

Newsletter
Spring 2014

Networks

Supported Living Services

www.enableinc.org/networks.html

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Spring is here and Networks is excited to bring you the third edition! A few changes have been made. We welcome two new case managers and another case manager back to the Networks SL team! In this edition, you will find updated news regarding



programs and policy changes. You will also read articles written by fellow consumers sharing their stories and issues that are most important to them.

My name is Stephanie Sweeney and I have had the opportunity of interning here for the past few months. I have learned a great deal from both the wonderful staff and consumers here at Networks. I hope some of the presentations we provided were helpful to you as well. The planning of the Intimate Relationship and Safety Educational Forum held at the Massachusetts Hospital School in May was carefully designed to give you important information. The workshop was presented by Megara Bell, a professional educator who spoke about safety and communication. It was a big success and I would like to thank all who attended! I have enjoyed my time here and have even had the pleasure of meeting some of you. Thank you to those who contributed to this newsletter, I have enjoyed working with you!

PCA News

A new program recommended by the Council on PCA training will be collecting data

on how successful the curriculum of the training is. The PCA New Hire Orientation Program is put into action in an effort to ensure PCAs across the Commonwealth receive consistent information. The curriculum was developed by consumers and other members of the stakeholders. The program is available to be viewed at <http://www.mass.gov/pca/outreach/new-hire>

The program will be state wide after the pilot period is over, on July 1st. The PCA needs to be trained only if they are new to MassHealth. If they've worked as a PCA for MassHealth before, then training is not required. If hired after July 1st 2014, they must go to training. Eligible PCAs will receive notice via mail from their fiscal intermediary stating information on the required training. PCA training will be three hours and PCAs will be paid for the three hours. It is the PCA's responsibility to find where and how to get to these trainings.

The Consumer can option out and train their own PCAs. However, if a consumer is non-verbal or has a guardian, the PCA has to go to a training. The consumer would have to do the entire three hour training. If they wish to train their own PCAs, they must send a form back to their Personal Care Manager (PCM) stating that and then they will receive a packet of materials to do so. Consumers have 60 days to option out. If they do, and change their minds, the PCA can still go to a training. If the PCA feels that the consumer did not do a good enough job, they can go to a training, but will only be paid once. Once the training is completed by the consumer, they have to send the completion form in. The PCA will be paid in 6 days after that.

If there are questions please contact the PCA Workforce council at pcacouncil@state.ma.us or

PCA Workforce Council

600 Washington Street, Room 5189

Boston, MA 02111

New RIDE Policy

The MBTA the RIDE has planned to change their policy this spring. The no-show/ late cancellation policy is intended for those passengers who cancel late or do not show up. This causes problems for other passengers that made it on time. The MBTA feels that not only does this waste time for others but also wastes fuel. In order to prevent this from happening, the no-show/ late cancellation policy will be used. The RIDE will record each time customers cancel late or do not show.

Late cancellations occur when a customer cancels their trip less than an hour before the scheduled pick up. If the time of the trip changes due to appointment delays, it will not count as a late cancellation; however the RIDE strongly encourages calling in advance. No-show occurs when a customer does not show within 5 minutes of the scheduled pick up time. If the vehicle does not arrive at the correct location within the 30 minute window, the customer will not be marked as a no-show. The violations will count as a missed trip and customers with excessive missed trips may be suspended.

Suspensions may occur when customers repeatedly miss trips. Period of suspension varies depending on repeated violations. Violations within the same 12-month period will be recorded. A written warning will be given to customers as a 1st suspension. Those customers with a 2nd suspension will be suspended for a 1-month period and a 3rd suspension results in a 2-month period suspension. Those

customers with a 4th suspension or succeeding suspensions will be suspended for a 3-month period. Each customer who violates the policy will receive a notice of each violation and the dates of suspension as well. Customers who are suspended under the policy may also have their subscription services cancelled. In such circumstances, customers must reapply to be considered for a new subscription. Renewed applications will not be considered until four months after the end of the suspension period. MBTA the RIDE uses this chart to define excessive no-show or late cancellations.

Total trips scheduled per month not cancelled per policy	Maximum no-show / late cancels per month before penalties
1 - 12 one-way trips (up to 6 round trips per month)	2
13 - 25 one-way trips (up to 3 round trips per week)	4
26 - 40 one-way trips (up to 5 round trips per week)	6
41 - 60 one-way trips (up to 1 round trip per day)	8
61+ one-way trips (more than 1 round trip per day)	10

As a reminder, Networks Supported Living case managers are willing to assist you to find transportation. Try to plan ahead and be on time and the RIDE will be a great amenity to you!

