Moving into your first apartment is typically one of the proudest moments of most people’s lives, but for people living with disabilities that moment can be scary, anxious, dangerous, or may not come at all. There are many challenges and barriers that must be taken into account and often information is scarce. The co-authors of this article are on opposite sides of that momentous life event and as such have insight which will hopefully help others in moving forward and achieving independence.

Living independently is possibly with the right support.

PATHS TO LIVING INDEPENDENTLY

By Marlene Brockington & Steve Gruzlovic

Continued on PG 2
Marlene Brockington is a young woman, living with disabilities. She has been living in her family home with very supportive parents, but has decided to take steps towards living on her own.

“My family was scared when I decided to pursue this, they did not know if my daily care needs could be met. Even though they were scared, they were still supportive of my decision but they had no idea how to start planning. I started by asking my support coordinators questions, mainly about Project Freedom because it was the most I ever knew about independent living. They asked me why I would want to do this when I had supportive family. For me, I know my parents are older and I always had it in the back of my mind that they won’t always be there. I’ve always been independent, so I feel a drive to do things on my own. My coordinator set me up with a community support agency and I began looking. What I found is that many places say they are accessible and when you get there the only thing that is accessible is the parking! There were a lot of roadblocks just finding a place I could get my wheelchair into. In an effort to help me, my support coordinator supervisor found PCIL and recommended I call,” described Marlene.

When Marlene reached out, PCIL connected her to Steve Gruzlovic to provide peer support and insight from his experience. Steve is a young man who has been living independently for about four years, and has made it his goal to help others living with disabilities to achieve independence.

“I know what Marlene is trying to do is hard, and I’ve seen what can happen if it’s not done properly. When I moved out on my own I made mistakes, I did not have the right supports in place and it was very difficult. Just learning how to pay a bill or grocery shop was difficult. I had to start with basic things like learning how to turn on a stove. There was a lot of anxiety; I went from complete dependence to independence. I have learned from my mistakes, achieved independence, and I want to help others do the same to avoid the issues and pain I went through,” remarked Steve.
PATHS TO INDEPENDENT LIVING
Continued PG 2

It is the details and considerations which we have been working on that we want to share with all of you. These are things that can not only be challenging, but are often overlooked. Understanding the area you are moving into can be very important. Is it close to needed amenities like pharmacies or banks? Are there other people with disabilities already living there? Is it a senior community and you are a younger person? Not understanding these details can lead to issues from bills paid late to missed medications or even feelings of isolation and loneliness. Knowing what questions to ask a potential landlord is another major concern. You need to know if they will make modifications such as installing bathroom grab-bars or if you, as the renter, have to do that. How many modifications are allowed in a unit, who pays for them, and how are they handled should you move out? You need to know what to look for in hiring people to help you. If you have a budget through an organization like DDD or Medicaid, how much can you really access? You must learn how to build a schedule for those employees and ensure coverage if caregivers move on or are sick. Understanding how to secure insurance coverage for expensive medical equipment is another concern often not considered. Most insurance companies require specific riders in addition to standard coverage. You have to learn how to communicate with caregivers. It is easy to talk to family who already know what your needs are but to talk to others can be another issue entirely! More than anything else is being honest with yourself. Be honest about what you can and can’t do so you can plan for what you’ll need help with. Setting up supports and making sure your needs are met does not happen overnight. It must be carefully planned to avoid negative or dangerous situations.

“I know a lot more now than when I first started. I have applied for a voucher, as well as signing up for waiting lists at housing options that meet my accessibility needs. I had an idea at first, but I was unsure how realistic it was; now I know it is possible, I’m nervous but I’m hopeful and moving forward,” says Marlene.

Marlene is much calmer and better informed about what a good fit looks like in a living situation than she used to be. She has become more patient and more assertive about her needs, which is good because she needs to be that way.

