorder on and lets it go. Later he'll play it back and listen to everybody wishing him a Merry Christmas. He'll say, "I'll remember Mom when she's dead, because I have her voice on tape. And I'll say, "You will. You'll remember all of us."

Based on an interview with Artie's sister, Judy. Artie, a MAB resident since 1978, lives in Watertown.



Keith

Keith is the youngest of the three of us. When he was born they mentioned something about putting him in Fernald, but it wasn't an option; there was no way that my mother was going to abandon her kid. My parents would bring Keith everywhere, church, their friends' houses. He was always fun to be around. He was always a happy kid.

He went to school at Cardinal Cushing every day on the bus, but then it got to be too much and he stayed over during the week, coming home on weekends and holidays. He loved Sister Anna, Sister Marie, and Sister Margaret. He was an altar boy, and did a wedding down there once. He was there for ten solid years.

**As my mother used to say,
"He continues to amaze me."**

When Keith graduated from Cardinal Cushing he came back home. He went to a day program and was on a waiting list for a group home. My mother wanted Keith to be settled in his own place before she died. She was just waiting for something good to come along. I was worried about something happening to her suddenly and I didn't want Keith to be dumped somewhere. Luckily he ended up in a good spot here. The staff is wonderful, and he likes the guys he lives with. He knew them from a social program at Hyde Park High where my mother worked. Parents that knew each other would get together and take them bowling and things like that.

Keith has been working since he got out of Cardinal Cushing. He packages lotion at a workshop and volunteers for Meals on Wheels. He knocks on the doors and brings the meals in to people. They're happy to see him.

He loves saving his money up for trips. This summer he went to Virginia Beach. He loves going swimming and eating hamburgers and ice cream.

Keith loves being with family. We took him to see his first hockey game last year and three times, after each period, he thought it was over and would say, "Can we go eat now?" He loves TV, especially "The Three Stooges." The Sound of Music and Mary Poppins are his favorite movies. He goes to music class on Tuesday nights. He loves John Phillips Souza marching band tunes and Christmas carols the best. He has an amazing memory. He's the one who always remembers everyone's birthday.

As my mother used to say, "He continues to amaze me."

Based on an interview with Keith's brothers, Kevin and Brian. Keith, 47, lives in West Roxbury.



Christina

Christina was born with hydrocephalus. Years before, when they didn't have a surgical procedure for hydrocephalus, they assumed these babies would die. They tried to prepare us before we saw Christina at the hospital, but my first impression was just how beautiful she was. She had lovely pink skin and a tiny bow mouth. We fell in love with her.

We want the world to view Christina as someone who has medical needs but who deserves to be treated with dignity and respect.

She was medically fragile from the beginning. When she left the hospital at six weeks old, she already had an Individual Service Plan from Early Intervention. This was 1981 and it was a good time to be born with special needs. There were a lot of services and no waiting lists. We had a physical therapist and an infant stimulation therapist, both coming twice a week. They became part of the family.

For the first year she had apnea and could stop breathing at any time; she couldn't be left alone for a minute. At six months she started having grand mal seizures and they put her on medication. It was clear that neither of us could work full time and take care of Christina at home. I guess one of us could've been at home full time and the other work, but neither of us wanted the responsibility of being home full time. Going to work was a break.

When Christina was a year old she started to go to a day program, Early Beginnings, at the Mass Hospital School in Canton. When she was five she went to the Kennedy Day school at Franciscan Hospital. When she turned 14 she was able to get a personal care attendant to help us get her up in the morning and get dressed. We were allowed 18 to 20 days of respite care a year, about one weekend a month. You'd have to schedule it a year in advance, because if something came up last minute and you called, they'd be booked.

Our lives were so regimented. Everything was structured to accommodate all the people that came and left our house; orchestrating everything was such a production—the dinner hour, the medicine, the bus schedule. It was like running a business. I remember talking with a friend, before Christina was born, who had a very disabled child, and being daunted by how much responsibility it was. "It's not a responsibility," he said. "It's your child. It's part of you."

As Christina approached adulthood we wanted to give her a membership card to the world and see her life unfold. We developed relationships with different groups in the neighborhood; one day a week she'd go to the Salvation Army and help them pass out prizes to the children in an after school program. The next year she went to a dinner program at the Epiphany School once a week and helped them set the table. We had gotten to the point where Christina was an active member of this community and we were worried that she'd lose all that if she went into a residential placement as an adult; we didn't want to put her in a room for the rest of her life.