Back to Reality

By: Mary Jane Bruni

About 30 years ago, I suffered from an aneurism and a hemorrhage while driving home from work. I had a car accident as a result from the hemorrhage and aneurism in my head. I was able pull over my car and someone found me on the side of the road and called an ambulance. They took me to the hospital, I was in a coma for about 2 months. When I woke up in the hospital, I did not know what was wrong with me or how I got there. I woke up around Thanksgiving Day, I saw it as a gift. The doctors told me I had been blessed, I got to go back to my father's house for Thanksgiving dinner. While they were repairing the bleeding in my head, they also found out that I had a tumor that was causing pressure. I had to get surgery right away. They were able to get a piece of the tumor out and sent it to the lab and found that it was not cancerous. I was very happy to find that out. During surgery to remove the tumor, I had a stroke which pre-

vented them from finishing the surgery.

Years later, I went in for the second surgery. Unfortunately, my head suffered so many traumas from the operation that it lead me to my disability. I could no longer see out of my left side. It was a tough decision in my life. I had to go to a nursing home for about 6 years until I felt it was time to get out. I did not like being there because they strip you of everything. They take away self-confidence, self-esteem and self-independence. I did not belong there. I did however enjoy going on recreational day trips. I wanted to leave because I knew it could be better. I got connected to Networks and my case manager helped me find my current apartment and I have been here since. It was a big change in my life and a new beginning.

In between the first and second surgeries, I was volunteering at the Mass Rehab Commission. I helped type envelopes and labels for about 6 months. I enjoyed volunteering for them. Since being with Networks, I get

better care. I am now able to do errands and shop in local stores independently. I am also going back to school to get my degree. I am happy with what I have accomplished and where I am in my life today.



Don't Lose Hope By: Bob Coe

I was working as an assistance performing arts teacher at the Mass Hospital School. They closed the program down and a lot of people lost their jobs. I got sick for a few months, I couldn't even go outside. When that

happened, I decided to start selling my paintings and created an art business called Creative Endeavors. I started selling painting at different art galleries and by word of mouth. Instead of being bored, I tried to make myself feel as if I was going somewhere.

I thought of the Caribbean and the colors and architecture. I decided to do some abstract painting with the Caribbean as the inspiration. I lost some ability to paint really well with my hands. Rather than thinking, I can't do this, I thought more on the positive side. I started thinking different ways of painting. I experimented and tried painting with the paint brush in my mouth. I had a PCA hold the canvas. Some of the painting was drip painting and I incorporated that with Jackson Pollock technique. I was inspired by his art. I thought it would be a good way to try my skills.

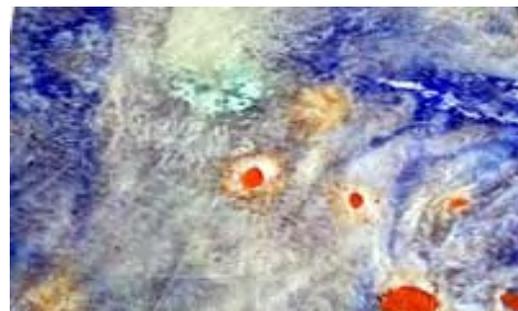
From there my art blossomed and I started using syringes to inserts areas in the painting. I would suck the paint up and put it in specific areas to add some touch to it. I could

make it look as if something exploded on it. I that painting, I just closed my eyes and thought thought it would work out pretty well, and it about my aunt. I thought it was great to con- did! When I played music while painting such tribute to my aunt. Sometimes you find things as Metallica, Alanis Morissette and Santana, in art that you didn't expect.

my abstract painting turned into action art. I While I was at Massasoit, on Disability didn't even think about it, I just started paint- Day with Helping Hands, I came up with an ing with my feeling. Without even thinking at idea to paint while dancing. Another student all, you'd be surprised with what you come up played keyboard and drums while I was danc- with. Art is unlimited and I just kept expanding ing. I started getting creative and painted using from that original idea. It really made me feel all different techniques. My PCA at the time as if I wasn't just sitting inside. got in the middle and one of the syringes I was

One of my aunts had cancer, I wanted using to paint exploded onto her clothes. I to make her feel good. I made her a painting thought to myself I'm now doing PCA art! It's for her to look at. By the time I gave her the interesting because one idea turned into a huge painting, there ended up being an image of a fun experience. I've realized, when you're woman in the painting. I did not even know I creative, amazing things will follow. Even if painted a woman. My aunt said that she could you think, you're not good at art, you just have see an angel in the painting. She said that it to try the right medium, and you just got to made her live longer. It was a miracle. Years have fun. There is always another way to do before, my grandmother died of the same can- something and that's the way I live my life.