The challenges of moving to an independent living situation are daunting, but can be achieved. Take your time, do your homework, and don’t be afraid to reach out for help. You must know a potential living situation and you must know yourself. Moving out on your own can be one of life’s most rewarding moments, so it is important to do it right.

If you or someone you know is living with disabilities & needs support to achieve their goals, please contact PCIL, we are here to help. (609) 581-4500.
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The Ready to Achieve Mentoring Program (RAMP) recently had their yearly conference in Washington D.C. At the conference RAMP sites from all over the country came together to share with each other different strategies and techniques. Mentors left the conference charged up ready to take on the challenges of the upcoming year. Mentor coordinators from each site brought youth along with them for the experience. The youth went on a tour of DC in which they visited the national monuments as well as the National Air & Space Museum. Each youth did a presentation on the highlights of their past year as a RAMP mentee. The youth provided the audience with power point presentations and video footage of the speakers they’ve met, the work sites they’ve visited, and the skills they’ve learned. Some parents of the mentees also participated when we did a very fun and exciting scavenger hunt throughout the nation’s capital. Each mentee talked about how much they enjoyed the trip and how they couldn’t wait to get back home to tell their peers about the RAMP program. RAMP ON!!

PCIL is looking forward to more success with RAMP as we close out 2018! If you are interested in becoming a RAMP mentor please contact Antoine Nelson, Mentor Coordinator, at 609-581-4500 or antoine.nelson@pcil.org.
School is out and beach weather has finally arrived. The community Connections Recreation program has seen a great response to our recent events and several of our perennial favorites are just around the corner!

In April we offered a workshop on natural ways to prevention & wellness using laughter yoga techniques held at The Hamilton Public Library. In May we attended The Trenton Thunder versus The Reading Phillies at Arm & Hammer Park, a grudge match between rivals that did not disappoint and was followed by a fireworks display! In June we coordinated another collaborative effort with the Night of Live Performances held in the fellowship hall at St. Mark’s United Methodist Church. This collaboration featured performers from The Music Box, The Arc Mercer, St. Mark’s, and The Key of Awesome Music. St. Mark’s generously donated the room and our newfound friends at Bluelight Music donated stage lighting. There was a great response to the event which saw over one hundred people in attendance as well as a large number of volunteers. I’d like to thank all who worked so hard to make this, and other events, successful and I look forward to working together in the future! In July we’ll be attending a rare opportunity to watch the 2018 Eastern League Home Run Derby as All-Star Break while be held in Trenton this year!

If you, a loved one, or a friend wants to get involved as a participant or volunteer please contact us. The more we work together, the more successful we will all be, and the more we’ll get to know the communities we share. As the year rolls by we’ll have lots of great events to look forward to so keep your eyes peeled for those yellow flyers!

Yoga and More!

In April, PCIL consumers stretched out with some yoga and later in June they went to St. Mark’s Night of Live Performance.
Baseball

PCIL consumers enjoying America’s favorite pastime, baseball and fireworks!
In the Spring 2018 issue of FORWARD, we began a joint effort with PCIL and the Mercer County ADRC to take a look at the effects opioids have on the disability and aging population. In that article, the functionality and history of opioid use were examined as well as a challenge to the stereotypical user depiction. In this issue, I want to provide first-hand insight from people who have direct experience with chronic pain, disability, and opioid use. I spoke with two individuals who wanted to help shed light on what factors put people living with disabilities at a higher risk than most people might assume and in fact at a higher risk than people who don’t face such challenges. Both individuals are living with significant disabilities.

