

PIN POINTS

a newsletter from

Philadelphia Independence Network

JEVS Human Services'
New Community Based Program,
Where Young Adults with Disabilities
Live in Their Own Apartments,
with Supports

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About the

Philadelphia Independence Network

The Philadelphia Independence Network (PIN) is the first program of its kind in the Philadelphia area. PIN was formed when parents, concerned about the future of their young adult children with disabilities, sought the guidance and leadership of JEVS, a well-established and respected, non-profit human services agency, to begin a ground breaking model of care.

With PIN, young adults living with disabilities are taking a big step in life. They have moved into apartments. Some live by themselves and some with roommates. They are living independent of their families and receiving supports from JEVS. These supports are based on an individual's needs and include planned social activities, group and individual learning on how to deal with the ups and downs of daily life, how to interact with others and get along, and how to accomplish all those required daily tasks like cooking and feeding yourself, laundry, cleaning your home, getting to and from places, paying bills, etc.



Some members of the PIN community.

All PIN members are expected to be part of the community. They do not sit home all day. They either have jobs, attend school or participate as a volunteer. If any members are unsure of what they can do or what they want to do, JEVS can help with vocational assessments, and job coaching and development.

Our founding members have taken huge strides, enjoying themselves and feeling good about all they have achieved.

We are continuing to build our Narberth community, looking for additional members, but we aren't stopping there. As the program grows and we reach a desirable size in Narberth, we will look for other communities in and around Philadelphia as the next setting for PIN.

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A Parent's Story of Letting Go

My name is Jennifer and I want to share my story of letting go. Ultimately, many of us have our own version of the same story. Sometimes we move along painlessly, other times we feel so stuck. I have a great quote on my desk that states, "Sometimes your only available transportation is a leap of faith." So, this is my story.



My son Peter is 27 years old. There have been many days where his ability to be present and in the world was impossible. Pete suffers from a rare medical disorder that went undiagnosed until he was 7 years old. Many families have been through this frustrating journey – searching for answers. Early on, the specialists suggested that my concerns with Pete's development were all in my head, "You are too nervous, you worry too much," thereby dismissing the problem and blaming me.

His medical problems came to the forefront when he was in 8th grade. Pete suffered ill health on and off for the next 8 years. He began to have cyclical episodes of illness which required monitoring, medication and vigilant caretaking. Without proper intervention, this crisis would be life threatening. Our family's world was ripped apart. I became his nurse and companion, and a specialist in understanding his body. Throughout the next 8 years, I became his primary caretaker, his advocate and his well of faith, someone to tell him that things would get better. A parent and child could not have been more intertwined.

During periods of calm, we tried to continue on the path to independence and Pete attempted to live in Connecticut where he attended a vocational and life skills program. Ill health resurfaced and Pete returned home. We lived on the same rollercoaster of cyclical ill health for the next year. When Pete began to feel better, he initiated the idea of returning to school in Connecticut. I left home with him and I put into place the

supports for him to live separate from us. I found attendants to help monitor his health and help with his daily living and set up relationships with physicians, specialists, emergency facilities and ambulance services.

After 6 months, I left Connecticut. My team was in place. Peace lasted a few months, and then it became clear it was not possible to manage 220 miles away. Pete came home.

Defeat was felt all around. The cyclical ill health continued. Pete's guilt at "ruining our lives" was enough worry to set off more crises and ill health. We all felt that we lived in an alternate universe, in an orbit of despair. The cycle continued: desire to be independent, failure, despair, ill health, and dependency.

Pete found an internship as a teacher's assistant at the elementary school he attended. After almost 2 years at the job, Pete stated that he wanted a change. He wanted to work closer to home and in the company of peers. Pete went to Trader Joe's and made an application. They readily understood the health uncertainties and there would be absences. That was acceptable to Trader Joe's and they hired Pete. He is coming up on his one year anniversary there.

I have been in on the planning of PIN since its inception, believing that it is important to continue to plan for Pete's independence from us, regardless of his state of health. As my family ages, we have to put a system in place for Pete's future. Before PIN, I just wasn't sure what that would look like.

