***Disability Issues***

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*Providing individuals with disabilities, their families, friends, and advocates with relevant information to enhance their quality of life, health, and employability options.*

Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital. Its main campus located in Boston, as well as Spaulding Rehabilitation Hospital Cape Cod, two long term care facilities Spaulding Hospital Cambridge and Spaulding Hospital North Shore and two skilled nursing facilities, as well as twenty three outpatient sites throughout Eastern Massachusetts. Spaulding is a teaching hospital of Harvard Medical School and the official rehabilitation hospital of the New England Patriots. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by U.S. News and World Report in its Best Hospitals survey with a #5 ranking in 2011. For more information, visit [www.spauldingnetwork.org](http://www.spauldingnetwork.org/).

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**From the Editor:**

Dear Readers,

Since I was a little girl, I have loved going to see live performances and art shows. Since I do not consider myself very artistically talented, I am in awe of the wondrous art that people create. I once told a friend who said he was not comfortable singing hymns in church that he can contribute to the music by receiving the song because every singer needs someone to hear and appreciate the song being sung. Similarly, being an art aficionado is typically how I contribute to the art world. In this arts-themed issue of *Disability Issues*, there are certainly many artists and artistic expressions to celebrate!

To wax a bit poetic, art is what helps to elevate the human spirit and connects us to what it means to be human. Song, dance, drama, literature and visual art moves us, inspires us, stirs us to action, and touches us on a spiritual and emotional level. Members of our society often see “different” first when they see a person with a disability or someone from a different culture or ethnicity. Art has the power and possibility to bridge differences by tapping into what we have in common, and not just those things that set us apart.

Art also feeds the soul in a reciprocal way; from the artist who creates it to the person who experiences or appreciates it. By tapping deep into their own pain and joy, artists express our universal experiences of triumph, defeat, strength and tenderness. Through their art, they not only show us who they are, but who we all are.

In the words of one of our most beloved leaders, President John F. Kennedy once said, “If art is to nourish the roots of our culture, society must set the artist free to follow his vision wherever it takes him.” To our artists in the disability community, thank you for your courage of boldly revealing yourselves to us and creating art that invites more wholeness in the world.

Marianne DiBlasi, Editor

**Turning the Charlestown Navy Yard into a Haven for Art**

**By Tim Sullivan**

Among the features that Spaulding Rehabilitation Hospital has for its patients is a commitment to the use of art to help engage visitors. That commitment also extends to the community by providing exhibits and pieces in its public spaces that speaks to that mission.  These exhibits also enable Spaulding to foster economic independence for working artists with disabilities by displaying their work for sale. Collaborating with its neighbors at the HarborView at the Navy Yard, the corner of First Avenue and 16th Street in the Navy Yard now has two exhibits open to the public that speak to the themes of hope and perseverance.

The first exhibit, “The Art of Recovery - Finding Strength through Art at Spaulding Rehabilitation Hospital” is on display on the first floor of the HarborView at the Navy Yard, 250 First Avenue. This exhibits focuses on art created from painstaking brush strokes in therapy sessions to patients documenting their new world view through photography. The theme is how art plays a pivotal role in their care and ultimately their recovery.

The exhibit features art created by the Spaulding Pediatric Unit patients, former Spaulding patient and photographer [Sebouh Kendellian](http://sebouh.9f.com/) (available for purchase) as well as a sampling of artistic contributions from all across the globe to Spaulding during their treatment of survivors of the Boston Marathon Bombings. The exhibit is open 9am-5pm to the public and will run into early 2015.

Also open to the public through the Spaulding Peace Art Gallery is the exhibit “Panes of Recovery” featuring the Artwork of Ted Roland. Ted Roland is a self-taught stained glass artisan who has created pieces reflecting his passions for cycling and music among other topics. From his varied work, Ted has selected eight pieces for this, his first public exhibit. Through his own experience and expression he seeks to inspire patients, families and others in their rehabilitation journeys. This exhibit is viewable on the first floor of Spaulding Rehabilitation Hospital, 300 First Avenue from 10am-8pm each day.