The first is a young man who has opted to remain anonymous due to the sensitive nature of our conversation and we will call him John for the use of this article. John has been prescribed a wide variety of opioid pain medications following several medical procedures. Doctors prescribed such medications for as long as 2 months and offered no alternates to pain relief. He has never gone outside of medical professionals to acquire pain pills, but he has been offered them by people who knew he was taking them medicinally. He has also been asked several times if he would sell his prescriptions, which would have been very profitable, but he declined for fear of repercussions from the law. One of his personal assistants did steal an entire prescription of oxycodone while working with him. He did admit to being concerned about the possibility of dependence and to having tried using alcohol to achieve the same effect without the intensity of opioids. It has been multiple years since he has taken opioid pain medications but he stated that because of his physical disabilities, doctors would readily prescribe him pain medications. Even though he was resistant to over-using and profiting from his prescriptions he knows many folks in similar situations who chose different paths.

The second person I interviewed is a young woman named Timika. She was adamant that her name be published as she wants people to know her thoughts and experiences on the subject. She is living with cerebral palsy and a seizure disorder. In her early 20s, she began experiencing what would turn out to be chronic pain. Doctors prescribed her a wide variety of opioid medications which she was

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never given a time frame for how long they should be taken. Doctors did recommend she try over-the-counter medications, which Timika reports never had any effect on her pain, but doctors never suggested physical therapies or holistic methods as a possible option for relief. She also had been offered pills on the black market (which is acquiring medications without the use of a doctor’s prescription) as well as approached to sell what she had been prescribed. She too was concerned about the possibility of dependence, and was upset by the lack of information given to her by the doctors treating her pain. Multiple times she did her own research and opted not to continue prescriptions of drugs such as methadone. She also disliked the euphoric feelings of pain medication and tried using alcohol as a less-intense alternative. After 18 years of taking prescriptions, she decided to stop. It took her several weeks and she even left town. During that time, she had multiple withdrawal symptoms and it was a very traumatic experience, but she feels it was the best thing she’s ever done. Despite this experience, she did not feel that she was addicted because she was only following doctor’s orders. She also knows many people who were not able to leave using pain pills behind and who have turned to the black market and other illicit drugs.

Both individuals feel that opioids should not be the only options doctors turn to for pain relief and they both fully support new methods of treatments including dietary options, medical marijuana, physical therapies, acupuncture, and other alternatives. Timika applauds medicinal marijuana as the best treatment she has ever received. It addresses her pain and does not have the negative side effects that years of opioid medications had. She said her demeanor, personality, and moods were severely negatively affected by opioid pain medication. “I am not hateful, I eat, I have gotten back the things pills took away from me” she said about her new treatment plan.

These stories are not isolated incidents. Many people living with disabilities are exposed to opioids and even develop dependence while simply following the direction of medical professionals. Many may not realize they are living with addiction while still others turn to outside sources and give in to the temptation of over-use, and selling their prescriptions to others. If you have found yourself in a situation where addiction to an opioid is a problem, do not hesitate to reach out to adrc@mercercounty.org or 609-989-6663 to find out where to get help. Additionally, the Progressive Center for Independent Living at 609-581-4500 can also help to direct your concern to available support.

For immediate access to someone who can suggest some local resources, call the Mercer County Addictions Office at 609-989-6897. If you want to react to this article or make any suggestions, email adrc@mercercounty.org. We’d like to hear from you!
Do you want to buy a car? Go to school? Maybe save for end of life expenses? These are things that people without disabilities are free to do, but Medicaid and other means-based entitlement programs that many people living with disabilities rely on have often not allowed this to be without the risk of losing their benefits. When it comes such programs, there are 2 areas of your finances looked at: how much money you have (assets), and how much money you have coming in (income). ABLE Accounts were enacted to empower individuals to save money for larger expenditures, while maintaining the benefits crucial to their needs. ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families, were created as a result of the passage of the Stephen Beck Jr., Achieving a Better Life Experience Act of 2014 or better known as the ABLE Act. This represents the first time in history that the United States government has officially recognized the added expense of living with a disability. Since the signing into law of the ABLE Act, states across the country have been developing their own ABLE programs. On June 18, 2108, The NJ Department of Human Services announced that ABLE accounts can now be open in New Jersey.

