Disability Rights Activist, and the founder of the first Center for Independent Living, Edward Verne Roberts, or Ed Roberts as he became known, would have been 78 years old on January 23, 2017. Roberts contracted polio at age 14 and was paralyzed from the neck down. Requiring an iron lung, or a respirator, to breathe, he attended high school in California by telephone before attending in person in his senior year. Early on, Roberts encountered obstacles as a

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DON’T BURST YOUR BUDGET

By Steve Gruzlovic

In today’s uncertain economic times it is important to be mindful of your budget and find ways to make every dollar stretch more than ever before. There are many ways to accomplish this by making simple minor changes.

One way is to cut the cord with your cable provider. With the use of streaming services such as Netflix and Hulu for both television and movies you can save a significant amount of money by reducing the channel package and other fees associated with standard cable service. If you are apprehensive about cutting the cord to cable completely, many companies offer a basic package of channels that are included with your high speed internet. It is not often advertised and you often times do have to ask.

The second way is to use technology to your advantage. With the use of a smart phone or a basic Internet connection you can be on your way to savings. Apps offer valuable information at a moment’s notice. This is especially true when going to restaurants to enjoy a meal. Review sites such as Yelp will sometimes offer a coupon if you “check in” or leave a review on a social media site. This helps the restaurant because they receive valuable exposure while you are saving money by using the coupon. Coupon websites also offer great deals on almost anything one can imagine. Many websites also offer the ability to find the lowest price per item within a given area; this is extremely beneficial in order to save money.

The final way is to simply ask. A lot of times deals are not often advertised and special rates are not given unless the customer inquires. The success rate is not as great as the other two methods mentioned above. Getting discounts is easier often times if a competitors deal is mentioned, because a company does not want to lose a customer so they a more willing to honor the price then lose the relationship.

There are many other ways to save money than those mentioned above. A lot of it takes simple research which ends up going a long way to the goal of saving the most money possible so that you do not burst your budget.
HONORING EDWARD ROBERTS

Continued from Front

result of his disability. He was refused the right to graduate from high school because he had not completed physical education and driver education courses. The decision was reversed after his mother petitioned the school board for his diploma. After two years of attending a local college, he was accepted to the University of California, Berkley, but the university was unaware of Roberts’ disability and refused to admit him, saying that his iron lung would not fit in his dormitory room. Roberts challenged the administration and ultimately was admitted. It was at Berkley that he worked with the university to develop the Physically Disabled Students Program. This program was run by and for students with disabilities to provide wheelchair repair, attendant referral, and peer counseling. He earned a bachelor’s degree in political science in 1964 and a master’s degree in political science two years later.

Roberts and other members of the Physically Disabled Students Program came together in Berkley, in 1972 to form the first Center for Independent Living. This was an advocacy group that fought for changes that would give people with disabilities access to community life. In 1976 Roberts was appointed as the Director of the California Department of Vocational Rehabilitation. This was the same agency that deemed Roberts too disabled to hold a job. As director, he facilitated the establishment of independent living centers throughout the state. He also traveled to lobby for disability rights in the US and around the world.

2017 CAMPERSHIP ANNOUNCED

By Danielle Lewis

PCIL is pleased to announce the 2017 Campership will be underway shortly. Campership funds are awarded to Mercer County resident’s between the ages of 4 to 25 who have a disability and are interested in attending a summer program or camp of their choice. These funds are dependent upon the family’s annual gross income and the total members residing in the household. Stay tuned for more information. If you have any questions about Campership contact Danielle Lewis at PCIL, 609-581-4500.
RECREATION ROUND UP
By Suzanne Peins

Recreational events continue for PCIL consumers, thanks to a renewed grant through Mercer County. Here’s a recap of recent events;

Please note; We want to hear from you! Let us know what fun activities you like to do or would like to try with your PCIL friends. Call us or e-mail us. We are always open to new ideas.

In November, about 15 people enjoyed lively conversation, shared stories about their jobs, and exchanged silly jokes and riddles at Uno’s Pizza in Hamilton Twp.

December was celebrated with PCIL sponsoring an Ugly Sweater/Holiday party at Project Freedom, Hamilton. Participants as well as PCIL staff and volunteers played games, won prizes, participated in a gift exchange, posed for photos, enjoyed a catered dinner, and of course participated in the Ugly Sweater contest. Tina P. won 1st Place, Louie P. 2nd place and Tyffany S. won 3rd place for the most festive sweaters. Everyone enjoyed themselves and new friends were made.