cer. Some believe that it is my grandmother as the guardian angel. I'm just happy that I was able to give her something special. When I did



Advice

By: Bob Coe

When I was 14, my foot got caught in my wheelchair and I injured my knee. I got stuck, and all of the weight went to my knee as I was falling over. From this incident I couldn't walk anymore, even with long leg braces. I was permanently in the chair. Later, I discovered other health problems such as chest congestion. I experienced difficulty in breathing, stomach issues and cardiac issues. I started using different equipment when needed. It was difficult at first trying to adjust to that. When I tried new treatments, I realized it started to positively affect my everyday life.

I have also realized that my singing lessons in the past has helped me with my breathing today. I would use that method and before a concert, I realized it really made a difference when I sang. It trained me to hold my diaphragm and let a little air out every time I sang a few notes and let a little air back in. This way, when I became exhausted, I would try

this method and I wouldn't have to gasp for breath. This skill has definitely helped me in some circumstances that has kept me alive. Some people call me the human ventilator. Sometimes what you learn in your past, can really help you later on.

About a year later I started getting rushed to the hospital with Gastroenteritis often. Every time I had it, they would send me home with IB electrolytes. Later every time I started experiencing it, I drank Gatorade for the electrolytes. I also tried avoiding greasy foods such as pizza which I ate a lot. I had trouble swallowing certain things and I started to lose my appetite. I got a feeding tube and I

would imagine the food that I was craving to suppress my wants with my needs. When I got a G-tube it seemed to really help but I still wanted to do something about it. I went to Boston Children's Hospital and they gave me a Farrell valve that would take gas out of my stomach. I also took vitamins and Benefiber and started drinking a lot of water.

Later my back started to curve 25% and a vent at night and it helped me contain my energy throughout the day. When I was sick, I the doctors wanted to put rods in my back. After surgery I lost some strength but instead of would use some treatments with the vent on. I getting angry I figured I could adapt to do tried a lot of different methods such as Cough things. There is no giving up, I found other Assist to further prevent being sick. On top of ways. I've had many surgeries and instead of my regular medications, I would use Saline panicking, I learned to stay positive. Leading Nebulizer in between. Because I believe that up to a surgery, I would be aggressive with my proactive is better than reactive, I started using care. I would treat pre-surgery the same way as these methods more often. I realized when I if I had bad pneumonia. On the day of the surgery, I would joke around and keep a light mood. For example, in my last surgery, I did it with no Anesthesia; I told the doctor he was doing a good job stitching me up and that he would make a great seamstress. He said I was the first person joking around during a surgery. By joking around, it not only helps me but also makes the people around me feel better too. I feel that by doing this, it would help my mind-set about going into my surgery. I also feel that it helps me recover from my surgery quicker.

I modified some methods that I have realized made a big difference. I started to use I thought of a way that would help me and my healthcare worker to keep energy.



I did some research and found a vest equipment that would benefit both of us. The equipment is good for the consumer and the PCA by keeping you out of the hospital and also reassures a job for the PCA. When you have a good team, PCAs and nurses and everything is going well, try to consider each other. Instead of getting mad, explain yourself and communicate. People get tired, people have difference in opinions but try to give people the benefit of the doubt. It is also better to make opinions yourself instead of listening to ideas made by

others. Sometimes I felt that by not saying anything and dealing with it myself, I would give less work to my case manager. I have realized that this can have a domino effect because by not telling them, it can create more work for them and the problem can get worse.

Still Moving On

By: Joe Dunn

I was 32 years old, with my own business and a beautiful family. I had a landscaping construction and excavation business. I was very busy and I was a very well-known person in my town. On July 12th 2005, I was living in Scituate and I was coming home from work. I was three houses away from my house and I got hit by a car on my motorcycle. Unfortunately, it was a hit and run. I ended up in South Shore hospital for the night and they brought me to Brigham and Women's hospital. After being in a coma for a month, I was at Spaulding rehab for 10 months. Not a lot of people came to visit me or support me at the time of my accident. As time went on, I met

new people and found new friends that taught me to learn the qualities of people. While I was in the hospital, I met someone that I thought was a nice person. She offered to have me rent a room and live there and it turned out to be a very bad situation. I decided to move out to my current home in Rockland in May 2007 and ever since, everything was good news.