ABLE accounts allow people with disabilities to save money and be able to easily access it, as opposed to Special Needs Trusts. When you have an ABLE account, as long as you are spending the money on disability related items, you don’t have to justify your purchase. Here is a list of the areas you can use your money in your ABLE account with: Education, health and wellness, housing, transportation, legal fees, financial management, employment training and support, assistive technology, personal support services, oversight and monitoring, funeral and burial expenses. However, if you use your ABLE account money for anything other than those listed, it will count as income and be taxed as income, as well as being charged an additional 10% federal tax penalty.

Each state’s ABLE program is unique and New Jersey’s is no different. There are 2 types of ABLE accounts available. One is a savings account and one is an investment account. In order to open either account, you will need

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$25 and can open it up online, over the phone, or by mail. To be eligible to open an account, you will need to have a disability diagnosed before the age of 26 and be eligible for either SSI or SSDI. You do not need to certify your disability at the time of opening your account, but you will need to recertify annually.

Unfortunately, you can only have one ABLE account, so you cannot have both a savings and an investment account at the same time. The investment accounts have several options of investments in stocks and bonds and can range from a very aggressive strategy of 90% in stocks and 10% in bonds, all the way to 10% in stocks, 30% in bonds and 60% in cash. Each level of investment is different and it all depends on how aggressively you want to invest your money. The investment accounts also adhere to the above regulations, just like the savings account option.

Now the nitty gritty...

Each year, you or your loved ones can put up to $15,000 into your ABLE account and everything up to $100,000 will not count towards SSI assets. However, going over $100,000 will begin to count towards SSI assets. Also, the maximum allowed in an ABLE account is $305,000. You can even sign up for an automatic contribution to your savings or investment accounts so that money is moved to your ABLE account regularly. Each year, NJ ABLE will report your total withdrawals from your account to the IRS and the dates and amounts of your withdrawals to the Social Security Administration, so it would be beneficial to keep records of your withdrawals in case you need to verify the expenses.

Fees...

Each month there will be a $2.00 service fee and a quarterly account maintenance fee of $15. If you chose the investment account option, there are investment costs ranging from 0.34% to 0.38% depending on your investment option.

How to get started...

You can compare and contrast different ABLE programs at the ABLE National Resource Center. Just because your state offers a program does not mean there aren’t better options for your situation elsewhere. Visit http://www.ablenrc.org/ to find the different ABLE programs available.

You can apply for New Jersey’s ABLE program online at https://savewithable.com/nj/home.html. For general questions, you can call NJ ABLE at (888) 609-8869 or email at nj.clientservice@savewithable.com.
Offering trainings to educate people about inclusions and awareness of people living with disabilities is one of the pillars that PCIL was built upon. On June 6th of this year we provided an interactive and educational program for the students of University Heights and Mc Galliard elementary schools in Hamilton Township. During this program students got to try a number of activity stations that demonstrate how difficult it can be living with a disability as well as an opportunity to speak to our director Scott Elliot about his experiences, both positive and negative. The students asked frank and honest questions and responses were given in kind. After seeing our presentation some of the University Heights students were asked by their teachers to write a letter about what they had learned, and those letters were given to us as a token of thanks. We are proud to know we have made a difference in improving the understanding of our community and we wanted to share some of the student’s thoughts with all of you:

“I realized everyone has a disability if that is glasses, speech, having a wheelchair, and much more.”

“I learned that no one is the same on the inside or outside.”

“I learned that a lot of people have disabilities and people have to work with these disabilities. I didn’t realize how hard it is to work with disabilities.”

“The interesting thing is that if you’re a person that sits in a wheelchair you can apply for jobs like being a teacher, tailor, and even in politics.”

“What I learned is that the basic things in life we take for granted is the challenges for others.”

“You taught me today that everybody has a different ability.”

There were many other touching and insightful thoughts in these young people’s writings and I wish we were able to share them all. Changing our culture starts with education. It will continue to be our mission to educate and empower those living with disabilities as well as those without.

