

Nick, Ilene and Barbara: Their Journey and Our Role

By

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Nick

One look at the smile on Nick's face and you get a sense of just how fun loving and personable this young man is. Whether he is talking about his businesses—he has two—his love of the outdoors, his affinity for animals or his obsession with pizza, Nick is a delight. He is also an adult with autism.

Nick's journey began at age 11 when he began attending the Saturday Program. It was there that he learned about riding public transportation, interacting with community members, and trying new and different things. Later as a teenager, he again broadened his horizons and spent two summers at the summer camp where children with and without disabilities come together for a fun week.

However, it was not until 2007 after graduating high school that Nick would experience his most dramatic successes. Nick has started two ventures—a dog walking and a vending machine business. Nick's support person assists him in keeping organized and teaches him business basics (i.e., keeping up with billing, stocking, customer service, etc.). Every day after walking the five canine friends, Nick returns home to hand write his customer invoices. Once a week he and a support member stop by his soda vending machine to collect the change and check on the stock.

Nick shares a Northridge home with Evan and Nadia. Since moving into his own home, Nick is more open to change...to trying new things. He now exercises at a gym, and loves to hike, bike and do almost anything physical. His affinity for pizza hasn't wavered though. If he could, he would eat it for breakfast, lunch and dinner. One of his favorite places is Marcelino's Italian Kitchen. Marcelino has become a family friend. He welcomes Nick behind

the counter to make his favorite pizza, which is meatballs, onions and mushrooms.

Nick is full of wanderlust. Most of all he is a people person and loves sharing time with family and friends.

Jay Nolan

Everyone must find his/her own path in life. With the help and assistance of friends, family, allies, co-workers, and supporters, Nick has identified the direction in life he wants to pursue. It is our organization's honor and role to walk with Nick on his journey if and as long as he wishes us to accompany him.

Jay Nolan is not an organization that has the power or capability of granting wishes or fulfilling dreams for people wanting to move forward with their lives. What we do is provide assistance and support, which has been asked for by the person and his/her circle. We are only a very small part of the overall plan to help Nick move from where he is to where he wants to be.

Human service organizations, including Jay Nolan Community Service, have gone through many different transformations over the past thirty years. We went from an organization that wanted just to do something for people with autism and other developmental disabilities to an organization that felt it knew what was best for the person and his/her family. We then moved from that belief system to one that tried to do our best by believing that we could help change people to ultimately realizing that we are just a small part of what it really takes to have a person live a valued life in the community.

What is needed for organizations, such as Jay Nolan Community Services, is to recognize our place in the scheme of things for people with autism and other developmental disabilities. Equally important is for people with

disabilities and their families, friends, co-workers, allies and supporters to realize that the “system of services” is not the sole answer or panacea for all their issues or concerns. A good support agency can help under certain conditions, for certain periods of time and for certain functions. However, organizations can never be counted on as the long term solution/answer for people who are very vulnerable such as people with autism and other developmental disabilities.

If people are truly going to be a part of their community and be fully included, people with autism and other developmental disabilities will need to have clear dreams, solid circles of support, outstanding person-centered planning and support, a lot of hard work, a little luck and a willingness to be in this for the long haul.

This is not a new model of services or another point on the continuum. It is a way of life.

Ilene

Having been a member of Ilene’s circle of support for over 11 years, she has not only touched my life (third author), but the lives of all those she encounters. I have always been able to see the love she has for everyone around her. When we first met, she came running from another room, landed on the couch next to me, and grabbed my hand. I was instantly overwhelmed by her love.

She played the piano for me, and shared the adventures and stories of her life, such as how she was born in Chicago in 1961 and is a proud sister of two younger brothers “who are very smart.” She never leaves out the minor details, like dates or locations, for Ilene will tell you it is all “important you know!”

Ilene has worked since she moved on her own in 1991. She currently works, and has for the last 13 years, in the gift department at the UCLA Foundation

at a position that was specifically designed for her. On her recent return from a vacation to Hawaii, Ilene's boss was relieved to have her back since no one could perform her job like she can. She is also the chair of her own meetings, where she keeps other members "in check" with her gavel.

With her wonderful circle of support, Ilene's friends have introduced her to many different aspects of society, consisting of dancing, the application of make-up, and the "Hollywood scene." She lives in a one bedroom apartment on the Palms area of West Los Angeles. Living in the vicinity of Hollywood and having a staff member who is an actress, Ilene feels that she too, is a celebrity. Because of this, Ilene has walked onto countless movie sets, always "schmoozing" with the stars.

Over the years she has spoken at several conferences, and can even be seen in the documentary, "Fires of the Mind," where her 120 word per minute typing speed is featured. She is also a national spokeswoman for "Healing Gaia", a holistic nature-based program for people with disabilities.

I enjoy and cherish the time I spend with Ilene. With a strong support system, Ilene lives a fulfilling life and has touched the lives of many. She has made me a stronger person, and I am excited about our friendship in the years to come.

Jay Nolan

We are so proud of the accomplishments of Ilene and Nick, but the truth is that these are their accomplishments and not ours. Our role is to listen, support, suggest, be there when needed, do what we are being asked to do with quality and integrity. However, we must always remember that it is their journey in life and not ours.

