A 'Joy' to Us All By Antoinette S. Johnson

When my co-worker Ann Martinelli and entered Jov Harootunian's home, we instantly felt the 'joy' and warmth. It was obvious that we were in a 'joyful' home. Yes, Joy's personality is true to her name. According to Nadirah Buchanan, group home supervisor, "Her name fits her because she is always smiling and hugging [staff and family] ...when you look at her you can't be upset even if you're having a bad day. She never gets upset. She's very pleasant. With her it's always a good day." As we walked throughout Joy's home and into her bedroom, Nadirah informed us that Joy likes music and dancing. She and Nadirah 'joyfully' danced to the Beach Boys music.

Joy lives in a beautiful ranch-style home in Union County with rich brown hardwood floors throughout. In addition, the kitchen and living areas are large and open. She even has a swing on her deck. Her home is beautifully decorated and each person who lives in a home owned by Community Access Unlimited (CAU) lives in the home with the understanding that it is their home and no one enters without knocking. As stated by Billy Busch, director of membership development, "This is their home." It is treated like any other home in any neighborhood-with respect. This neighborhood is lively and familyoriented. On any given day you can see people walking, running, riding bikes, and pushing strollers.

TRANSITION

Transitions take time. Every person who transitions to the community is different. CAU worked hard to make sure the transition was done right for Joy. The first order of business was making sure everyone (family and staff) was on board with the journey and mission ahead.



Billy met with Joy's mom and sisters and they saw the home after it had just completed the construction phase. The family loved the neighborhood and asked lots of questions, which is encouraged by CAU. Joy's transition was a slow process. They had to take it one step at a time with her and not move too quickly. It was difficult for her to get into the van at first and that was probably because the CAU van was a minivan, which is much smaller than the vans used at North Jersey Developmental Center (NJDC). Each day she would take an additional step that would get her closer and closer to her new community home. The staff at NJDC informed the CAU staff that since Joy likes coffee, it would be a good idea to give her coffee, which would help her to get off the minivan once they arrived at her new home. She finally did it! She was able to get off the minivan and stayed at the new home for a few hours. Then they took her back to NJDC and eventually brought her back to her home for good. Just as it was difficult getting her on the minivan and off the minivan after arriving at her new home, it was equally as difficult to get her on the minivan to take her to her day program. She would start out going to the front door of her home, then outside, then inside the van. The process took about two weeks, but she now goes to her day program with no problem. They found music was helpful in calming Joy as she rode in the minivan. Joy attends her day program five days a week. program, she is able to put together LEGO's®, does crafts that include cutting and pasting, and she is able to get out into the community with the day program by going shopping and doing other community activities.

One thing that CAU prides itself on is the ability to connect with families in addition to the individuals they serve. "I look at it as the more the family is involved the better," said Billy. Families look out for their loved ones best interest. They want their loved ones to be safe in the environment in which they live. Billy and representatives from CAU will do whatever they can to ensure families are not worried about their loved one's safety. As it relates to Joy's family, Joy's sisters, Diane, Joanne, Christine, Gail, and Ellen, have written and contributed to a very poignant and heartfelt story about Joy's past life to the

present. Here is Joy's sisters' story from their perspective...

Joy's Story from Her Sisters' Perspective

By Joanne Harootunian

With contributions from Diane Scully, Christine Johnson, Gail Bariexca, and Ellen Mackin

Joy is the youngest of six girls. She grew up in Summit, New Jersey with her Mother, Father, Papou (Grandfather in Greek) and her sisters, Diane, Joanne, Christine, Gail and Ellen. Dad and Papou died when Joy was in her teens. She attended a pre-school program with other children who had Down Syndrome and attended school until the age of 20. She then participated in a workshop program through Union County Training Center. By then, three sisters were married and one lived out of state. Joy moved with her Mother to Toms River and attended an Easter Seals program in Forked River. Joy was always a "happy" person but was very stubborn in her ways. If she did not want to go in the car, it was a struggle for Mother. Mother was getting older and finding it harder to handle the day to





day living activities for Joy. In January 1995, one of Joy's oldest sisters was in a terrible car accident. Joy was placed in Totowa at NJDC for emergency respite care while Mother stayed with her injured daughter. Joy was then placed permanently at NJDC at the age of 28.