If your organization is interested in this or any other training offered by The Progressive Center for Independent Living please contact us at: (609) 581-4500 or inf@pcil.org

For more information on training programs please visit http://pcil.org/program-summaries/

Member of the Cornell University ADA Trainer Network
Raising Awareness for an Integrated Community

Local elementary schools participate in demonstrations to learn what it might be like to live with different disabilities.
Ewing High School Students at the Dare to Dream Conference

By Renee Pfaff

PCIL and Ewing High School have been collaborating for quite a while now to help students transition to adult life. Pictured is a group of Ewing High students who participated at the Dare to Dream Student Conference at Rider University on May 16th, 2018. PCIL assisted the group in developing and preparing for the activity. We spoke about the importance of verbal and non-verbal communication when advocating for oneself. Part of the activity included breaking the audience into small groups and playing a game of Emotional Charades. After regrouping and reviewing the tips on communication, the group shared a 5 minute video on their Unified Sports Program at the school. We are proud of the hard work these and all of the other students we have worked with have done, and proud to be a part of them achieving their full potential!

MEET SARALEE

Hello my name is SaraLee Cummings. I am the new Transition Specialist with PCIL. I obtained my Bachelor’s degree in Communications from Rutgers University. I am passionate about making a difference in the lives of others and becoming a meaningful contributor to my community. I enjoyed and have extensive experience working closely with urban youths, planning and facilitating year round enrichment activities. I am excited about this great opportunity that has been granted to me and I look forward to being of service to others.

PCIL welcomes SaraLee as a new transition specialist!
TRENTON, N.J.—Mercer County Executive Brian M. Hughes announced that older adults in Mercer County again will have the opportunity to receive fresh-produce checks that will enable them to purchase locally grown fresh fruits and vegetables at participating farm stands.

Eligible older adults will receive checks to redeem fresh produce at various vendor sites throughout the County. Each person will receive five $5 checks that total $25 and are valid until Nov. 30, 2018. Kindly note that checks will be distributed on a first-come, first-served basis.

“The Farmers Market Check Program offers older adults an increased opportunity to include a nutritious choice to their eating habits. It also helps the older adult who may be struggling financially to get the most for their money,” Mr. Hughes said.

The Farmers Market program was developed to provide low-income older adults with checks...
MERCER COUNTY OFFERS CHECKS FOR FRESH PRODUCE

Continued from page 15

they can use to purchase fresh produce grown by New Jersey farmers. The Mercer County Nutrition Program is the lead agency and coordinator in Mercer County for the Senior Farmers Market Nutrition Program, and has been for a number of years. Qualifications are as follows: a single person’s income must not exceed $22,459 per year or $1,872 monthly; a couple’s income must not exceed $30,451 per year or $2,538 monthly.

Documentation is required for certification that includes:
- Identity and residency proof (driver’s license, utility/phone bill or birth certificate)
- Income proof (current income tax return, Social Security statement, Food Stamps/SNAP verification or Medicaid card)

The Mercer County Nutrition Project reminds older adults of these guidelines:
- You must be 60 years of age or older and live in Mercer County to receive checks.
- You must provide proof of income.
- You may not pick up checks for anyone other than yourself, unless you are serving as a proxy.
(IMPORTANT: Call the Nutrition Office for these details; see number below.)
- Checks are to be signed in front of the farmers. Do not send signed checks to the market with a friend. The farmer has the right to refuse to honor them.
- Checks may be used only at certified farm stands -- not grocery stores. Stands will display a yellow poster indicating that they accept these checks.
- Only one set of checks per person will be awarded each year.
- Couples can each receive their own set of checks.

For more information, contact the Mercer County Nutrition Program for the Elderly, Senior Farmers Market Program, at (609) 989-6652.
The 2018 Mercer County Senior Art Show was on exhibit at the Meadow Lakes Gallery in East Windsor through August 3rd.