Our older daughter had been urging us to find a place for Christina. She'd say, "Mom, even retarded people want to live on their own." Luckily we were able to find a day program at TILL that uses the surrounding neighborhood for activities, and she loves living at MAB's group home in Roslindale. She's very happy to see us and is very comfortable when we say goodbye. We want the world to view Christina as someone who has medical needs but who deserves to be treated with dignity and respect.

Based on an interview with Christina's parents, Diane and Tom. Christina, 30, lives in Roslindale.





Tim

Before Tim was born we knew something was wrong. They did an alpha/beta protein test when I was pregnant and said there was a big chance he'd be disabled. My doctor was a strict Catholic, but he told me that if I wanted to have an abortion I could. I chose to have Tim.

Timmy was a funny looking kid right from the get-go. His eyes couldn't focus and he couldn't hold his head up. He was floppy. The doctor gave him a CT scan when he was six weeks old but the results were inconclusive. I put the phone down and cried and paced. A pediatric neurologist did an ultrasound of his brain and diagnosed agenesis of the corpus callosum.

Tim has been my best teacher. He has taught me patience over and over again. He has taught me perseverance.

Tim started early intervention at four months, took his first steps when he was 2 ½ and didn't start talking until he was 3 ½. When he was nine they put him into an integrated classroom and that was the worst. The teacher was determined to teach Timmy to read and write and he reacted with terrible behaviors: spitting, hitting, punching, kicking, yelling. You name it, he did it.

He started at private school as a day student but after a few months I became totally frazzled. My ex husband was long gone, and I was trying to take care of Tim and his brother by myself. Tim was totally out of control; he broke his brother's tooth with a hammer, and put a magnet up his nose. The behavior specialist said that Tim having both agenesis of the corpus callosum and Sotos Syndrome was like having my house hit by two bolts of lightning at the same time.

Tim became a residential student at Ivy Street School when he was almost 15. When he started he had to be restrained five to ten times a day, but after a couple of years everything changed. The structure and consistency were perfect for Tim. There were no ifs, ands, or buts. If you were on consequences for bad behavior you couldn't go out. It was a while before Tim could go out. About four years. But finally he got it.

Tim got a job walking dogs at the MSPCA. He loves dogs, and it made him feel good about himself. He works stocking shelves at Trader Joe's. He's doing good there. He talks too much to his co-workers, but he'll do anything that they ask him to. He needs constant repetition and reminders about how to act, but he's learning.

Tim likes to be independent. I can remember at Ivy Street when they wanted him to go to a corner store by himself. I was having heart failure over this. We worked out a plan where he would do it many times with a staff member and then do it with a staff member shadowing him, and then they got him a watch and told him to be back by a certain time. I was amazed.

Tim has been my best teacher. He has taught me patience over and over again. He has taught me perseverance. He has taught me that the glass is more than half full; it's all the way full. Tim has a great, great heart. He's taught me to look at the bright side.

Based on interviews with Tim and his mother, Jane. Tim, 25, lives in Brookline.

Beth

Beth was born on the way to the hospital, a hundred yards from the entrance. I read that music helps you get in rhythm for child birth, so I sang “Yankee Doodle Dandy.” Bob didn’t know the words, so he sang “Be Not Afraid I Go Before You.” In retrospect, these words have been the spirit that has guided Beth’s life.

It was worrisome when Beth wasn’t developing according to the normal growth charts: turning over, standing up, talking. At 18 months we started early intervention, travelling 45 minutes each way. I had planned to go to grad school. When Beth was born, she became my grad school.

She went to Groton public schools through fifth grade, always in a mainstream classroom, because we thought that being with normal children would provide constructive models for Beth. Each year was different, depending on the particular teacher. Her second grade teacher was wonderful; she planted gardens with Beth and had tremendous patience. We looked at school as being a place for Beth to develop socially and feel like she was a part of things.

Beth can’t be described by a single diagnosis. A lot of her issues are language based, and while her ability to communicate developed slowly and sporadically, her ability to make herself understood depends greatly on how comfortable she feels in the environment. Now is never where Beth is. She’s always in the past or future. A lot of the pain she felt at school she couldn’t talk about until years later.

Sixth grade was a disaster. The teacher, who sat way over on the other side of the room, couldn’t understand Beth whatsoever. Everything was so complicated: different colored folders for each subject. I spent hours in the classroom trying to help Beth get organized. It was clear that she would never be able to succeed and go on to middle school where they had to change rooms for different classes and the cafeteria was noisy and confusing. We advocated for Beth to leave the public school setting. She did a year at the Lab school, then six years at Cotting as a day student. She spent a lot of time on the bus.

