About 20 years ago, after being in the human services field for several years, I was in a meeting with a leading disability advocate in the state of New Jersey (who happened to be my boss) about employment for people with disabilities. During the meeting he looks over at me and said “Scott, you and I are escapees.” Of course, I had no clue what he was talking about, but soon found what that meant.

An escapee is a person with a disability who is fortunate enough to get and hold a quality job, is not on Social Security, and is not totally dependent on public entitlements to lead a good life. Anyone who can accomplish this is an escapee from a system of disincentives that only discourage seeking and obtaining gainful employment. We have far too few escapees in New Jersey, and as an employment first state, this must change.

With some adjustments to this system, many more people with disabilities would be able to go through the all-or-nothing disincentive threshold and be able to continue working and expanding their earning...
capability (which also means paying taxes). That is a win-win for the individual, and the state. This is the direction that is often expressed and has been the impetus for programs such as NJ Workability, and PASP (something which has allowed me to continue my career path) support options for the individual wanting to work. These programs are intended to be the mechanism which can allow for the “escape” I’m writing about. A happy medium of care needs being met, along with vocational goals, but too often contain loop-holes and built-in barriers which can be as great a source of disappointment and de-motivation, as they are a path to independence.

Disability advocates and decision-makers in the state (and the nation) must work together to understand what it’s going to take to make the system more accepting, more sensible, and therefore more conducive to further “escapee” success stories from the no-win systems currently in place here in NJ. Even the happy medium is a win-win for many eager to work because it would create some balance in their lives and positive feelings of contributing to, and being connected with, their communities.

The bottom line is we have many individuals ready and willing to work and wanting to achieve gainful, competitive, and integrated employment opportunities. With 70% of people with disabilities unemployed, system change should be a matter of simply understanding the benefit to individuals, our tax base, and the fact there is absolutely no down side to the changes needed to make significant sensible progress for so many members of our community.

Scott Elliott

“We have far too few escapees in New Jersey, and as an employment first state, this must change”
After an almost 40 year career in the aging network and pending retirement in early 2021, let this be my ‘swan song’ submission of materials to FORWARD. Most rewarding in my career, are the lasting memories of working with those living with memory concerns/dementia/Alzheimer’s disease and their family/friends as caregivers. I dedicate these writing to them...one more time!

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

Some would say that the title of this article – Aging Well – is an example of a dichotomy (a division or contrast between two things that are or are represented as being opposed or entirely different). Let’s see about that!

By now, you know the landscape: 1) the number of Americans 65 and older is projected to double from 52 million in 2018 to 95 million by 2060; 2) the population will be more racially and ethnically diverse; 3) more older adults are working longer; 4) and more older adults are aging in place.* Additionally, 1) Alzheimer’s dementia is increasingly understood as a disease that may span many years changes occurring decades prior to symptom onset; 2) older adults
with dementia are more likely to have multiple chronic conditions; 3) disparities in the risk of developing Alzheimer’s are most prominent among African Americans, Hispanics and women; and 4) lifestyle plays a prominent role in the cognitive status of older adults and socialization, be it at work or at play, adds to one’s physical and mental well-being.

Much of the current news about aging well focuses on one brain being healthy - a healthy brain opens the door to fully participate in aging well.

So how does one take care of their brain? The Centers for Disease Control and Prevention (CDC) and the Alzheimer’s Association have published a 2018-2023 Road Map for The Healthy Brain Initiative. It is designed to spread understanding of and support for cognitive aging as a central part of public health practice.

A strong recommendation is to adopt a public health approach that can play a critical role in paving the way for a healthy course towards aging well. Begin by accelerating risk reduction at a younger age. Weave practices to reduce risk for problems associated with aging to include paying attention to preventing head injury, smoking cessation, healthy eating, increased physical activity and stress management. Advance early detection and diagnosis of cognitive changes and encourage symptomatic treatments and interventions. Interventions should include financial and legal planning, supportive services for all involved to include counseling and mental health advice and encourage managing one’s associated chronic health conditions.

When cognitive changes such as dementia, Alzheimer’s or related disease do occur, public health can play a critical role in ensuring safety and quality care along the caregiving journey.

During these changing times, so much attention has been paid to social isolation and loneliness. Take some time and examine what it is that allows you to age well. Aging well is achievable!