In 2008, I wanted to get myself back on track. I started to go to Braintree Rehabilitation for physical and occupational therapy. My independence has greatly improved, I've been able to do a lot of things on and off over the years. In 2011, Father Bills in Quincy helped me with housing. I found it tough to learn to deal with being in pain all of the time and I had to learn to adjust to take many different medications. It was a very uncomfortable transition and I try to spend as much as I can up in my wheelchair. I was able to consult new people and share information to get them jobs. I was compensated by finding them work. I had found payment programs to help stay on top of

my household bills. I had to learn about all the different things that were available to people with disabilities that I was able to take advantage of. Now I am able to do all my own finances and billing and I used craigslist to find PCAs. I had to weed out bad PCAs and I got acquainted with new people to help manage myself better.

I met my case manager about 6 months ago. They help with hiring and firing PCAs. With Networks I let them know when I'm looking for a PCA. Networks makes sure I get quality people with the help of a CORI check. They bring people out to introduce me. I like to keep a good environment for people to work in so I keep a positive outlook on life. I used to have unqualified PCAs. I like to have my basics covered and make sure I'll have someone here for me. I try not to have anyone in a bad spot. I also get nursing hours and it helps me stay independent.

I try to stay busy and I feel it helps me stay motivated and positive. As a quadriplegic,

one of my main concerns is exercising. I try to go exercise twice a week and swim once a week at the Quincy and Hanover YMCA. I always have and am an active fit person.

Through hard times, I think about my kids and they are what keeps me going. My next goal for myself is to start working again. I want to start my own business in landscaping and excavation of doing septic systems. For anybody who reads this, it's always a good thing to stay positive and accept the help that's out there because that's what it's for. Thank you for reading my story.



Become more Independent with Assistive Technology

By: Paul Remy

Today assistive technology (AT) is giving people of all ages with disabilities the ability to lead independent and rewarding lives.

Text-to-speech software for computers and apps for tablets are converting text into speech so the sight impaired can enjoy reading by listening. Those with speech impairments and only able to press a single switch, have the power to communicate, use computers, continue their education, surf the net and play online games with friends. Some paraplegics are even trying to perform daily tasks, such as eating and drinking independently by manipulating robotic arms with their thought patterns.

For the past 33 years Professor Lester Cory, co-founder and President of Society for Human Advancement through Rehabilitation Engineering (SHARE), has been designing and fabricating assistive technology and has seen the rapid developments in this field. I first met

him in 1983 when I began attending Southeast- letters of the alphabet through a piece of Plexi-
ern Massachusetts University (now known as glas. This method of communicating is fast to
UMass Dartmouth). Having Cerebral Palsy, those who are proficient at using this low-tech
which limits the use of both of my hands; he technology, Cory said, but unfortunately many
and his dedicated organization have helped me do not want to take the time to learn.

many times since then. Now, SHARE is work- The Engineering Professor asked one of
ing on a tablet for me that will compensate for his graduate students, Philip Viall, to work
my speech impairment so I can communicate with him to design and build a system to allow
more effectively. Linda to communicate independently. The two

My fellow Commissioners on the Sharon engineers knew the 22-24 year-old woman
Commission on Disabilities agreed with me it from Little Compton, Rhode Island did not
would be a good idea to have an assistive tech- have the hand dexterity or head control to use a
nology presentation, hoping it would be a vehi- head pointer for typing on a computer key-
cle for helping others with disabilities. The board. However, she had enough head control
Commission teamed up with Sharon Council to hit a single switch voluntarily, which gave
on Aging and hosted such an event last Octo- them an idea: They purchased a TRS-80 com-
ber, and Cory was one of the guest speakers. puter from a local Radio Shack and developed

First, he captivated listeners by telling a program that scans rows and columns of let-
them about SHARE's first client, Linda Tex- ters, words, sentences, phrases, and com-
ceira, who has Cerebral Palsy and is unable to mands. When the scanning cursor highlights a
talk. Back in 1981, she could only communi- letter, for example, that Linda wants to select,
cate with her parents and relatives when they she simply presses the single switch with her
followed her eyes while she was looking at head, and that letter appears on top of the

of the screen. In a robotic voice, a speech synthesizer spoke for her after she composed messages using the single switch. Cory thinks that Linda was the first person in the world at that time to communicate using a home computer.

The TRS-80 computer was very limited at what it could do, and the early speech synthesizers were extremely difficult to understand. When the IBM PC and the MAC made their debut in the early 1980s, they revved up the development of assistive technology. Today, anyone, even single switch users like Linda, can use their computers

turning on and off lights, changing TV channels, changing the room temperature, and controlling household appliances. Single switch users also can use off-the-shelf software which is accomplished by using dual monitors: one has the scanning program that acts like a virtual keyboard, and the other displays the regular applications.

