

Beginning the Transition to Adult Life

by Maryann B. Hunsberger



Crunch time.

So many families of young adults with developmental disabilities know exactly what that means as their son or daughter enters their last year of high school.

So, although Sue Gazzarra began planning for her daughter Stephanie's transition to adult life in 2006 when she was 19, two years later when Stephanie entered her final year of school in the

fall of 2008, her mother knew it was crunch time.

"The idea that a child with severe challenges will be an adult is something a parent doesn't want to think about. But the reality was that I would be dealing with an adult child. No longer would the little yellow bus, which had provided a comfortable parameter for my life, be coming for her in the morning.

“Intellectually, I knew transition was coming, but I kept thinking it was one of those things I could worry about tomorrow. Transition is one of those things you shouldn’t put off, but you do. School, for better or worse, provides a structure. It’s easier to not cope with the future, because the stress of dealing with the present is hard enough. Suddenly, her last year of school was here and it was time to make choices.”

Working with Stephanie’s teacher, the family looked at traditional day programs while actively trying to get more information on self-directed day services.

During her 2006 enquiries, Gazzarra has learned that DDD had a self-directed option.

“I had no idea,” said the Browns Mills resident.

“You can’t fit her into an environment,” Gazzarra said. “You have to make the environment suit her, because when she’s not happy, nobody is happy.”

Stephanie has autism and that creates sensory issues. She becomes anxious when exposed to crowds, noise or visual stimuli. The resulting anxiety can bring on seizures.

“We really didn’t see any alternative that fit hers and our needs as well as the self-directed one,” Gazzarra said. “I’m not saying the day programs weren’t good. They just wouldn’t have been good for her.”

Gazzarra began attending a series of meetings at DDD’s Voorhees office. A support coordinator worked with the family to make an Essential Lifestyle Plan (ELP).

“It’s a mega document where you list anything that anyone would ever want to know about your child—what she likes to do when she gets home from school, what her favorite TV programs are, what music she listens to, what her health situation is like, which medication she takes, what foods she cannot eat, what foods she likes. They asked what someone would need to know about Stephanie in an emergency and what quirks she has. I explained that she gets upset if every light in the room isn’t on. She will point to the lights and you have to get up and turn on all the lights. Since she is nonverbal, someone would wrack their brains trying to figure out why she would be getting upset.”

The ELP is a document in progress, so new components can be added at any time. Gazzarra and a support coordinator make necessary changes to the document online.

“One section lets you add new things. For instance, we were at the store and Stephanie was unhappy. I sat her in a chair near the pharmacy section for 10 minutes. After relaxing, she was okay to continue walking around. If Stephanie becomes upset in a crowded setting, it calms her to sit off to the side for a little bit. It hadn’t occurred to me to add something like this to the plan before.”

The self-directed option has allotted 25 hours of services each week. Gazzarra advertised for staff. She received calls and resumes from 35 individuals, so she spent most of June interviewing potential employees. She chose one employee to work 10 hours each week.

“She is already working with another family, so she didn’t have to go through the long approval process. The mother of the other family saw the ad in the Burlington County Times and called to recommend her.”

Gazzarra is still interviewing to fill the remaining 15 hours. Easter Seals handles criminal background checks and drug screens for the applicants and disburses paychecks.

Next is figuring out exactly how to instruct Stephanie’s support people about what they will be doing.

“It will take us another six months before Stephanie’s program is up and running. I’ll make a schedule each week that will include working on life skills and community skills. If certain things don’t work out, we’ll change course.”

Gazzarra would like to see Stephanie doing volunteer work. They are making arrangements with the Browns Mills Recreation Department for Stephanie to work there, building on basic office skills she learned in her last year in school. Gazzarra is also making plans for Stephanie to assemble silverware for the lunch program at the Browns Mills Senior Citizens’ Center and help out at the food pantry connected to a local church.

Gazzarra plans to take this one step further by approaching her school district concerning other students with significant disabilities who are aging out of the school system.



“The scariest part is change. The educational setting, for better or worse, provides structure. When your child leaves school, that structure is gone. The decisions that were made by professionals in the school district will now all be made by us.”

— Sue Gazzarra

“I’d like these kids to have opportunities to do volunteer work. There are opportunities out there, but it will require synergy between the community, school and DDD to put these in place.”