More ideas can be found at:
www.nia.nih.gov/health/cognitive-health
www.matherinstitute.com/about-us/current-research/
www.prb.org/aging-unitedstates-fact-sheet*

November is recognized annually as National Family Caregiver’s Month. In 2020, it takes on a whole new meaning! Call to Area Agencies on Aging in New Jersey skyrocketed with requests for emergency food, home-delivered meals, in-home assistance, telephone reassurance, shopping and errands. Family members who may never have thought of themselves as ‘caregivers’ were thrust into the realization that parents, relatives, neighbors, partners, spouses and those living with disabilities were less able to function independently and would require far more support. What perhaps was more easily hidden in normal situations was now in the spotlight as day to day existence with one another amplified one’s living situations. The pandemic catapulted families, friend and neighbors to assist with the instrumental activities of daily living to include the need to assist with meal preparation, grocery shopping, personal hygiene, housekeeping, banking, etc. to name a few.

The combined increased stress related to caregiving with the decreased availability of help/support led to the unfortunate reality of isolation, depression, financial instability and decline in mental well-being of caregivers everywhere.

What many of us have come to understand is that the act of giving care and assistance to older adults and those living with disabilities need increased attention and support. This needs to happen from a federal level to the local level.

Suggestions made via a survey done by the Roslyn Carter Institute (October 2020) include: increased access to counseling and telehealth services, expanding caregiver workshops and coaching, connecting...
caregivers with peer support, expanding paid family leave policies, building better respite options and strengthening support for basic needs like food assistance and home health workers.

On the national front, the RAISE Family Caregivers Act, which became law on Jan. 22, 2018, directs the Secretary of Health and Human Services to develop a national family caregiving strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers, and will include:

• Promoting greater adoption of person- and family-centered care in all healthcare and long-term service and support settings, with the person and the family caregiver at the center of care teams

• Assessment and service planning (including care transitions and coordination) involving care recipients and family caregivers

• Information, education, training supports, referral, and care coordination

• Respite options

• Financial security and workplace issues

Locally in Mercer County, caregivers are urged to connect with the Senior Well-


To learn more about caregiver services, call the ADRC/AAA Contact Information Nationwide Toll-Free Telephone Number 1-877-222-3737 to be connected with your local office.

■ Eileen Doremus

NOVEMBER 2020: NAT’L FAMILY CAREGIVERS MONTH
The Better Health Program is a free membership program for people 65 years of age or older which combines medical education, interesting topics, and fun activities. As a member you can: participate as much or as little as you want. Bring your friends and meet new friends, participate in outings, and learn from doctors and professionals. The Better Health Program focus is on the whole person to create a personalized approach to wellness that is right for you.

MEMBERSHIP BENEFITS

- Educational Programs led by RWJ’s own Sara Ali, MD, Geriatric & Internal Medicine. Topics include aging, vaccines, memory disorders, healthy heart, atrial fibrillation (A-Fib) and more.
- Health education events including lunch-and-learn receptions with RWJUH physicians, on important health topics to help keep you vibrant and well.
- Fun activities including exploring music from the past, outings, and arts & crafts.
- Topics for an informed life, prescription review, common scams on seniors, estate planning, grieving a loved one who is still living, and more!
- An extensive list of holistic programs and services.
- Designated parking spots at RWJUH Hamilton.
- Discounts at the RWJUH Hamilton’s Gift Shop and Café.
- Discounted opportunities at RWJ Fitness & Wellness Center Hamilton.
- Good Nutrition and healthy eating sessions led by registered dietitian nutritionists.
- Community events and group activities with peers.
- Should you require hospitalization, your team may check in on you during your stay. You matter to us!
- Transportation may be available to our programs upon request.

To join or for more information call 609-584-6422.

Once you sign up, you will receive a Welcome Packet by mail, which includes a membership card to bring with you to community events and hospital visits. You will also receive instructions on where to meet your Better Health Program Team and pick up your free gift. All information is required to become a member.
VIRTUAL COMMUNITY CONNECTIONS
Hello everyone, as I look around and see the leaves turn color, the weather cool, and Halloween decorations go up, I almost have to remind myself that autumn is here! This year has passed by both as slowly, and as quickly, as I think I’ve ever seen. I suppose the unusual circumstances we all find ourselves in are at the root of how strange it feels to be looking at the end of 2020, but I am happy to report that the PCIL Community Connections Recreation Program is still going strong, despite the year’s adversity! While there have been disappointments like not being able to host our annual picnic or softball game, we have still seen many smiling faces, had a lot of good times, met new and interesting people, and expanded our skills and knowledge of the community around us, albeit from in front of our computers, tablets, and smart phones.