Dr. John O'Brien and Connie Lyle O'Brien have written in the Ethics of Possibility about how direct support workers show up in people's lives. As usual, they are so on target with their analysis. How direct support workers

show up is critical. It is our goal that all direct support workers show up as generators of possibility. Jay Nolan tries to do what we can to get parents and other family members to show up seeing themselves not just as mothers, fathers, brothers, sisters, cousins, but also as generators of possibility.

All of us like Cirque de Soleil; we enjoy the performers doing such magical things. However, the reality is that before the event people must make sure that the wires are tied down, the lighting is set, the music is ready to go on, etc. Without all those behind the scene details, the performance would not be successful. However, none of us buy tickets to see these people do their jobs. They do not receive the thunderous applause nor should they.

Barbara

When I (second author) first met Barbara, she was being kicked out of Independent Living Services for being too defiant. Her father and she came and sat in my office and talked about all of Barbara's issues, such as changing in front of open windows, taking off without letting anyone know where she was going, dressing inappropriately for weather and occasion, refusing to clean or sometimes even change her clothes. I sat back in my chair and thought, "Wow, she is going to be easy to support and probably a lot of fun." After her taking off for about the 100th time, usually to buy ice cream, I did have some serious concerns about Barbara's safety. I would go look for her and find her at 10 pm, walking down the street in shorts and a tee shirt, eating ice cream in December.

We spent a lot of time with Barbara in the first few years trying to understand why when she could do whatever she wanted when she wanted, she needed to be sneaky and worry all of us. Slow learners that we were, we finally figured out she liked all the attention when we would find her. Barbara, while extremely independent needed a lot of attention. She would

take it positive or negative. As we started to gear her support around attention, she began to blossom.

About a year ago, one of Barbara's old teammates from Special Olympics developed dementia. Barbara and this woman had not been great friends as they had always competed for the hot guys. However, Barbara found out about this woman's health and asked if she could come over and start spending time with her. As we support the woman, we asked her and she agreed. Barbara started going over every day and hanging out, talking and reading to the woman and then asked if she could assist the staff in any way. As the woman's health declined more, the staff really needed a second pair of hands and Barbara was more than willing to help. After about a month of this, we asked Barbara if she would be willing to make this a job and become an IHSS provider. The regional center liked the idea as she would be a second staff on to assist another staff. Barbara has been doing this job for eight months now and is more responsible and hard working than most of the other staff that works there. She genuinely is concerned for this woman's health and well being and does the extra stuff that we can forget when we are busy providing care, painting toe nails, styling hair, reading to her or listening to music with her.

Due to her working, Barbara finally saved up enough money to plan a vacation. She decided to go to Universal Studios and Hollywood. She asked her old roommate to go with her and they planned the trip together. Once the date was set, Barbara came to us and asked, "What will happen to the woman I support while I am gone? Who will do all the things I do?" It was so amazing to hear Barbara be so genuinely concerned even when she was about to do something she has always wanted to do. After much reassurance, that we would make sure the woman was ok while she was gone, Barbara did go on her vacation and had the time of her life. This is the first vacation she has been able to plan for herself and do exactly what she wanted to do. She was so happy.

Barbara still needs her attention sometimes and reminds us if we forget. However, she is just as happy focusing on another person and giving back all and more of the attention she has received.

Jay Nolan

We have been struggling with how to assist people with autism and other developmental disabilities to live full, rich and inclusive lives. We have been struggling with our role in helping people to achieve their dreams and goals. What we found out is that we cannot be the answer or at least we cannot be the only answer to this very complex and challenging goal. We are just midwives on people's journey. We are behind the scene helping and supporting "the mother" to give birth. That is our role – that of the midwife.

While significant progress has been made in education, community living, employment and other environments for people with autism and other developmental disabilities, inclusion into the real fabric of community life has remained an elusive goal for the majority of people with autism and other developmental disabilities.

The goal of living in your own home with appropriate supports tailored to your needs is to have you live with whom you want to live and to receive the support in the intensity, duration and frequency that you want by the person you want to provide that support. However, this goal has its challenges and is elusive. That doesn't mean we should not pursue it, but it does mean we need to be truthful about how difficult it is to get it right. At times we do not realize how hard it is to really do the job well.

This is true not only during the current economic crisis facing all of us across the country, but even when the economy is vibrant and things are prosperous.

People with autism and other developmental disabilities remain impoverished materially and financially, vulnerable, wounded, and

disenfranchised. All of our efforts cannot negate how society perceives people with autism and others with developmental disabilities. Nor can we eliminate all of the things have been done to people with autism and other developmental disabilities. What we need to do is our job! We need to do our job as well as possible even if we will most likely never eliminate the pain and suffering that people who are vulnerable live with in our society and continue to experience .

This could lead to organizations saying it is too difficult; it is not worth the effort; this person is too wounded. Let's just give up. But if people are going to be true community members and live fulfilling lives then there are miles and miles to go before we sleep and we need to continue to do our very best work. We must walk with people on their journey. We must be open to new ideas, new concept and strategies, and have whatever it takes attitude.

Organizations that are really going to try and meet people's needs must embrace what John O'Brien has written "we must embrace error, ignorance and fallibility." These are all great teachers of good learning organizations. We try to be a good organization that is honored to support people with autism and other developmental disabilities in pursuing their dreams and following their hearts on their personal journey in life.