Gazzarra is still apprehensive about her daughter’s future.

“The scariest part is change. The educational setting, for better or worse, provides structure. When your child leaves school, that structure is gone. The decisions that were made by professionals in the school district will now all be made by us. Before, we were part of the process, but the school officials did the work of putting things into place. Now, we do the work. Many people won’t be able to do this, so they will send their children to a traditional day program.

“I think what we have worked out will work well for Stephanie. But, it’s a challenge. And I am in complete panic mode when I think about how budget cuts might affect whatever program I create.”

Stephanie understands that this change will be taking place, and her mother is helping her realize

that her new life will contain many elements of her life before graduation.

“She will continue doing things that she did as a student, such as swimming at Burlington County College’s pool, doing laundry at the laundromat, going grocery shopping with a list and visiting the library. It will build on and increase the life skills she learned in school.”

Gazzarra’s hope is that self-directed day services will help Stephanie to live her life as independently as possible.

“I hope this program helps her live up to her potential. We won’t live forever, so we expect that she will live independently of the family at some point. But, that goes into the waiting list problem, which is a whole other story. Maybe parents need to think outside the box for that, too. Lots of families are looking into joining together to start their own residences. I think families will take more and more of the lead as time goes on.” P&F

Council Sponsored Project Creates Art for All Seasons

by Maryann B. Hunsberger



Gail Levinson,
Executive Director

Arts Unbound is the brainchild of Cate Lazen.

Shortly after attending a show featuring artists with disabilities, Lazen learned that the child she carried had a rare chromosomal defect that could result in an intellectual disability. Her child was born without any effects from the chromosomal abnormality, but Lazen's experiences and her background in art, education and community housing led her on a search for outlets for artists with disabilities. She found none.

In keeping with the agency's mission to employ individuals with disabilities in the arts field, they are working on a project designed to create an income stream for persons with developmental disabilities through the sale of artwork on the retail market. This has been made possible through a grant from the New

Jersey Council on Developmental Disabilities.

This past year, they have produced greeting cards with 17 images and have met the shared goal—as outlined in the grant—of selling \$7,000.00 worth of cards.

“In this first year, we set about creating a line of greeting cards for sale to the general public, which included a line of general greeting and holiday cards,” said Gail Levinson, executive director of Arts Unbound. “We have been selling these cards to individuals who come into our gallery, to corporate purchasers, to people who are involved with us as volunteers and to donors.

“Our hope over the next several years is to expand and create even more products,” Levinson said.



"I created Arts Unbound to legitimize the artistic ability of people with disabilities and expand their vocational opportunities," Lazen said.

Besides selling the artists' work in their gallery, Arts Unbound promotes their work through exhibitions and art fairs statewide. The organization has about 250 individuals participating monthly, ranging from 10-year-olds to seniors. Classes are offered both at their studio and at various off-site locations, including public and private schools, senior centers, nursing homes, assisted living centers and agencies serving people with disabilities. Although most of their work is done in Essex, Union and Morris counties, they have begun expanding to Bergen. They hope to branch into Monmouth soon.

"We are eager to become a statewide organization and will hire teachers throughout New Jersey

wherever students are interested in learning visual arts skills," said Levinson. "We only hire

professional artists or art teachers who currently travel to teach. If a group of agencies in one particular county is working with us, we can hire an art teacher in that county."

Classes are conducted either by fee-for-service or with support from a variety of foundations. They serve a number of students through the Division of Developmental Disabilities. Some of those have incorporated art lessons into their Essential Lifestyle Plan as a component of the Real Life Choices program.

NJ SHARES (a nonprofit organization providing communications and energy assistance to low

income people), in partnership with Verizon NJ, has purchased an image created by Dashir Johnson, a 17-year-old student with autism, for their 2010 holiday greetings line.

“His exceptional work in digital design has been highly regarded by those visiting our gallery,” Levinson said. “His whimsical designs convey the ongoing intricacies of social interactions between family and friends.”

Dashir became a student at Arts Unbound after a teacher at his high school entered his artwork in a contest. He won. And Dashir’s mother, Shalonda Johnson, promptly enrolled him in lessons.