“Spaulding’s commitment to art is evident throughout our hospital as it plays a major role in creating a healing environment,” said Oz Mondejar, Senior Vice President of Mission and Advocacy at Spaulding. “In addition to that, we are committed to providing opportunities for working artists with disabilities to display their powerful work both for the enjoyment of our community as well as an avenue to income for them. It’s the perfect complement to our mission to improve the quality of life for the communities we serve in any way possible.”

For many artists with disabilities simply finding opportunities to display their work is a significant barrier before even accounting for the chance to get income from their work.  Since 2010, Spaulding’s Peace Art Gallery has been committed to providing portions of its gallery space to artists with disabilities so they can display work and sell their art.

The gallery rotates its exhibits with three – four per year. Artists interested in being part of future exhibitions should contact Colleen Moran, Director of Work Force Development and Volunteer Programs at 617-952-6927.

*Tim Sullivan is Director of Communications, Partners Continuing Care & The Spaulding Rehabilitation Network.*

**Special Needs Arts Programs**

**By Heidi O’Mara**

For more than thirty years, the *Special Needs Arts Program (SNAP)* has been enriching the lives of individuals with intellectual disabilities through music and visual art programs. *SNAP* provides people with disabilities opportunities that celebrate each person's unique abilities while cultivating their creative expression, building peer relationships, and fostering self-esteem. Through music performances and art exhibits, members share their accomplishments with others, fostering community involvement and inclusion.

The Sing-a-Long Chorus program offers weekly evening music rehearsals from September through May for adults ages 20+ that includes time for socializing and refreshments. These groups have become a community of deep friendships and support for each other. The acceptance and camaraderie they encounter each week provide a measure of stability, comfort and belonging. One parent shared what the Chorus meant to his daughter, *“My daughter Alicia has participated in SNAP choruses for about 30 years. This has been the core of her social life.  Each week she is excited to spend time with her chorus friends who have become her long-term support network.”* The choruses perform at their own concerts in the spring and fall. Additionally, they engage in community outreach by presenting concerts at nursing homes, hospitals, residential communities for senior citizens, and at local community events.

The Special Artists program offers fall and spring arts and crafts classes on Saturday morning for adults 20+. Activities include painting, drawing, clay work, fabric painting, and a variety of seasonal and holiday crafts. Recently, the participants had the opportunity to display their artwork in an art show open to the public. The program provides opportunities for expanding social skills. As a result of confidence and skills gained from the visual arts program, members are now participating in community groups, such as The Bedford Center for the Arts photography club, and outside art shows at community organizations. A participant in our Fall 2014 session had this to say about her experience, “*I like making things in art class and giving them to people.  I like using whatever color I want when we paint.  I like seeing what other people make and hearing why they used those colors at the sharing time at the end.  I like following the directions when the teacher puts them up.  It feels good when other people see my work.”*

In addition to singing and creating art, *SNAP* provides an enjoyable and supportive social experience for the participants, their families and volunteers. Each chorus rehearsal includes time for sharing personal stories that creates genuine friendships and a strong peer support network in times of struggle. For more information on *SNAP*, visit [www.snapsing.org](http://www.snapsing.org), call (781) 460-3599 or email info@snapsing.org.

*Heidi O’Mara is the new Executive Director at SNAP. Ms. O’Mara has spent her career in the non-profit world, working to empower and create opportunities for people.*

**Opportunities for Artistic Growth at Gateway Arts**

**By Zoë Wyner**

Gateway Arts is a studio art center for people with disabilities located in Brookline, MA. Five years ago, they started a unique program to support artists in developing their work and their careers in the field. This program, now known as the Artist Training Program (ATP) is operated through Studio A, a space that was founded in 1997 for artists with psychiatric disabilities, spectrum disorders, and head injuries.

Since its’ inception, ATP has served over sixty artists with various diagnoses. ATP is a 17-week program led by two artists with degrees in education and fine art. Participants have access to a wide range of studio materials and facilities that inspire creative exploration and growth. Artists spend 6 hours per week in the studio creating artwork. They spend another 3 hours weekly in seminars that address topics such as creating an artist statement, bio, and resume, marketing, pricing of work, and business fundamentals. As a product of these seminars, the artists complete the program with a portfolio in both digital and physical format, business cards, and a number of art materials so they can continue producing artwork on their own.