The exhibit, which is sponsored by the Mercer County Division of Culture & Heritage and the Office on Aging, features original artworks created within the past three years, from drawings and paintings to crafts and more, by Mercer County residents age 60 or older.

“Mercer County has so many older adults who tap into their creativity to create new works of art,” said Mercer County Executive Brian M. Hughes. “I am looking forward to seeing the work of many talented artists on display this summer.”

A professional juror selects two winners, one professional and one non-professional, in each of the 11 categories. These winners move on to the statewide competition, the New Jersey Senior Art Show, to be held Sept. 20 through Oct. 26 at Meadow Lakes, a Springpoint Senior Living Community on Etra Road, just off Route 571, in East Windsor.

This is an annual event and your participation is encouraged!

For more information visit http://www.mercercounty.org/departments/culture-and-heritage/senior-art-show.
THE NATIONAL DISABILITY INSTITUTE “AT” LOAN PROGRAM

Millions of people living with disabilities rely on assistive technology to overcome challenges every day. Access to assistive technology devices such as, hearing aids, wheelchairs, communication boards, or vehicle modifications, can mean the difference between dependence and independence. In recent times, innovations in technology have empowered people to achieve more than ever before. The only downside can be the financial cost of these technologies. Often if you don’t have resources to cover the cost of assistive tech it can remain out of reach for those who need it. National Disability Institute (NDI) can not only help you find needed equipment but can also help you afford it through their AT Loan Program which provides affordable loans from $500 to $30,000 to residents of New Jersey.

These loans can be applied for online. NDI provides a large amount of resources including frequently asked questions, an orientation course to the program, an assistive technology guide for New Jersey and more.

For more information please visit: https://www.realeconomicimpact.org/asset-development/assistive-technology-loan-program
Or contact Laurie Schaller at (202) 449-9521 or email lschaller@ndi-inc.org.
NOTICE OF PUBLIC HEARING

Be advised, the Mercer County Office on Aging/ADRC will be conducting a public hearing in order to solicit testimony from the public on the current needs and issues of Mercer County’s older adult community and their caregivers. The findings of the hearing will be utilized in the Mercer County Office on Aging 2019-2021 Area Plan Contract. The Mercer County Office on Aging/ADRC invites anyone wishing to express their views on the aforementioned subject matter to attend a public hearing on the following date.

DATE AND TIME
Tuesday, August 7, 2018
10:30 AM - Noon

LOCATION
Mercer County Connection
957 Highway 33, Hamilton
Hamilton Shopping Center

Individuals wishing to provide testimony may pre-register by calling the Mercer County Office on Aging/ADRC at (609) 989-6661. Pre-registration is not required to testify; however it is recommended in order to insure that your comments and concerns are heard.

An abstract of the 2017-2018 Area Plan Contract is available for review at the Mercer County Office on Aging and the Mercer County Connection and may be viewed on the Mercer County website at http://www.mercercounty.org/departments/human-services/aging-disability-resource-connection/office-on-aging

Signed,
Eileen E. Doremus, Executive Director, Mercer County Office on Aging

Brian M. Hughes, County Executive
Marygrace Billek, Director, Department of Human Services
Progressive Center for Independent Living
3525 Quakerbridge Road
Suite 904
Hamilton, NJ 08619

Phone: 609-581-4500
Fax: 609-581-4555
E-mail: info@pcil.org
Site: www.pcil.org

MARK YOUR CALENDARS!
Exciting events on the horizon!

AUG 15 - Annual PCIL Softball Game
AUG 21 - Annual PCIL Picnic & Pontoon Boat Rides at Mercer County Park
SEPT 23 - Annual PCIL A Taste for Success
Later this summer: A Tour of Grounds for Sculpture, Percussion Workshop, Circus Skills Presentation & Training, and more!

Don’t forget to renew your PCIL membership for event discounts.

FREE MATTER FOR THE BLIND AND HANDICAPPED