In January PCIL sponsored a Bowling Night. Folks met at Colonial Bowling Lanes in Lawrenceville to socialize and show off their bowling skills. It was great for everyone to get out, socialize and show off their bowling skills! Watch the mail for upcoming events. As the weather warms up, we hope to do more activities outside.
Movies and television have provided some of the greatest moments in pop culture. For individuals with visual disabilities sometimes getting the whole picture of everything within a scene can be difficult. The popular streaming service, Netflix, aims to change this by introducing several accessibility related features.

Netflix will provide audio description for many popular titles in its streaming and disc rental libraries. Audio description technologies let people who are blind and visually impaired know what is happening in scenes without dialogue or scenes with significant visual elements via an audio description track that contains narration of the visual elements that is synchronized with the show or movie. Television and movie studios will create the audio description tracks and provide them to Netflix. Without audio description, individuals that are blind and visually impaired do not know what is happening in scenes without dialogue.

Netflix will also make its website and mobile applications accessible to individuals who are blind and use screen-reading software to navigate websites and apps. Screen-reading software is an interface between people who are blind or have low vision and computers and/or mobile applications. The software creates an audio version of text and images that appear on a screen that it reads aloud to a user. The user then controls the computer or mobile device by pressing keys or tapping on a mobile application.

Currently the features are available for a significant portion of the library with full expansion expected to happen within the coming months. This will enable a better and fuller entertainment experience for all including those with visual impairments.

For more information please visit https://www.disabled-world.com/communication/netflix-blind.php
The Progressive Center turns 20 this year. It is an important milestone to be remembered and celebrated. For 20 years, we have stood with people with disabilities in Hunterdon and Mercer counties to advocate with them for equal access and rights, for better programs and services, and for a truly inclusive community and society. Through good and bad years, PCIL has striven to provide consumer-driven services to empower people with disabilities to be independent.

Much has changed in 20 years. People with disabilities have emerged from seclusion and segregation in greater numbers and with the power to effect change in some situations. Nevertheless, the near future looks bleak as frustration with political deadlock and bickering and fear of economic decline breeds mistrust and hatred of laws designed for people’s rights and liberties. Being “different” is now cause to be marginalized and discriminated against.

During these troubled times when the “safety net” for people with disabilities is threatened with meat-axe changes, you can count on PCIL to stand up for and with people with disabilities to oppose these threats as best we can. Our strength and power to resist these threats comes from you, the consumer or member of PCIL. Without your support, without your collective voices, without your willingness to take actions when asked, PCIL cannot be heard in this new struggle. PCIL is here for you as we all face a future of uncertainty and fear. Join with us so that our next 20 years can be brighter, safer, and more inclusive for everyone.

MEET SAMANTHA
By Samantha Culbertson

Hi, my name is Samantha Culbertson. I am one of the newer support coordinators at PCIL, as of September 2016. I’ve received my bachelor’s degree in psychology from Kean University. I began working in this field about 4 years ago. I initially started working in direct care, assisting individuals with developmental disabilities and mental health issues. I was then promoted and began supervising approximately seven group homes. I then began counseling, providing Illness Management & Recovery therapy to individuals suffering from mental health issues. I look forward to furthering my career here at PCIL, and continuing to help individuals and families in need.
My name is Tyff Sukiennik and I was a proud competitor in the 2017 Winter Olympics which occurred on February 6th and 7th at Mountain Creek in Vernon, NJ. This year I competed in the 100 and 200 meter Snow Shoeing race. I earned 1st place in the 200 meters and won 5th place in the 100 meter race. I was prepared to participate in the 4 x 100 relay, but unfortunately it was cancelled due to poor weather conditions.

The highlight of this experience was being selected to carry the torch and lighting the cauldron during opening ceremonies. It was a day I will never forget. I also enjoyed riding on snowmobiles. This was my first time on a snowmobile and I had a blast being a passenger. Also, all athletes were invited to a dance during closing ceremonies. We shared good food and enjoyed a great night of music. It was a great experience.

Earlier this year Access Link revealed “Phase One” of their new company portal. This new portal was developed in response to customers who have often stated that Access Link needs to improve communication between the company and the customer. It also helps address the widespread complaint that customers have to wait too long on the phone to receive assistance and is an attempt to reduce the amount of traffic on the phone lines.

In Phase One, customers are able to review several details about their reservation; these include confirmation number, pick up point, the opening and closing of the ride window, estimated time of arrival, destination, and the fare for the ride. Other advantages of using the portal are the ability to cancel a ride with the click of a button and update contact information with ease. Customers are also able to request subscription rides via the portal as well.