During and after the program, the Gateway Gallery and store serve as a venue for the artists to display their work. Gateway has a large customer base comprised of individuals in the community who have supported the organization for years, which provides the artists in the program with a unique opportunity to have their art viewed as they are finding their paths as artists.

***Recent ATP artist testimonials:***

“Gateway has a particular way of helping people – they listen,

and give us suggestions and help our ideas grow. They helped me think for myself. They helped us be more
confident. They make us feel like we matter. “ KJ

“ I had lost my ability to speak – I knew I could paint and draw,

but my stroke had made me forget how. Gateway helped me remember.” KJ

“… because of the patience of [the staff at] Gateway, I learned and developed skills I hadn’t ever thought about as an artist.” KJ

“One of the most important things I gained from [Gateway] was the invitation they gave me to be more creative. I was encouraged to explore my art in more depth. Also, leaving the program

with something tangible was incredibly valuable. To be able

to show someone my portfolio, or give them a business card – that’s huge.” RN

***Interested in ATP? Here’s how to apply:***

* Get in touch with us at Gateway. We will set up a studio tour and an interview where we can assess the artist’s work and determine whether Gateway is a good fit.
* If it seems that the artist will benefit from the program, the artist will contact their counselor at Massachusetts Rehabilitation Commission (MRC) or request a counselor from MRC if they do not have one. **NOTE:** Getting an MRC counselor generally takes around 3 months. Please refer MRC to Gateway with any questions.
* After receiving referral information, Gateway will set up a four-week assessment to further determine the artists’ eligibility for the program by setting a goal to be met. If this assessment is successful, the artist will be recommended for program participation.

For more information on the Artist Training Program, please visit, <http://www.gatewayarts.org/services/artist-training-program/>

To set up an interview or for other program information, please contact: Zoë Wyner at 617-734-1577 or wynerz@vinfen.org.

*Zoë Wyner is the Studio A Manager at Gateway Arts. She graduated from Lesley University where she studied education as well as visual arts. Outside of Gateway, she produces works using clay and other 3D mediums. Her work can be viewed at* [*http://zoewyner.com/*](http://zoewyner.com/)

**Portraits of Two Artists**

**By Sandy Alissa Novack**

***Jane Tarlow*** was the middle child of three girls and was considered rebellious and an introvert. In elementary school, she took to art to find a sense of freedom and peace; she liked to draw kittens and trees with crayons. However, she did not feel committed to art when she was young. To obtain a sense of freedom and peace as she was growing up, she turned to tennis, skiing, and water skiing. During high school, Jane was diagnosed with mental health issues and did not feel freedom and peace for decades.

Her older sister learned of Gateway Arts and thought it would be a great idea for Jane to onced again use her art talent. Seventeen years later, Jane still is associated with Gateway. She had never felt she was a great artist, but she knew it continued to give her an emotional outlet. At Gateway, she learned of artist, Frida Kahlo, and her painful life of acquiring polio as a child and also being in a bus accident that left her with pain issues. Jane felt she could identify with Frida, someone who also used art to find peace, as well as to express her pain.

Over the years, Jane has focused on acrylic and watercolor painting, and has tried ceramics, glazing bowls and mugs. Though she does not carve out chairs and tables, she has a knack for painting flowers and vines on ready-made furniture. Trying to maintain energy, Jane works mornings on her art and does physical activity in the afternoon – Iyengar yoga twice a week at a community class to help her focus on self and peace of mind, swimming twice a week at a local school’s pool that is open to the public, and also work outs twice a week on a stationery bicycle and treadmill.

Jane tells me that Gateway provides a way to socialize with other artists. When she makes something attractive, it makes her feel successful. When people appreciate her art and buy it, not only does the sale bring her some income, it also adds to her sense of being valued and her growing identity as an artist.

Jane encourages people who may never have tried art before to give it a try, in any form. She says that you may grow artistically, socially, emotionally, and spiritually.