Life took a wonderful turn earlier this year when Pete's health improved. His health has been stable for many months, and crises have been almost non-existent. Gradually, Pete has begun to stand tall and lose the fear that was etched on his face, and we began to do the same. Pete moved into an apartment with a

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with a roommate. They are some of the founding members of the PIN program.

And here's the part that I think a lot of us have in common. As a traditional stay-at-home mom, I shopped, prepared meals and did laundry for our children. Old habits die hard, and it was difficult for me to let go of that role. But on his own, Pete is doing a wonderful job! He prepares his and his roommate's meals, does laundry, pays his bills, cleans his apartment and directs his own life. He is able to take care of himself. Without the move, Pete would not have made the strides he has. It isn't

possible to have the same sense of independence while living under your parents' roof.

What I have learned in my heart is: Our children with disabilities mature later than typical children, but maturation happens; we must find a way for our children to live outside of our homes as we all age. They must prepare for their independent adulthood, with supports if needed; and our children are looking for our affirmation and approval; they know they have our love. Never give up. Take the leap.

At Home in Narberth

I'm David, one of the pioneer members of the Philadelphia Independence Network. For the past three years, I had been living in White Plains, NY, where I was one of the first members of the POINT program. Late in July, I moved into my apartment in Narberth. Now, I'm closer to my family, friends, and sports teams. I love living in Narberth. It's convenient, friendly, safe and charming.

People from JEVS hireAbility are helping me look for a paying job. In the meantime, I'm volunteering at three different places - MANNA, Magee Rehabilitation Hospital (both in Center City Philadelphia) and a pet shop in Narberth. I take the train or bus or walk, and it's so easy to

get everywhere in Narberth. I walk to the grocery store, drug store, bank, hardware store, movie theater and restaurants, and take the train or bus to the YMCA, Philadelphia sports stadiums, my doctor's office or to visit my family.



David and his dad enjoying a café in Narberth



Downtown Narberth

Narberth feels friendly and safe. It feels like home. My apartment looks really cool and is very comfortable. In a lot of the stores, people know my name. I have my own banker who is always helpful and nice if I have questions about my checking account. Narberth is quiet, safe, pretty and comfortable, and I can go to Center City when I want to. I vote here. I used to think I'd live here for a little while, and then move to a Center City condo. Now I think "Why would I ever move?"

David is one of the founding members of PIN.

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Young adults enjoying one of the planned and supervised PIN activities



Independence: The Heart of Who We Are

The Philadelphia Independence Network (PIN) was envisioned as a community where young adults with disabilities could live independently while receiving the supports and services they need.

Our dream is now a budding community, with a growing number of young adults living in the charming and easily accessible borough of Narberth, PA.

We chose the name Philadelphia Independence Network so the name itself would set this program apart and define its mission.

We knew that just because a young adult had a disability didn't mean he or she couldn't live independent of his or her parents as well as outside of the traditional dependent residential homes. We also knew independence didn't mean isolated. For us it meant a supported community.

Webster's New World Dictionary defines independence as, "not ruled or controlled by others. A desire for freedom." Since independence has a different meaning for each of us, we want to share the views of some of our members.

How Some PIN Members Define Independence

"For example, I can choose when to eat dinner, I make the decision when I need to come home for the night. But there are many more responsibilities that come along with being independent like making a budget and not spending more money than I have."

"Independence means getting stuff done on my own. While I appreciate the help of my parents, it's important to me personally to be able live, cook, etc. without my parents' help."

"Independence means freedom and the ability to do things on my own."

"Independence means what I have been doing the last two and a half years (well, first with my friend, now by myself). I have a job that I really love doing (too bad it is only part time). I can hang out with my friends on my days off or whenever I can."

"To me being independent and having independence is doing stuff on your own without help or supervision. Being independent to me means doing things on my own, having freedom and living the good life."

"I define independence as being able to choose and make decisions for myself. Not needing to be told or reminded by other people to do something. Having control of my own destiny and my own life is very important to me."

"I define independence as freedom from others that make it very difficult for me to make my own decisions, choices, and conclusions. I also feel if you don't learn basic life skills you will never be able to become independent, because you will need supervision all of the time."



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