Since 1981, SHARE has helped more than 3,400 people. Cory noted that one client

had electrodes implanted in her brain, enabling her to use a computer with her thought patterns. This is a new and fascinating technological breakthrough, but Cory said it might take years before determining if many could benefit

from this technology. But speech recognition, which has matured in recent years, is giving people with disabilities who are able to talk the ability to use computers and other devices just by speaking. And with eye movements, some of SHARE's clients are using eye gaze technology for composing WORD documents and emails.

Being able to call for help in emergency situations, assistive technology is also allowing people with disabilities and senior citizens to live independently. Recently, Cory said, a company developed a wearable device that detects when someone has fallen and automatically contacts a family member or a first responder for help.

Randi Sargent from MassMatch, a Massachusetts Rehabilitation Commission program

that promotes the use of assistive technology, spoke next. Her son has Cerebral Palsy and uses assistive technology and her family lives in a universal designed home. She stressed the importance of universal designed homes - they are accessible to people of all ages and abilities. Then Sargent explained how MassMatch is helping people with disabilities. MassMatch has a low-rate loan program for those who have low-fixed incomes to purchase assistive technology. The organization also has many other programs, such as working with schools - ensuring students with special needs get adaptive equipment for helping them to pursue a good education, and a new one, which Sargent is in charge of, that refurbishes used wheelchairs.

To learn more about MassMatch, go to www.massmatch.org. Also, you can watch the entire presentation at www.sharoncod.org. For more information on SHARE, go to www.share.umassd.edu



Sarah Is Back!

Sarah Booth originally worked for Networks Supported Living in 2011, and through an exciting chain of events has returned to the Supported Living team. Sarah graduated from Bridgewater State University in 2011 with a B.A. in Psychology and Social Work, concentrating in disability issues. Through her education and life experience as a Case Manager for various populations, Sarah has learned the

art of advocacy, how to creatively solve problems, to empathize with others, and to listen. Sarah chose this profession because she has a knack for assisting others and enjoys the intrinsic rewards from doing so. After hours, Sarah enjoys spending her time creating a self-sustainable organic farm in her backyard...YEE-HAW! We welcome Sarah back to the Networks SL team!



Meet Jen!

Jen grew up in Auburn, MA and graduated with degrees in Sociology and Psychology from Fitchburg State University. Currently she is pursuing a Master's degree in Social Work from the University of New England. Her goal is to continue with case management once she has completed her degree. Previously she worked as a case manager with at-risk youth, and still works part time as a youth care counselor. In Jen's free time she enjoys running, playing ice hockey and the guitar.



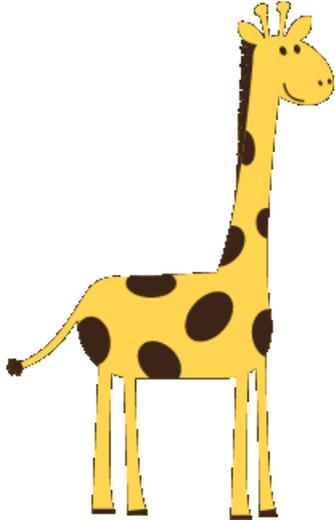
to meeting you all! Jen will be a great new addition to the Networks Supported Living team!

Meet Bena!

Bena graduated from Bridgewater State University with a bachelor's of communication in 2004. Most of her work experience since graduation has been in human services. She interned at a place called Best Buddies in her senior year working with Cerebral Palsy clients . She started working at the May Center in 2005 as a relief staff then a teacher's aide to a teacher. She enjoyed working with Autistic and developmentally delayed clients whom ranged from age 5 to 75 years old. Later, Bena became a residential direct care staff/ case manager. In addition to working with the May Center Bena also worked as an overnight Supervisor at Cardinal Cushing and worked as an Applied Analysis Behavior associate educator dealing with early intervention clients. Through working in the human service field Bena has certainly learned to be patient and empathetic. Bena says her greatest joys have been seeing consumers grow and progress throughout their stay at each center she has worked at. We are lucky to have Bena as a part of the Networks Supported Living team!



Upcoming Events!!!



Consumer Council Meeting at the Attleboro Capron Park Zoo!

Place: 201 County St. Attleboro, MA 02703

Date: Wednesday, July 9th from 2pm– 4pm

**This is a great opportunity to meet others and explore
the Attleboro Park & Zoo. Admission is free and there
will be refreshments provided.**

Please contact your CM to set up transportation.

Networks Supported Living Services

*Aspiring to provide individuals and families with the means, opportunity
and power to develop their full potential in the community.*



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