***Ruby Pearl*** says she started drawing at 3 years of age. Her parents kept giving her art supplies, which kept her drawing. At age 4, she saw an advertisement on television for a national art contest for adults. She used markers to draw a scene that she visualized in her mind and her mother sent in her entry. Ruby won first prize!

She reports that at the age of 3 she was a victim of incest and painting was a means to cope. She painted dark pictures of evil faces. She says she became obsessed and could not stop drawing faces. In between dark pictures, she did a lot of scenery. Then and now she can only paint things she is passionate about, which is an issue at times when she is offered a commission that does not involve people as she feels more comfortable with people. She points out that the majority of her paintings are of women “in a quiet, perfect sweetness of solitude”. She begins by painting the eyes and develops a relationship with the person in the painting to evoke the emotion she is seeking to express. Her paintings with the theme of solitude sell often.

Ruby has been married multiple times. After her last divorce she found herself numb and homeless, living in her car. She then came to live for one year at the Pine Street Inn and began thinking about how to change her life, which led her to Massachusetts Rehabilitation Commission (MRC) for help to get a job. A savvy employee there said a regular job would not work for her given that mental health issues left her with panic that had made her leave many jobs after a few weeks. MRC suggested Gateway Arts. Even when living in her care, Ruby had used art supplies to make one of her all-time favorite paintings from her imagination so the idea of Gateway interested her.

Twenty years ago, Ruby interviewed at Gateway. She did not view herself as an artist, she thought art was just a way to express herself. Ruby explains that Gateway does not teach people how to paint or do other forms of art. They allow you to go in the direction you yourself want. They do not want to change you, they accept you for who you are with the health or disability issue you come with because your disability informs your art. Ruby says, “Express your ability within your disability.” And she adds, “I make use of my life experiences in my art, but I do not plan to, rather the art expresses it.” Ruby adds that Gateway Arts has also given her the courage and ability to live the life she never thought she could have. For the first time, she has a home with her very own bedroom, kitchen, living room and bathroom to share with her cat, Bruno.

When her first work sold at Gateway, it came as a surprise to her. She still did not view herself as an artist and she could not grasp why someone would by her artwork. As more works sold, she came to understand that she is not only an artist, but a professional artist. People “get” the emotions in her artwork, and some people collect her art.

Now in her 60's, Ruby reflects on where she is currently with her art, saying “My heart is spilling out, more than it ever has, within my paintings. My understanding of my own emotional path for decades has led to deeper emotions expressed in my paintings.” Ruby’s paintings can be viewed at [www.rubypearl.org](http://www.rubypearl.org).

*Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G**is a Social Worker and a consumer advisor on the Beth Israel Deaconess Medical Center’s Universal Access Advisory Council.*

**Arts for All**

**By Sahar Ahmed**

Every nonprofit has a story to tell; a reason for why that organization has to exist. Brio’s story is one of passion and vision based from a meeting I had with one person that changed my perception of disabilities; a topic I arrogantly thought I knew a lot about.

In the year 2001, I met an artist by the name of Wolfgang Stange. At the time, I was working as the executive director of a nonprofit organization in Cairo, Egypt that educated, employed and advocated for people with disabilities. Wolfgang is the founder, director and principle choreographer for the AMICI Dance Theatre in London. The first time I met Wolfgang, I was deeply moved. He told me a story about a Christmas party in Negombo, Sri Lanka at a home for the disabled where he became aware of the audience who was watching local school children performing. He watched the residents of the home and wondered how it must feel to always be watching performers, to be excluded, and he couldn’t bear it. That's when he decided to concentrate on investigating possibilities of different ways to dance as a form of creative expression for people who otherwise would never have the chance to develop their artistic potential. For the next two months I worked with Wolfgang and together with a cast of 60 people of all different ages and abilities produced a show that was performed at the Cairo Opera House. The performance was sold out and the facial expressions of the performers and the audience were ones I would never forget. Until now, I have never seen a longer standing ovation. From that day on, I was convinced by the transforming power of the arts.