Currently customers still need to call the Access Link phone line to book standard rides. Several representatives from Access Link say the hope is to eventually be able to book a ride through the portal, but no timetable for that feature has been announced.

In order to use this new feature basic internet access is required. If anyone would like additional information they can visit the website or call and speak to a representative at 1-800-955-ADA1 (2321).
Recently I had the pleasure of accompanying my friend Scott to the U Penn Medicine Perelman Center in Philadelphia. He was being evaluated to see if he would be a candidate for the newly released drug, Spinraza. It was fascinating – the doctor explained who is eligible, how the drug works, and what the Perelman Center is doing. Everything is so new, she explained, that they still need to get the drug, add it to their formulary, and to develop procedures for its administration. She is asking for everyone to spread the word because there hasn’t been any treatment up to now. The Perelman Center is proceeding quickly and hopes to begin administration to adults sometime in late Spring. The drug requires loading doses – the first 3 doses are 2 weeks apart, then the 4th dose is given after 4 weeks. The maintenance dosage is every 4 months for life. It is extremely expensive ($125,000 per dose), plus there are costs associated with its administration (it is injected into the spinal fluid and requires a spinal tap for accurate placement). Because of this there is an extensive application process facilitated by the Muscular Dystrophy Association (MDA) representative, but BioGen is committed to getting the drug to all who qualify (diagnosis of Spinal Muscular Atrophy (SMA) 1, 2 or 3).

After meeting with Scott’s doctor I was full of questions so I began researching this promising new medication. It was developed by Ionis Pharmaceuticals and is being marketed by BioGen. It is the first and only drug available to treat SMA, a rare and often fatal form of Muscular Dystrophy (a leading genetic cause of death in infants and toddlers). Persons with SMA have a mutation in the Survival Motor Neuron gene 1 (SMN1). This gene produces SMN protein that is critical to the function of nerves that control our muscles. Without it, the nerve cells cannot properly function and eventually die leading to the debilitating and often fatal muscle weakness. Persons with SMA have at least one copy of the SMN gene (SMN2). The SMN2 protein is missing an important piece and Spinraza targets this gene, enabling it to make more complete SMN protein.

There was a clinical trial (ENDEAR) involving 121 infants, diagnosed with infantile-onset SMA prior to 6 months of age and less than 7 months old at the time of the study, in which 81 received the drug and 40 did not. The FDA asked for an interim analysis and the results were so promising (47% reduction in risk of death or permanent ventilation) that the trial was converted to an open-label study where all surviving patients received the drug. The FDA granted fast track designation and priority review for Spinraza. While the clinical trials were conducted on infants and toddlers, this drug has been approved for adults as well.

So, what is Spinraza? A modern miracle…
MEET VIOLETTA
By Violetta Freshchenko

Hello, my name is Violetta Feshchenko and I have started working at PCIL as a support coordinator in September of 2016. I received my Bachelor of Science in Public Health degree from Temple University in Philadelphia, PA. Currently I am working on my Master’s degree in Public Health at Thomas Jefferson University in Philadelphia, PA. I have worked as a support coordinator/care manager for older adults in Delaware County for five years.

LOCAL ASSISTANCE AND RESOURCES
By Renee Pfaff

It’s Tax Time- Starting in February, Mercer County Connections will offer the AARP Tax-Aide, which is a free program thru AARP Foundation to guide people with low to moderate incomes through their taxes, making sure they receive all the deductions and credits they’re entitled to. The trained volunteers will assist with preparing and filing your federal income tax return with the IRS, free of charge. They are providing free tax assistance February 1st thru April 14th on Mondays, Wednesdays, and Fridays. This is by appointment only, so please call 609-890-9800 to reserve your spot.

Winter Is Here – The County of Mercer, working in coordination with the New Jersey Department of Community Affairs, will be accepting applications for the Low-Income Home Energy Assistance Program (LIHEAP). Appointments will be taken for Tuesdays and Thursdays from 10am to 12pm. This appointment can be scheduled by calling 609-989-6858 or 609-989-6959. If you prefer to be a Walk-in, you may do so on the 2nd & 4th Saturdays of the month between 10am and 1pm.