Joy lived at NJDC for 18 years and attended a workshop for a short period of time. She participated little except for holiday dances, lunches out and some social activities in the community. When Governor Christie closed NJDC in Totowa, the IHP team suggested a community placement. As Joy's guardian, Mother was hesitant about Joy's moving into the community because of her very low mental ability, the transition and the non-acceptance into the community. Mother and one daughter visited the Cranford home in the summer of 2013, met some staff members, who were very

friendly and supportive. After the home visit and program services and discussion with her daughters, she thought this would be best for Joy. Mother and some of the sisters attended all the meetings for transitioning. The day of transitioning did not go as smoothly as everyone hoped. There was major difficulty getting Joy into the vehicle to transport her. once the vehicle got to the Cranford house, Joy got out of the car and walked right into the house!!!

One of the most helpful aspects of Joy's transitioning was having the support staff assist the family. They were understanding of the family's fears and very caring and supportive to everyone. They included professional staff, nurses, state workers and care takers.

Today, Joy is much happier, smiles more and wants to go out in the community. Her posture has improved as well as her verbal communication. She counts, recites the ABCs and laughs more. She has learned more in the community setting than in the last 19 years!! Joy is learning everyday living activities like setting the table and doing some laundry. The Cranford home is a family atmosphere with more individual care, and closer with easier access for frequent family visits. Joy goes out to dances, church whenever possible, recreational and social events in the community. She loves to listen to music at home, likes to sing songs and dance. However, cutting her fingernails and toenails is very challenging for all. Joy hates this part, but likes to have her nails polished!!! Joy lives with two other women in the home. She is up at 6:00am and attends a day program in from 8:30am-2:00pm Monday through Friday.

Joy's move into the community is "a long time coming." It is something the family has



wanted for years. The family is thrilled with all of Joy's improvements. Joy's Mother and her sisters' feel living in the community has many advantages. One is the residence resembles a family home living. The close proximity to family allows her family to visit whenever they want. Mother visits as often as she can, but she does not drive the Parkway anymore so whenever she can get a ride from Toms River, she visits Joy. Mother does communicate via phone to say hello or discuss Joy's well-being.

The family hopes and dreams for Joy's future to be a happy one. We want Joy to be part and function in a community setting, to live in a "family setting" for as long as she can, enjoy her life, have fun and to be as self-sufficient as she can. Some advice for families looking into community living: make sure to check out the actual home and the community, visit with the staff, ask many questions and look at the great programs that are offered. All in all, community living for Joy and others is a

great opportunity with more one -on-one staff. The family is thankful for all the support given to us.

WILLINGNESS TO WORK

CAU is grateful for the family's willingness to work with them in placing Joy in their care. Families are encouraged to visit their family member often. CAU suggests the family call before going to their loved one's home as they are often out in the community enjoying life. They want to make sure they are home when the family comes to visit. The family can visit their loved one in the home or take them out. We were told that Joy is doing fabulously in her home. She has learned to make her bed, help with cooking, helps with laundry by folding the laundry and putting her clothes away, and she does dishes. She is "very good with verbal directions," said Nadirah.

The CAU staff are just in love with Joy. Billy said, "Joy has not changed a tad bit since I met her at North Jersey. She was always happy and friendly." Rolondo Zorrilla, assistant executive director said, "The staff have built a great relationship with her." Rolando mentioned that he likes that fact that Joy likes to experience new things and likes to go out. Recently, she went bowling, and he said it was great to see the picture of Joy bowling.

The sky is the limit for Joy. Her mother, Catherine, feels finding the CAU home was such a blessing. CAU and her family will continue to support her in her growth in the community. Taking on the community one step at a time has been the reason why Joy has been so successful. By progressing slowly, Joy is a success story and will continue to be with the support of CAU and her family.