In 2004, I moved back home to the United States and I had every intention of continuing this work. I saw how the arts can change a person’s self-perception and the perception of others. The thought became a lingering obsession and I needed Wolfgang’s help. I sent countless emails, called and I even went to visit him in London to get advice on what to do. However, Wolfgang simply told me that I did not need him and I had everything that it takes….passion. He told me the most important thing to remember is, “everything is possible and that there is no such thing as being too disabled.”

In 2008, I created Brio Integrated Theatre. At Brio, our motto is ***Arts for All*** because we believe that creativity has no boundaries. We strive to break down misconceptions regarding people with disabilities. Since 2008, we have provided free community performance workshops and other creative arts instruction to people with all levels of abilities. Our Art workshops have included; Mask making, Cooking/Creating and Eating it too, DJ workshops, Hula-hooping and Dance workshops, Painting and Photography workshops, West African Drumming and Bully Transformation workshops.

In 2013, we began a pilot internship program for students with disabilities because we wanted to provide young adults with disabilities the same employment and career transition opportunities as their peers. We also made a concentrated effort to make our programming available to underserved communities where resources may be limited and where access to free arts programs would be needed. In 2014 Brio’s outreach programs included Roxbury, Dorchester, Mattapan, and Lynn.

Through my journey with Brio I have met some gifted disabled artists who have enriched our programming. Our doors are open for disabled artists who would like to share their skill and talent with our community. We provide employment opportunities for guest artists and we invite artists with disabilities to come forward and join us.

Brio Integrated Theatre was created to break barriers and eliminate stereotypes regarding disabilities using all art forms as a medium. For more information about Brio Integrated Theatre, please visit [www.biotheatre.org](http://www.biotheatre.org) or call 781-353-9247. Brio Integrated Theatre is located in Winchester MA.

*Sahar Ahmed is the executive director of a Winchester based nonprofit called Brio Integrated Theatre.*

**Theatre with a Twist**

**By Mary Jane Fietze**

“If you have met one person with Asperger’s you have met one person with Asperger’s,” Robert Wilson said when he discussed Asperger’s and the arts with me. I said “you are very smart” and he replied, “That’s the thing. People with Asperger’s have IQ’s that are off the charts, but their social skills are the lowest.”

I really knew very little about Asperger’s before I interviewed Robert, but after speaking with him I knew much more. He was a wealth of information. Robert said that he is a very linear thinker and needs a step-by-step approach to projects. He is very “task oriented” while being “hyper-focused.” It is this attention to details that enabled him to learn Chinese at an early age. He spent his fifteenth birthday in the “forbidden city” of Beijing, China as a *People to People International Student Ambassador*; a program that was conceived by Eisenhower **“**to bridge cultural and political borders through education and exchange.”

This attention to detail also explains why autistic savants are often geniuses in music or art, yet are sometimes non-verbal. According to Dr. Stephen M. Edelson, “The autistic savant is one of the most fascinating cognitive phenomena in psychology”. But there are no gray areas for those with Asperger’s. Everything is black and white, which leads to social skill challenges. Robert is still learning that there is a middle ground when approaching social situations and he is learning to compromise.

These real life situations are often acted out at a Drama Therapy class, which Robert attends every Tuesday at *Theatre with a Twist Inc*., in Acton. The theater is in the process of being renovated and fully ADA accessible. The class is for adults, ages 18-28 with Asperger’s or other disabilities. Robert’s mom, Mary Spinosa, runs the class. She meets with each new client and their family before the first class. Each participant must sign a contract committing to an inclusive safe environment, which includes no teasing**.** An improvisational scenario might pertain to a relationship at work or a romantic relationship. Everyone in the group is encouraged to open up and share. Often others might have experienced a similar situation and it helps to know they are not alone.

Mary has been studying Drama Therapy since 1979, not knowing that she would soon be applying it to her real life situation with her first-born, Robert. The group also attends social events, such as country western dancing, pool, darts at a sports bar, and karaoke. Robert said that a lot of his classmates have become close friends. Theatre with a Twist welcomes everyone to try out for productions. Many from the class have gone on to perform on stage in *Grease* or *Bye, Bye Birdie, s*ome of the many shows that Theatre with a Twist has produced. Others have worked behind the scenes as part of the integral Technical department that helps to stage a production.