Ivy Street was the next step, where she could learn to live more independently in the community. It forced her to develop other aspects of herself so she could move on to having a full life as an adult. When she graduated, the Department of Developmental Services said she was too high functioning to be eligible for residential support. She couldn’t come back to Groton because there’s nothing for her here: no peers, no jobs, no transportation, there aren’t even sidewalks where she could safely walk to the store.

DDS reconsidered, and Beth now lives with two other women in Newton, with staff available overnight if needed. Special Olympics have always been important to her, feeling the joy of being part of the team. She works at the Jewish Community Center as an attendant, folding towels in the women’s locker room, and volunteers at the Watertown Public Library. She feels good about her jobs, the particular skills that she’s mastered. She’s active in the Asperger’s Association and goes to their monthly pizza and games night. She just went on a trip to one of the Harbor Islands with them. Beth has a pretty full life now. We’re in our 60s and our goal is to be able to fade back and feel secure that Beth has a good life.

Based on an interview with Beth’s parents, Nancy and Bob. Beth, 26, lives in Newton.

Ivy Street was the next step, where she could learn to live more independently in the community. It forced her to develop other aspects of herself so she could move on to having a full life as an adult.





Brendan

When Brendan was born he was beautiful but he had a big head. The doctors did a lot of testing but concluded that we must have a lot of big heads in our family. By the time he was eighteen months old he was behind on all his developmental milestones and it was clear that he was delayed. He was so sweet and loveable but he wasn't progressing according to the normal timetable. We got him involved in early intervention and the doctors recommended a wait and see approach, so I was surprised when he was ready to enter kindergarten and they recommended a totally separate special needs classroom.

Right from the beginning school was a nightmare for Brendan. The other kids teased and made fun of him, even in a special needs classroom. He didn't have any friends. They called him names. It made me so furious. I felt helpless. There was nothing I could do to protect him.

When Brendan came to the Ivy Street School was the first time he really felt safe. No one made fun of him. He didn't have to feel ashamed. Everyone accepted him for who he was, and he progressed. I'll never forget the day he called me as he was walking to Trader Joe's by himself for the first time. I was so proud of him, and so happy for that independence.

As an adult he's really blossomed. He has a job washing dishes at Matilda's, a coffee shop in Watertown. They love him there. He works there five days a week and volunteers walking dogs at the MSPCA. He met a girl at the MSPCA who he likes, but was too nervous to talk to for a long time. He recently broke the ice with a conversation about Harry Potter. He blushes when he talks about her.

He lives in a group home in Brookline with four other guys his age. He knew a couple of them from Ivy Street. In a few years we hope he'll be able to move towards having more independence. He spends a lot of his free time reading. He loves Stephen King, the scarier the better. He loves walking to the Chinese restaurant near his house and grabbing dinner. He loves watching movies with the family and going tubing in the summer.

I love that he has a real life like everyone else. It's so important that he's been treated with respect and given choices about the life he wants for himself. He's a contributing member of society and has relationships with people that make him happy. That's all I want: for him to be happy.

At Ivy Street Brendan did a stand-up comedy routine in the talent show. He was amazing, so comfortable in his own skin. I asked him how he learned to do it. He said, "Sometimes I study other comedians. Maybe I'm just gifted."

Based on an interview with Brendan and his mother, Toni. Brendan, 23, lives with four other guys in their twenties in Brookline.

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Photography

Photograph of Ruthie taken by Krystle Engelen. All additional photography by Meg Landers.

Meg Landers is an artist and photographer who has worked on humanitarian, commercial, and fine art projects for more than 25 years. She has actively exhibited in both juried and group invitational shows in the United States, Canada, and Germany. Her photographs are in a number of publications and corporate and private collections. She maintains a studio on the Lexington property where she and her two children live.



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Stories

Interviews conducted by Barbara Salisbury. Stories drafted by Barbara Salisbury and edited by Julie Wisnia and Elizabeth Matthey.



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MAB Community Services has been creating opportunities for people with disabilities since 1903. Our three programs are the Ivy Street School, MAB Adult Disability Services, and the Massachusetts Association for the the Blind and Visually Impaired. Our experience allows us to forge strong community partnerships to meet the pressing need for high quality services and transform lives. MAB is a proud member of ADDP.



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