Mercer County Community Connections is located at 957 Highway 33 (Acme Shopping Center) Hamilton, NJ 08690. To view their full calendar events, please go to www.mercercounty.org

DD Supports Program; New Guide-
The Division of Developmental Disabilities, (DDD), has developed a new resource book to help guide families utilizing the Supports Program. This document, The Supports Program Policies and Procedures Manual: A Quick Guide for Families was developed by the New Jersey Department of Human Services Division of Developmental Disabilities. A PDF copy of the guide is available at; http://www.state.nj.us/humanservices/ddd/documents/family_guide_to_supports_program_policy_manual.pdf
I had a brain tumor when I was nine years old and it damaged my nervous system. My tumor was destroyed through radiation therapy but there still are some remaining dead tumor cells. Because of my tumor, I use a wheelchair most of the time when I am outside for a long time. I also use a walker sometimes when I am at home or for short-distance walks. Because of my tumor, I also have limited motor skills so I have trouble writing and I type all my papers for college. I also record lectures on a Livescribe pen which allows me to jot down keywords in a special notebook while the pen is recording helping me to take notes.

I have been studying at The College of New Jersey (TCNJ) for almost eight years now; I received my Bachelor’s Degree in History there in the spring of 2013 and I am currently in graduate school in the MA in English program. As an undergraduate out of high school, I was debating whether to become a History or English major because those were my two favorite subjects. I chose to become a History major at TCNJ as an incoming freshman just before my first semester. During my senior year I decided I wanted to find another area of study for graduate school and since TCNJ is a great local college I figured it would be ideal if I could stay there. I heard that their MA in English program is really good and because of my love for English, I decided to take some under grad English classes to see if I really wanted to enter this program. I enjoyed these classes and received good grades in them so I entered the MA program in 2014 and took my first graduate class that fall. Currently, I am taking my sixth graduate class and I need a total of 10 classes to graduate from the program.

Although, TCNJ is a great college there are a few obstacles I had with accessibility. Not all of the buildings have automatic doors but most of them do in the front entrances, including the buildings I used the most in my college career; Bliss Hall, where the English classes are, and the Social Sciences Building (SSB), where the History classes are. The Office of Differing Abilities, which is now called the Disability Support Services (DSS), made sure that all my classes were either in one building or buildings that are near each other; this office is meant to help disabled students have a good college experience. The DSS keeps a record of all the TCNJ students with disabilities and they have people who type out letters of accommodations for each student to give to their professors for each class at the beginning of each semester. I am one of the few students in a wheelchair at TCNJ and most of the disabled students there have other physical disabilities. The DDS also provides equipment that disabled students need for classes. For example, they give out lap desks for students who cannot sit in a regular desk. They also provided a laptop without internet access for me to type out my answers for exams. There is also a program for people with intellectual 

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disabilities at TCNJ called The Career and Community Studies Program (CCS).

Bliss Hall used to be an old dormitory building so it is smaller and narrower than the newer buildings on campus such as the SSB. TCNJ added an annex wing to Bliss where all the classrooms are and the old part of the building is mainly offices. There is a small over ground tunnel or tube that connects the regular part of Bliss to the annex and the portion of the tube on the second floor has steps; so I cannot go from the English offices on the second floor of Bliss to the second floor of the annex, where some of my classes are. As a result, I have to take the freight elevator in the annex instead of the regular elevator in Bliss to get to the second floor classrooms in the annex. Most of the bathroom doors at TCNJ are not automatic and some of the bathroom doors are heavy. They did install an automatic bathroom door in the Student Center after I complained about this once a few years ago by sending an e-mail to the Vice-President for Administration at TCNJ. I hardly use the Student Center anymore and they are in the process of renovating it so I do not know if they kept the automatic bathroom doors. Recently, they built a new mall of stores and apartments called Campus Town that is located on the edge of campus and, to my knowledge, only the Barnes and Noble bookstore has an automatic front door.

My goals after I get my MA degree are to eventually get a PhD and become an English professor someday and write on the side; I would like to publish my autobiography.

Winter is a great time to cook up something warm and comforting for lunch or supper. Visit the above listed link for a great soup recipe! It is just three easy steps! This soup has only 120 calories per cup and the cooking time is only 45 minutes with prep time of 15 minutes and serves six.
If you are reading this article you are most likely giving care, have cared for, or will be caring for someone important in your life. The likelihood that you are a parent, an adult child, a good friend or a spouse/partner is also quite high. You also may be one of the many home care workers – from doctors/nurses in critical care through end-of-life companions and pastoral assistants – whose availability and presence keeps older adults and those living with disabilities in their homes and communities of their choice.

Where ever your care responsibility lies, there is an urgent appeal to spotlight both informal and formal caregivers and their acts of compassion and/or duty. However, the network of caregivers is waning and, given the sheer numbers of the aging population and parents caring for children with special needs, something needs to be done.