“I thought it would be good for him to participate in something he loves,” she said. “He’s so artistic. He doesn’t just draw what he sees. If he’s drawing a beach, he sees the shapes of the

Dashir’s Chanukah pictures



The gallery features art in many styles and media.

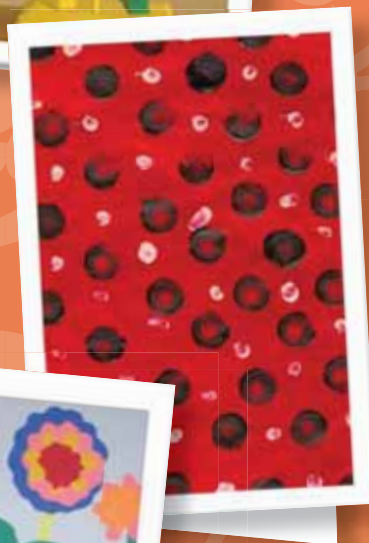
clouds and the colors of the ocean, not just a beach. Every week, he does pieces in class that are displayed. When Verizon chose his image, I was overwhelmed! It was so exciting

“Dashir isn’t really concerned about those things. He doesn’t draw for money or to get his pictures displayed. He just does it because he loves it.”

“Arts Unbound offers individuals a chance to learn the art business from the ground up,” said Levinson. “It gives them an outlet for their art and provides skills to work in the greater arts community. This work is important and we hope to continue expanding and supporting artists with disabilities.”

The Arts Unbound Greeting Card Collection

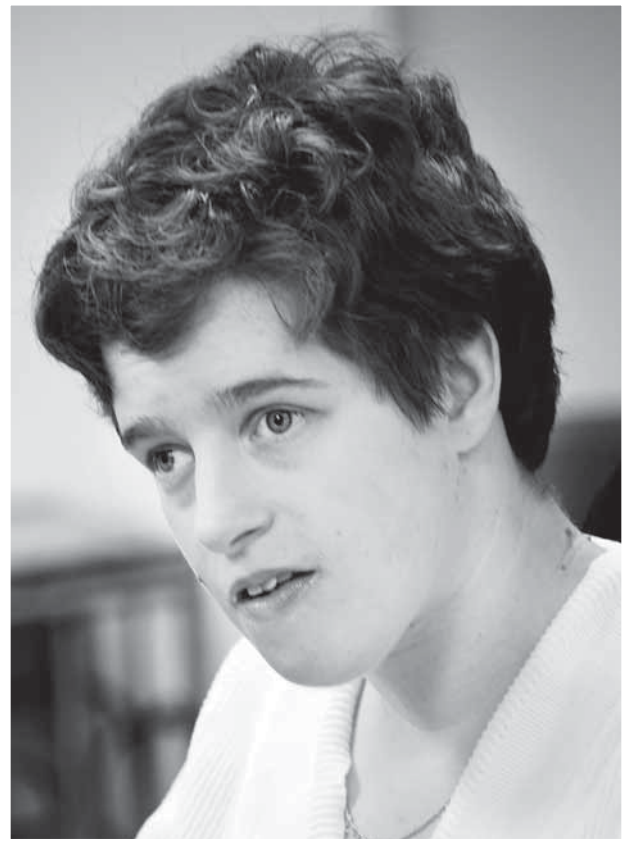
Supported by the New Jersey Council on Developmental Disabilities. For customized corporate orders (quantity pricing) or to purchase packs of 20 cards (single image or mixed) at \$30.00 per pack, please visit our online store at <http://www.artsunbound.org/store.htm>. To purchase single cards for \$2.50 each, visit us during normal gallery hours, or call 973-675-2787.



For more information on Arts Unbound, call (973) 675-2787, or e-mail info@artsunbound.org, or go to www.artsunbound.org

Here to Serve in Bergen County

by Maryann B. Hunsberger



As the new facilitator, Lauren Valenta is fired up over the recent and upcoming activities of the Bergen County Monday Morning Network.

The network recently secured a wheelchair ramp for an apartment complex for one of its residents, and convinced a local restaurant to add more accessible parking and a van access aisle.

Since the network considers information dissemination to be an important part of their work, they have referred many individuals to disability-related agencies.