If you’re not aware at this point, PCIL has been hosting recreation activities using the Zoom virtual meeting software every Friday afternoon. On our end, we have been working hard to make sure these virtual happenings either teach new skills, which we can use independently, or expose us to recreational resources available in our communities (or both whenever possible!). Since I last penned this section of our quarterly newsletter, we have connected with organizations like the Rutgers Cooperative Extension of Mercer County, who taught us lessons on gardening & nutrition, as well as sharing how to further connect to the great programming they offer. We’ve had yoga classes, singing lessons, drawing and crafting, choreography and dance lessons, an awesome set of sessions with naturalists from the Mercer County Parks Commission, and more!

I’m not bragging here, though I am proud of our efforts, and of the ability of our participants to adapt just as easily to a major change of format. I’d like to thank everyone who has provided us with feedback and thanks over the past several months. You may not know it, but that really helps sustain the efforts, as does every smile during an activity, every person recognizing a friend that was only a stranger a few Zoom sessions ago, every report of a new garden growing, nutrition habits upgrading, or new knowledge being applied. To that end, we will continue to bring these activities in this format for the foreseeable future. On the horizon are things like a virtual Halloween party, a lesson on puppetry, the opportunity to get a taste of what learning circus skills is like, further insight into video game creation (our friends at Game-U gave an awesome presentation this September!), and much more.

Want to find out more? Like & follow PCIL on Facebook at: www.facebook.com/progressivecenternj. Or just email us at: reed.thomas@pcil.org.

Reed Thomas
J WorkAbility, a Medicaid Buy-In (MBI) program, provides Medicaid benefits to eligible workers with disabilities whose earnings and resources exceed typical Medicaid limits. It allows the program’s enrollees to receive healthcare and other crucial services so that they can work, engage meaningfully in their communities, and lead independent lives. Multiple studies have shown that working in the community not only helps pay bills, but is also associated with improved physical, mental, and emotional health.

Unfortunately, many individuals with disabilities are or become ineligible for NJ WorkAbility for the following reasons:

1. **Job loss.** Although current NJ Workability enrollees will be allowed to retain their Medicaid benefits through the end of the COVID-19 public health emergency, there is no provision in New Jersey’s laws for a temporary or grace period providing for continued Medicaid coverage following job losses. In contrast, MBI programs in twenty-one other states include grace periods of continued Medicaid eligibility following job losses, thereby allowing the unemployed to focus on job search and their return to work.

2. Having **unearned income** more than $1,064 per month, the limit for a single person in 2020. Included in unearned income are:
   - paid leave and unemployment benefits;
   - benefits based on the parents’ work records because of their retirement, disability, or death;
   - two-thirds of Child Support received by adult disabled children from parents who are divorced.

A CALL TO ACTION FOR LEGISLATIVE REFORM TO EXPAND ACCESS TO NJ WORKABILITY
Twenty-five other states do not impose separate unearned income limits on their MBI enrollees.

3. Having **earned income** more than NJWorkAbility’s limit of about $5,380 per month. Some people turn down job offers or promotions, or work less hours than they would otherwise, because they do not want to lose Medicaid benefits. MBI programs in eight states do not have limits on earned income.

4. Having income or assets above the limits for a married couple. NJ WorkAbility’s financial eligibility determination rules require the inclusion of spousal incomes and assets. Twenty-two other states only count the individual’s earnings and resources in financial eligibility determinations.

5. **Being older than 64 years old**, the upper-age limit of NJ WorkAbility. Twelve other states allow workers with disabilities, ages 65 and older, to retain eligibility for their MBI programs.

If you have been denied eligibility for NJ WorkAbility, you CAN help bring about changes so that more New Jerseyans with disabilities in the workforce and those who want to return to work after job losses can be eligible for NJ WorkAbility. The more challenging and changing nature of the job market following the COVID-19 pandemic has raised the level of urgency for our advocacy.

PCIL is collaborating with advocacy organizations across New Jersey to advocate for legislative reform to expand access to NJ WorkAbility by removing the above five major barriers to eligibility. To achieve our goal, we are compiling individuals’ testimonials, to be presented to New Jersey legislators.

In your testimony,
- briefly outline the barrier to eligibility for NJ WorkAbility you’ve faced, and
- include your full name, mailing address, telephone number, and email address.

In addition, it would help our advocacy efforts if you could contact NJ legislators. If you plan to do so, please let us know so that we can coordinate our efforts and provide you with additional support.