Here is where we are heading. A recent article from The Hill.com (1/27/2017) shares that the population of people aged 65 will nearly double between

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Forty-eight million Americans have some degree of hearing loss. Living with a hearing loss should not prevent one from being able to communicate with others, especially close family members and friends. The Americans with Disability Act established the Telecommunications Relay Service which requires internet and telephone companies in the United States to pay a fraction of their fees into this fund. Everyone’s phone bill has an item called the Universal Service Fee that is part of the overall bill. It ranges from $.80 to $1.50 depending on where you live. This fee is what funds the availability of a product made by ClearCaptions named Ensemble. Ensemble is a captioned phone that displays text of conversations in real time on a large touch screen so you can see and hear what callers are saying.

To learn more, call 908-208-9415 to speak with Terry Hurley or e-mail him at terry.hurley@clearcaptions.com. He is eager to give you further details.
Mercer County proudly announces the continued offering of Skills2Care a proven, evidenced-based program to support dementia caregivers. Designed to help caregivers successfully deal with the daily challenges of care giving, a specially trained occupational therapist is paired with a caregiver to create individual actions plans that will build skills to manage behaviors that can cause caregiver distress.

Participation in the program is free of charge to family members and is a service being provided through the Mercer County Office on Aging and their subcontracted agency, Independent Domain. Skills2Care is part of regularly offered services through Title III funding of the Older Americans Act.

Skills2Care is a home-based, caregiver-centered, problem-solving oriented program. After an extensive assessment of current home safety, functioning level of the person with dementia and the emotional well-being of the caregiver, plans are made for a series of 3-6 additional visits. Each additional session will re-emphasize practicing of learned skills, stress reduction techniques and ways to enhance caregiver well-being. On-going education about the dementia process is offered.

The end result? Caregivers will learn new and creative ways to communicate with the person with dementia, understand and respond to dementia-related behaviors, simplify the home environment, and simplify everyday tasks creating a safe, meaningful home atmosphere for all. These skills will enhance caregiver confidence and well-being, while reducing caregiver stress.

To learn more about Skills2Care or to learn how this program can help you, kindly direct all inquiries to the Mercer County Office on Aging by calling 609-989-6661 or by e-mail at edoremus@mercercounty.org
Care That You Care
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now and 2050 and 70 percent of them will require some sort of long term care. It further states that the Bureau of Labor Statistics estimates that we will need an additional 1.1 million caregivers to care for this population. Additionally, a Boston Children’s Hospital study collected data from more than “40,000 parents or guardians nationwide with special needs – representing 5.6 million children – needing assistance from everything from feeding to breathing equipment and additional therapies.” (Disability Scoop, 1/6/2017)

Low wages, limited healthcare benefits, inadequate training for workers, and few possibilities for career advancement are some of the reasons that jobs for caregivers have become less attractive. High administrative costs draw away from the final paycheck for their workers. Many workers are holding down two jobs to make ends meet.

Family members actually provide the bulk of care giving and incur exceptional out-of-pocket costs. In a report from AARP entitled Family Care giving and Out-of-Pocket Costs: 2016 Report, family caregivers, on average, are spending roughly $7,000 per year on care giving costs and those caring for an adult with dementia reported almost twice that amount. Employers, many of whom are unaware, are losing valuable work productivity when employees participating in care giving activity from their work place such as making calls to doctors or scheduling appointments. Many employees have to work different hours or have to take significant amounts of time off, paid and unpaid, to care for their loved one. Families caring for those with special needs lose out on an estimated $3,200 in earnings.

What is being done to address these workforce concern? That is what we will explore in the upcoming issues of this newsletter. Realistically, the concerns need to be explored and discussed in many arenas. Legislators need to hear caregiver stories and support national initiatives to support caregivers. Employers can offer increased opportunities for families to care for their loved ones by offering respite, having employee assistance programs hold support groups and educational sessions. Benefits for caregivers need to expand through company insurance offerings, tax credit assistance, and the availability of affordable home and community based programs, just to name a few.

Beyond the financial stresses of care giving, are the emotional and physical strains that are not easily measured or managed. Taking a holistic view of the role and responsibility of care giving will help immensely in the provision of support. Further exploration is needed.

How can you help? We want to hear from you. What are your challenges as caregivers? What suggestions/solutions can you share with us that will help you on your care giving journey? Send us your thoughts via e-mail to info@pcil.org.
NEW EQUIPMENT
By Suzanne Peins

On February 7th, The Commission for The Blind brought an updated computer system for people that are blind and visually impaired to the PCIL office in Hamilton Twp. This includes a new desktop PC, monitor, sound bar, CCTV, i-pad, and Braille display. Come to the office and check it out!