The structure of a script is comforting, yet challenging. Once an action becomes routine, the performers excel. Robert worries that people perceive him as different because people with Asperger’s “don’t understand social nuances.” He may indeed be different but he is extremely intelligent and eclipses others at most things that he attempts.

The Drama Therapy Class has space available for new students and they are also opening additional classes for different age groups. For more information, visit [www.theatrewithatwist.org](http://www.theatrewithatwist.org). Mary Spinosa can be reached at theatrewithatwist@gmail.com or 978-302-0985. Theatre with a Twist is located in Acton MA.

*Mary Jane Fietze Has been living with Multiple Sclerosis for 24 years. She writes for* The Burlington Union *about disability topics and has been on the Burlington Disability Access Commission, BDAC, for 13 years. Mary Jane has won several awards in hand-cycling and enjoys demonstrating her ability to kids as part of BDAC’s “differently-abled talks” to schools.*

**Love and Intimacy Corner**

**Ask Ms. Love**

**Characters with Disabilities in Erotica**

**By Ms. Love**

I recently read *Ageless Erotica* (Seal Press, 2013), an anthology edited by Joan Price, which is supposed to be erotica to which elders can relate. I bought this book because elders are not prime characters in a lot of erotica, at least not yet. Such characters are increasingly in demand by customers, so we may see more soon. Also, I hoped that characters with disabilities, which are even harder to find in erotica than elder characters, would be found in this book.

The book is well written and composed of nicely varied erotica. However, I think “ageless” in the title is wishful thinking because a lot of the characters are middle-aged and hardly my idea of older adults. Only a few characters in the entire book are into their 80s. On a positive note, there were a few characters with disabilities. A character in “Hand Jobs” by Kate Dominic is in her mid-50s and has a repetitive stress injury and arthritis. “Blind, Not Dead” by Johnny Dragona also features two middle-aged characters who are blind. For a lovely depiction of intimacy and sexuality into your 80s, read Bill Noble’s “At the Wane of the Moon”; this is probably my favorite example of romantic erotica in the book. The wife is described as “pale as a wraith” and having a “furrowed scar on her chest”, the husband is described as frail and hobbling, and they definitely know how to talk sexy! In Linda Poelzl’s “Endless Praise, Timeless Love” we read about another 82 year old man and we tenderly see how everyone, no matter what their health or disability, can have intimacy needs.

Joan Price is an advocate for ageless sexuality and I agree with the concept, but feel future books published should include intimacy stories of more characters that are older than middle age. Similarly, I believe that the disability community not only has an interest in books and stories featuring characters with a range of disabilities that model our own experiences with our sexuality, but I bet many of us could write such stories, too. Here is to the future of characters with disabilities being featured in erotica more often, and in a positive, sexually healthy way!

*The Love and Intimacy Corner welcomes questions and requests for topic areas from readers; please send all suggestions to* *DI.LoveandIntimacy@gmail.com*

**INFORMATION BRIEFS**

**“Focus” on Vision Impairment & Blindness Conference – 10th annual**

Meeting the Needs of Individuals with

Intellectual Disability & Vision Loss

**March 11, 2015**

 **8:00 am - 3:30 pm**

 **Four Points by Sheraton, Norwood, MA**

**Keynote Speaker: Susan L. Connors M.D.**

MGH and Mass General Hospital *for* Children, Assistant Physician Pediatrics and Medicine, Instructor in Medicine, Harvard Medical School, and the MGH Lure Center in Lexington.

**Keynote Topic: ”Seeing Autism Clearly”**

**Register by February 26, 2015:**

Registration Brochure and Form, including CEU information, can be downloaded from the "Training and Events" section of the DDS website: [www.mass.gov/dds/visionloss](http://www.mass.gov/dds/visionloss) and from the “Perkins Professional Development Calendar” on the Perkins website: [www.perkinselearning.org/events-monthly](http://www.perkinselearning.org/events-monthly) .

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Lisa DiBonaventura at Lisa.DiBonaventura@state.ma.us or call 508-384-5539.

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