Email your testimony to: info@pcil.org with “NJ WorkAbility” on the subject line.
Direct any questions to:
- Reed Thomas: (609) 581-4500 x 121
- Steve Gruzlovic: (609) 947-6607
- Nantanee Koppstein: (609) 799-2769

Together, we can make changes in New Jersey so that people with disabilities can keep Medicaid benefits thus enabling them to work to their full potentials; to become more financially self-sufficient; to engage more fully and meaningfully in their communities; and to lead independent lives.

- **Steve Gruzlovic**
  & **Nantanee Koppstein**
There is no doubt that 2020 has been a difficult year for some people. The COVID-19 pandemic has impacted America in ways many of us never imagined, and left devastation in its wake. At the same time civil upheaval and uncertainty has been adding to an already tumultuous time. I was feeling depressed and hopeless after two of my friends from Adelphi University passed away, one of them 3 weeks after his 25th birthday, and another from COVID-19. As a student of history and politics, the passing Ruth Bader Ginsberg was also upsetting. However, there are some things that I am grateful for despite 2020 feeling to me like the worst year ever.

I am grateful for some of the activities and accomplishments that kept me busy. I won a lot of prizes from Instagram activities and a LinkedIn live event. I am also grateful that I got the time to read books which have been on my radar for a while because it helps me expand my horizons and gain new insights and perspectives. I am grateful I got to learn how to play some new piano songs, especially the 2nd movement of Moonlight Sonata by Beethoven, because it made me feel more accomplished. And I am also grateful that I got to finally watch Dead Poets Society, Good Morning, Vietnam and Mrs. Doubtfire with Robin Williams online, as well as every episode of the Nickelodeon shows Zoey 101, Avatar: The Last Airbender, and The Legend of Korra. These helped take my mind to happier places during the pandemic. I am grateful that I got to see Jimmy Carter set a record as the oldest living US President at the age of 96 to help make the other disappointments this year a little more bearable.

Finally, I am grateful for all the good times from the virtual activities I participated in with PCIL. I loved the coping with kindness and autumn drawing activities that I participated in around my birthday this month. I am also grateful we got to celebrate the 30th anniversary of the Americans with Disabilities Act, and I am grateful that I got to see friends I haven’t seen in person at both the PCIL and Mercer County Community College Intervarsity Christian Fellowship Zoom meetings. And I am grateful that for technology because I can use it to keep in touch with people during quarantine.

Richard Ni
Meet our newest staff!

MEET TERESA

Hello Everyone!! My name is Teresa Pirretti and I have been a Support Coordinator with PCIL since July 2020. I have an A.S. in Early Childhood Education and a B.A. in Psychology. I have worked in the Human Services field for 20 years. I started my career as a DSP in mental health. I then shifted my focus to the I/DD population by working as an Assistant Manager and then a Manager in a group home. I love helping the ID/DD population live life on their own terms. When I am not working, I enjoy reading, music, video games, and watching Broadway musicals on film and once COVID ends, in the theatres once more. I am very excited to be a part of this extraordinary team at PCIL.

MEET VICKI

Greetings everyone! My name is Vasilia, but I tell most people to call me Vicki. I am a DDD Support Coordinator here at PCIL since March 2020. I have an Associates degree in Education K-12 and a Bachelors in Psychology. Currently, I am taking classes at Capella University to earn my Masters of Science in Clinical Mental Health Counseling. At my previous jobs, I have worked as Assistant Manager in a group home, a wellness specialist in the community, a residential specialist, and a direct support professional. I have experience working with individuals that have developmental disabilities with a diagnosis of co-occurring mental illnesses. I enjoy working with this population because I love to do advocacy work and find that individuals with disabilities often teach me life lessons that no other population can really teach. One of my favorite quotes from Wonder is, “In a world where you can be anything, be kind”. I am very excited to work for PCIL and look forward to meeting everyone!
My name is Sandy Griffin. I have been a member of The Progressive Center for Independent Living for over 3 years. I have been working at GIANT grocery store for about one year. I would like to tell people about what it’s like working with a disability that not everyone knows about.

I think people often do not understand that people with disabilities sometimes learn new things differently than their coworkers. I’d like people to understand that sometimes I feel like I’m not meeting expectations of my coworkers and managers and have a hard time communicating my frustration. My disability makes reading and numbers a challenge. Sometimes my brain clicks and the reading is easier but sometimes I have a real hard time.

My disability has made me tough. In the past, people have treated me like I am not smart and I feel like I have to prove myself all the time. I am working on communicating better and sharing my feelings. Giant can communicate with me and my job coach about areas that I can improve. For example, when I had trouble with remembering how to prepare different fruit and vegetable trays I would always have to ask the manager or a coworker. My job coach was able to prepare a book with photos so I could be more independent.