“Many individuals don’t know that such agencies exist, so we do a great deal of information and referral for people with disabilities in Bergen County,” said Valenta.

The network also does ongoing work to promote voting.

“I personally helped with voter registration at Bergen Community College. We registered a good number of people with and without disabilities. We sent out surveys to the local polling places to assess their accessibility, but haven’t yet gone out

to see the polls. We hope to do this soon. Our members have also worked at the polls on Election Day.”

The network continues to carry out accessibility tours of different towns in Bergen County.

They will visit Giants’ Stadium this coming year and report their findings to the owner. And Barbara Lee, Monday Morning Coordinator, said that the group would also survey the rest of the complex that houses the stadium.

“The network has also been working closely with architects to ensure that the Xanadu Shopping Center at the Meadowlands Sports Complex will be fully accessible,” Lee said. “They will assure that the center will have adequate parking spots, elevators, automatic doors and other necessary things.”

The group also plans to survey the Bergen Medical Building.

“We want to be sure that everything meets the ADA requirements, since some of our members have brought up questions and concerns about

this building,” said Valenta. “We will contact the doctors whose offices are in the building as well as the building owner.”

Valenta and the network plan to conduct the same kinds of assessments throughout the county. An accessibility check of the 50-plus store Bergen Town Center is also on the agenda.

“After we do an accessibility survey, we will contact the owner with the details of any problems, asking them to follow up. If any individual stores have problems, we will contact store managers in addition,” Valenta said.

Valenta said her network hopes to make Bergen County a leading area in the state for accessibility and disability friendliness.

“Anyone who has a concern within Bergen County can bring it up at our meetings and we will determine what we can do as a group to resolve the issue. Hopefully, other parts of New Jersey will see what we are doing and follow our lead.”

Valenta, 34, a Bergen Community College graduate who majored in liberal arts, also serves on the Bergen County Division of Disability Services Advisory Board.

“We discuss current services and activities, as well as those that we hope to implement. The advisory board helps to decide how to put grant money to the best use for people with disabilities in Bergen County.”

Valenta volunteers with CP of North Jersey in Livingston, helping to run a women’s support group at Horizon High School. She also talks to the students about transitioning to adult life, so they will know their post-graduation options.

“It’s important to help them deal with the anxieties of facing adult life.”

Valenta is a member of the New Jersey Transit ADA Task Force. The task force has monthly meetings with NJ Transit to work on the goal of assuring that every train station in New Jersey is accessible. They have been working with their legislators on A2046, a bill to increase funding of their County Senior Citizen and Disabled Resident Transportation Program.

Valenta, who lives with her family, hopes to someday find paid employment in the field of disability.

“Once I get a job and learn what housing options are available, I’d like to move out within the next few years. I am hoping that my volunteer work will make me better known in the disability community so I can eventually be paid to work with people with disabilities.”

Valenta attended Partners in Policymaking in 1998, while she was in college. Valenta said that Partners improved her leadership and advocacy skills and made her a more vocal advocate. It was during one of the Partners weekends that she learned about Monday Morning. When she finished college, she began attending the meetings regularly.

Valenta is excited because the Monday Morning facilitators throughout the state have resumed attending retreats geared toward helping them improve their leadership skills. According to Lee, these retreats will take place on a quarterly basis.

“We will focus on one or two topics at each facilitators retreat,” Lee said. “At the August retreat a guest speaker reviewed facilitator techniques, explained how to recruit new members, discussed outreach and publicity and talked about effective communications when approaching legislators or people in the community.”

“A major goal of the Council (the New Jersey Council on Developmental Disabilities) is to promote the “No R Word Campaign” in the community. We are now in the process of figuring out how the networks will take part. Right now, they are passing out buttons, pamphlets and bumper stickers, but we’d like to have a more formal procedure for working on this,” Lee said.

Both Valenta and Lee are encouraged by the direction the Bergen Network is taking.

“We’re setting good goals and focusing our activities on making local improvements for people with developmental disabilities,” Valenta said. “And we’re looking forward to working with other Council projects on statewide campaigns.”

The Bergen County Monday Morning Network meets on Thursdays from 11 a.m. to 1 p.m. at the offices of Heightened Independence and Progress (HIP) at 131 Main St., Suite 120, Hackensack, New Jersey. **P&F**