

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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Inside this Issue

Page 1

Why I Decided to Join the Philadelphia Independence Network

Pages 2

The Struggle of Finding the RIGHT Kind of Independence: A Parent's View

Page 3

PIN Postings – Members' Minutes from PIN Activities

Page 4

Parents' Perspective: A Partnership with JEVS

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Why I Decided to Join the Philadelphia Independence Network, or as I like to call it, The PIN Group

by Gabrielle

For the longest time I never thought I would be the one who joined PIN because I couldn't see myself as a member of that group and I didn't think it was for me. It just wasn't the right time yet. That was then, but now things are totally different. I can now proudly say that I am a member of the PIN Group and I consider us to be like a small family!



It was towards the end of December of last year when I finally came around to my senses that this would probably be something good for me. I have to say now that it was in fact a smart move, and I haven't regretted it yet - a very good thing. So I contacted Marnisha Henry (who is FANTASTIC by the way if you don't know already) to schedule a time to meet with her as a get to know you meeting. I made it for January 19th at Chili's on City Avenue since it was kind of like in between for both of us. Boy, did we hit it off right away. We ended up staying there for 3 hours. Just talking and talking.

Soon after talking with her I knew that the decision I made was in the bag! That meeting was what made me feel so certain about this. My feelings haven't changed, not one bit. I haven't even been in this group that long and yet I have a title. I'm the group's secretary. I love it! I really feel like I add something special to the group. Everyone appreciates me and my minutes. It's wonderful.

Everyone is entitled to one life and it is so important to make the most out of it, no matter what you do. If there's something that interests you, like a certain skill that you may have or a hobby, I say then Go For It! Go pursue it because otherwise you might regret it later when it's already too late. No one should be told that they can't or won't ever be able to do something. I truly believe in that. For an example: Living on my own and being fully independent. I shouldn't be held back or told that I can't live on my own, be in my own 1 bedroom apartment and make decisions for myself. Most importantly that's what my parents want for me also. Interested in hearing excerpts of our secretary's notes, read on...

For excerpts of our secretary's notes, please turn to page 3.

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The Struggle of Finding the RIGHT Kind of Independence: *A Parent's View*

by Linda

Let me tell you about my 21-year-old daughter, Stephanie. She has so many strengths and abilities. Amongst her strengths is her love of reading. And when you talk to her one on one, she reveals a depth of intelligence and wit. However she also carries a number of diagnostic labels and conditions. These latter attributes have us concerned about her future. They challenge our hopes and our plans for her to live a full, productive life. How can we plan for the eventual time when we will no longer be around to support her? We have had to change our definition of "independence" for her.



Because Steph is a twin we have had a built-in "control" example to measure her developmental growth throughout the years. We were alert to her comparative delays at meeting her milestones, so early intervention was always a part of the game plan. We started with speech therapy and occupational therapy in preschool and continued on with Special Ed classrooms and eventually private schools for "Children Who Learn Differently." Steph always tested and performed with intelligence scores generally within the normal, even sometimes the high normal range, but with curious unexplained gaps and disabilities. In many ways she typifies the perfect SWAN, that is: a child suffering from the "Syndrome Without A Name."

Despite some trials and stumbling blocks, Steph benefited from the academic and social supports available to her at her high school. She participated on the girl's volleyball team, was a model in a student fashion show and volunteered at a local animal shelter. We were very proud of her successes and had happy expectations when she was accepted to a small Liberal Arts college that had a very good program of academic supports for students with special needs. The school was nearby, but not local, so Steph lived in the dorm.

Unfortunately, we soon found out the difference between academic supports that the college did have and social and emotional supports that it lacked. Also, it was at college where the more

disabling aspects of Stephanie's Asperger's Syndrome came to the fore. Steph was unable to reach out to other students or build a community of friends from her classes. She soon felt isolated and depressed. After a number of trips up to school to give her parental support and encouragement, it became clear that college was not a good fit for her at that time.

As much as we love Stephanie and want to shelter her and provide for her, we also know how important it is for her to grow and develop away from us. As a mother, I have to come to terms with my urge to overprotect her. So, even though one path did not work out as we had hoped, an independent life—at least one as independent as she is capable of having—is still an important goal we have for her.

Enter the Philadelphia Independence Network. Within the framework of PIN and with the backing of JEVS Human Services' programs, Stephanie is now able to live away from home—with supports. She shares an apartment in Narberth, commutes to work at Giant Food Store, volunteers at Habitat for Humanity and makes plans to get together with friends. Yes, she even calls up friends to make arrangements to meet them for activities herself!