I have always been very independent and able to take care of myself. My support team encourages me to be more vulnerable and to share when I have a tough day instead of bottling up all my emotions. They understand my disability and are compassionate when I need help.
As everyone knows, there are many services that have switched to virtual programming to keep all participants safe. The Support Coordinators at Progressive Center for Independent Living are no exception. Normally, Support Coordinators are physically able to visit with the people we serve. During this global pandemic all contact we have with our clients is via phone or sometimes Zoom. During our monthly check-in, Support Coordinators have asked for the opinions of the people we serve. The questions given were as follows: “Do you like virtual services? Why or why not? And lastly, would you like virtual services to continue?

All the individuals who provided their opinions saw good and bad aspects to virtual services. Most people surveyed stated that they were happy to see their friends/teachers over Zoom, though they miss the physical connection and comradery in person activities provide. There were also some individuals that liked the slower and relaxed pace of virtual sessions because of the ability to stay at home, thus reducing any anxiety they may feel. Individuals that are employed are also feeling ready and eager to return to their jobs.

Using these virtual services has allowed life to continue, skills to be learned, and goals to be met in the face of adversity. Perhaps the biggest takeaway from exploring the use of these methods from the end-user’s perspective is that nearly everyone understands the need to change in this way, has been able to effectively adapt, and doesn’t bear any ill-will because of it. Even though working virtually has filled a necessary gap during the pandemic, most people look forward to a time when we can all get together safely in person again.

— Teresa Peretti
In New Jersey, a child becomes an adult at the age of 18. What this means is that all parental rights transfer to the child on his or her 18th birthday. This law stands regardless of whether or not the child has an intellectual or developmental disability. Some people with IDD need someone to make decisions for them, so their parent or guardian goes through a legal process to keep guardianship of their adult child. That works for some people with disabilities, but not all. There are several alternatives to guardianship to look into before you and your child decide which one is right, and one of those alternatives is Supported Decision-Making.

Supported Decision-Making allows a person with a disability to appoint people to help them make big decisions in their lives such as medical and financial decisions. They pick a few people they trust to explain to them what they need to decide and provide choices. Ultimately, the person with a disability gets the final decision.

I learned about Supported Decision-Making in a workshop with New Jersey Partners in Policymaking last year. The more the speaker talked about it, the more excited I became. I made it my goal to secure Supported Decision-Making legislation to New Jersey.
When I turned 18 the only option I knew about was guardianship. While I must say I’m lucky to have guardians who are good at taking my wishes into account, there are times when I want a say in who knows about what I want to make decisions about, and you don’t get that when a guardian has to sign off on forms. It also means a lot to me because until this past year, I didn’t know much about the services I receive from the state. How can you make your own decisions when you don’t understand the services you receive?

There are many ways that people with disabilities, their families, and especially specialists and disability lawyers who work with transition aged kids with disabilities, can get involved in the Supported Decision-Making Movement on a state and national level; and there are many resources too. The group that’s leading the movement is the National Resource Center for Supported Decision-Making which has links to resources as well as ways to get involved. The American Civil Liberties Union has a packet for people with disabilities and their families on how to make a Supported Decision-Making agreement and the Autistic Self-Advocacy Network has a packet on Supported Decision-Making laws on an international scale with breakdowns for each individual US state.

One of the factors that impact the outlook of life for people with disabilities is the ability to make our own choices. People with disabilities who are given the opportunity to use Supported Decision-Making are happier and healthier than people with disabilities who could be able to use it if they are given the opportunity.

I wrote to my Senator asking about bringing Supported Decision-Making legislation to New Jersey and in mid July she responded. She is interested in sponsoring a bill for Supported Decision-Making and is working on a draft. I hope that legislation is signed into law.

The National Resource Center on Supported Decision-Making:
http://www.supporteddecisionmaking.org/

The main site for the ACLU and the Supported Decision-Making part of the site:
https://www.aclu.org/

The main site for ASAN and the Supported Decision-Making part of the site:
https://autisticadvocacy.org/
https://autisticadvocacy.org/?s=supported+decision+making

New Jersey Partners in Policymaking:
https://rwjms.rutgers.edu/boggsceneter/projects/NJPartnersinPolicymaking.html

Julia Simko
PASP offers consumers choice, flexibility, control and the opportunity to manage their personal care services through the receipt of a cash allowance.

CONTACT US NOW!

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Articles and photos in this issue have been curated by both the Progressive Center for Independent Living and Mercer County Aging and Disability Resource Connection.

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