A major factor in Stephanie's current successful foray into life is PIN's Program Director. She serves as a compassionate listener and, at appropriate times, a motivational coach. It is through her knowledge and insight into each member of PIN that she can keep the lines of communication open between the participants, help to manage the group dynamics and generate a sense of a community amongst them. This is so important to someone with Steph's disabilities.

So, yes, we have modified our definition of independence to include necessary supports that PIN can provide. We can now see a way for Stephanie to mature and to grow up and away from the insular cocoon of home and be as independent as she can be. We highly recommend it!

Visit us at:
www.jevs.org

Email us at:
pin@jevs.org

PIN Postings

PIN Minutes:

Met Thursday, March 22, 2012

- 7 PIN members attended: Myself, Courtney, Adam, Avi, David, Stephanie and Marnisha. There were some visitors also: David L., Jake, Bruce and Peter.
- This week's gathering turned out to be a "big" group. There were 12 of us altogether! We all met in the back courtyard area of Adam's apartment complex. Talked there for a while. Marnisha introduced all of us to the "visitors".
- One thing that we talked about possibly doing (PIN members/parents too) was this fundraiser walk/bike race for the illness that Peter has. When I have more info about it, I will post it on the calendar. So if anyone is interested in doing it they can sign up that way!
- We went out for a bite to eat. We went to the sandwich shop located in town. It's actually right across the street from David's apartment. Sat inside.
- It was a lot of fun. Stayed there for a long time! The service was a little slow, but the food was hot and tasty.
- Got to know David L. and his friend Jake a little bit. I like them both. We laughed a lot! I hope that we will see more of them. It definitely mixes up the PIN group a little bit. I think that will be good. Some variety is nice.
- One thing that I did notice last night when we were all sitting at the restaurant and afterwards -- we truly came together and were like a family! I haven't seen that before, but it was something special. I know that Marnisha noticed it also. There wasn't a single frowning face last night. Everyone was smiling and laughing.

IT WAS AMAZING!!!!!!!



PIN members enjoying some of our get-togethers



PIN Minutes:

Met Thursday, April 5, 2012

- Members of PIN who attended: Myself, Stephanie, Adam, David, Courtney, Marnisha and Avi.
- We all met up in Adam's apartment for our meeting. For the first time it was the "PIN" members, without Marnisha, that got the meeting started. It was great! We started coming up with some ideas to go on our calendar. This is what we came up with: day trip to a mall (maybe The Gallery?), Philadelphia Zoo (already posted!), play or a concert, The Franklin Institute, Dave and Busters, Phillies game, day trip to the shore (New Jersey), day trip to NYC, horseback riding (ideal on a trail) and finally miniature golf.
- In addition the "parents" are trying to schedule an event where everyone meets in a local park (Narberth) to have some food and play some games. That event is TBD.
- One thing that we talked about was "Marnisha's email assignment" that was sent to everyone. The question was "to define the word purpose". She wanted our opinions/thoughts about one's life purpose. Mostly everyone shared their answer. It was very interesting to hear!
- Next we started talking about focusing on the "PIN event" which is on the 29th. We will be representing PIN and started to practice how to respond to questions that may be asked. Stephanie and I will attend.
- We discussed a little bit more about that fundraiser walk/bike for Peter's sake. Since we got more information about it, this time we were able to post it on the calendar!
- Finally we came up with our next event for this month. We decided it should be a bowling outing! It is posted on the calendar, but it's not a 100% definite yet. Will know for sure hopefully soon. (to be determined.)

It was nice seeing everyone!!! See you all again soon!

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Parents' Perspective: *A Partnership with JEVS*

by Jerry and Lois

When we began plans to start what is now the Philadelphia Independence Network (PIN), our first concern was finding the right social service agency partner. Several well-informed friends and acquaintances suggested that we speak to JEVS. From our first exploratory meetings, we, and the other founding families, knew that JEVS was that partner. The JEVS team enthusiastically embraced the passionate engagement of the families in the design and structure of PIN. Our ideas, suggestions and cautions were all part of the planning that launched the program. The JEVS Board of Directors, the Chairman of the Board, and JEVS CEO Jay Spector were as excited as the families about this newly formed partnership. As our young adult children living Narberth display growing confidence, competence and independence, it has become clear that the collaboration between JEVS and the families and friends of PIN has helped create a vibrant and successful program.

The collaboration continues as PIN grows. The PIN Steering Committee, a joint committee combining JEVS/PIN staff and PIN parents & friends that meets monthly, leads the growth and development of the program. Other committees are focused on program enrichment, fund raising, volunteer opportunities, and finance. JEVS encourages parental involvement, and welcomes the knowledge, experience and skills families can contribute to PIN.

JEVS and the families see each other, and this collaboration, as essential to the success of PIN. Together, we have created an ongoing and exciting partnership to help build a vibrant community for our children.

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